# CONTEXTUALIZING ATTITUDES, FRAMING DISABILITY: UNIVERSAL DESIGN AND STRUCTURAL VIOLENCE THROUGH THE LENS OF THE ACCESSIBILITY EXPEDITION

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#### **ABSTRACT**

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#### **EXPEDITION**

#### LAUREN COPELAND-GLENN

Using a framework of structural violence (Farmer 2005), this thesis examines the ways in which the United States education system maintains stereotypical tropes about disability through enculturation (Spindler 1963, 1965). A lack of awareness and understanding of the cultural beliefs that create real barriers for disabled people is prevalent and replicated within our education system and larger society. I draw upon ideas of how disability and disabled people are viewed through two lenses borrowed from disability studies, the medical model and the social model (Linton 1998) and Universal Design. Finally, an intervention, the Accessibility Expedition is explained and discussed as a way to change attitudes toward disability by providing experiences that allow engagement with disabled people and encounters with the barriers cultural norms create for them.

#### **ACKNOWLEDGEMENTS**

For many reasons, this thesis took me well over a decade and a partial topic change to complete. Over that time, I had numerous supporters both personal and academic. My most recent committee members (I had many over the years) pushed me to the finish line and encouraged me through my final drafts. Dr. Emery Eaves sat with me over coffee as I proposed ideas and focused my writing and found my voice, then ignored me when I questioned if I was ready, because I was. Dr. Kerry Thompson gave me options and guided me through a catalogue change, then backed me to the end. Dr. Chris Lanterman enthusiastically joined my committee and allowed our joint research to be central to my new thesis, his friendship and mentorship taught me about disability rights and justice and helped me focus my anthropological lens in that direction. I am forever grateful to them all. And, of course, my first mentor in anthropology, Dr. Miguel Vasquez took me under his wing and showed me how to engage in community-based participatory research and activism. He shared his love of Guatemala and encouraged my interests in Latin America and education. I am lucky and grateful to have such a group in my life.

I began graduate school when my daughter, Cyanne, was six years old, she is now a sophomore in college. She grew up attending lectures, visiting archaeological sites and the Hopi Mesas, learning to flint knap, sometimes attending classes, listening to my cohort debate topics, being the regular subject of my class projects, and watching me study and write. She was and is my most ardent supporter. In many ways, I finished this for her.

To my parents who helped me raise my daughter so I could work in the lab, attend class, or conduct an interview or observation. They taught me how to be kind and compassionate, resourceful and brave. They made my educational goals possible so I could, in turn, make my life better through education.

Finally, I want to acknowledge three of my NAU mafia accomplices Byl Bryce, Michael Terlep, and KC Carlson. They never let me quit and made me an honorary archaeologist along the way. Anthropology would not be the same without them.

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This thesis is a long time in the making. I began my graduate school journey more than a decade ago, collected a copious amount of data and research on a completely different topic, and floundered in writing that thesis, due in part to my own disability (severe and debilitating migraines). At the same time, I fell into a job that provided an opportunity to engage with the disability rights movement, where I used my applied anthropology skills to develop an innovative practice to allow participants to engage with the environment in a way that allows allyship and empowerment of people with disabilities instead of pity and further othering. I now have envisioned a new thesis that draws upon both my original thesis research and my current academic endeavors.

Disability is a regular part of the human experience. Enculturation dictates the way it is viewed in a larger cultural context. In the United States of America, the school system (public and private) is a major facilitator of enculturation. Through overt practices such as segregated classrooms and denial of services or denial of attendance, children are taught that disability is outside of the norm and therefore encouraged to engage in a status quo of othering (Linton 1998; Dolmage 2017).

So much of our lives as Americans<sup>1</sup> in the United States relies upon the education system to provide context to our understanding of the world. This context often centers the powerful and marginalizes everyone else. While each marginalized population (racial, ethnic, gender, disability) community experiences particular oppression and exclusion, there are parallels among and between underserved minority populations that are tangible and relevant. However,

<sup>&</sup>lt;sup>1</sup> I use American to refer to the dominant culture of the United States of America although I recognize that other countries in the Americas also refer to themselves as American. In this text American equates to U.S. culture.

disability is often not described as a part of diversity when talking about how to improve the educational outcomes of our minoritized populations. A lack of awareness and understanding of the cultural beliefs that create real barriers for disabled people is prevalent and replicated within our education system and larger society. I draw upon a historical frame of disability including ideas of how disability and disabled people are viewed through two lenses borrowed from disability studies, the medical model and the social model (Linton 1998). I will discuss the limitations of the use of specific language and labels placed upon disabled people and how the use of Universal Design (Center for Universal Design) can shift the cultural gaze using an evaluation framework I refer to as the Pity to Power Continuum (Lanterman and Copeland-Glenn) which looks at cultural dynamics that elicit a pity response, effectively dehumanizing and disempowering disabled people, and the dynamics that help to shift understanding to a place of allyship and power for disabled people. I also situate this research and practice within structural violence oppression hierarchies (Farmer 2005; Bourdieu 1977; Bourgois 1995; McLaren 1986; Rosaldo 1989; Wolf 2001) created to maintain power and privilege.

# I. The American Education System as Enculturation

"The American public school system, and the professional educators who operate it, have been subjected to increasingly strident attacks from the public and from within its own ranks. My premise is that these attacks can best be understood as symptoms of an American culture that is undergoing transformation – a transformation that produces serious conflict" (George Spindler, 1965:132).

Much has changed since Spindler's writing. For example, the creation of the Department of Education by President Jimmy Carter in 1979, charter schools and school choice, Section 504 of the Rehabilitation Act (Section 504:1973), Individuals with Disabilities Education Act (IDEA)

(IDEA:1990), and the passage of the Americans with Disabilities Act (ADA) (ADA 1990). Spindler's assertion, however, that attacks on the public school system were due to a culture system in transformation is as true today as it was in those years of the Civil Rights movement and the Disability Rights movement of the 1970s when Brown vs the Board of Education was ubiquitous in the minds of those fighting for integration (Nielsen 2012).

Today, despite efforts toward inclusive classrooms and desegregation, segregation based on disability is still prevalent and we find ourselves again undergoing a turbulent transformation. Scholars of education and anthropology argue that the troubling times of transformation never cease but rather ebb and flow depending on political contexts and engrained structural violence (Ravitch 2010; Spindler 1963, 1965; Warren 1988; Freire 2009; Wolf 1982, 2001; Vigil 2002, 2012).

Anthropologists have long described the power and process of enculturation (Mead, Boas, Benedict). Enculturation is not a static tool but flexible and changing to allow for adaptation to new environmental pressures. The outdated idea that culture evolves on a spectrum from barbaric to civilized following an evolutionary line of change has long been rejected (Tylor, Morgan, White, Steward), but that does not mean that culture does not change and shift and bend as necessary. Spindler (1965, 1988) discussed the enculturative processes that exist within a structured school environment and that those initial enculturative experiences provide a framework for future beliefs about and within an individual's educational lifetime. My study seeks to provide insight into the enculturative process of beliefs about disability that ultimately perpetuates incorrect notions about "normalcy" and provides the foundation for discrimination within the larger American cultural framework. Data show that disabled people are disenfranchised from and oppressed within the educational system at all levels (Domage, Linton,

Lavani & Broderick, Henley). I describe how this occurs in practice and then describe an intervention to engage with disability in a positive and proactive way, moving participants forward on the Pity to Power Continuum through the Accessibility Expedition.

The literature reflects continued oppression of disabled people within our education system on a number of levels (Dolmage 2017; Linton 1998; Lavani & Broderick 2013; Nario-Redmond, et al 2017). Not only are disabled students discriminated against through our poor allocation of resources but so too are our teachers caught in a system of inadequate education. The disparities begin at the top, in the very halls of academia - higher education - that our nation cherishes. Dolmage writes, "Disability is studied; people with disabilities have been research resources. More than this, higher education has been built upon such research" (2017, 4). Dolmage also notes that the physical structure of academia is one meant to exclude "to justify its work and to ground its exceptionalism..." (2017, 3). This "exceptionalism" reflected in the architecture with grand staircases and ramp-less entrances, have left lasting physical and attitudinal barriers for disabled people.

# II. Situating the Researcher – Reflexivity in Practice

I was lucky enough to have been selected to attend an ethnographic field school in Guatemala the summer before entering graduate school. I was older than everyone else. I had left my six-year-old daughter behind with friends and my parents. I felt like I had to so that I could be a real anthropologist. I don't really know what that means now but I was inspired by my mentor Dr. Vasquez and his wife, and my friend, Marina, who is Guatemalan. They met in a different village on the other side of the lake during the height of the civil war in the 1970s. I felt drawn somehow.

I lived with a wonderful family in the village community of San Pedro La Laguna on the shores of Lake Atitlán in the Guatemalan highlands. My family ran a Spanish language school for tourists and rented out a handful of casitas. I lived in one of the casitas for my seven-week stint. My family lived in the main house and the casita next door. The parents, one son and his wife, and their youngest daughter. Their oldest daughter lived in la Ciudad (Guatemala City) and did human rights work; as I was arriving in Guatemala she was traveling to New York City to speak to the United Nations on the plight of the Mayan people. They welcomed me, soothed me when I cried from the culture shock and missing my daughter, helped me with my Spanish, and talked with me about their lives.

Guatemala is a study in exits and arrivals. Extranjeros from the United States and Europe (mostly Europe) line the shores of the villages around the lake. They've purchased land and built restaurants, bars, houses, and hangouts. Gringolandia it was called in San Pedro. The longer I stayed the more I realized how displaced the Mayan community had become because of these interlopers. The village center is high on a hill on the slope of the San Pedro volcano. It's bustling with tiendas, carnecerias, fabric stores, clothing shops, food stands, family run restaurants, and at the very center a church. The extranjeros rarely made the vertical climb into the real part of the village. Instead preferring to stay on the flat shores where they had created something that was more familiar to them. I remember thinking, why come here if you aren't interested in the culture or the people? Trustafarians someone called them. It was a good description. They took advantage of cheap land on a European or U.S. budget. They bought up the land closest to the lake. Land that once belonged to the local community where they could fish and grow crops on flatter, safer land (there are dozens of stories of farmers literally falling out of their milpas because of the steep terrain). The other problem is that all of their money

stayed in the extranjero community. Since they weren't regular visitors to the village, they didn't help the local economy.

The field school required that I create a mini ethnography. I noticed that a number of local people, families, like my own, ran Spanish language schools. That these schools drew in the extranjeros as well as regular tourists and travelers. I learned that two villages around the lake actually drew in tourists because of the number and quality of the Spanish language schools: Panajachel, the main and largest village and San Pedro la Laguna. They controlled the narrative, teaching their students Spanish but also about Guatemala, Mayans, and the civil war.

A quieter exit exists as well. One we hear about all the time in the United States, emigration to the United States or even to Mexico. This exit is mostly of men, young men. My host sister, Rosa, and I had many long conversations about this emigration. She told me one story of her friend crossing the U.S. Mexico border in a van that crashed sending her friend to the hospital and killing his traveling companion. We talked about the dangers and the rewards. About the remittances that save families. But we also talked about the holes that these young men left in their communities that the women had to fill.

When I returned to the U.S. I started to think about how I could incorporate my experiences in Guatemala with my thesis topic and interests in the U.S. I knew I couldn't travel for my thesis research. It would need to be based in the U.S. and preferably in Flagstaff. I met with Dr. Vasquez, we talked about places familiar to us both. It was comforting. But the most influential conversation I had was with Dr. Cathy Small. I had worked with her on a project through my job at Big Brothers Big Sisters that was designed to set up a mentoring program for Tongan immigrants in the San Jose, CA area. I told her about my conversations with Rosa. She pointed out that while it's the men that may emigrate, by the second generation it's the women

who are more educated. That was the spark. What happened to the boys? What is it about American culture that allows the girls to be more academically successful (though maybe not more economically successful)? I realized this wasn't something unique to Tongans. It was the same in other immigrant communities. It was the same in the Latino community in Flagstaff. I decided that I needed to understand the enculturation process of immigrants, of boys, of girls. It needed to be children. What is the main vehicle for enculturation of children outside of the home? The formal education system. I decided I needed to be in an elementary school. To see if I could identify places where we teach boys that school isn't important, or at least where boys and girls interpret messaging differently. My topic broadened just a bit because it wasn't really possible to only include second generation immigrants, so I let my topic encompass all Latino boys.

I spent way too long at my research site. I collected way too much data. I was overwhelmed by it. I felt like I couldn't do justice to the topic, to the boys who let me into their lives, to the teachers who let me into their classrooms; to my Latino friends who I grew up with and who I watched get in trouble for things our White peers didn't - who taught me to recognize injustice because I was a witness – and never let me forget that I'm a White girl too, but they'd adopted me. So, I sat stuck for ten years with a never-ending migraine and regret.

But in those ten years I began a new journey of justice work. I found and dedicated my career in higher education to the ideas of inclusion, diversity, equity, and justice for "underrepresented," "minoritized," "othered" people and a new topic emerged. I engaged with NAU's Commission on Disability Access and Design (CDAD) and began to see disability. I am a lucky person to have been gifted experiences that many have not had. In the fourth grade, my classmates and I were joined by a new student. He used a wheelchair and had an aid. I later

understood that he had cerebral palsy (CP) but as a child the medical diagnosis didn't matter. He was our friend. In junior high, I was one of maybe a dozen girls (the fact that we were all girls is a research topic for another time) selected to participate in a special PE class that incorporated the students from the segregated disability class into a "regular" PE class. Many of the students would be classified as having developmental disabilities. We played basketball and flag football, lifted weights, and practiced our archery skills together. For years after junior high and high school, some of my fellow classmates lived in residential group homes so I would still run into them around town. I had not thought critically about the political or social situating of people with disabilities yet, my introduction to structural violence was still many years away.

During graduate school, I secured a graduate assistantship with, at the time, the four diversity commissions. I was assigned to work with CDAD and they embraced my interest in their work. After my graduate assistantship ended, I remained a member of the commission. I began to understand the ways in which our cultural constructs disable people. I became a cochair of the group for two terms and worked to build upon an idea generated in partnership with a student organization dedicated to students with disabilities. This idea led to the development of an intervention that helps to shift the focus of disability from a deficit an individual has to a cultural issue that can be changed (the solution isn't to "fix" the individual but to recognize how cultural norms exist to disable certain human forms). And now, while the population I am studying has again changed, the structure and theoretical framework still remain the same. It is possible to replace almost all instances of "Latino boys" with "disability" or "disabled" and see the same effects of a system designed to perpetuate the elevation of American cultural norms of Whiteness and able-bodiedness over all other identities. Structural violence leading the way for the maintenance of the status quo.

# Chapter 2: Theoretical Approach

Numerous educators and anthropologists have studied the education system with regard to minority achievement and gender differences in educational aspirations and beliefs, not as many have studied disability. For this research, my theoretical frameworks include structural violence as defined by Johan Galtung and modified and used by Paul Farmer, disability study's paradigms of medical and social models of disability, and Universal Design. Since the Supreme Court ruling in Brown v. Board of Education in 1954 (Zirkel and Cantor 2004:1) declaring segregation unconstitutional, integration of disabled students has been a rallying cry for disability rights advocates. Anthropology has focused very little attention on disability and mostly through the lens of medical anthropology. The American Anthropological Association's (AAA) Disability Research Interest Group (DRIG) is firmly situated within the Society for Medical Anthropology. Even with their statement that, "We situate the medicalization of disability as a sociocultural phenomenon with political consequences, and contend that there is much to be said about disability that exists outside of the realm of biomedicine" (DRIG 2022), the situating of the DRIG in this space subtly (or not) reinforces the construct that disability is a medical issue to be overcome and dealt with instead of a "sociocultural phenomenon." The AAA adopted the following Statement on Disabilities in 1993:

It is moved that the American Anthropological Association, in keeping with the American Disabilities Act, urges faculty to adopt and apply an attitude of acceptance, adventure, collegiality, and respect toward disabled persons in the attainment of their goals, and commit themselves to becoming knowledgeable with regard to disabilities through interactions with disabled persons (including students), seeking expert input, and reading texts outside of mainstream anthropology on the topic of disability.

Understanding the medical and social models of disability is vital to shifting the frame of disability from condition based medical intervention to understanding the ways in which the

larger culture and society works to disable people who have not historically been included in the design and structure of the world in which we live. Shifting worldviews is challenging. As an anthropologist who studies her own culture, I still must seek out the emic and etic to understand where the cultural beliefs are contained and perpetuated. Linton states, "the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy" (1998, 11). The medical model of disability seeks to "treat" or "fix" the individual and their ailments while reducing the person to only their condition. The social model on the other hand points out "the social [and cultural] processes and policies that constrict disabled people's lives" (Linton, 1998, 11).

Language and how it is used is also an important component to the social model. Two core ways of thinking about identity currently exist – person-first and identity-first. Person-first language (I am a person with a disability) seeks to distance the person from any disability to help others see them as a human first, someone who happens to have a disability, as well as remove them from the negative stereotypes and stigma that we have been enculturated to believe about disability. Identity-first language (I am disabled) seeks to reclaim disability and own it as an integral part of a person. Identity-first language rejects the negative cultural constructs and instead seeks to reflect disability as a normal part of human existence and that it is society that disables people who do not fit the constructed norm (AHEAD 2022). I use both ways to describe disability throughout this thesis, "[b]oth options have implications for how we think about disability" (AHEAD 2022) and both are used by the disability community.

Farmer sees structural violence as the deeply embedded inequalities of modern social and political structures allowing those in power to make and enforce the rules and those with little to no power to suffer the consequences of marginalization (2005). As a medical anthropologist,

Farmer uses this framework to explain disparities in health and healthcare, but I see structural violence as a strong theoretical framework for the study of disability within education and the larger cultural context as well. Statistically, disabled, minority, and economically disadvantaged students across the board fall far below their non-disabled, middle class, white peers in test scores, high school completion and college attendance (NCES 2018). This is not by mistake, but rather the product of a system structure created for one class which excludes other classes because of the exclusive knowledge and supports required to effectively navigate the structure.

Defining structure also means defining the cultural space that provides the systemic knowledge of place. Defining the education system through the use of habitus seems to provide the boundaries of understandings not easily voiced or explained. Bourdieu describes habitus as "...the material conditions of existence" (Bourdieu 1977, 407) of everyday life. Children are not often able to explain their beliefs, yet they are viscerally affected by the environment within which they are enculturated. Because enculturation is both explicit and implicit children cannot often voice or even recognize the messages conveyed about right and wrong or good and bad, and instead internalize these messages. As children grow older the internalized messages of self grow into firm beliefs about their particular role within the education system specifically and the world in general. In the case of my research, the habitus helps to explain the environment of the education system and the reactions of the players involved.

I did not know it when I began my thesis research into the power of enculturation through the education system, but I was in fact modeling my study on work George Spindler began more than 50 years previously in the 1960s. The connection between the education system and enculturation as a tool to ostracize marginalized populations intrigued me. As I grasped for theory to help guide my analysis I came across Spinder's work *Education and Culture*:

Anthropological Approaches (1963). Doubt in my anthropological abilities that had been slowly creeping into my brain began to retreat as my thoughts seemed to be presented in front of me as if I had written them myself. Interpretations of cultural phenomena that I thought were purely my own were reinforced by a respected and prolific anthropologist. I felt vindicated and emboldened to complete my research, to add, in whatever small way, to the vast inventory of educational research conducted by anthropologists.

To begin to address the barriers erected both physically and attitudinally for people with disabilities, an idea was formed to show people the barriers that society creates through a firsthand experience originally named the Accessibility Scavenger Hunt but later renamed the Accessibility Expedition given the problematic association with the word scavenger.

The Accessibility Expedition (AE) builds on the work of Burgstahler & Doe (2004) to offer an innovative approach to promoting accessible design that avoids negative outcomes from some of the typical simulation activities and offers a facilitated exploration of design features that enable or constrain equitable access and participation for individuals with and without disabilities. The goal of the AE is to help participants see their environment through a lens of equity and inclusion rather than through simulated experiences. Universal design is "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (North Carolina State University 1997, n.p.). Embedding the lens of universal design within the AE is significant because "[u]niversal design is ultimately a process that empowers people by giving them more control over their lives and choice in the things that they do or the way in which they do those things" (Salmen 2011, 15). Providing participants with opportunities to explore ways in which a design can constrain control provides a strong foundation for advocacy and change.

The AE engages participants in a guided conversation about various features of a public space, such as a university campus through a universal design lens. Disabled individuals, personnel knowledgeable of ADA Standards for Accessible Design, and universal design advocates lead groups of participants through specifically selected areas of campus and discuss features of physical and landscape design, including paths of travel, building features and

amenities, ingress and egress, and other temporal design considerations, such as the placement of event signage, that may present various challenges to accessibility, usability, and safety. Each group follows a carefully designed set of tasks that take them through buildings into restrooms, on elevators, into classrooms and lecture halls, across pedways, and into coffee shops. Groups are asked to experience and evaluate the levels of access afforded to individuals within the group and infer who may or may not be able to access the spaces and reflect on the characteristics of people who were likely considered in the design process. During the AE, participants take photos and share them via a designated Twitter hashtag to discuss and process following the campus exploration during the AE debrief.

The AE helps to educate the participants in basic Americans with Disabilities Act (ADA) and Architectural Barriers Act (ABA) design requirements and in the basic principles of universal design (UD). Through its approach to engage with design guidelines *and* the lived experiences of people with disabilities, the AE has the potential to positively impact accessibility efforts and systemic thinking for institutions and their disability resources offices as well as those that focus on the physical environment.

"Universal design continues to be relevant to the design of built environments in today's society as a means of addressing the broadest needs of people and populations regardless of abilities, needs and roles" (Watchorn et al. 2014, 71). Indeed, understanding that equitable participation means that *all* are able to participate together is one of the main foci of the AE. Facilitators of the AE bring their knowledge of ADA design standards and universal design to demonstrate that the ADA requires minimum levels of accessibility for disabled persons, while universal design intends to create spaces that are inclusive and usable for all people.

# I. Description of AE Practice

An integral element of helping AE participants explore design features is the embedded investigation of features of physical and exterior spaces that reflect the application of universal design. Universal design was conceptualized by Ronald Mace, a wheelchair user and architect, along with colleagues from North Carolina State University (Story et al. 1998). Mace found that many of the design solutions mandated by the Architectural Barriers Act, were valuable for many users, not just those with disabilities. Additionally, he found that most design solutions were cost-effective and aesthetically pleasing when implemented appropriately at the beginning of a design project. In their work to articulate principles of effective design, Mace and his colleagues established the Seven Principles of Universal Design (see Table 1). The Center for Universal Design (CUD) at North Carolina State University, which Mace helped to establish, defines these principles and provides basic guidelines for each of The Seven Principles of Universal Design (Center for Universal Design 1997).

TABLE 1. The Seven Principles of Universal Design

Principle	Description
Principle 1: Equitable Use	The design is useful and marketable to people with diverse abilities.
Principle 2: Flexibility in Use	The design accommodates a wide range of individual preferences and abilities.
Principle 3: Simple and Intuitive Use	Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
Principle 4: Perceptible Information	The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

Principle	Description
Principle 5: Tolerance for Error	The design minimizes hazards and the adverse consequences of accidental or unintended actions
Principle 6: Low Physical Effort	The design can be used efficiently and comfortably and with a minimum of fatigue.
Principle 7: Size and Space for Approach and Use	Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

*Note:* Adapted from the Center for Universal Design (1997)

As participants in the AE arrive at a designated, central location to begin the exploration, they are randomly assigned to a group, 1-5 depending on the number of group facilitators; ideally groups are not larger than 20. The AE facilitator provides a welcome and outlines the event and rules. Each group is provided an initial set of tasks to complete and a path to follow. The task sheets include questions to consider and expectations for equitable participation. These considerations and expectations are designed to bring attention to accessibility challenges that individuals without disabilities might take for granted (see Table 2).

TABLE 2: Accessibility Expedition Considerations and Expectations

Questions to Consider	Expectations for Participation
• Who is, and who is not, able to use this? Why?	Participants should:  Not take stairs.
Who is, and who may not be, considered in this design? Why?	<ul> <li>Not step off of or onto curbs.</li> </ul>
• Who is, and who is not, able to participate in an activity here? Why?	<ul> <li>Ensure that everyone gets to the destination in the same way.</li> </ul>
<ul> <li>Who do you think was involved in the design decision here and who might</li> </ul>	<ul> <li>Follow stated campus rules (e.g., use crosswalks).</li> </ul>

Questions to Consider	Expectations for Participation
not have been? What makes you think this?	
What does this design enable and what does it constrain? Why?	

Each group is asked to make numerous observations and document their observations with photos along the way. Photos are sent to a predefined Twitter hashtag for review during the debrief. At the end of the first leg of the route, the next task is located in an envelope bearing the active International Symbol of Accessibility (ISA) with a raised tactile outline of the shape. Groups are provided relevant sections of the "ADA Checklist for Existing Facilities" (Institute for Human Centered Design 2016) on the AE for guidance on properly measuring features, such as the height of a counter or turning radius in a restroom stall. Tools such as measuring tapes and smart levels for gauging slope are also provided to the groups. The use of tools helps participants understand the difference between meeting a minimum requirement, such as the ADA Standards for Accessible Design, and thoughtful, inclusive design, as suggested by the principles of UD. Group leaders help to point out features in spaces that are examples of design barriers, minimally accessible design, and inclusive design. These experiences allow participants to become better advocates when they encounter a potential barrier and to provide suggestions for changes to improve the physical and social inclusion of people with disabilities in every space on the campus.

Following the exploration, participants meet to process the findings and dialogue the pros and cons of certain environmental features discovered on the AE. This conversation focuses on design considerations for accessibility, usability, and safety, rather than simply an imagined challenge faced by people with disabilities. An integral and critical element of the AE and conversation is the participation of individuals with various disabilities. These referents allow for a grounded dialogue that exposes stereotyped and pity-based perspectives of disability experiences and foregrounds the lived experiences of people with disabilities. Individuals versed in ADA accessible design standards and universal design are also an integral part of the discussion to provide guidance to help participants understand why some decisions may have been made and how better design could go beyond minimum code compliance.

#### I. Future Work

Anthropologists in the 21st Century are far from the armchair. We seek to understand cultural constructs and then engage with those constructs to produce positive change where we can. The Accessibility Expedition has seen promising results in lessening the attitudinal barriers around disability. Future research needs to include a mixed methods approach to determine the level of influence an intervention like the AE can have for students as well as faculty and staff. Deploying the AE outside of a university setting is important to our understanding of larger systemic change. Can an intervention such as this work within a smaller company, a large city system, or an elementary school? These are important questions to answer in the future. The research will measure participants pre-AE knowledge and attitudes and then again post-AE. The desire is that through publication of the article, others will institute their own AE and can share their experiences to help to gather a large data set to evaluate.

I am also interested in researching the gap between minority students and White students who are identified as having a disability in the K-12 system and those who attend college.

Students who have disabilities and need accommodations in K-12 either have what is called an Individualized Education Program (IEP) or a 504 Plan (DO-IT 2022). According to the Office of Special Education Programs' (OSEP) Fast Facts report, more than 55 percent of students with IEPs or 504 Plans are students of color (2021a). The graduation rates for students of color with an IEP or 504 Plan ranges from 65 percent to 77 percent (OSEP 2021b); however, according to a Postsecondary National Policy Institute report, students of color are being served at a much lower rate than their White counterparts in higher education (2022). Some recent research by the

National Longitudinal Transition Study 2 (NLTS2) has begun to look at this problem, but more is needed.

More work focusing on disability, including intersections with other culturally constructed identities such as race, is needed within anthropology. Disability is a social construct and at the same time has real medical implications. Anthropologists are well situated to uncover and unravel the cultural components of disability. Medical anthropology often offers critique of societal constructs of medicine, health, and wellness. I understand why research on disability has found a home within the Society for Medical Anthropology, but given the particular stigma associated with the medical field and medicalization of disability, it seems that this continues to perpetuate the situating of disability as a medical problem to be solved by the individual as opposed to reflection of the larger cultural construct. Anthropologists such as Ginsburg and Rapp (2013 & 2020), Hartblay (2020), Kasnitz (2020), have long studied disability through an anthropological lens and their work certainly exists outside of a medicalized model. I am proud to be among these anthropologists.

#### II. Conclusion

The exclusion of disability as a normal component of the human experience is perpetuated within the education system from kindergarten through post-secondary education. As the major force for enculturation, teachers are ill prepared for the realities of the education system. They have been raised on bootstrap ingenuity and elitist notions of the potential for change. Teachers earnestly practice what they learn, that disability must be handled and managed to provide the best outcomes for all students. Segregated classrooms still exist for the most severely disabled students. Through continued othering and exclusion of disability in important and formative environments, disability is not seen as a normal part of being human. Non-

disabled children do not learn that using a wheelchair is not a deficit but a tool to move within and access the world, or that service animals are working and need to focus. Disabled children do not learn they are "normal." Instead, children whisper questions about why someone has a cane or uses a letter board to adults who are embarrassed that their child has noticed the difference. Afterall, this is how they were taught to engage with disability too; to ignore that disability exists as a kindness and move on. And the belief that it is kind to ignore disability influences and infiltrates higher education. The system, on all levels, has created deficits, morale disintegration, repeated cycles of poor integration practices and poor graduation rates. This cycling of oppression, crafted exclusion from the benefits of the system, and lack of cultural capital within the system is the epitome of structural violence. The Accessibility Expedition is a tool to begin to change the structure. To empower the oppressed and to reset the American cultural narrative around disability.

Wolf discusses stratification through anthropological interpretations of dependency theory and World System theory, focusing his attention on the so-called developing world and small-scale societies to illustrate his arguments about capitalism's undermining of indigenous cultural systems across the world and the creation of unimaginable wealth and devastating poverty. In *Europe and the People Without History* (1982), Wolf's narration and critique of European capitalism opened the door for analysis of large-scale societies and their hegemonic control of world political, economic and social systems (McGee and Warms 2008, 268). He also advocated for the voices of the observed to be used within the academic analysis of anthropological research as a tool to even the narrative of history between the wealthy and powerful and the poor and oppressed (McGee and Warms 2008, 268). Wolf's framing of power relationships and identification of voice have strong implications within my work as a way to

critique and narrate the story of the United States education system both historically and through the eyes of the participants. Similar to Philippe Bourgois's study of El Barrio, I hope to bring to light the contextual repression of disabled people in the education system. Bourgois's work, in my mind, complements the frameworks of Farmer and Wolf through his use of political economy to identify the players, their roles and the structural underpinnings of oppression and inequality present (Bourgois 1995).

This is ultimately a story about education and the power that structural change can make when the enculturative practices in our education system shift to recognize disability and the barriers the structure creates. This is a story of childhood and enculturation practices that perpetuate systemic problems framed here as structural violence. This is a story of America at its finest and at its worst; a place that asks the world to, "Give me your tired, your poor, your huddled masses yearning to breathe free, the wretched refuse of your teeming shore. Send these, the homeless, tempest-tost to me, I lift my lamp beside the golden door!" (Lazarus 1883) yet fails time and again to satisfy the invitation. This is the story of disability and disabled people who find themselves engaged in a system that does not meet them where they are and routinely denies access through years of exclusion. This is the story of a system in dire need of change, or perhaps demolition. From the ashes of the old comes the new. It is also a story of change, advocacy, allyship, and empowerment through knowledge and new enculturative experiences like the Accessibility Expedition designed to crumble the structure.

#### References Cited

#### ADA

1990 Americans with Disabilities Act. ADA website. Accessed November 27, 2022. https://www.ada.gov/pubs/adastatute08.htm.

## AHEAD Statement on Language

2022 AHEAD website. Accessed November 28, 2022. <a href="https://www.ahead.org/professional-resources/accommodations/statement-on-language">https://www.ahead.org/professional-resources/accommodations/statement-on-language</a>.

# Bennett de Marrais, Kathleen and Margaret D. LeCompte

1999 The Way Schools Work: A Sociological Analysis of Education. New York: Longman. 3rd Edition.

# Bernard, H. Russell

2006 Research Methods in Anthropology: Qualitative and Quantitative Approaches. 4th edition. Lanham: Altamira Press.

# Bourdieu, Pierre

1977 Structures and the Habitus. *In* Anthropology in Theory: Issues in Epistemology. Henrietta L. Moore and Todd Sanders, eds. Pp. 407-416. Malden: Blackwell Publishing.

# Bourgois, Philippe

1995 From Jíbaro to Crack Dealer: Confronting the Restructuring of Capitalism in El Barrio. *In* Articulating Hidden Histories: Exploring the Influence of Eric R. Wolf. Jane Schneider and Rayna Rapp, eds. Pp. 125-141. Berkeley: University of California Press.

2003 In Search of Respect: Selling Crack in El Barrio. 2nd edition. Cambridge: Cambridge University Press.

# Burgstahler, Sheryl and Tanis Doe

2004 Disability-related Simulations: If, When, and How to Use Them in Professional Development. *Review of Disability Studies*, 1(2):4-17.

# Center for Universal Design

1997 The Seven Principles of Universal Design. North Carolina State University website. Accessed September 12, 2022.

https://projects.ncsu.edu/ncsu/design/cud/about\_ud/udprinciplestext.htm.

#### Disability Research Interest Group (DRIG)

2022 Society for Medical Anthropology website. Accessed November 25, 2022. <a href="https://medanthro.net/interest-groups/drig/">https://medanthro.net/interest-groups/drig/</a>

# Dolmage, Jay Timothy

2017 Academic Ableism. Ann Arbor: University of Michigan Press.

#### DO-IT Center

2022 What Is the Difference Between an IEP and a 504 Plan? DO-IT Center website. Accessed November 27, 2022. <a href="https://www.washington.edu/doit/what-difference-between-iep-and-504-plan.">https://www.washington.edu/doit/what-difference-between-iep-and-504-plan.</a>

# Farmer, Paul

2005 Pathologies of Power: Health, Human Rights, and the New War on the Poor. Berkley: University of California Press.

#### Freire, Paulo

2009 Pedagogy of the Oppressed 30<sup>th</sup> Anniversary Edition. New York: Continuum International Publishing Group, Inc.

# Ginsburg, Faye and Rayna Rapp

2013 Disability Worlds. Annual Review of Anthropology, 42:53-68.

2020 Disability/Anthropology: Rethinking the Parameters of the Human, An Introduction to Supplement 21. *Current Anthropology*, 61(suppl. 21):S4-S15.

# Hartblay, Cassandra

2020 Disability Expertise: Claiming Disability Anthropology. *Current Anthropology*, 61(suppl. 21):S26-S36.

# Henley, Ariel

2020 There's a Mathematical Equation That Proves I'm Ugly. In Disability Visibility: First-Person Stories From the Twenty-First Century. Alice Wong, ed. Pp. 39-46. New York: Random House Press.

#### **IDEA**

1990 Individuals with Disabilities Education Act. Department of Education website. Accessed November 25, 2022. https://sites.ed.gov/idea/statuteregulations/#statute.

#### Institute for Human Centered Design

2016 ADA Checklist for Existing Facilities. Accessed September 9, 2022. <a href="https://www.adachecklist.org/checklist.html">https://www.adachecklist.org/checklist.html</a>

#### Jung, Hyang Jin

2007 Learning to Be an Individual Emotion and Person in an American Junior High School. New York: Peter Lang Publishing.

#### Kasnitz, Devva

2020 The Politics of Disability Performativity: An Autoethnography. *Current Anthropology*, 61(suppl. 21):S16-S25.

#### Lanterman, Chris and Lauren Copeland-Glenn

2022 Pity to Power Continuum. Evaluation framework in development.

# Lazarus, Emma

1883 "The New Colossus." Plaque engraving on base of the Statue of Liberty. NY, New York.

#### Linton, Simi

1998 Claiming Disability: Knowledge and Identity. New York: New York University Press.

# McGee, R. Jon and Richard L. Warms

2008 Anthropological Theory: An Introductory History. New York: McGraw Hill.

#### McLaren, Peter

1986 Schooling as a Ritual Performance: Towards a Political Economy of Educational Symbols & Gestures. New York: Routledge.

## Mead, Margaret

1971 Early Childhood Experience and Later Education in Complex Cultures. *In* Anthropological Perspectives on Education. Murray L. Wax, Stanley Diamond, and Fred O. Gearing, eds. Pp. 67-90. New York: Basic Books, Inc.

# National Center for Educational Statistics (NCES)

2018 Status and Trends in the Education of Racial and Ethnic Minorities. Washington D.C.: U.S. Department of Education.

# Postsecondary National Policy Institute

2022 Students with Disabilities in Higher Education report. PNPI website. Accessed December 13, 2022. <a href="https://pnpi.org/wp-content/uploads/2022/10/StudentswithDisabilities">https://pnpi.org/wp-content/uploads/2022/10/StudentswithDisabilities</a> October 2022.pdf.

# Office of Special Education Programs (OSEP)

2021a Fast Facts: Race and Ethnicity of Children with Disabilities Served under IDEA Part B. Department of Education website. Accessed November 26, 2022.

https://sites.ed.gov/idea/osep-fast-facts-race-and-ethnicity-of-children-with-disabilities-served-under-idea-part-b/.

2021b Fast Facts: School Aged Children 5 (in Kindergarten) Through 21 Served Under Part B, of the IDEA. Department of Education website. Accessed November 26, 2022. <a href="https://sites.ed.gov/idea/osep-fast-facts-school-aged-children-5-21-served-under-idea-part-b-21/">https://sites.ed.gov/idea/osep-fast-facts-school-aged-children-5-21-served-under-idea-part-b-21/</a>.

# Paley, Vivian Gussin

2000 White Teacher. Cambridge: Harvard University Press.

#### Rosaldo, Renato

1989 Culture & Truth the Remaking of Social Analysis. Boston: Beacon Press.

Salmen, John P.S.

2011 Universal Design for Academic Facilities. *New directions for student services*. 134:13-20.

# Schensul, Jean J. and Margaret D. LeCompte

1999a The Ethnographer's Toolkit, vol. 2: Essential Ethnographic Methods. Lanham: Altamira Press.

1999b The Ethnographer's Toolkit, vol. 3: Enhanced Ethnographic Methods. Lanham: Altamira Press.

#### Section 504

1973 Rehabilitation Act. Department of Labor website. Accessed November 25, 2022. <a href="https://www.dol.gov/agencies/oasam/centers-offices/civil-rights-center/statutes/section-504-rehabilitation-act-of-1973">https://www.dol.gov/agencies/oasam/centers-offices/civil-rights-center/statutes/section-504-rehabilitation-act-of-1973</a>.

# Spindler, George D.

1963 Education and Culture: Anthropological Approaches. New York: Holt, Rinehart and Winston, Inc.

Story, Molly Follette, James L. Mueller, and Ronald L. Mace

1998 The universal design file: Designing for people of all ages and abilities. Raleigh: North Carolina State University.

#### Varenne, Hervé

1977 Americans Together, Structured Diversity in a Midwestern Town. New York: Teachers College Press.

# Vigil, James Diego

2002 Personas Mexicanas Chicano High Schoolers in a Changing Los Angeles. Mason: Cengage Learning.

2012 From Indians to Chicanos The Dynamics of Mexican-American Culture. 3rd edition. Long Grove: Waveland Press. Inc.

# Watchorn, Valerie, Helen E. Larking, Danielle Hitch and Susan Ang

2014 Promoting participation through the universal design of built environments: Making it happen. *Journal of Social Inclusion*. 5(2):65-88.

#### Wolf, Eric

1982 Europe and the People without History. Berkley: University of California Press.

2001 Pathways of Power: Building an Anthropology of the Modern World. Berkley: University of California Press.

# Zirkel, Sabrina and Nancy Cantor

2004 50 Years After Brown v. Board of Education: The Promise and Challenge of Multicultural Education. *Journal of Social Issues*, 60(1):1-15.

Appendix A

The Accessibility Expedition: Viewing Design Through the Disability Lens

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**Abstract** 

Physical accessibility at colleges and universities is a perennial and challenging issue. Some

campuses have made efforts to address these challenges through a variety of advocacy initiatives,

while others have used disability simulations to bring greater awareness to campus communities

around physical accessibility. An alternative approach to disability simulations and other

accessibility awareness exercises is the Accessibility Expedition (AE). The AE engages

participants in an exploration of campus spaces facilitated by disabled individuals and

individuals knowledgeable of ADA Standards for Accessible Design and/or universal design.

The exploration is followed by a debriefing session to discuss barriers to equitable participation,

as well as evidence of accessible or universal design practices. The description, rationale, steps

for implementation, and observed outcomes of the AE practice are discussed.

Keywords: accessibility, physical spaces, facilities, postsecondary

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# **Summary of Relevant Literature: Simulations and Universal Design**

Physical accessibility at colleges and universities is a perennial and challenging issue (e.g., Gilson & Dymond, 2012; Woods, 2016; Salmen, 2011). While some campuses have made efforts to address these challenges through a variety of advocacy initiatives (e.g., Agarwal et al., 2014), disability simulations are often used in attempts to increase awareness about the experiences of individuals with disabilities within the physical environment (Burgstahler & Doe, 2004; Levett-Jones et al., 2017; Nario-Redmond et al., 2017; Silverman et al., 2014). Many simulations have focused on physical or vision impairment (Flower et al., 2007) or hearing loss (Nario Redmond et al., 2017). Disability simulations often position participants in wheelchairs, or have them wear blindfolds, or earplugs as they complete a set of tasks (Nario Redmond et al., 2017). Disability simulations can create stereotypical, incomplete, or inaccurate perceptions of the experience of individuals with disabilities (Burgstahler & Doe, 2004). In their meta-analysis of disability simulation studies, Flower et al. (2007) found that outcomes of such simulations are mixed. For example, simulations may increase empathy among those who participate in them (Nario-Redmond et al, 2017), but can increase participant sympathy toward those with disabilities as well (Silverman et al., 2017). They can create distress among participants (Nario-Redmond et al., 2015), negatively impact participant judgement regarding the capabilities of individuals with disabilities (Silverman et al., 2017), and perpetuate pity and negative stereotypes of individuals with disabilities (Lalvani & Broderick; 2011; Valle & Connor, 2019) because simulations do not represent an authentic experience of disability. The potential negative outcomes of disability simulations (Burgstahler & Doe, 2004) suggest that alternative approaches must be considered that can lead to action toward more accessible and inclusive college campuses.

The Accessibility Expedition (AE) builds on the work of Burgstahler & Doe (2004) to offer an innovative approach to promoting accessible design that avoids negative outcomes from some of the typical simulation activities and offers a facilitated exploration of design features that enable or constrain equitable access and participation for individuals with and without disabilities. The goal of the AE is to help participants see their environment through a lens of equity and inclusion rather than through simulated experiences. Universal design is "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (North Carolina State University, 1997, n.p.). Embedding the lens of universal design within the AE is significant because "[u]niversal design is ultimately a process that empowers people by giving them more control over their lives and choice in the things that they do or the way in which they do those things" (Salmen, 2011, 15). Providing participants with opportunities to explore ways in which a design can constrain control provides a strong foundation for advocacy and change.

The AE engages participants in a guided conversation about various features of a public space, such as a university campus through a universal design lens. Disabled individuals, personnel knowledgeable of ADA Standards for Accessible Design, and universal design advocates lead groups of participants through specifically selected areas of campus and discuss features of physical and landscape design, including paths of travel, building features and amenities, ingress and egress, and other temporal design considerations, such as the placement of event signage, that may present various challenges to accessibility, usability, and safety. Each group follows a carefully designed set of tasks (see Appendix A) that take them through buildings into restrooms, on elevators, into classrooms and lecture halls, across pedways, and into coffee shops. Groups are asked to experience and evaluate the levels of access afforded to

individuals within the group and infer who may or may not be able to access the spaces and reflect on the characteristics of people who were likely considered in the design process. During the AE, participants take photos and share them via a designated Twitter hashtag to discuss and process following the campus exploration during the AE debrief.

The AE helps to educate the participants in basic Americans with Disabilities Act (ADA) and Architectural Barriers Act (ABA) design requirements and in the basic principles of universal design (UD). Through its approach to engage with design guidelines AND the lived experiences of people with disabilities, the AE has the potential to positively impact accessibility efforts and systemic thinking for institutions and their disability resources offices as well as those that focus on the physical environment.

"Universal design continues to be relevant to the design of built environments in today's society as a means of addressing the broadest needs of people and populations regardless of abilities, needs and roles" (Watchorn et al., 2014, p. 71.). Indeed, understanding that equitable participation means that ALL are able to participate together is one of the main foci of the AE. Facilitators of the AE bring their knowledge of ADA design standards and universal design to demonstrate that the ADA requires minimum levels of accessibility for disabled persons, while universal design intends to create spaces that are inclusive and usable for all people.

# **Background** and participation

The AE originated at Northern Arizona University (NAU) as part of events sponsored by the NAU 4 All student organization, whose mission encompasses advocating for the creation of inclusive spaces and reduction of attitudinal barriers across the campus. While the AE has ostensibly focused on physical and wayfinding characteristics of the campus, conversations resulting from the AE also involve dialogue around attitudinal barriers to equitable participation

and inclusion for all marginalized groups. When the AE was first conceived, and for many years and at many AHEAD conferences, this event was known as the Accessibility Scavenger Hunt. Feedback from Indigenous individuals on campus suggested that the word scavenger could be offensive to some constituents. As a result, a re-envisioning of the name took place. The Accessibility Expedition was chosen to imply and foreground an adventure of the unknown and a feeling of discovery.

NAU 4 All and NAU's Commission on Disability Access and Design (CDAD)<sup>2</sup> partner to organize and facilitate each AE. Since the event's inception, the partnership between NAU 4 All and CDAD has resulted in a semi-annual AE, exploring different areas of the campus each semester. During the fall semester, the AE is an anchor event with NAU's Disability Pride and Heritage Month (DPHM) in October, which features a series of events to highlight and privilege the disability experience, to confront ableism in all its forms, and to bring attention to the contributions of individuals with disabilities to society. In the spring, the AE shifts to south campus to ensure full coverage of the campus environment, including historic and modern spaces.

#### **Description of AE Practice**

An integral element of helping AE participants explore design features is the embedded investigation of features of physical and exterior spaces that reflect the application of universal design. Universal design was conceptualized by Ronald Mace, a wheelchair user and architect, along with colleagues from North Carolina State University (Story et al., 1998). Mace found that many of the design solutions mandated by the Architectural Barriers Act, were valuable for

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<sup>&</sup>lt;sup>1</sup> NAU's Commission on Disability Access and Design is a body that serves as advisory to the Office of the President on issues related to individuals with disabilities, accessibility, design, and other disability-related matters. Membership in CDAD is voluntary and is representative of staff, students, and faculty from across the institution.

many users, not just those with disabilities. Additionally, he found that most design solutions were cost-effective and aesthetically pleasing when implemented appropriately at the beginning of a design project. In their work to articulate principles of effective design, Mace and his colleagues established the Seven Principles of Universal Design (see Table 1). The Center for Universal Design (CUD) at North Carolina State University, which Mace helped to establish, defines these principles and provides basic guidelines for each of The Seven Principles of Universal Design (Center for Universal Design, 1997).

**Table 1**The Seven Principles of Universal Design

Principle	Description
Principle 1: Equitable Use	The design is useful and marketable to people with diverse abilities.
Principle 2: Flexibility in Use	The design accommodates a wide range of individual preferences and abilities.
Principle 3: Simple and Intuitive Use	Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
Principle 4: Perceptible Information	The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
Principle 5: Tolerance for Error	The design minimizes hazards and the adverse consequences of accidental or unintended actions
Principle 6: Low Physical Effort	The design can be used efficiently and comfortably and with a minimum of fatigue.
Principle 7: Size and Space for Approach and Use	Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

*Note:* Adapted from the Center for Universal Design (1997)

As participants in the AE arrive at a designated, central location to begin the exploration, they are randomly assigned to a group, 1-5 depending on the number of group facilitators; ideally groups are not larger than 20. The AE facilitator provides a welcome and outlines the event and rules. Each group is provided an initial set of tasks to complete and a path to follow. The task sheets (see Appendix A) include questions to consider and expectations for equitable participation. These considerations and expectations are designed to bring attention to accessibility challenges that individuals without disabilities might take for granted (see Table 2).

Table 2
Accessibility Expedition Considerations and Expectations

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<ul> <li>Who is, and who is not, able to participate in an activity here? Why?</li> </ul>	stairs.  off of or onto curbs.  nat everyone gets to the on in the same way.  tated campus rules (e.g., use

Each group is asked to make numerous observations and document their observations with photos along the way. Photos are sent to a predefined Twitter hashtag for review during the debrief. At the end of the first leg of the route, the next task is located in an envelope bearing the active International Symbol of Accessibility (ISA) with a raised tactile outline of the shape (see Appendix B). Groups are provided relevant sections of the "ADA Checklist for Existing"

Facilities" (Institute for Human Centered Design, 2016) on the AE for guidance on properly measuring features, such as the height of a counter or turning radius in a restroom stall. Tools such as measuring tapes and smart levels for gauging slope are also provided to the groups. The use of tools helps participants understand the difference between meeting a minimum requirement, such as the ADA Standards for Accessible Design, and thoughtful, inclusive design, as suggested by the principles of UD. Group leaders help to point out features in spaces that are examples of design barriers, minimally accessible design, and inclusive design. These experiences allow participants to become better advocates when they encounter a potential barrier and to provide suggestions for changes to improve the physical and social inclusion of people with disabilities in every space on the campus.

Following the exploration, participants meet to process the findings and dialogue the pros and cons of certain environmental features discovered on the AE. This conversation focuses on design considerations for accessibility, usability, and safety, rather than simply an imagined challenge faced by people with disabilities. An integral and critical element of the AE and conversation is the participation of individuals with various disabilities. These referents allow for a grounded dialogue that exposes stereotyped and pity-based perspectives of disability experiences and foregrounds the lived experiences of people with disabilities. Individuals versed in ADA accessible design standards and universal design are also an integral part of the discussion to provide guidance to help participants understand why some decisions may have been made and how better design could go beyond minimum code compliance.

### **Outcomes**

While no formal qualitative or quantitative analysis of the AE has yet been completed, positive outcomes are suggested by dialogue that occurs in the activities that suggests that

participation in the AE results in increased knowledge about universal design of the physical environment, increased understanding of the lived experience of disabled individuals, and concrete suggestions for making physical environments more accessible.

Positive outcomes observed also include increases in advocacy by students, faculty, and staff in key areas across campus. Participant discussions reflect an understanding of aspects of designs that result in spaces that are either accessible or inaccessible to disabled individuals, as well as design that creates equitable and inclusive environments for all institutional constituents. Additionally, participants gain an awareness of barriers to equitable participation for which project cost or complexities of barrier remediation create implementation limitations. Evidence of a shift in understanding and focus on universal design is seen in regular advocacy for universal design by the Facility Services project managers in their interactions with outside design firms and construction companies selected for capital projects on campus. The ADA Coordinator and members of the CDAD are no longer the main (or only) entities ensuring compliance with code and advocating for universal design.

Other outcomes of the AE include positive increases in knowledge and understanding that led to intentional, well-informed advocacy from students, staff, and faculty in a way that does not create pity for people with disabilities. Rather, such advocacy foregrounds the need for full inclusion in all design conversations. Over the more than 10 years of this semi-annual event, important observations and findings have led to powerful student advocacy. Most notably, student participants in the AE identified barriers to accessibility in the university bookstore and post office. The post office, located in the basement of the bookstore building, did not have an accessible entrance. Wheelchair users were assigned separate post office boxes at the top of the stairs and had to ring a doorbell to call an attendant to retrieve parcels too large to fit in the

boxes. Additionally, the only access to the bookstore was through a locked side entrance at the top of an exterior ramp.

After the bookstore site was included as a stop on the AE, it became apparent to the participants that it needed extensive but important renovations for accessibility. Students wrote letters advocating for more accessible access to both levels of the building. As a result of their advocacy, the installation of an elevator that provided access from street level to the lower post office level and the main level of the bookstore was subsequently completed.

Another example that illustrates the importance of collaboration and partnerships developed from participation in the AE, is the construction of an all gender restroom in the campus library. After the exploration of the campus library, the debrief conversation centered on the observation that the existing restrooms are a challenge for those needing an attendant or a service animal or more space for a larger wheelchair, among other observations. The library accepted the challenge to fix the problem and engaged in a collaboration with CDAD, and others, to advocate for the renovation of an unused custodial space into a single stall, all gender restroom.

The elevator at the campus bookstore and the library restroom are only two examples of many improvements that the university has made as a result of the AE. Some of these projects have been larger capital projects, such as adding braille signage throughout the campus library or replacing and expanding existing concrete paths of travel to address slope, width, detectable barriers, and maintenance. The advocacy from the AE has also led to less costly improvements, though no less valuable. For example, weekly updates are now provided during the summer months of construction to report specific information regarding construction updates, alternate paths of travel, and other wayfinding information. Specific and targeted participation has also

yielded advocates in important areas of campus, such as project managers in construction, design, code enforcement, and space planning professionals. Further, academic administrators and faculty in relevant departments (e.g., construction management, civil engineering) are also critical participants in the AE.

### **Engaging the Community**

A secondary outcome of the AE is the broad interest and participation of the university community. Each year, scores of participants join the AE from various units and classes to learn about the continuing design challenges and progressive design solutions across campus. NAU's Facility Services department participates regularly and has taken an active role in processing the findings and taking action to respond to issues raised in the AE. The Facility Services staff who join the AE take pride in the positive design features highlighted during the event. The AE is also used as a professional development opportunity for people in the construction trades, environmental sustainability, and project management.

Facility Services is only one constituent participating in the AE. Students from disciplines all over campus join the event, including those from construction management, education, and the disability studies academic programs. Staff and faculty members, some with disabilities themselves, from a variety of departments also join the AE each semester. Facilitation in the AE for individuals with mobility impairments is mandated by the protocols of the AE (e.g., all participants must use the same path of travel). For participants with sensory impairments, participation is facilitated with sighted guides or ASL interpreters, not as accommodations for participation but as a model for inclusion.

The continuous development of the AE suggests an increasing interest in accessibility and universal design across campus. For example, the Dean of Students Office requested that the

AE be included in Homecoming events last year to highlight for alumni and parents the history, growth, and continuing opportunities for development of campus design.

The AE has further evolved to include a greater emphasis on the features of campus that reflect the university's commitment to universal design. The additional emphasis on universal design features also helps to bring increased consciousness to participants of the ways in which design can positively impact a diverse population of community members. When potential barriers are discussed following the actual campus walk, participants begin to view these barriers as new opportunities for remediating physical barriers and facilitating inclusive participation. While the AE is not intended to constitute a stand-alone curriculum, the conversations about disability, representation, barriers, and universal design persist and infiltrate the work of faculty, staff, and students from across campus in disciplines stretching from health and human services to engineering to education to history. Participants learn from one another and explore how to apply these experiences in their own disciplines and work.

Another outcome of the AE is its incorporation of UD practices and other disabilityrelated topics into course curriculum for disciplines that have a direct impact on design and
construction. For example, NAU's construction management program requires attendance and
participation in the AE by students in its introductory course. During the COVID-19 pandemic,
the AE was modified into a self-directed project students could complete from home,
investigating their homes and neighborhoods. While not as effective without the discussion, it
still provided an opportunity for students to engage with their environments using a new lens.
Students in the construction management program go on to work for large and small construction
firms, universities, and to open their own businesses. Experiencing the AE provides first-hand
understanding of the barriers created for people with disabilities when they are not considered in

design from the beginning, or how often simple design changes can eliminate those barriers and make spaces better for everyone. Including a framework of universal design provides students a vocabulary to use in their future roles. This is a larger attitudinal shift for students who most often have not considered the ways in which design of the environment continues to disable people.

## **Implications and Transferability**

The AE has wide reaching implications for institutions interested in establishing their own events. The model is straightforward to follow and can result in a level of empathy, understanding, and empowerment not available through typical simulations. It is also flexible enough to be implemented in a variety of contexts including conference sessions and course modules. The AE model avoids creating or exacerbating pity for people with disabilities. Instead, it sheds light on real barriers experienced by real people. The model is nimble and can be applied to any environment, including virtual environments, as long as four conditions are met:

- 1. People with disabilities lead and participate in each group.
- 2. People with significant experience in code compliance (i.e., ADA, WCAG) and universal design construct the tasks and participate in each group.
- 3. Both barriers and examples of accessible and/or universal design are included in each group's physical or virtual destinations.
- 4. The AE ends with a debriefing that consists of a discussion of observations and experiences centering the voices of people with disabilities.

NAU has worked hard to ensure that disability is included in the diversity, equity, inclusion, and justice framework of the university. The disability resources office does not directly manage or run the AE. However, staff from this office provide invaluable expertise on disability-related and

accessibility topics as groups traverse campus and then discuss their findings. Other institutions may need to rely solely on the disability resources office to design an AE. Regardless, disability resources offices are key constituents in a successful event. Other groups who may have vested interests in accessibility, universal design, and the experiences of disabled individuals may also be invited to participate in an AE. Each institution will be able to identify its own set of interested collaborators, based on its composition, needs, and accessibility/universal design allies. The following are groups, other than Facility Services, that are invited to participate in NAU's AE:

- Student organizations (especially student organizations on disability or diversity)
- Committees, working groups, and others focused on disability inclusion
- Academic programs like construction management, civil engineering, computer science
  (for virtual events), architecture or landscape architecture, informatics, health and human
  services, geodesign/parks and recreation management, geography and planning
- Library
- Education, special education, and disability studies programs
- Community partners
- Administration
- Parking services

#### Conclusion

Full inclusion of people with disabilities on university and college campuses takes more than a committed disability resources office. A substantial shift in the continuum from pity to power will require a critical examination of the physical and attitudinal barriers that are foundational to the ways in which we construct our environments. Allies from across campus

must come together to enact change. The AE is a promising practice for advocacy and ally building. Providing students, staff, and faculty with tools to evaluate their environments promotes lasting change across the institution. Outcomes of the AE suggest that it is an effective tool to educate and engage a wide range of campus constituents from students to administrators. The grassroots nature of the AE centers the voices of people with disabilities and empowers them to move from passive user to central advocate. Through participation in the AE a deeper understanding of both the power and the pitfalls of laws such as the ADA is gained and then built upon using the framework of universal design.

The AE forces disability to the forefront and creates empowered advocates and allies. The diversity of representation among participants from various units and groups across the institution also helps to build partnerships between groups and departments who may not normally engage. Students gain knowledge in the complicated functioning of the university and begin to see where their power lies in advocating for change. Longer-term effects are reflected in the quality collaborations and engagement of people with disabilities in university wide conversations on master planning, inclusion on hiring committees, and requests for advice and consultation from across campus. The AE at its core is a tool for inclusion with a mission to meet people where they are and provide guided and supportive movement toward understanding and advocacy.

#### References

- Agarwal, N., Calvo, B., & Kumar, V. (2014). Paving the Road to Success: A Students with Disabilities Organization in a University Setting. *College Student Journal*, 48(1), 34-44.
- Burgstahler, S., & Doe, T. (2004). Disability-related simulations: If, when, and how to use them in professional development. *Review of disability studies*, *1*(2), 4-17
- Center for Universal Design (1997). The seven principles of universal design. Retrieved from <a href="https://projects.ncsu.edu/ncsu/design/cud/about\_ud/udprinciplestext.htm">https://projects.ncsu.edu/ncsu/design/cud/about\_ud/udprinciplestext.htm</a>
- Flower, A., Burns, M. K., & Bottsford-Miller, N. A. (2007). Meta-analysis of disability simulation research. *Remedial and Special Education*, 28(2), 72-79.
- Gilson, C. L., & Dymond, S. K. (2012). Barriers impacting students with disabilities at a Hong Kong university. *Journal of Postsecondary Education and Disability*, 25(2), 103-118.
- Institute for Human Centered Design (2016). ADA checklist for existing facilities. Retrieved from <a href="https://www.adachecklist.org/checklist.html">https://www.adachecklist.org/checklist.html</a>
- Lalvani, P., & Broderick, A. A. (2013). Institutionalized ableism and the misguided "Disability Awareness Day": Transformative pedagogies for teacher education. *Equity & Excellence in Education*, 46(4), 468-483.
- Leo, J., & Goodwin, D. (2016). Simulating others' realities: Insiders reflect on disability simulations. *Adapted physical activity quarterly*, 33(2), 156-175.
- Levett-Jones, T., Lapkin, S., Govind, N., Pich, J., Hoffman, K., Jeong, S. Y. S., et al. (2017). Measuring the impact of a 'point of view' disability simulation on nursing students' empathy using the Comprehensive State Empathy Scale. *Nurse education today*, *59*, 75-81.
- Nario-Redmond, M. R., Gospodinov, D., & Cobb, A. (2017). Crip for a day: The unintended negative consequences of disability simulations. *Rehabilitation psychology*, 62(3), 324.
- North CarolinaState University. (1997). The principles of universal design. Raleigh, NC: Center for Universal Design, North Carolina StateUniversity. Retrieve from http://www.ncsu.edu/ncsu/design/ cud/about\_ud/udprinciples.htm
- Silverman, A. M., Gwinn, J. D., & Van Boven, L. (2015). Stumbling in their shoes: Disability simulations reduce judged capabilities of disabled people. *Social Psychological and Personality Science*, 6(4), 464-471.
- Salmen, J.P.S. (2011). Universal Design for Academic Facilities. *New directions for student services*, 134, 13-20.
- Story, M. F., Mueller, J. L., & Mace, R. L. (1998). *The universal design file: Designing for people of all ages and abilities.* Raleigh, NC: North Carolina State University.

- Valle, J., & Connor, D. J. (2019). *Rethinking disability: A disability studies approach to inclusive practices* (2<sup>nd</sup> ed.). New York, NY: McGraw-Hill.
- Watchorn, V, Larkin, H. E., Hitch, D., & Ang, S. (2014). Promoting participation through the universal design of built environments: Making it happen. *Journal of Social Inclusion*, 5(2), 65-88.
- Woods, B. N. (2016). Bobcat Accessible: An Ethnographic Study of Manual Wheelchair Use as it Relates to ADA Accessibility and Design at Texas State University.

## Appendix A

**Tasks** 

## Group 1: Task 1

Tweet pictures and location description using #NAUDPHM

## 1. Start at the SAS building

## 2. Go to the Aquatic and Tennis Complex (ATC) (20 minutes)

- **a.** How did you get there? Describe the path of travel and entrance. Can everyone travel together?
- **b.** Find the All Gender changing/restroom. Was it easy to find? Could you get to the pool deck easily? Could you find it again from the pool deck?
- **c.** How about a soak in the hot tub? Who is, and who is not, able to participate in an activity here? Why?
- **d.** Are you hungry after your trip to the pool? Visit the vending machines.
- **e.** Find the viewing area and your next task. What do you notice about who is included in this space? Is anyone excluded?



### PROCEED TO YOUR NEXT TASK!

## Group 1: Task 2

Tweet pictures and location description using #NAUDPHM

- 3. Make your way to the <u>West Entrance</u> of the HLC (main entrance) (10 minutes)
  - **a.** What do you notice about the crosswalk?
  - **b.** Describe the entrance? Can everyone travel together?
  - **c.** Find the Directory and your next task. How do you get to Disability Resources? Is this signage accessible and clear for everyone? Why or why not?



PROCEED TO YOUR NEXT TASK!

## Group 1: Task 3

Tweet pictures and location description using #NAUDPHM

## 4. Find the **East Entrance** of the Bookstore (20 minutes)

- **a.** Was the entrance accessible? Can everyone travel together?
- **b.** Exit the building on the west side. Is the signage clear? How did you get there?
- **c.** Before you leave go to the Post Office and find your final task. How did you get there? Can everyone get their mail?



PROCEED TO YOUR NEXT TASK!

# Group 1: Final TASK

5. Go to the SAS auditorium patio on the south side of the building for debriefing and snacks! (10 minutes)

Take note of any barriers you encounter along the way! Send pictures!

Appendix B

ISA for Task Envelops

