Public Transportation Access and Community Participation for Latinxs with Disabilities

BY

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DISSERTATION

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Yolanda Suarez-Balcazar, Chair and Advisor Robin Jones Akemi Nishida Susan Magasi, Occupational Therapy Sandra Magaña, University of Texas at Austin This dissertation is dedicated to two women who have inspired me throughout the course of the project. The first is my late grandmother, Sophie Salkas, who encouraged me from childhood to empower those who were marginalized. The second is my late colleague, Sara Capetillo, who passed away during the realization of the project and who worked alongside me to make it happen. Both of these women inspire my fight for social justice, disability rights, and humanism that only begins with this project.

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LIST OF ABBREVIATIONS

ADA	Americans with Disabilities Act
PARC	Participatory Action Research Consortium
ASL	American Sign Language
СТА	Chicago Transit Authority
IDD	Intellectual and developmental disability
NCD	National Council on Disability
РА	Personal attendant
RTA	Regional Transportation Authority
SES	Socioeconomic status
TCRP	Transit Cooperative Research Program
USDOT	United States Department of Transportation

I. INTRODUCTION

People with disabilities commonly encounter issues accessing and using transportation. Due to these issues in transportation access and usage, people with disabilities often experience isolation, they cannot receive the community services such as education and employment that non-disabled people can, and they often report health disparities due to trouble accessing medical care. These problems are magnified for Latinxs with disabilities, whose cultural, linguistic, and socioeconomic status (SES)-related contexts present even more barriers in accessing and using transportation services (Blumenberg, 2008; Casas, Arce, & Frye, 2004; Tal & Handy, 2010).

When studying transportation for people with disabilities it is important to specifically consider access to public transportation. People with disabilities rely heavily on public transportation to get around, especially compared to their non-disabled counterparts, and the use of public transportation among people with disabilities is growing (Transit Cooperative Research Program [TCRP], 2013).

Latinx is the gender-neutral term for people of Latin American descent living in the US. Latinxs are the focus of this paper because Latinxs are the largest and fastest growing minority ethnic group in the US (Torres-Gil & Lam, 2012; US Census Bureau, 2016). Furthermore, Latinxs tend to experience disability in unique ways compared to other people of color due to cultural, economic, and social factors. We must prepare professionals in the US with the cultural tools to work with this population to meet their needs since Latinxs are becoming an increasingly larger portion of the population. Furthermore, it is well-documented that Latinxs, and particularly Latinxs with disabilities and chronic health conditions, experience disparities in their ability to access and participate in their communities like other people of color, making access to

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community resources such as medical care for this population is more important than ever (Hammel et al., 2008).

As an additional point, it is important to note that this paper is making broad statements about Latinx culture that may not correspond to the beliefs of all individuals who identify as Latinx. Latinx people are quite a heterogeneous population, coming from many different countries with varying political histories, cultures, and racial make-ups, individuals with different educational and socio-economic levels by the time they migrate to the States, and even speaking different languages. Many Latinxs do not view all Latinxs as sharing a single identity (Magaña, 2000; Zea, Quezada, & Belgrave, 1994). However, due to shared cultural values between sub-groups of Latinxs, a shared history of colonialism, common barriers experienced in many realms including health care and transportation, and barriers related to language, the author has decided to reify Latinxs into a single ethnic group (Cohen, 2013; Rodriguez-Galan & Falcón, 2009; Suarez-Balcazar, Balcazar, Taylor-Ritzler, Ali, & Hasnain, 2013; Zea et al., 1994).

The ways that Latinxs with disabilities experience barriers to transportation in their communities are not fully understood by researchers. Transportation for Latinxs with disabilities is a highly under researched topic; however, research has already documented issues and needs in transportation for people of color and people with disabilities. Nevertheless, it is unknown what the overall issues regarding transportation access and community participation are for Latinxs with disabilities specifically.

This study will implement a social model-based theoretical approach using a mixed methods and guided by grounded theory to explore public transportation access and barriers for Latinxs with disabilities, and how public transportation access affects community participation for Latinxs with disabilities. The author hypothesizes that in Part I of this study, Latinxs with disabilities will document more barriers to accessing transportation and participating in their communities compared to non-Latinx white people with disabilities. A grounded theory approach in Part II of this study (Charmaz, 2012; Wee & Paterson, 2009) will be used in order to develop a model about how these compounded public transportation barriers might affect Latinxs with disabilities' participation in their communities.

II. LITERATURE REVIEW

A. <u>Transportation Barriers for People with Disabilities</u>

People with disabilities often experience barriers to accessing and using transportation compared to non-disabled people. Large-scale national studies on people with disabilities and mobility confirm this. According to the US Bureau of Transportation, six million people with disabilities report problems getting around their communities (The Americans with Disabilities Act and Accessible Transportation, 2011). A study done by Harris Interactive (2010) reported that 34% of people with disabilities said they had problems getting around, while only 16% of non-disabled people said the same. Problematically, this gap widened five percentage points since 1998. Similarly, this same report stated that 34% of people with disabilities reported that not having access to transportation was a problem for them, while only 11% of non-disabled people reported the same. A report published by Rosenbloom (2007) on the travel patterns of people with disabilities further supports the widespread conclusion that people with disabilities report more problems with transportation and subsequently travel less often than non-disabled people. These numbers are troubling; people with disabilities have many more challenges related to getting around compared to their non-disabled counterparts.

To clarify why these issues related to transportation might be occurring, one should consider studies on transportation for people with disabilities that have reported transportation disparities by disability type, income, and family structure. It appears that people with physical disabilities, as opposed to cognitive, sensory, or other disabilities, report disproportionally more problems getting around. According to the Rosenbloom (2007) study 75% of people with disabilities under the age of 65 who reported difficulties getting to different places also reported having a physical disability that affected their ability to walk. In a study by the TCRP (2013) the

top two reported barriers to fixed route transit use among people with disabilities related to physical accessibility. It appears that people with physical disabilities may report more issues to using transportation, though widespread barriers are reported by other disability groups, including people with intellectual and developmental disabilities (IDD), as well (Sherman & Sherman, 2013).

Furthermore, it appears that the link between disability and transportation access can be affected by one's income. Two-thirds of those who reported having problems getting around also reported having incomes below \$35,000 per year (Rosenbloom, 2007). A study by Wheeler, Yang, and Xiang (2009) reported that trouble getting transportation for a child with a disability was inversely associated with family income. Angel and Angel (2015b) hypothesized that the link between income and transportation barriers can be explained through neighborhood opportunities. The link between income and transportation barriers is apparent, but its mediators should be explored further.

Finally, it appears that family structure affects mobility for people with disabilities, who report relying on family members more often than non-disabled people do (Deka, 2014; Ing, Vento, Nakagawa, & Linton, 2014). A study by Deka (2014) in particular showed that people with disabilities are three times more likely to get a ride from someone in their household than to take public transportation. However, the author also explains that SES plays a role in this relationship, with families that give rides to a family member with a disability having generally higher SES than families who don't give rides. While these three factors: disability type, income, and family structure may complicate the relationship between disability and transportation, this fact is clear: people with disabilities have a hard time getting around.

1. **Barriers to public transportation for people with disabilities**

People with disabilities rely heavily on accessible public transportation to get around, especially compared to their non-disabled counterparts, and the use of public transportation among people with disabilities is growing (Bascom & Christensen, 2017; TCRP, 2013). In one particular study, 46% of people with disabilities used public transportation to travel in general and 40% relied on public transportation in order to get to work (Ing et al., 2014). These numbers are slightly more than the general population; ridership on public transportation in the US is reported as 34% (American Public Transportation Association, 2017), but these numbers vary depending on the study, the area of interest, and the availability of public transit in that area. Lubin and Deka (2012) estimate that mass public transit services are not available to one-third of the country, thus excluding approximately one-third of people with disabilities on location alone.

Economic considerations are another major factor affecting the quality of public transportation services for people with disabilities. Unsurprisingly, people with disabilities who are low-income are most likely to report using public transportation (Deka, 2014). The provision of public transportation is also based on economic factors. The cost of providing public transportation has increased 32% to 53% between 2004 and 2009 and funding for public transportation has only increased by 27% in the same time period (Lubin & Deka, 2012). This lack of funding has resulted in a decrease in the quality of public transportation services for everyone, but disproportionally affecting the people with disabilities who tend to rely more on public transportation to get around (Lewyn, 2001). Many public transportation programs offer fare incentives to people with disabilities and older adults, but despite these efforts, public

transportation riders with disabilities still cite cost as a barrier to public transportation use (Lubin & Deka, 2012; TCRP, 2013).

Despite the frequent use of public transportation by people with disabilities, many report problems accessing this type of transportation. A national report by Rosenbloom in 2007 found that a whopping 75% of people with disabilities who lived near public transportation reported not using it. This same study found that 13% of people with disabilities who reported using public transportation said they experienced problems when they tried to use it, such as trouble walking to stations or needing assistance while riding. The Rosenbloom (2007) report indicated that physical accessibility of buses, trains, and stations is not always adequate and compliance with accessibility policies is often reported by people with disabilities as being unsatisfactory. While this in-depth study is now ten years old, newer studies also show that people with disabilities commonly report barriers to using public transportation. In a study by Layton (2012), 36% of these participants who reported barriers to using public transportation reported that those barriers were related to physical access. Similarly, in a study by TCRP (2013), people with disabilities reported that their most common barrier to public transportation use was environmental barriers. Related to these environmental barriers, weather is also reported as a major barrier for people with disabilities in accessing public transportation (Bascom & Christensen, 2017).

Accessing public transportation vehicles and stations is an issue for people with disabilities when physical barriers are present in the physical environment. Environmental barriers can include issues with not only the transit vehicles themselves, but also sidewalks, pathways, curbs, and buildings related to public transportation access. DiPetrillo and colleagues (2016) performed case studies on environmental improvements in transit corridors and reported overwhelming success and satisfaction from all community members when environment accessibility was improved for people with disabilities. Specifically, DiPetrillo and colleagues evaluated "pathways to transit" or the built environment and infrastructure surrounding transit stops, stations, and vehicles, and concluded that the recent attention to policy and modifications to these corridors has improved transit access for not only people with disabilities, but also other transit users and residents of these areas. While people with disabilities may be disproportionally impacted by barriers in their physical environments, it is beneficial to all community members, disabled or not, to improve the accessibility of the physical environment.

Another barrier on public transportation for people with disabilities in more recent literature involves social attitudes towards people with disabilities riding on public transportation. Bezyak, Sabella, and Gattis (2017) found that negative attitudes from drivers and other passengers were reported as a barrier for people with disabilities when riding both fixed route and paratransit services. According to this study, discriminatory attitudes may result in discriminatory behavior that directly impacts one's ability to take public transportation. This is another piece of the barriers that occur for this community on an interpersonal level.

People with IDD or cognitive impairments are one group in particular that has reported barriers to fixed route public transportation at a high rate, especially compared to their counterparts with physical disabilities (Bascom & Christensen, 2017; Friedman & Rizzolo, 2016; Risser, Lexell, Bell, Iwarsson, & Stahl, 2015; Wasfi, Steinmetz-Wood, & Levinson, 2017). Risser, and colleagues (2015) did a review of the literature on public transportation barriers for people with cognitive impairments and found that barriers in accessibility, safety, vehicle standards, stop/station design, operational standards, and reliability of transit information were needs and barriers of this population. Travel training programs aim to facilitate public transit access for this population through individualized client-centered training with people with various disabilities, including people with IDD, which aims to eliminate these barriers to public transportation access (Lindsay & Lamptey, 2018; Wolf-Branigin & Wolf-Branigin, 2008).

2. Barriers to paratransit for people with disabilities

Another common mode of transportation for people with disabilities is paratransit. Paratransit is specialized, door-to-door transportation specifically for people with disabilities who cannot use regular fixed route transit due to their disability. Paratransit provides pick-up and drop-off service in the same areas that the fixed route transit runs and at similar hours (Fitzgerald, Shaunesey, & Stern 2000). In 2012, it was estimated that people with disabilities take 106 million trips per year nationwide using the paratransit service, and that number is growing (Golden, Chia, Ellis, & Thatcher, 2014)

While many people with disabilities use the paratransit service, many still may not be able to access it due to the structure of the service, cost, or practical barriers. Paratransit's structure is organized so that service is only offered within three-quarters mile of a regular bus route, which may exclude people who live outside of large urban areas. Some paratransit riders reported increased barriers when applying for the service due to their disability (Ing et al., 2014). People applying for the service must be eligible due to disability, but the eligibility process sometimes excludes people who still cannot take regular fixed route transit, especially people with non-physical disabilities, or even claims some people can be eligible even when they cannot use the service due to their disability (National Council on Disability; NCD, 2015). While paratransit can be a lifesaver to some people with disabilities who otherwise would not have a way of getting around, the service is not fully accessible to all.

There are several economic barriers to paratransit service to consider. Costs to provide paratransit services exceed those for regular fixed route transit (Fitzgerald et al., 2000;

Rosenbloom, 2007). Paratransit providers are not shy to share their budgetary qualms about providing adequate service; some agencies have even had to cut regular fixed route transit services in order to meet federal mandates on paratransit, leading to decreased service for everyone (Lewyn, 2001). Furthermore, by law paratransit can cost up to twice as much as regular fixed route transit, which may be a barrier for the many people with disabilities who are also low income.

Finally, some practical barriers to being able to use the paratransit service have been reported by people with disabilities. Customers report that the service takes too long to be practical, and that the drivers' negative attitudes toward riders are discouraging (Ing et al., 2014; Rosenbloom, 2007). Furthermore, in a study by Ing et al. (2014), common issues reported by people with disabilities when using the paratransit service were difficulties scheduling a ride and the service being too confusing for them to use. While paratransit providers must comply with ADA requirements, compliance with the ADA has not been historically adequate and more work needs to be done to ensure that paratransit is provided satisfactorily under the ADA (NCD, 2015; TCRP, 2013). These barriers to using Paratransit and other forms of transportation limit the opportunities for people with disabilities to be active in their communities.

3. **Barriers to personal vehicle use for people with disabilities**

Driving a personal vehicle or having someone with a personal vehicle give a ride is the most common mode of transportation for non-disabled people and some studies indicate that it is the preferred mode of driving for people with disabilities as well (Bascom & Christensen, 2017; Deka, 2014; Keysor et al., 2010). Rosenbloom (2007) reports that this preference toward driving is due to attitudes, infrastructure, and urban planning that encourage car use over other forms of transportation. According to Rosenbloom (2007), 70% of people with disabilities under 65 years of age and 60% of people over 65 reported driving themselves in order to get around, but this number appears to be changing. According to a study by Bascom and Christensen in 2017, that number went down to 33%. It is often difficult for people with disabilities to gain access to a vehicle due to economic barriers (the cost of owning and maintaining a car is relatively high), disability-related barriers (many people with disabilities cannot drive due to their disability), or a combination of barriers (buying and maintaining an accessible vehicle is especially costly), thus they rely on others to drive them or they take public transportation (Bascom & Christensen, 2017; Ing et al., 2014; Keysor et al., 2010; Murphy, 2016; Rosenbloom, 2007). A study by Murphy (2016) reports that shared modes of transportation, such as carpooling, are gaining in popularity, complement fixed route public transportation choices, and show increasing cost-effectiveness. Driving and vehicle access remain important issues in increasing transportation access and community participation for people with disabilities.

People with disabilities who do not drive themselves may get a ride from someone else in order to get around. People with disabilities are three times more likely to get a ride from someone than to take public transportation to get around (Deka, 2014). According to Rosenbloom (2007), 86% of people with disabilities get rides from others and 22% ride in taxis, but newer studies show this number declining (Bascom & Christensen, 2017). Having reliable social networks and car-centric attitudes are major factors in people with disabilities choosing to get a ride from someone else (Bascom & Christensen, 2017; Rosenbloom, 2007).

However, when people with disabilities rely on someone else to give them a ride, they are therefore dependent on someone else's schedule. The use of taxis and other forms of private paid transportation like ride share services are becoming a popular substitute for and/or complement to fixed route public transit for the general population (Hall, Palsson, & Price, 2017). But these services have a cost that may not be affordable for those on a fixed income, as many people with disabilities are.

Access to getting a ride is mediated by socioeconomic factors such as race, income, and household makeup (Deka, 2014). Furthermore, getting a ride from a family member adds burden onto the family and can be dependent on having access to an accessible vehicle (Ing et al., 2014). Getting a ride in a typical vehicle is not always accessible as not many people have accessible vehicles that can accommodate wheelchairs or other mobility devices. Driving and getting a ride from others are important ways that people with disabilities get around, but these modes may be more common among people of certain ages, disability types, and SES. Getting a ride from others may also be more common among certain cultural groups whose values emphasize interdependency (Tal & Handy, 2010). The cultural factors of transportation choice for people with disabilities will be fleshed out later in this paper. In conclusion, driving is an important form of transportation for people with disabilities, but may be more common and accessible for certain people with disabilities more so than others.

B. Barriers to Community Participation for People with Disabilities

It is well-documented that people with disabilities experience barriers to participating in their communities that their non-disabled counterparts do not experience (Hammel et al., 2008; Heinemann et al., 2011; Wasfi et al., 2017; White & Summers, 2017). Many of these barriers are influenced by environmental factors such as neighborhood contexts, community resources, and – of course – transportation, along with personal and demographic factors (Magasi et al., 2015). While it is unknown exactly how personal and environmental factors play a role in community participation for each individual with a disability, transportation is a factor cited by many people

with disabilities that affects their ability to participate in their communities (Hammel et al., 2008; White & Summers, 2017).

People with disabilities use transportation of various kinds to access their communities. For example, they may drive, use public transportation, or get a ride from someone in order to access employment, education, and health care, to engage politically, or to attend social events in their communities. Because of the strong tie between transportation and community participation, lack of transportation is directly related to lack of inclusion for people with disabilities in their community environments (Sherman & Sherman 2013), and access to services within the community is directly hindered when there are barriers to accessing transportation (Hammel et al., 2015). People with disabilities have a harder time participating in their communities when there are more transportation barriers (Kaufmann-Scarborough & Baker, 2005), and these barriers can be accentuated by other identity factors such as race, culture, SES, and language (Blumenberg, 2008; Flores, Abreu, Olivar, & Kastner, 1998). In fact, people of color who have disabilities report even more problems accessing transportation (Flores et al., 1998) and participating in their communities (Lamar-Dukes, 2009) compared to their white disabled counterparts. More on the intersection between race/ethnicity, disability, and community participation will be discussed later in this paper.

On a more positive note, being able to get around one's community is a vital part of feeling included and part of the community itself (Páez & Farber, 2012). Additionally, municipalities have found that increasing accessible public transportation options results in better mobility and social benefits not only for people with disabilities, but for the community as whole (DiPetrillo et al., 2016). In a study by Wasfi and colleagues (2017), the presence of public transit in a neighborhood increased the odds of people with IDD being able to complete the trips they

needed to, even if they do not normally use public transit. Evidently, increasing access to transportation can increase community engagement and independence for people with disabilities and results in improved communities overall.

1. Employment barriers

People with disabilities consistently report issues accessing employment. In fact, it is generally assumed that the discrepancy in employment rates between people with disabilities and non-disabled people is closely related to transportation. Lubin and Deka (2012) found that the employment rate for people with disabilities was 22% and the employment rate for non-disabled people was 71%. Of the people with disabilities surveyed, 76% "strongly believed" that transportation was an important factor in their job search. Clearly, barriers to transportation, especially public transportation, need to be addressed in order to even the playing field in employment for people with disabilities.

2. <u>Education barriers</u>

Transportation is vital to the inclusion of students with disabilities. Students with disabilities tend to report more trouble getting adequate transportation to school than nondisabled students (Wheeler, Yang, & Xiang, 2009). Students who have more severe disabilities have disproportionally more difficulties getting to school, but other non-disability-related factors, such as family income and child age, also make it difficult for children to get to school (Wheeler et al., 2009). More inclusive transportation options, such as taking a school bus with nondisabled students or taking public transportation to school, tend to be the best options for students with disabilities.

3. Health care barriers

People with disabilities often experience problems accessing medical care. Because people with disabilities perhaps rely on medical care more than non-disabled people, their barriers to accessing medical care are of particular importance. A study by James, Ito, Buonocore, Levy, and Arcaya (2014) determined that access to transportation was a prerequisite for access to health care, and they identified several pathways through which transportation affects overall health. Formal medical transportation services may play a role in increasing access to medical care for people with disabilities. In a study by Syed, Gerber, and Sharp (2013), access to Medicaid transportation assistance programs increased medication compliance, but income may also play a role in this relationship. Interestingly, Probst, Laditka, Wang, and Johnson (2007) reported that only 2.7% of medical trips nationwide were done by public transportation among the general population, but this number may be different for people with disabilities and access to public transportation may vary by location. Overall, health care is a vital community resource for people with disabilities and the link between transportation and health needs to be clarified.

4. Social participation barriers

People with disabilities' social participation and access to social activities such as spending time with friends, shopping, volunteering, and civic activities, is a topic of increasing interest among researchers. In a recent study by Bascom and Christensen (2017), almost 70% of people with disabilities reported that transportation issues had a negative effect on their social lives. It appears that the more inclusive transportation is for people with disabilities, the more effectively they can participate in their communities (Sherman & Sherman, 2013). People with disabilities tend to prefer more socially-inclusive transportation such as regular fixed route transit

and sharing a ride for social activities than they do for work or medical appointments (Deka, 2014; Páez & Farber, 2012). Páez and Farber (2012) identified both access to a car and access to public transportation as being key factors in increasing social participation for people with disabilities. People with disabilities tend to use a car (either driving or getting a ride) for visiting friends (Deka, 2014; Páez & Farber, 2012), but tend to use public transportation for other leisure activities such as shopping or visiting museums (Páez & Farber, 2012). It appears that transportation preferences may depend on the type of social activity desired.

C. Transportation Policy for People with Disabilities

Transportation policy has attempted to increase economic opportunities, health care access, and community engagement for people with disabilities. Specifically, this section will highlight Section 504 of the Rehabilitation Act, the Americans with Disabilities Act (ADA), and other policies relating to paratransit service and environmental access for people with disabilities. These policies are highlighted because of their direct relevance to increasing economic opportunities, health care access, and community engagement for people with disabilities.

1. Section 504 of the Rehabilitation Act

Section 504 of the Rehabilitation Act was the first major anti-discrimination law for people with disabilities in the US. Section 504 was signed in 1973 and mandated that programs receiving federal funding cannot discriminate against people with disabilities (El-Reyes, Liu, El-Gohary, Golparvar-Fard, & Halabya, 2016; Lewyn, 2001). Public transportation agencies receive federal funding to run their services, so this was especially historic in increasing people with disabilities' access to public transportation and consequently their community mobility. While Section 504 was responsible for increasing public transportation access for people with disabilities, it came with its own set of shortcomings. Perhaps the biggest shortcoming of the policy was that it was limited to programs receiving federal funding (Jones, 2011). Other programs that did not receive federal funding did not have to comply. Fixed route transit and paratransit providers who receive federal funding were covered under the act, but other forms of transportation such as shared ride services and taxis were not. Furthermore, Section 504 lacked the resources and support it needed in order to be fully implemented. Because of this, Section 504 unfortunately did not have a sweeping effect on making transportation more accessible.

2. The Americans with Disabilities Act

The ADA of 1990 is the most comprehensive civil rights law for people with disabilities in the US (Kaplan, Hernandez, Balcazar, & Keys, 2001). The ADA extended Section 504 to a broader set of programs and entities, not just programs receiving federal funding, and provided organized implementation and enforcement strategies (El-Reyes et al., 2016; Jones, 2011). Title II of the ADA covers "public entities," which refers to state or local government and their agencies, departments, or contractors, including public transportation agencies and their contractors (Jones, 2011). This section will focus on Title II of the ADA as it applies to public transportation services. The ADA is considered by many to have been successful in increasing community access and participation for people with disabilities. Since its passage in 1990, people with disabilities have reported improved access to jobs, more social inclusion, and better mobility in general (Pfeiffer & Finn, 1997). According to a study by Kaufmann-Scarborough and Baker in 2005, 58.8% of people with disabilities reported that access to public transportation had improved since the ADA was passed in 1990. Furthermore, public buses today are almost 100% accessible (98-99% according to various reports) (The Americans with Disabilities Act and

Accessible Transportation, 2011; NCD, 2015). Despite its widespread successes, the ADA has not solved all access issues for people with disabilities. A study by Kaufmann-Scarborough and Baker reported in 2005 that 14.5% of respondents reported that their disability still prevented them from using public transportation, despite the leaps in accessibility that the ADA generated. Not much improvement was recorded by NCD in their comprehensive study of transportation accessibility post-ADA in 2015; they found that unsatisfactory compliance to ADA regulations was a problem profoundly affecting transportation accessibility. In fact, noncompliance with ADA regulations is commonly cited as a problem affecting transit access (The Americans with Disabilities Act and Accessible Transportation, 2011; NCD, 2015). Furthermore, the benefits of the ADA are often limited to where there is public transportation access, leaving people with disabilities who live in rural areas underserved by accessible transportation options; studies have shown that only 54% of people have access to transit and less than 30% of people would call that access satisfactory (Lewyn, 2001). Finally, the ADA allows for exceptions to its compliance standards if an agency can cite "undue financial hardship." This means that if a transportation agency can prove that making its services accessible will cause them serious budgetary concerns, they do not have to comply (Lewyn, 2001; NCD, 2015).

D. <u>Limitations of Current Transportation Research for People with Disabilities</u>

Current research on transportation for people with disabilities is a broad and growing topic of study, but it is not without its limitations. There are several limitations with current research on transportation policy for people with disabilities that may be inhibiting these policies from reaching their full potential. Many researchers argue that there is a lack research on transportation for people with disabilities, and the research that is available does not come from the disability community itself (The Americans with Disabilities Act and Accessible Transportation, 2011; United States Government Accountability Office, 2012). More research needs to be produced fleshing out the transportation issues for people with disabilities taking into account disability type, income, neighborhood type, location, and family structure. People with disabilities must become more involved with this research at all levels.

The majority of the research on transportation for people with disabilities comes from a post-positivist perspective. This type of perspective is truth-seeking and strives for objectivity (Patton, 2015a). More recently, research on transportation for people with disabilities has begun to incorporate more constructivist methodologies, which value the subjective lived experience of transportation for people with disabilities. Studies like Hammel et al. (2015)'s grounded theory-based qualitative study on environmental supports and barriers to participation for people with disabilities and Johnson (1999)'s study on critical care transportation in rural areas using hermeneutic phenomenology allow people with disabilities to make meaning of their own experiences to create a subjective and contextually-framed picture of transportation for people with disabilities.

Finally, research on environmental barriers for people with disabilities has been criticized for not using diverse participant samples (Kockelman, Zhao, & Blanchard-Zimmerman, 2001). Researchers must promote full inclusion in research to diverse people with disabilities of various genders, races/ethnicities, and disability types. Transportation research can gain a lot from including diverse participants, research perspectives, and methodologies. This need for diversity can follow the current trend in Disability Studies research in becoming more intersectional (Artiles, 2013; Ben-Moshe & Magaña, 2014).

E. Research on Latinxs with Disabilities

Race and disability have historically been linked. Disability has been used for centuries to justify the unequal and discriminatory treatment of people of color (Balcazar, Suarez-Balcazar, Taylor-Ritzler, & Keys, 2010; Baynton, 2001). While modern science has rejected this outdated view, people of color still experience health disparities compared to their white counterparts. Proportionally, people of color experience disability at a higher rate than whites, even after controlling for SES (Artiles, 2013; Suarez-Balcazar, Balcazar, Garcia-Ramirez, & Taylor-Ritzler, 2014). Furthermore, people of color experience more and more complex barriers to receiving adequate health care and treatment, with lack of transportation being one of the barriers (Ben-Moshe & Magaña, 2014; Flores et al., 1998).

As an additional point, as mentioned earlier in this paper, it is important to note that this paper is making broad statements about Latinx culture that may not correspond to the beliefs of the heterogeneous group of Latinxs as a whole. However, due to shared cultural values, similar political histories, and common experiences of barriers and discrimination, "Latinxs" in this paper refers to one single ethnic group (Cohen, 2013; Rodriguez-Galan & Falcón, 2009; Suarez-Balcazar, Balcazar, Taylor-Ritzler, Ali, & Hasnain, 2013; Zea et al., 1994).

1. Latinx culture and disability

The Latinx cultural context has been shown to provide both barriers and protective factors in Latinxs with disabilities and their families. Some of the protective factors encouraged within a Latinx cultural context that have been identified in disability literature are: a sense of community and belonging, interdependence on other family members (familism), and using spirituality to cope (Cohen, 2013; Jurkowski, Rivera, & Hammel, 2009; Salkas, Magaña, Marques, & Mirza, 2016; Skinner, Rodriguez, & Bailey, 1999; Zea at al., 1994). However, the Latinx cultural context can also foster values that can sometimes be barriers to receiving services (Edwards, Blanchett, Crocker, & Ransom, 2005). Specifically, values such as familism, fatalism, and rigid gender roles have been associated with more negative health outcomes in Latinxs (Cohen, 2013; Zea et al., 1994). In a study by Holloway, Dominguez-Pareto, Cohen, and Kupperman (2014), Latinx families of children with disabilities who held traditional Latinx gender roles showed worse outcomes than Latinx families with more equal gender roles. The role of culture in the outcomes of Latinxs with disabilities is multifaceted, however, and gets complicated with the introduction of what is known as the "Latinx health paradox." Some unique Latinx cultural phenomena that appear in the disability literature are described next.

a. **Familism**

The role of the family is especially salient in Latinx culture. The name given to the cultural importance of the family in Latinx culture is "familism" or *familismo* in Spanish. With familism, the family is treated as a single, interconnected system where family members are expected to support one another, depend on one another, and act in ways which honor the family unit (Cohen, 2013; Zea et al., 1994). For Latinx families where one or more family member has a disability, familism often motivates families to care for the disabled family member together in the home. Each family member may play a unique role in support each other through all kinds of challenges related to health and disability (Cohen, 2013; Suarez-Balcazar et al., 2016). For example, Latinx older adults report higher dependency on family members and caregivers, as opposed to non-family caregivers and residential care, than do white older adults (Hazuda & Espinoza, 2012). While the authors credit this difference to SES and disability severity, another hypothesis is cultural preferences to family-based care. This hypothesis is supported by Hayes-Bautista, Chang, and Schink (2012) who found that Latinx families more

often choose community-based care for their aging loved one than institutionalized care. Familism, while often seen as a positive cultural value, can also have some negative consequences. Familism can often result in increased distressed for family caregivers of people with disabilities and can often discourage families from seeking formal help and supports from outside the family (Cohen, 2013). The role of familism for Latinx families of people with disabilities is an interesting one that warrants a closer look.

b. Latinx health paradox

Latinxs appear to experience what scholars and professionals call the "Latinx health paradox." While Latinxs experience higher rates of disability and health risks and lower rates of insurance and preventative care compared to whites, they tend to live longer and have lower mortality rates (Bowen & Ruch, 2015; Rodriguez-Galan & Falcón, 2009). Although Latinxs experience increased rates of discrimination and disparities in access to health care, they tend to live an average of 2.2 years longer than whites (Hayes-Bautista et al., 2012). Some scholars believe this paradox is because Latinxs have a biological tendency to acquire less disease-related disability (Bowen & Ruch, 2015). However this theory does not account for the racial and biological differences within Latinxs as a group. There is other evidence to suggest that the paradox is likely due to cultural rather than genetic or biological factors. Remarkably, whites who live in primarily Latinx neighborhoods also experience health benefits (Ruiz, Campos, & Garcia, 2016). Furthermore, some studies show that the longer Latinxs live in the US, the more likely they are to acquire poor health outcomes (Bowen & Ruch, 2015; Priest & Wood, 2015). This lessening of Latinx protective factors was once thought to have occurred due to acculturation, but newer research shows that it is more likely due to built-up experiences of discrimination that negate the effects of any protective factors (Isai et al., 2015). Interestingly,

Puerto Ricans do not exhibit the benefits of the Latinx health paradox, perhaps because they tend to experience especially more severe discrimination compared to other Latinx groups (Rodriguez-Galan & Falcón, 2009).

Despite evidence that Latinxs may have better health outcomes compared to non-Latinx whites, there are still some diagnoses that are higher in Latinxs than in whites. Diabetes (Angel & Angel, 2015a), stroke (Sacco et al., 1998), and disabilities due to accidents (Sears, Bowman, & Silverstein, 2012) are all generally higher for Latinxs, and are likely mediated by cultural factors, though the pathways are not yet clear.

2. Limitations of research on Latinxs with disabilities

There are several gaps in the literature on Latinxs and health. First, disability researchers are not focusing enough on Latinx populations. Latinxs make up a large proportion of the population of the US and are the fastest growing minority ethnic group in the country (Casas et al., 2004; Torres-Gil & Lam, 2012). Because of the diversification of the US population, more health disparities research needs to be done using intersectionality and minority model approaches. Additionally, more health and disability research needs to be done with Latinxs in general. Researchers should explicitly seek out Latinx participants and be forthcoming about their Latinx participants' many specific identity traits so that other researchers have accurate demographic and epidemiological data about Latinxs.

Many of the gaps in the literature center on the ambiguous relationship between the Latinx cultural context and health outcomes. Future research must work to identify the pathways of both positive and negative relationships between the Latinx cultural context and health outcomes using intersectional frameworks. This will likely explain many of the inconsistencies we see in some of the disability-specific disparities that Latinxs experience. Much of the research on race and disability has been framed under a positivist framework using the medical model of disability (Artiles, 2013). Recently, race and disability research has begun incorporating social determinants of health and minority models of disability (Artiles, 2013; Edwards et al., 2005), but these frameworks are not without their limitations. Disability Studies, Critical Race Studies, and Feminist Studies scholars criticize the social determinants of health model for still being too biologically-based and not putting enough emphasis on lived experience and identity. Asch (2001), in her essay on how Critical Race Studies and Feminist Studies can influence disability research, encourages the use of the minority model in health disparities research. The minority model fits better with race and ethnicity research because it defines disability, like race or ethnicity, as a minority identity created by shared social experiences of oppression. It also allows for a more nuanced study of intersectionality, which may produce new and exciting knowledge in the field of health disparities.

Other limitations of research on Latinxs and health include methodological considerations. Latinxs, by nature, are a heterogeneous group. They come from many countries, speak many languages, and hold various beliefs and values. Much of the literature analyzed in this paper has not been clear about the intra-group differences that Latinxs exhibit. Many authors fail to specify whether participants were foreign-born or US-born, many exclude Spanish-speaking Latinxs from research due to lack of language resources, and many fail to report country of origin. George, Duran, and Norris (2014) reported in a systematic review of minority participation in research that Latinxs especially encounter many barriers to participating in large-scale research. These barriers include linguistic barriers to research participation, exclusion by sampling bias, distrust of institutional research, and disinterest in participation in research. These complications lead to murkiness in the data we have on Latinx health and disability.

F. Transportation Barriers for Latinxs

Latinxs experience additional barriers to accessing and using transportation due to their cultural, linguistic, and SES-related contexts. The rapid growth of the Latinx population means that the US needs to consider Latinxs when developing new policies and infrastructures, including those for transportation (Casas et al., 2004). Overall, not much is known for certain about the transportation habits of Latinxs with disabilities specifically. There is a lack of research on transportation with this precise population. This section will attempt to tie together transportation habits for people with disabilities with transportation habits for people of color, immigrants, and Latinxs in order to better understand how Latinxs with disabilities might get around and the barriers to transportation they might experience.

1. **Barriers to community participation for Latinxs with disabilities**

There is ample evidence to suggest that community participation is directly influenced by personal and demographic factors such as race, ethnicity, SES, and gender. Latinxs in particular, despite a desire to participate civically and socially in their communities, report less community engagement compared to other ethnic groups (Sandoval & Jennings, 2012). In a study by Suarez-Balcazar, Agudelo, Mate, and Garcia (2018), Latinx young adults with disabilities identified lack of affordable transportation as one of the many barriers to participating in recreational activities in their community. Compounded with the barriers to community participation experienced by people with disabilities in general, Latinxs with disabilities likely experience even more barriers to participating in their communities.

Common barriers to community participation exist for Latinxs with disabilities across disability types. Many of these barriers are related to SES. Many Latinx families have trouble paying for adequate health care because they are uninsured (Angel & Angel, 2015a; George et al., 2015; Parish, Magaña, Rose, Timberlake, & Swaine, 2012; Rodriguez-Galan & Falcón, 2009). Another barrier that many Latinxs face relates to language. Many Latinxs only speak Spanish or are not fluent in English. This leads to fewer service options for Spanish-speaking Latinxs compared to English-speaking Latinxs or whites and they are exposed to less information about health or disability (Barrio et al., 2008; Hayes-Bautista et al., 2012; Povenmire-Kirk, Lindstrom, & Bullis, 2010). Many Latinxs also have difficulties finding culturally-competent providers who share similar cultural perspectives and values about health (Magaña, 2000; Muesser et al., 2014; Povenmire-Kirk et al., 2010). Finally, some barriers to community participation for Latinxs are related to immigration status. Undocumented Latinxs do not have access to the same state or federal programs that documented Americans do, and their fear of deportation may discourage undocumented people from seeking out some community services (Angel & Angel, 2015a; Povenmire-Kirk et al., 2010).

2. Transportation barriers for people of color

There have historically been differences between whites and people of color regarding access to transportation. The United States Department of Transportation (USDOT; 2000) reported that people of color have not been as mobile as whites and have not experienced the same changes in transportation patterns. Many of these racial differences in transportation behaviors can be linked to SES. Some socioeconomic variables that have been thought to influence travel behavior are age, household composition, income, education, residential location, vehicle availability, and time spent in the US. Studies have shown that the closer a person of color's SES is to that of their white counterparts, the more similar their travel behaviors are as well (USDOT, 2000). Unsurprisingly, people of color tend to utilize public transportation at a higher rate than whites (Myers, 1996; USDOT, 2000). Because of this difference in transit behavior, people of color tend to spend more time traveling than whites do. Interestingly, when looking at travel behaviors of people of color, disability is a demographic variable often ignored in analyses. More complex research on transportation with people of color should be performed that includes disability-related data.

3. Transportation barriers for immigrants

Immigrants, from various countries of origin, exhibit unique travel behaviors due to their life circumstances, cultural contexts, and economic situations. The literature has shown some clear trends in transportation behavior of immigrants over time (Casas et al., 2004; Myers, 1996; Tal & Handy, 2010). When immigrants first arrive to the US, they rely primarily on public transportation to get around. This is the most economical transportation option, and it usually compliments their choice to live in urban areas near people that share their culture. The longer they live in the US, the more likely they are to begin driving. Within 5-10 years, many immigrants have moved out of their urban cultural neighborhoods to more suburban areas where they have access to a private vehicle, which serves as their primary mode of travel (Myers, 1996). As they spend more time in the US, their travel behavior increasingly resembles that of the rest of the country (Myers, 1996).

Cultural factors may also affect transit choices. For example, attitudes and beliefs about transportation may influence immigrants' preference for public transportation (Tal & Handy, 2010). Furthermore, there may be gender differences about driving and travel that perpetuate after immigration (Blumenberg, 2008). A study by Shin (2017) explores the trend of inter-familial carpooling in immigrants who live in ethnic neighborhoods. These unique travel behaviors are important to understand when looking at the travel behaviors of Latinxs, many of whom are immigrants themselves.

4. <u>Transportation barriers for Latinxs</u>

While many of the trends in travel behaviors of immigrants translate directly over to Latinxs, there are some unique cultural factors that affect the transportation choices of Latinxs. Generally, Latinxs tend to use communal transportation (getting a ride from others, shared ride services, public transportation) over private transportation (Blumenberg, 2008; Tal & Handy, 2010). Predictably, Latinxs tend to use public transportation at a higher rate than whites (Blumenberg, 2008; Myers, 1996). These transportation trends could be due to cultural contexts that encourage community interdependence, but also economic factors: Latinxs tend to make less money than non-Latinx whites (Casas et al., 2004), and are less likely to own their own cars (Blumenberg, 2008). They are also more likely to lack a driving license. Latinxs that do own cars tend to buy older vehicles and tend to share them with multiple people (Casas et al., 2004). Coupled with their large family kinships, Latinxs are likely to share a single vehicle between several adults. Latinxs are less likely to know about transportation service available for people with disabilities due to language barriers and are therefore less likely to utilize accessible transportation (Blumenberg, 2008). Finally, Latinxs tend to live in homes with large families and/or relatives and with more people who are employed, which makes it especially important to look more closely at the ways Latinxs travel to work (Casas et al., 2014). These transportation trends may also hold for Latinxs with disabilities, though this sub-group has not been as extensively studied.

5. <u>Transportation barriers for Latinxs with disabilities</u>

Latinxs with disabilities likely experience compounded barriers to transportation and community participation; however, there is very little literature on transportation for Latinxs with disabilities specifically. Transportation has been reported as the number one barrier to Latinx families when bringing their children to medical appointments (Flores et al., 1998). Another study showed that long commute times directly related to low mammography rates for urban Latina women (Graham, Lewis, Flanagan, Watson, & Peipins, 2015). One can only imagine how vital transportation would be for Latinx with disabilities who may need to access medical care frequently. In another study, Latinx youth with disabilities and parents of Latinx youth with disabilities found that transportation issues in accessing recreation facilities and supermarkets were a barrier to healthy lifestyles (Suarez-Balcazar et al., 2018) When exploring issues in transportation for Latinxs with disabilities, researchers need to distinguish barriers related to disability and barriers related to culture. Language is commonly reported as a barrier to accessing medical care in Latinxs with disabilities (Rodriguez-Galan & Falcón, 2009). When Latinxs do access medical care, they are more likely than whites to do so by walking or taking public transportation compared to driving (Probst et al., 2007). This means that accessible environments and accessible public transportation options are extremely important to Latinxs with disabilities, for whom medical appointments may be more frequent. This data supports other studies on transportation use by Latinxs that reiterates the importance of public transportation to this community. While paratransit and formal medical transportation may seem like viable options for Latinxs with disabilities to get to medical appointments, not all Latinxs are able to access these services due to language and citizenship barriers (Rodriguez-Galan & Falcón, 2009). Coupled with the data that the US promotes increasingly car-dominated infrastructures, this is troubling for Latinxs with disabilities. Their accessible travel preferences are likely not being prioritized by policymakers or urban planners. Clearly more work needs to be done in this arena to clarify what the transportation barriers are for Latinxs with disabilities specifically.

G. <u>Transportation Facilitators for Latinxs with Disabilities</u>

While there are many barriers that Latinxs with disabilities experience in accessing and using transportation, the literature has also identified some facilitators that can support Latinxs and people with disabilities in becoming more mobile. Like with transportation barriers, the research on transportation facilitators for Latinxs with disabilities as a specific group is scarce, so the researcher must extrapolate from current research on people with disabilities in general, Latinxs in general, immigrants, and people of color with disabilities. People with disabilities tend to experience fewer transportation barriers when the transportation vehicles and the physical environment is accessible and free from barriers (Layton, 2012; Rosenbloom, 2007; TCRP, 2013). Like general riders, riders with disabilities are more satisfied with transportation that is reliable and timely (Verbich & El-Geneidy, 2016). Latinxs (and all humans) thrive in communities where they feel safe, have access to community events, and can be around their peers (Angel & Angel, 2015b). Opportunities for interconnectedness with others is especially important for Latinxs whose cultural context emphasizes community and belonging (Zea et al., 1994). Providing ample opportunities to travel in one's preferred manner would facilitate community access. For Latinxs with disabilities, this means that community environments should be physically accessible and provide plenty of public transportation options. Transportation services and applicable information should be available in languages other than English. In fact, ride share services have seen success in accessing Latinx clients by hiring bilingual drivers, playing off the linguistic and cultural preferences of Latinxs (Rodriguez-Galan & Falcón, 2009). Furthermore, transportation services that incorporate Latinx culture's emphasis on community and interconnectedness can be a facilitator to getting around. While it has not been shown in the literature, Latinxs may have more opportunities than whites for shared rides

and getting rides from members of their communities. This is an area that researchers should concentrate on in order to facilitate transportation access for Latinxs with disabilities.

H. Limitations of Transportation Research on Latinxs with Disabilities

To summarize, there exists very little research that specifically examines barriers and facilitators to transportation and community participation for Latinxs with disabilities. Research on transportation for people with disabilities and on Latinxs in general indicates that both groups experience disparities in transportation and community participation. Latinxs with disabilities, though, have mixed outcomes compared to non-Latinx whites with disabilities. Latinx culture offers some protective factors that may facilitate access to transportation and community participation; however, Latinxs' status as people of color can also be a disadvantage in accessing one's community and transportation, so it is unclear how a Latinx identity affects transportation access and community participation.

Research on transportation for people with disabilities is generally done from an economic standpoint. Cost-benefit analyses and money saving recommendations are common themes in transportation research (Griffin & Priddy, 2005). Winter and Williams (2001) argue that transit agencies do not put enough monetary value on people with disabilities, so the economic benefits that a community receives when people with disabilities fully participate are not fully realized. This takes away from the equal economic opportunities that people with disabilities are given. Griffin and Priddy (2005) argue that economic models of community participation are meaningless until people with disabilities have full participation in society. Transportation research that uses alternative approaches to this economic focus may be particularly useful in identifying the ties between transportation and community access for Latinxs with disabilities.

Taking into consideration the needs of the Latinx community, along with the needs of people with disabilities, it would be beneficial conduct transportation research that uses mixedmethods research approaches that are based in the community, and that are consistent with the social model of disability. This type of research has been done with people of color with disabilities, but it has not incorporated transportation into a framework on community participation for Latinxs (Angel & Angel, 2015a; Mirza et al., 2013). This type of research would address some of the current limitations in transportation research for people with disabilities and additionally bring to the table more diverse cultural perspectives.

III. THEORETICAL APPROACH

A. <u>Theoretical Perspectives in the Literature</u>

1. **Common theoretical perspectives in disability research**

Historically, disability research has been performed using the moral model of disability and the medical model of disability as theoretical frameworks. The moral model of disability was the reigning way of thinking about disability before the advent of modern medicine, and still shapes thinking about disability today (Longmore, 1987). The moral model defines disability as a defect caused by sin. On the other hand, in a medical model approach, disability is seen as a problem localized within the individual. Using a medical model framework, researchers and medical professionals can create and evaluate medical interventions that targeted the individual: their behaviors, their biology, and their bodies (Goodley, 2010).

The contemporary field of Disability Studies seeks to shift disability research toward a social model approach. The social model of disability is the idea that disability is a social rather than a medical construct (Goodley, 2010). According to the social model, people are disabled by their environments more so than by their physical impairments (Meekosha & Shuttleworth, 2009). Disability Studies endorses interventions that target the social environment, such as increasing accessible transportation options for people with disabilities, or changing people's attitudes toward people with disabilities.

2. <u>Common theoretical perspectives in disability research with Latinxs</u>

Just as with disability research in general, more socially-based theories in disability research with racial and ethnic minorities are beginning to emerge. Disparity models that can account for social factors in racial and ethnic differences in the disability experience show that intersectionality has begun to gain popularity with social science researchers. Fundamental Cause Theory (Magaña, Lopez, Aguinaga, & Morton, 2013), Pathways to Care (Lopez, Barrion, Kopelwicz, & Vega, 2012), Multiply Determined Risk (Ruiz et al., 2016) and Social Determinants of Health (Edwards et al., 2005) are socially-based theoretical frameworks that have begun to emerge in modern research on disability and race. These frameworks identify environmental, social, and cultural factors associated with health disparities and allow for the study of intersecting social identities. This changed much of the modern research on disability from medical and biological causes to social causes, such as neighborhoods, access to resources, and interactions with systems and organizations. This theoretical shift in the study of disability with people of color has also sparked a shift in research methodology. In the past, disability research, including disability research with racial and ethnic minorities, was primarily done using a positivist paradigm and using quantitative methods (Artiles, 2013). Now that social and environmental factors are being considered predominantly in theory, we are beginning to see more community-based participatory research, more ethnography, and more qualitative research with the communities of interest (Erevelles & Minear, 2010; Haack & Gerdes, 2011; Mirza et al., 2013). These methods seem to fit well with the social theoretical foundations of both disability and race/ethnicity, and allow research to impact change in social policy, including transportation policy, for these groups.

3. <u>Common theoretical perspectives in transportation research</u>

The majority of the research on transportation for people with disabilities uses post-positivist research approaches and aligns with a medical model perspective. Economic models of transportation dominate the field of transportation research. Research on transportation for people with disabilities is generally done from a business standpoint. Cost-benefit analyses and money saving recommendations are common themes in transportation research (Griffin & Priddy, 2005). These theoretical approaches do not coincide well with the contemporary perspectives in research on Latinxs and other racial and ethnic minorities with disabilities (to be described in the next section).

The ADA is one of the first major policies to recognize the social aspects of disability, including disabling environments. The ADA's theoretical underpinnings resemble those of many other public policies (Switzer, 2001). While the ADA stems from a Disability Studies-centric philosophical orientation (the social model of disability), compared to academic fields like Disability Studies, the ADA's theories are quite pragmatic and cater more toward policymakers rather than taking a philosophical approach. Research done from this perspective could have the goal of making transportation options less disabling for people with disabilities and affect transportation policy that aims to change the environment instead of the individual. This approach would coincide well with contemporary research approaches in Disability Studies and contemporary approaches in research on Latinxs and other racial and ethnic minorities with disabilities.

B. <u>Theoretical Approaches Grounding this Study</u>

1. **The social model**

The main theoretical approach used in the study is the social model of disability. The social model is a common theoretical framework in the contemporary field of Disabilities Studies and has been previously recognized in this paper as the idea that disability is a social rather than a medical construct and that people are disabled by their environments more so than by their physical impairments (Goodley, 2010; Meekosha & Shuttleworth, 2009). Because of its popularity in the field of Disability Studies and its utility to be combined with approaches in related fields such as transportation, health disparities research, and ethnic studies, the social model is the main theoretical approach employed in this research.

2. Limitations of the social model

As theoretical framework, the social model has not been without its own critics. The social model has been criticized for over-emphasizing the social experience of disability and devaluing the physical aspects of the disability experience (Oliver, 1996; Owens, 2015). Critics argue that there are undeniable physical differences between disabled and non-disabled bodies that the social model fails to recognize (Owens, 2015). Furthermore, the social model does not appear to address other forms of discrimination such as racism or sexism; it is only addresses *ableism* or discrimination based on disability, which limits the model's practical use (Oliver, 1996).

Furthermore, the way that the social model has been developed may engender some racial bias within the model. Theories surrounding disability and health have historically been produced by white researchers and have not included people of color in their development. People of color are often excluded from the type of research that produces scientific theoretical knowledge (Bell, 2006; Hilton et al., 2010). Rarely do disability researchers and theorists take into account racial minority groups. Even in Disability Studies, people of color have only begun to appear as either researchers or subjects. This consistent erasure makes the study of disability essentially "white-washed" and not reflective of minority perspectives (Bell, 2006). Contemporary researchers of people of color in fields such as Disability Studies, Critical Race Studies, and Feminist Studies encourage taking an intersectional approach to health and disability (Artiles, 2013; Asch, 2001; Ben-Moshe & Magaña, 2014). The social model is still being tested against this type of diversity.

3. <u>Benefits of using social model in transportation research</u>

Despite its shortcomings, the social model of disability is already useful in race research and disability research, and is gaining popularity with researchers in these fields, but how can the social model add to research on transportation? Because community participation is a key target of transportation research, the researcher argues that transportation research should include a socially-based theoretical framework such as the social model. In transportation research, social model-based theoretical frameworks such as social determinants of health, ecological models, and social justice are beginning to emerge (Graham, Keys, & McMahon, 2014; Hammel et al., 2015; Sherman & Sherman, 2013; Wolf-Branigin & Wolf-Branigin, 2008) and can better capture the impact of environmental barriers for people with disabilities and people of color.

4. <u>Ties to the socio-ecological model</u>

The socio-ecological model is a key theoretical foundation for the current study on transportation for Latinxs with disabilities. There are many parallels and points of connection between the socio-ecological model and the social model. Socio-ecological models focus on contexts; they describe the way an individual interacts with different levels of their environment (Richard, Gauvin, & Raine, 2011; Suarez-Balcazar et al., 2014). Bronfenbrenner (1989) was the original theorist behind the ecological model. He used the model to study child development in different contexts (Suarez-Balcazar et al., 2014). Clearly, the social model and the socioecological model share a focus on social, rather than individual, sources of change and influence. The principle of interdependence is shared between the social model and the socio-ecological model; researchers in both realms recognize that co-existence is a vital part of society. Likewise, the two share a heavy emphasis on the contextual and cultural environment. The environment mediates the behavior of individuals and impact their ability to participate in the community.

The socio-ecological model has been commonly used to guide research on racial and ethnic health disparities (Simplican, Leader, Kosciulek, & Leahy, 2015; Suarez-Balcazar et al., 2014). It has also been employed in transportation research with people with disabilities to uncover various levels of barriers to community access and participation (Hammel et al., 2015; Magasi et al., 2015; Sherman & Sherman, 2013). Given its utility and effectiveness in a number of connected fields, including transportation research, the socio-ecological model will also guide the current research.

5. **Borderlands theory**

Borderlands theory is another theoretical framework that will be employed in this paper. Borderlands theory is an interdisciplinary philosophical framework first conceptualized by Gloria Anzaldúa (1987), a Chicanx author and poet, to refer to her duality of identities living on the US-Mexican border. Anzaldúa's borderland, while obviously referring to the physical border between the US and Mexico where Anzaldúa lived, is also a metaphor for living on the margins of several different identities and not fitting in with one particular community, a sentiment shared by many Latinxs in the US, and Latinxs with disability may particularly relate to this metaphor. One can argue that Borderlands theory is indeed applicable to research with Latinxs with disabilities. Latinxs with disabilities perpetually live in the hypothetical "Borderlands" of competing identities. The cultural values found in a Latinx context, like those of other minority ethnic groups, have not yet been fully incorporated into the academic study of disability (Bell, 2006). At the same time, Latinxs with disabilities may feel rejected by their own ethnic culture's marginalizing views toward people with disabilities. Like Anzaldúa, Latinxs with disabilities might not feel comfortable with either depiction: mainstream American representations of disability, or Latin American representation of disability.

To settle these two worlds, this research will follow Bost (2009)'s reconciliation of Borderlands theory as a theoretical approach. Bost has identified disability themes in the literature of several Chicanx authors, including that of Anzaldúa. Analyzing the literature, there are several similarities between the ideas of these Chicanx authors and several themes in critical theory and Disability Studies. Borderlands theory is hopeful to be able to bridge the gap between the objective study of disability and the lived cultural experience of Latinxs with disabilities.

IV. METHODOLOGY

A. <u>Research Questions</u>

The current study explored the following research questions:

- What are the barriers to public transportation access (both fixed route and paratransit) for Latinxs with disabilities?
- 2) Are the barriers to public transportation access for Latinxs with disabilities different from the barriers to public transportation access for non-Latinx whites with disabilities?
- 3) How do these barriers to public transportation access affect the way that Latinxs with disabilities are able to participate in their communities?

B. **Definition of Concepts**

Public transportation is defined as any mass transportation services that are publicly available and provided by municipalities. Public transportation can include both fixed route and paratransit services. Fixed route transportation is commonly referred to as "transit" and can include buses, trains, ferries and other vehicles that run on regular, pre-determined, prescheduled routes with no variation. Paratransit services are commonly referred to as "paratransit" or "ADA" and are federally-mandated transportation options for people with disabilities. Paratransit is a shared-ride, curb-to-curb service that must be scheduled in advance. Transportation barriers are defined by the study participants and include anything that makes it more difficult for people to access transportation services. Some examples of transportation barriers might be availability and hours of transportation services, physical accessibility of transportation vehicles, and boundaries of the transportation service. Community participation is another variable of interest in this study which is defined by Latinxs' with disabilities ability to utilize the medical, recreational, social, education, and work-related resources in their communities.

C. Hypothesis

Based on the literature review presented here, the researcher hypothesized that there are indeed differences in the barriers to public transportation use between Latinxs with disabilities and non-Latinx whites with disabilities and that these barriers do indeed affect community participation for the Latinx disability community. The researcher hypothesized that the barriers to public transportation may fall into several different categories at several different levels of interaction, such as interpersonal, systemic, and environmental. The different categories that barriers might fall into would likely be similar to what is found in the existing literature for Latinxs, people with disabilities, immigrants, and people of color and might be related to lack of accessibility or enforcement of accessibility of the transit system (e.g., lack of ramps and lifts on transit vehicles, operators not calling out stops during transit, broken or cracked sidewalks near transit stops) or may be related to linguistic barriers that non-English-speaking Latinxs may face (e.g., transit brochures not being available in their preferred language, information to appeal paratransit decisions not being available in their preferred language). However, the researcher also recognizes that there may be other barriers not mentioned in extant literature.

The researcher explored the possible barriers to community participation for Latinxs people with disabilities using a grounded theory, social constructivist approach based on the social model of disability and the socio-ecological model.

D. Overall Design of the Study

The current study employed a sequential mixed methods design: Part I utilized quantitative methods that informed Part II of the study which utilized qualitative methods. Clark and colleagues proposed four types of mixed-methods designs including triangulation, explanatory, exploratory and embedded. This mixed-method study is designed to triangulate and explore. Specifically, the researcher will triangulate by comparing qualitative and quantitative data to see how they complement each other (Clark, Huddleston-Casa, Churchill, Green, & Garrett, 2008) By contrast, the exploratory approach will allow the researcher to use qualitative data to answer questions about barriers to transportation.

A mixed methods approach was chosen because of its fit with the research questions. The first two research questions identified barriers for Latinxs with disabilities and also compared barriers for Latinxs with disabilities to barriers for non-Latinx whites with disabilities. These first two research questions were answered well through quantitative survey responses, but were enhanced through qualitative exploration. The third research question was answered using both quantitative data from survey responses and qualitative data from focus groups. Mixing interpretivist and positivist elements encourages a plurality of perspectives in research instead of just one single perspective (Mertens, 2010). Research that bridges several different fields – transportation studies, Latinx studies, and disability studies – can certainly benefit from the preferred research approaches of each field and work to cover each approach's limitations. Positivist elements in research can comply with the demands of validity and rigor required by transportation organizations and policymakers, but also providing qualitative, interpretivist components that fit well with Disability Studies (Oliver, 1996; Woodhams & Lupton, 2014).

Finally, mixed methods allows for triangulation of data as well as member checking (Robinson, David, & Hill, 2016).

E. Part I: Quantitative Approach

1. Design

Part I of the research study used quantitative methods to perform an analysis using data from an existing national survey on public transportation barriers for people with disabilities. Responses from Latinx respondents with disabilities were compared to responses from non-Latinx respondents with disabilities and notable differences between responses from the two groups were noted.

2. Data source

The data source for this part of the study was the Transportation Access and Experiences Survey. This survey was conducted by the ADA National Network and the ADA Participatory Action Research Consortium (ADA-PARC). The survey from here on will be referred to as the "PARC transportation survey." This was a nationwide survey implemented online using Qualtrics. Online surveys are commonly used for research with participants with disabilities because they are accessible for people with hearing and vision disabilities, are private, and are able to be completed in the location and at the time of the participants' convenience. The survey link was active from May 24, 2016 to February 1, 2017. The data from the study is available as archival data to the researcher. The purpose of the survey was to improve researchers' understanding of the accessibility of public transportation and use the information to make improvements to public transportation access for people with disabilities at regional and national levels. The study examined the experience of public transportation by people with disabilities across the US.

3. Sample

People with disabilities were recruited nationally through online advertisements announcing the internet survey. In total, 2,534 people filled out at least some of the survey. The criteria for selection into the study were people with lived experience of having a disability who are living in the US or its territories. Participants who completed the survey were excluded if they reported that they lived outside of the US or US territories. In total, 798 people were excluded because they did not report that they lived in the US or US territories or they reported that they lived outside of the US or US territories (e.g., Ontario, Canada). This means that 1,736 eligible participants responded to the survey. All of these eligible individuals reported that they had a disability.

Because this particular study's focus is on differences in transportation use and reported barriers between Latinx and non-Latinx white participants, the researcher believes it to be beneficial to report demographic data and transportation habits of eligible participants of only these two ethnicity groups. Latinx participants are defined as those participants who identified as being of Latino/a, Hispanic or Spanish origin OR those who filled out the PARC transportation survey in Spanish. Non-Latinx white participants were defined as those participants who endorsed their race as white and did not endorse being of Latino/a, Hispanic or Spanish origin. These participants also met disability and location eligibility criteria. This gave the researcher a subtotal of N=1,462 participants, 119 (8.1%) of whom were Latinx and 1,343 (91.9%) of whom were non-Latinx white. Individuals from 48 states, Washington, DC, and Puerto Rico appear in the analysis.

The demographic information for eligible Latinx and non-Latinx white participants with disabilities is presented in Table I. To summarize, the vast majority of the participants (75.4%)

were between the ages of 25-64 years old. In terms of disability type, over half of the participants (55.1%) indicated that they had a physical disability. Over one-quarter (27.9%) indicated that they had a chronic health condition. One-quarter (25.0%) indicated that they had a vision disability. In terms of SES, the sample was fairly low-income, with almost half of respondents (47.0%) indicating that their annual household income was under \$40,000. The sample appeared to be well-educated; 76.9% of respondents indicated that they had at least some college education. About one-third of the sample (33.6%) was employed full-time and an additional 18.1% were employed part-time.

Latinx and non-Latinx White Disability Subsample (N=1,462)					
	<u>% of Total</u> <u>Participants</u> <i>N</i> = 1,462	<u>% of Latinx</u> Participants 119	<u>% of non-</u> Latinx White <u>Participants</u> 1,343		
Percentage by Ethnicity	100	8.1	91.9		
Gender					
Female	59.2	54.1	60.0		
Male	39.3	45.0	39.1		
Other	0.8	0.9	0.8		
Disability Type					
Physical Disability	55.1	50.4	55.5		
Vision Disability	25.0	19.3	25.5		
Hearing Disability	14.8	12.6	15.0		
Speech/Communication Disability	11.2	8.4	11.5		
Cognitive Disability	14.2	12.6	14.3		
Intellectual Disability	9.0	10.1	8.9		
Autism Spectrum Disorder	7.3	5.0	7.4		
Psychiatric Disability	18.9	14.3	19.3		
Chronic Health Condition	27.9	24.4	28.2		
Other	8.3	10.1	8.2		
Age					
Under 24 Years Old	8.0	10.3	7.8		
25-44 Years Old	30.6	33.6	30.4		
45-64 Years Old	44.8	47.7	44.6		
65 Years Old or Older	16.6	8.4	17.3		
Annual Income					
Below \$24,000	31.9	26.1	32.5		
\$24,001-\$40,000	15.1	18.5	14.8		
40,001-\$74,000	17.9	16.0	18.0		
\$74,001-\$100,000	7.8	8.4	7.7		
Over \$100,000	6.6	2.5	6.9		
Prefer Not to Say/No Response	20.7	28.6	20.0		

TABLE IPARTICIPANT DEMOGRAPHICS

Latinx and non-Latinx White Disability Subsample (N=1,462)					
	<u>% of Total</u> <u>Participants</u> <i>N</i> = 1,462	<u>% of Latinx</u> <u>Participants</u> 119	<u>% of non-</u> Latinx White <u>Participants</u> 1,343		
Receiving SSDI	51.2	50.5	53.5		
City Size Information					
Urban	89.7	78.9	84.9		
Rural	9.7	3.4	10.3		
Did not respond	5.8	17.6	4.8		
Highest Education Level					
Less than High School Degree	4.1	3.6	4.2		
High School Diploma or GED	16.0	15.2	16.2		
Associate's Degree or Some					
College	22.6	31.3	22.0		
Bachelor's Degree	25.1	26.8	25.1		
Graduate or Professional Degree	29.2	17.9	30.4		
Other	2.4	5.4	2.2		
Employment Status Unemployed/Not Looking for					
Work	12.0	9.8	12.2		
Unemployed/Looking for Work	9.0	9.8	9.0		
Employed Part-time	18.1	16.1	18.4		
Employed Full-time	33.6	44.6	32.9		
Self-Employed	3.7	2.7	3.8		
Student	5.7	5.4	5.7		
Homemaker	1.3	0	1.4		
Retired	16.0	11.6	16.5		

TABLE I (continued)PARTICIPANT DEMOGRAPHICS

Three demographic variables showed statistically significant differences across ethnic groups: gender, city size, and Social Security Disability Insurance (SSDI) beneficiaries. Over half the overall participants (59.2%) indicated that their gender was female. It appeared that the proportion of female respondents was significantly lower for the Latinx sample compared to the non-Latinx white sample (X^{2} [3, N=1,462]=70.977, p=<.001), with 54.1% of Latinx respondents reporting they were female. Based on data created from location information provided by participants, 89.7% of overall participants indicated that they lived in urban (as opposed to rural) areas. This proportion was significantly lower (results achieved through Fischer's exact test, p=.037) for Latinx respondents compared to non-Latinx white respondents at 78.9%; however, 17.6% of the Latinx respondents chose not to share location information, as opposed to only 4.8% of the non-Latinx white sample, so it is unclear how the urban/rural spread of the two participant sample groups can compare to one another. Over half of overall respondents (51.2%) indicated that they received SSDI benefits. This proportion was significantly lower at 50.5% for Latinx respondents vs. 53.5% for non-Latinx white respondents $(X^2[2, N=1, 462]=20.323,$ *p*=<.001).

4. Recruitment

The PARC transportation survey utilized convenience sampling in order to recruit participants. The online link to the survey was sent out from ADA-PARC and the ADA National Network to various disability and transportation organizations in the US and its territories. Some disability organizations that were targeted to distribute the survey were various Centers for Independent Living, the University Centers for Excellence in Developmental Disabilities network, the Independent Living Research Utilization network, and numerous disability advocacy groups. Anyone with a survey link was able to take the survey or pass it on to others, so it is difficult to track which people and organizations were used to distribute the survey and recruit participants.

5. **Procedures**

During the survey's active phase (May 2016 to February 2017), participants were asked to complete the online survey at their convenience. Before completing the survey, participants were presented with an informed consent page and had to indicate that they read and understand the information and that they consent in order to move to the survey itself. If needed, paper copies of the survey were available to be completed by hand or read over the phone, in English and in Spanish. Data is not currently available to identify how many and which participants completed non-online versions of the survey.

The survey contained fifty questions and was estimated to have taken 20-25 minutes to complete. Almost all of the questions were multiple choice format with a few requesting openended responses. Topics in the survey included current transportation habits, satisfaction with fixed route and paratransit service, barriers to fixed route and paratransit use, disability-related questions, and demographics.

6. <u>Statistical analysis</u>

The statistical analysis procedures for Part I are outlined in this section. The quantitative analytic approaches in this section are organized by research question.

After preliminary cleaning and analysis of the data, it was suggested by the PARC transportation survey research team that participant responses on transportation barriers and community participation be re-coded in order to better organize them. In the survey, participants were asked in a Likert-type scale questions how often various issues with transportation were a problem. The scale included the responses "never," "rarely," "sometimes," "usually," and

"always," and an option to leave the question blank. After initial analysis of the data, researchers on the PARC transportation survey team found that most of the responses to these questions were somewhere in the middle of the scale. It made more sense to re-code these responses under "yes" and "no;" the re-coded "yes" response would include responses of "always," "usually," and "sometimes" while the re-coded "no" response would include responses of "never" and "rarely."

a. **Research question 1**

To reiterate, research question 1 is: What are the barriers to public transportation access for Latinxs with disabilities? This question was addressed by looking at descriptive data for only Latinx participants. Some of the sections containing variables of interest in answering this research question were: fixed route availability, paratransit availability, reported use of fixed route, reported use of paratransit, reported satisfaction with fixed route services, and reported satisfaction with paratransit services. The researcher explored means, medians, standard deviations, percentages, and variance of these variables for Latinxs with disabilities.

b. <u>Research question 2</u>

To reiterate, research question 2 is: Are the barriers to public transportation access for Latinxs with disabilities different from the barriers to public transportation access for non-Latinx whites with disabilities? This question was addressed by comparing means between the responses of two groups: Latinx respondents and non-Latinx white respondents. The researcher compared means through independent samples *t*-tests and Chisquare tests for responses between the two groups in each of the following sections: fixed route availability, paratransit availability, reported use of fixed route, reported use of paratransit, reported satisfaction with fixed route services, and reported satisfaction with paratransit services.

Independent samples *t*-tests were used when the dependent variable was reported on a scale, such as questions about the availability of fixed route and paratransit, and understanding of transit-related rights and responsibilities. Chi-square tests were used for responses about satisfaction and use of fixed route and paratransit, which are dichotomous variables. Statistical differences between the two groups were noted.

The areas where there significant statistical differences were found between Latinxs and non-Latinx whites were used to develop Part II of the study, which is a qualitative analysis of transportation access and community participation for Latinxs with disabilities.

c. <u>Research question 3</u>

To reiterate, research question 3 is: How do these barriers to public transportation access affect the way that Latinxs with disabilities are able to participate in their communities? This question was addressed by both descriptive statistics and means comparison tests. In terms of descriptive statistics, the researcher explored the means and standard deviations of the responses related to community participation for Latinxs with disabilities. For means comparison tests, the researcher performed Chi-square tests comparing responses about community participation between Latinxs and non-Latinx whites and comparing responses about community participation using paratransit to community participation using fixed route. Statistical differences between the two groups were noted.

The areas where there are statistical differences between Latinxs and non-Latinx whites were used to develop Part II of the study, which is a qualitative analysis of transportation access and community participation for Latinxs with disabilities.

F. Part II: Qualitative Approach

1. Design

Part II of this study utilized qualitative methods to develop a model as to how the noted differences in transportation barriers between Latinxs with disabilities and non-Latinx whites with disabilities might affect Latinxs with disabilities' community participation. Part II used notable quantitative findings from Part I to guide discussions on the topics of interest.

This part of the study employed focus groups with Latinxs with disabilities to discuss and interpret the findings. Focus groups are a type of group interviewing method (Patton, 2015b). In focus groups, a researcher moderates a group of people who share similar experiences or traits as they discuss various topics as a group (Patton, 2015b). Focus groups allow researchers to collect a large amount of data from many participants in an efficient manner. Furthermore, focus groups also allow for intra-group discussion on the topic of interest. A benefit of focus groups in disability research is their ability to amplify the voices of marginalized communities, such as people with disabilities and people of color (Kroll, Barbour, & Harris, 2007). Focus groups fit well with many different philosophical approaches, including a social constructivist approach, like the one used in this qualitative part of the research study, and a positivist approach, like the one used for the quantitative part of this study (Barbour, 2007). Focus groups are often used to shed light onto quantitative data, as they will be used in this study (Krueger & Casey, 2015). Because of their fit with many different approaches, focus groups allow for flexible methods to analyze the data. Additionally, focus groups' experiences of co-learning and problem-solving make it a good method to use with more pragmatist participatory research approaches, which fit with the practical policy-based goals of the current study (Keiffer et al., 2012). Overall, the benefits of using focus groups in this research study with the Latinx disability community are

they are flexible, efficient, low-cost, and help structure the data production process through interaction (Barbour, 2007; Kruger & Casey, 2015; Patton, 2015b).

In spite of these benefits, researchers must take careful considerations when using focus groups with the disability community. Focus groups are limited by the participants' ability to physically arrive at a specific location. This is especially important to note for a study that is targeting people who may already be experiencing transportation problems; the focus groups may produce a skewed sample of participants who already have reliable access to transportation and to their communities. This challenge can be offset by providing transportation stipends for participants. Secondly, focus groups are bound by the limited time the researcher has with the participants. The focus group moderator must be cognizant of the participants' time and utilize it efficiently. Considerations for managing time may include repeating questions that need repeating, allowing participants to get up and move around as they please to take care of their physical bodies, and reminding participants of the focus group schedule. Third, the quality of focus group data can be affected by facilitator skills, so having a skilled and prepared researcher moderate the focus groups is beneficial (Keiffer et al., 2012; Patton, 2015b). Researchers must research the community with which they will be conducting the focus group before they begin to ensure adequate competence on the group's values and cultural contexts (Billson, 2006; Umaña-Taylor & Bámaca, 2006). Keiffer et al. (2012) offers some words of advice to researchers conducting focus groups with disabled people. Keiffer and colleagues suggest that focus groups be conducted with moderators that have similar traits to the participants (such as ethnicity, race, and disability status). The moderator of these focus groups was sure to disclose her personal ethnic and disability identities, and she employed a culturally-Latinx focus group co-facilitator. Furthermore, the Keiffer et al. (2012) study recommends that focus groups begin with an

icebreaker activity to build community among the participants. The focus group moderator began the focus group discussion with an ice breaker activity to build rapport with and among the participants. Finally, focus group moderators working with people with disabilities must make efforts to ensure that the focus group is as accessible as possible to participants and their varying disabilities, especially including participants with communication-related disabilities and IDD (Kroll et al., 2007). The focus groups were conducted in buildings that met ADA accessibility requirements. ASL interpretation, Braille materials, and electronic materials were provided upon request, and participants who needed a personal attendant (PA) were encouraged to bring them to the focus group. Likewise, the researcher heeded advice from the aforementioned researchers who have worked with the disability community and minority communities to ensure that disabled and ethnic minority participants' voices were heard, recognized, and used to contribute to the body of knowledge about transportation for Latinxs with disabilities. More on the specific techniques utilized can be found further on in this section.

2. <u>Setting</u>

Focus groups took place at the Disability Health and Social Policy Building at UIC in Chicago, IL, Access Living in Chicago, IL, Community Support Services in Cicero, IL, Progress Center for Independent Living in Blue Island, IL, and Progress Center for Independent Living in Forest Park, IL. All of these locations are either urban or suburban locations in the Chicagoland area, provide services to the Latinx disability community, and are known to the Latinx disability community.

It is important that the research includes perspectives from multiple transportation and location contexts in order to reflect upon nationwide data collected from the PARC transportation survey. Chicago is a large city with cultural diversity and a large and active Latinx community. Data from the US Census Bureau (2016) shows that Latinxs make up about onethird of the population in Chicago (29%) with most of the Latinx population having roots in Mexico (79%). Around one-fifth of Latinx residents report speaking Spanish as their primary language (21.5%). Furthermore, the suburbs in particular are home to quickly flourishing Latinx communities with some of the largest growth in Latinx population in the country (Paral et al., 2004; US Census Bureau, 2016). Chicago and its suburbs have a large network of public transportation, both fixed route and paratransit. In total, almost a third of residents in the Chicago metro area (28.3%) report using public transportation as their most common mode of transportation (US Census Bureau, 2016), but transit users are dispersed differently throughout the city and suburbs. Chicago's city public transportation, bus and light rail service provided by the Chicago Transit Authority (CTA), saw a total of 497.7 million rides in 2016. While the suburban public transportation, provided by Pace bus and Metra commuter rail, only saw 108.8 million trips in the same year (Regional Transportation Authority; RTA, 2017). Clearly, public transportation in the city is much more extensive and more widely-used in the city compared to the suburbs. The difference in transportation use in these two areas make them complementary to each other in this research study and allow the researcher to study the experiences of Latinxs with disabilities in two different transportation contexts: one widespread and one lacking.

Finally, the Chicagoland area was ultimately chosen as the geographical for these focus groups because of the researcher's familiarity with the area, the area's large population of Latinxs with disabilities, and the area's access to diverse transportation systems.

The focus group settings were all places that provide disability-related services. For example, Access Living and Progress Center are centers for independent living that serve people with disabilities in the Chicagoland area. Community Support Services is an organization serving people with IDD and their families. UIC is a large urban university which hosts a hospital and a family clinic. The Disability, Health, and Social Policy building at UIC hosts and number of disability-related research and community activities. Community Support Services, UIC, and Progress Center are located in Chicago's Latinx neighborhoods and in Latinx-dense Chicago suburbs. It was important that the spaces for the focus groups be public forums so that they are accessible to participants, both physically and logistically. The researcher relied on these partner community organizations that serve Latinxs with disabilities in order to form trustworthy partnerships to connect with the Latinx disability community and recommend spaces for the focus groups that were welcoming and accessible to this community. Furthermore, it was important that the spaces be located in Latinx communities so that it is convenient and familiar for Latinx participants. Finally, it is important that the spaces were accessible by public transportation, since that is the topic of the study.

3. **<u>Recruitment</u>**

The goal for recruitment was to have a mix of focus groups in the city and suburban locations, a mix of languages used in the focus group discussions (English or Spanish), and at least two parent focus groups.

This study used purposeful, targeted recruitment to Latinxs with disabilities through the assistance of Latinx disability community organizations. Organizations solicited for support in recruitment for the focus groups included El Valor, Access Living, the Family Clinic at UIC, Community Support Services, UCP Seguin, the Progress Center, the Lake County Center for Independent Living, the Achieving Independence and Mobility Center for Independent Living, and the Joliet Disability Resource Center. The researcher contacted these organizations in January of 2018 and asked them to distribute the recruitment announcement for the focus groups

to their members and clientele. Recruitment for the focus groups lasted until June 2018, when the researcher determined that data saturation was beginning to be reached.

Recruitment announcements were available in both English and Spanish. The recruitment announcement described the purpose and procedures for the focus groups, the inclusion criteria, and some basic ethical considerations, such as voluntary participation and audio-recording of the focus group. The announcement also mentioned that the study had been endorsed by the Institutional Review Board at UIC, and applicable compensation information. The appendix of this paper provides this study's recruitment announcement in both English and Spanish. Each announcement requested that interested participants call or email the primary investigator to enroll in the focus group and to discuss scheduling. The primary investigator's email and phone contact information was provided in the recruitment materials.

Table II shows the break-down of participants in each focus group, organized by location, language, and parental status.

Number of Participants in each Focus Group by Location, Language, and Parental Status							
Location	<u>Spanish</u>	<u>English</u>	<u>Spanish</u>	Total			
	Disabilities	Disabilities	Parents Parents				
Progress Center, Blue Island	7	2	5	14			
Progress Center, Forest Park	6		7	13			
Community Support Services,		5		5			
Cicero							
Access Living, Chicago	8	8		16			
UIC, Chicago	3		3	6			
TOTALS:	24	15	15	54			

TABLE IIFOCUS GROUP PARTICIPANTS

Participants were scheduled into each particular focus group based on their affiliation with a particular agency. For example, if the participant saw the recruitment announcement for the study when they were at Access Living, this is the focus group they were likely to enroll in. If no focus groups were scheduled that met the participants' language or scheduling needs, they were invited to participate in the focus groups at UIC. If participants in a particular location had different preferred languages (English vs. Spanish) then the researcher scheduled multiple focus groups to accommodate language preference.

In hindsight, the suburban/urban dichotomy for the focus groups did indeed reach its goal of including both urban and suburban perspectives; however, not all the suburban focus groups contained only suburban participants and vice versa. Many participants in the focus groups that had ties with certain organizations travelled from the city into the suburbs or into the city from the suburbs, or vice versa in order to attend the focus group at the location they preferred. Thus, the focus groups in most locations were conducted with people from both the city and the suburbs. This means that comparisons between city and suburban experiences of transportation cannot be analyzed; however, both perspectives are included in the data obtained through the focus groups.

4. Sample

The eligibility criteria for this part of the study include being a person who selfidentified as Latinx, who self-identified as a person with any type(s) of disability or had a child with any type(s) of disability or chronic health condition, who was 18 years of age or older, who spoke either English or Spanish, and had familiarity with the public transportation system in the Chicagoland area. Latinx identity included the many ethnic identification, including Latina/o, Chicano/a, Hispanic, and Mestiza/o. The majority of the Latinx participants had heritage in Mexico, but Puerto Rico and the Dominican Republic were also represented. Many different disability subtypes were represented in the participant sample, including physical disabilities, chronic illness, intellectual disability, psychiatric disability, being blind, or being Deaf.

Parents of children with disabilities were also included in this study along with disabled people themselves, though Latinx parents and Latinxs with disabilities did not participate in the same focus group with one another. The decision to include parents of children with disabilities was encouraged by the study's partner organizations because these parents often come to the community organizations seeking assistance with transportation for their child. It is welldocumented that parents of children with disabilities experience many barriers accessing transportation for their children, and this affects their child's ability to access important community resources such as health care (Flores et al., 1998; Jacob, Kirshbaum, & Preston, 2015). Other evidence to include parents in a study about Latinxs with disabilities includes Latinx culture's emphasis on familism (Cohen, 2013; Jurkowski et al., 2009; Skinner, Rodriguez, & Bailey, 1999; Zea et al., 1994). The researcher decided to separate the parents from the people with disabilities in different focus groups so that the first-hand experience of public transportation as a disabled Latinx would not be confounded with the experience of parting a child with a disability.

Participants were informed that their participation was voluntary. In seven instances, the potential participant indicated that they were unable to attend the scheduled focus group. In ten instances, participants who had previously expressed interest in the focus group and received a reminder call failed to attend the focus group. One participant committed to one focus group and then switched to another date. Some participants chose to self-exclude based on a number of different self-exclusion criteria. Part of the consent to participate included consent to being audio-recorded. All participants signed a consent form before participating and no participants were excluded due to non-consent to being audio-recorded. Furthermore, participants were asked to self-exclude if they did not believe they could tolerate a one-and-a-half to two hour discussion session with several other people or if they could not reliably get to the focus group location. No participants cited these as reasons why they did not participate, but several participants failed to attend a focus group they committed to. It may have been because the participant did not feel up to a lengthy group discussion or they could not reliably get to the focus group location. Two participants self-excluded because they did not feel like they had enough knowledge about public transportation to participate in a focus group on the topic.

In total, ten focus groups were conducted with 2 to 8 individuals per focus group. Table II provides pertinent details about each focus group sample.

As an applicable side note, the researcher did not know if the participants had already completed the PARC transportation survey from Part I of this study. Furthermore, the researcher

did not know if a parent and their child with a disability had both participated in the focus groups unless that information was shared by the participant (which occurred in one case).

5. **Procedures**

The focus group procedures followed protocol recommendations by Krueger and Casey (2015).

Generally speaking, the potential participant would see a flyer at a partner community organization providing information about the study. This potential participant would then call the researcher and express their desire to participate. The researcher would share with the participant a short description of the study, its inclusion criteria, and a summary of informed consent. If the potential participant still had interest (all but two potential participants), and met all eligibility requirements (all remaining participants), the researcher would then schedule them into a focus group. Knowing the participant's disability identity (parent or person with a disability) and their preferred language (English, Spanish, or either), the researcher would then provide at least one possible date and time for a focus group that had already been scheduled with a partner organization. If more than one date was available, the participant would state their preferred date and location.

During this phone call, the participant was also asked if they would need any accommodations. Accommodation requests included: Braille materials, large print materials, American Sign Language (ASL) interpretation, accompaniment by a PA, and wheelchair accessibility. The researcher made sure all accommodation requests were fulfilled two weeks before the scheduled focus group.

Participants were reminded via phone, email, or text of the day and time of their scheduled focus group one or two days before the scheduled session. Not all of the participants

responded to the reminder call, but the researcher left a voicemail, sent an email or a text, and planned on the participant coming even if they did not confirm.

Focus groups were separately scheduled based on language and parental status such that parent focus groups would consist of only parents and not people with disabilities, English focus groups would consist of only participants who spoke English, and Spanish focus groups would consist of only participants who spoke Spanish. No live translation from Spanish to English (or vice versa) was provided.

Focus groups were not consciously separated based on disability; however, there was one group of participants that were recruited from an agency that serves young adults with IDD, thus the focus group at this location included participants that all identified as people with IDD. For all of the focus groups, the researcher was be mindful of identity-related and accessibility-related issues that can arise in focus groups with cross-disability participation. For example, she was sure that participants with communication-related impairments had the opportunity to express themselves fully, without being talked over by other participants. The researcher ensured that all written materials, including the consent form, contained accessible language (e.g., plain language, avoiding jargon) and were available in Braille, large print, and electronic copies if requested. One focus group welcomed ASL interpretation for Deaf participants. Because focus group participants are bound by a shared identity, the researcher worked to ensure that cross-disability groups still had a shared sense of disability identity.

When participants arrived to each venue, they were asked to take a seat. Most venues had a table with chairs and spaces for wheelchairs to gather around. Other venues had just a circle of chairs. Either way, participants would sit facing one another. As participants arrived, they were given an informed consent form to read and sign. The researcher provided a summary of the

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consent form as individual participants arrived. Some participants did not complete the phone screener prior to arriving to the focus group site. These individuals heard about the focus group from a fellow participant or from the host organization. These participants were administered the phone screener. If someone did not meet the eligibility criteria at the focus group, it was because they arrived as the PA of another participant. These individuals were invited to stay as non-participant listeners in the group.

Food and refreshments were provided for participants. The researcher worked with each organization to determine which food and refreshments would be best. Examples of refreshments were pizza, cookies, and soft drinks and sandwiches, bottled water, and chips. Participants were welcome to help themselves to the refreshments throughout the focus group.

Once the consent and screeners had been completed, the researcher would introduce herself, summarize the consent form and privacy expectations to the whole group, and provide general rules for the focus group participation. Participants then introduced themselves as an icebreaker activity. The focus group co-facilitator was next to introduce herself. The co-facilitator was a fellow UIC graduate student in disability studies who was born in Colombia and a native Spanish speaker. She participated in seven of the ten focus groups.

Next, the researcher turned on the audio-recorders and the group began discussion on the research study material. Participants were asked to share their experiences on public transportation (including fixed route and paratransit services). A specific focus group guide including all questions posed during the focus groups can be found in the appendix. Next, notable findings from the quantitative part of the study were presented to the group. Focus group members were asked to discuss reasons why the findings might have come out the way that they did for Latinxs with disabilities and to discuss the implications that these reported barriers might

have on community participation for Latinxs with disabilities. Participants received a fact sheet describing the findings. The fact sheet was available in English and Spanish, Braille, and large print. A copy of the fact sheet in both English and Spanish can be found in the appendix. The researcher read aloud all information on the face sheet. Finally, the group was asked to discuss ways to disseminate the findings of this study in order to better serve the Latinx disability community, and finally participants were given the opportunity to discuss any additional related topics or ask any applicable questions.

The researcher ensured that all information was discussed within the time frame. Each focus group lasted one and a half to two hours, including time to complete consent forms and the ice breaker activity. Participants received a stipend on \$25 upon completing of the focus group.

After completion of the focus groups, recordings of the group discussions were transcribed in their original language. Transcriptions were done by GoTranscript for Spanish language focus groups and Rev for English language focus groups. Quotes were translated from Spanish to English by the researcher and co-facilitator when they were used directly in this paper.

6. <u>Analysis</u>

Analysis of the qualitative focus group data involved thematic analysis guided by grounded theory. Grounded theory is a good fit for data analysis when the goal of research is to create new theory out of existing data (Lingard, Albert, & Levinson, 2008). The goal of this grounded theory research is to create a working model as to why Latinxs with disabilities report certain barriers to public transportation and how their reported barriers affect community access and participation. Grounded theory's iterative and indicative process will guide the data analysis rather than premeditated hypotheses or sensitizing concepts (Charmaz, 2012). Before the data

collection for this part of the study began, the researcher had already gathered some sensitizing concepts for the analysis since this study is being performed as part of a doctoral dissertation project and a literature review has already been performed. However, the researcher was sure to guide the participants open-mindedly through the focus groups to try to garner new ideas to create a novel theoretical model on public transportation access and community participation for Latinxs with disabilities.

The approach to grounded theory implemented in the current study is borrowed from an approach used by Wee and Paterson (2009). Wee and Paterson used grounded theory to create a model on participation for people with disabilities, similar to the current study. Their approach to grounded theory was a revised model to Strauss and Corbin (1994)'s conceptualization of grounded theory. Wee and Paterson's approach began with the use of open coding, in which the researcher produces general codes for all collected data. Next, the researcher performed selective coding, which generates applicable categories related to the research question(s). Finally, the researcher used theoretical coding, which ultimately leads to the production of a theoretical model related to Latinxs with disabilities, public transportation access, and community participation. Theoretical coding involves discovering overlaps in the data, relationships between the data, and sorting the data into categories. This is the most vital part of grounded theory research because it goes beyond the data itself to create a written narrative of how the data connects to answer the research question (Charmaz, 2012; Rasmussen, Akinsulure-Smith, & Chu, 2016).

This researcher also implemented elements of the constant comparison method advocated for by Glaser and Strauss (Charmaz, 2012). In the constant comparison method, the researcher constantly compared new data with existing data applicable to each category or theme. This process is inductive, strives not to be influenced by existing theory or sensitizing concepts, and is iterative. With that said, the researcher constantly analyzed the data as it was being collected and tried to purposefully sample new participants in order to reach data saturation. For example, after a focus group with Latinx parents of children with IDD, the researcher found some themes in the data that she wanted to explore with a sample of Latinxs with IDD. The researcher then reached out to an organization that serves young adults with IDD and scheduled a focus group with their Latinx consumers. She was able to talk to this group about some of the themes she found with parents to see if these themes held up similarly with people with disabilities. Using the constant comparison method in grounded theory, the researcher's goal was to create a novel theoretical model related to Latinxs with disabilities, public transportation access, and community participation.

The design of Part II of this study is a multiple-category design, which allows for comparisons between different subgroups. The researcher compared responses of the Spanishspeaking participants to the responses of the English-speaking participants. The researcher also compared responses of Latinx parents of children with disabilities to responses of Latinx people with disabilities. The design of this study does not allow for disability subgroup comparisons (e.g., the experiences of Latinxs with physical disabilities vs. the experiences of blind Latinxs) or city vs. suburban comparisons.

Focus group data was analyzed in the language that it was transcribed into, which is also the language it was originally produced in. Translation of focus group data into English as a nonoriginal language occurred for directly quotes used in this paper so that it can be accessible to the study's primarily English-speaking colleagues and dissertation committee. Translation was done by the bilingual researcher and the Latinx co-facilitator. While the researcher speaks Spanish fluently, she is not a native speaker. Her native Spanish-speaking co-facilitator assisted the researcher in analysis and translation in Spanish. Furthermore, since Spanish language varies in different countries and areas, the researcher received translation assistance from other members of the Latinx community from many different countries in order to ensure that her translations are culturally-appropriate.

G. Rigor of Qualitative Analysis

The researcher implemented several techniques to improve the rigor of the qualitative data analysis. The techniques implemented include bias-checking strategies, data triangulation, prolonged engagement, inter-coder agreement, and forming an audit trail. In constructivist research, bias and subjectivity are recognized and used as research tools with which to construct the data (Patton, 2015a); however, in order for bias to be properly identified, it is helpful for the primary researcher to check these personal biases. First, the researcher has included a section on subjectivity in this paper where she talks about her background, biases, and relationship to the participant community. She was always open about her identities to her participants and partner organizations.

Second, the researcher participated in peer debriefing where she discussed subjectivity in the data with the culturally-Latinx co-facilitator after each focus group and throughout the data analysis process. The goal of peer debriefing was to implement some reflexivity where the researcher could identify her own biases and reflect upon them, but also to process the data and to add richness to the data analysis.

Third, the researcher candidly memoed throughout the qualitative data analysis, a technique often used to identify biases. She also discussed any seemingly-contradictory data and

findings with her co-facilitator and partner organizations to evaluate her own reflection on the data. The goal of these techniques was not to eliminate bias, but rather to identify and control it.

Data triangulation techniques were implemented into the research. The sequential mixedmethods design of the study inherently employs data triangulation; quantitative results were member-checked in the qualitative focus groups. But furthermore, the results from the focus groups were discussed with partner organizations. Since the partner organizations work closely with Latinxs from various cultural contexts and with a myriad of disabilities, they often gave more insight and a different subjective point of view to the qualitative data. Often, the researcher would come to an organization with a specific question that she had about the data (e.g., "Participants are saying that X and Y are related, but I can't figure out why that is. Can you shed some light on this relationship?"), and request that the organization give an informed opinion. The same question was asked to at least two organizations to ensure multiple perspectives were being captured.

The researcher displayed prolonged and consistent engagement with the focus group data. This was done to increase the credibility of the results. This study took place over a period of five months, from February to June 2018, with an additional three months for data analysis (June to August 2018) and reliability testing (August 2018), and an additional five months for member checking, (June to November 2018). Throughout the first five months, the researcher was simultaneously collecting and analyzing data, which is a common technique in grounded theory research (Charmaz, 2012). This prolonged engagement allowed the researcher to build relationships with the data, the participants, and the community. It also allowed the researcher time to create a temporal and spatial context for the data. For example, this data was being collected during a time when immigrants, and particularly Latinx immigrants were being

systematically oppressed by the presidential administration, and instances of this oppression were vividly conveyed by the media. This context is important to understand for any discussions related to Latinx ethnicity and human rights in the US during this time period.

Inter-coder agreement is a form of data triangulation used during the data coding and analysis. Inter-coder agreement was done in the current study. Excerpts from coded participant data were randomly chosen and de-coded. These de-coded excerpts were given to a third-party coder who is not familiar with the data (i.e., not the co-facilitator), but who does have experience working with the Latinx disability community. The third-party coder then coded the data and discussed codes and themes with the primary researcher. This was done several times throughout the data analysis process: once with the co-facilitator, and twice with a bilingual third-party who was unfamiliar with the data. A reliability score was calculated for the third-party coders. For each inter-coder reliability testing, the alternate coder was given a five-page excerpt of a focus group transcript. The coder was then requested to code the excerpt for applicable themes and subthemes. This excerpt was them compared to the researcher's excerpt of the same transcript. Inter-rater reliability was not calculated as a percentage or a ratio, but instead was used in a more inductive approach, more consistent with grounded theory, to perform the constant comparison method. All researcher-coded themes held up with the third-party coding data, and one theme was edited to add an additional social facilitator to community participation.

Finally, the researcher produced an audit trail. Audit trails allow other researchers to follow the same analysis methods and get similar results. It is essentially creating a chain of evidence to track methodology (Mertens, 2010; Rasmussen et al., 2016). Audit trails are another way to check biases. Inter-coder agreement is one way the researcher has created an audit trail. The researcher memoed about coding trends from the third party coder. Furthermore, the researcher memoed coding decisions and correspondences with the co-facilitator and partner organizations. The researcher also memoed while creating theoretical codes so that other researchers can verify her train of thought and connections between the data. This documentation is open to community partner organizations, the co-facilitator, and the third-party coder. Finally, an outline describing how themes were compiled and categorized and an outline of how the theoretical model was developed from these themes can be found in this paper. These outlines includes feedback from partner organizations, the co-facilitator, and the third-party coder.

H. <u>Ethical Considerations</u>

This study was implemented upon approval by Institutional Review Board at the University of Illinois at Chicago (protocol #: 2018-0169). While both quantitative and qualitative research may be susceptible to violations of ethics, qualitative research in particular provokes some unique ethical concerns due to its flexibility, openness, intimacy with participants, and tendency to be implemented with vulnerable populations (Brinkman & Kvale, 2008).

Confidentiality and privacy are of utmost importance in social science research, and particularly qualitative research that involves direct contact with participants (Patton, 2015b). Confidentiality and privacy will be taken very seriously throughout the entire research process and explained thoroughly to participants. The quantitative part of the study, Part I, only included de-identified data. The researcher did not know any of the names or identities of the participants involved. Privacy and confidentiality are a bit more complicated in qualitative research, when participants often reveal personal information. Privacy is even more imperative when using group research methods such as focus groups (Keiffer et al., 2012). All focus groups participants were required to sign an informed consent before participating. This informed consent addressed concerns related to privacy and confidentiality of group discussions and specifically asked the participants not to share focus group participants' identities or ideas outside of the focus group space. However, the informed consent was also required to state that due to the communal nature of focus group research, privacy and confidentiality cannot be 100% guaranteed. As suggested by Brinkman and Kvale (2008) and Gustafson and Brunger (2014), conversations about confidentiality and privacy should were ongoing throughout the research process so that researcher and participant knew their expectations. Furthermore, the researcher and co-facilitator worked to ensure participants were respectful of one another, that all participants felt comfortable sharing their ideas, and that no one felt left out of discussion nor obligated to share.

Overall, it did not appear that privacy was a big concern of the focus group participants. Many acknowledged that the material being discussed was not sensitive in nature and many even stated that it would be permissible to use their real names. Regardless, the researcher was clear and concise about the privacy expectations.

Because this research was done with the disability community, certain disability- and impairment-related ethical issues were considered. Disability researchers must be able to explain confidentiality and privacy issues in a way (and a language) that their participants understand. The consent form and its summary in the focus group guide were proofread and edited by one of the partner disability organizations to ensure that the language used was accessible and appropriate for the community (in both English and Spanish). Disability researchers must take careful considerations when using focus groups with this community. The researcher has extensive experience working with Latinx communities in Chicago and working abroad in Latin America. Furthermore, the co-facilitator also has experience working with the disability community in Chicago, South Carolina, and her home country of Colombia. Keiffer and colleagues (2012) suggest that focus groups begin with an ice-breaker activity to build community among the participants and rapport between researcher and participants, thus an ice breaker introduction activity was implemented into the current study's focus groups. As suggested by several researchers with the disability community, the researcher used the ice breaker as an opportunity to build genuine and professional rapport with participants before beginning the focus group activities (Brinkman & Kvale, 2008; Kelly, 2010).

Questions of power imbalance can arise in qualitative research. In general, researchers have more control over the projects than participants do and they should be mindful of their authoritative role (Kelly, 2010). This is especially pertinent when doing research with marginalized populations such as people of color and people with disabilities. Due to a history of colonialization, discrimination, and the current political climate in the US, many undocumented Latinxs may be wary of participating in institutionalized research (Cruz, 2008; George et al., 2015; Vaughn, Jacquez, Zhen-Duan, Graham, & Marschner, 2017). It may be best for the researcher working with Latinxs to not ask about documentation status as to not make participants anxious about the purpose of collecting that information. Neither part of this study, Part I nor Part II, requested information about documentation status or birthplace. Finally, language is especially important to consider when performing qualitative research with Latinxs. It is important that participants understand informed consent documents, participation instructions, and the purpose of the research. All documents related to the study are available in Spanish and English and have translated by and been checked for accuracy by native speakers of both languages. The PARC transportation survey was available in Spanish and English and could be read to participants over the phone by a bilingual researcher. All focus groups and data analysis was performed by a bilingual researcher in the language preferred by the participants. The participants' preferred language was be used for both collection and analysis of data so that

the researcher was able to comprehend the participants in the way that they were most comfortable speaking and in order to notice the nuances of each language. Finally, employing a culturally-Latinx co-facilitator to facilitate the focus groups was another tactic that addressed any potential power imbalances between researchers and participants. This tactic proved to be beneficial, as many participants alluded to the lived experience of being an ethnic minority as unique and important. Many even looked to the Latinx co-facilitator for validation of these statements. While the researcher addressed her identity as a person with lived experience of disability, it would have been even better if the researcher or the co-facilitator had a visible disability. This would have addressed the power imbalance that affects the disability community in a more direct and impactful way.

V. RESULTS

A. Part I Results

Quantitative results from Part I appear in the following section. Results are organized based on research question. The discussion section will integrate these results into a unified theoretical model on transportation access and community participation for Latinxs with disabilities.

1. **Research question 1**

Research question 1 asks: What are the barriers to public transportation access (both fixed route and paratransit) for Latinxs with disabilities? This question was answered using descriptive statistics on data from the Latinx subsample of the PARC transportation survey. A summary of these statistics appears in Table III.

Overall, 66.4% of Latinxs with disabilities indicated that they experience barriers that prevented them from using public transportation or using public transportation as often as they would like. Several highlighted barriers to fixed route and paratransit use appear in Table III. These were items for which at least half of Latinxs with disabilities endorsed experiencing problems at least some of the time:

Reported Problems at Least Some of the Time by at Least 50% of Participants		
	<u>% Reporting Problems</u>	
Barriers to Fixed-Route - General		
How much time it takes to get where I want to go	84.6	
Where the service runs	83.3	
How I am able to use the service during different kinds of		
weather	78.8	
The time of day or day of the week I am traveling	72.3	
How reliable the service is	66.2	
How reliable the service is during different kinds of		
weather	63.1	
How easily I can find information on the service	50.8	
How I am treated by drivers	50.0	
How safe I feel using the service	50.0	
Barriers to Fixed-Route – Fixed-Route Specific		
How often the service runs	81.5	
The availability of fixed route public transportation		
without advanced planning	71.2	
Availability of public transportation when you need it	70.0	
How many transfers I need to take	62.5	
The accessibility and safety of getting to/from stops	61.5	
The accessibility of the stops	60.6	
The announcements of stops	57.4	
How to use the service or to plan a route	56.7	
How close the stop is to my home	54.7	
Drivers understanding their responsibilities to people		
with disabilities	51.5	
Barriers to Paratransit - General		
How much time it takes to get where I want to go	85.7	
How flexible the service is	76.6	
How reliable the service is	74.0	
The time of day or day of the week I am traveling	69.4	
How reliable the service is during different kinds of		
weather	63.3	
Where the service runs	57.1	
How easily I can find information on the service	55.3	

 TABLE III

 PUBLIC TRANSPORTATION BARRIERS FOR LATINXS

Reported Problems at Least Some of the Time by at Least 50% of Participants		
	<u>% Reporting Problems</u>	
Barriers to Paratransit – Paratransit Specific		
How much time it takes for the service to arrive	87.8	
Making reservations	58.3	
Missing the pickup window	56.3	
The no-show policy	52.1	

TABLE III (continued)PUBLIC TRANSPORTATION BARRIERS FOR LATINXS

Overall, many Latinxs with disabilities experienced a number of challenges and uncertainties accessing public transportation. They also appeared to experience similar barriers when using fixed route and paratransit.

2. **Research question 2**

Research question 2 asks: Are the barriers to public transportation access for Latinxs with disabilities different from the barriers to public transportation access for non-Latinx whites with disabilities? This question was answered using *t*-tests and Chi-square tests to compare the responses on the PARC transportation survey on questions about fixed route and paratransit access between Latinxs and non-Latinx whites. A summary of these results can be found in Table IV. Notable differences are reported. Overall, there were indeed some differences in the barriers reported by Latinxs with disabilities and non-Latinxs whites with disabilities.

Reported Problems at Least Some of the Time on Fixed Route and Paratransit		
	% of Latinx Participants (N=119)	<u>% of non-Latinx</u> <u>White Participants</u> (<i>N</i> =1,343)
Barriers to Fixed Route Transit - General	``````````````````````````````````````	
How much the services cost	43.1***	24.3***
Where the service runs	83.3	79.4
How reliable the service is	66.2**	48.8**
How much time it takes to get where I want to go	84.6	76.8
The time of day or day of the week I am traveling	72.3	68.1
How easily I can find information on the service	50.8	38.3
How I am treated by drivers	50.0**	32.0**
How I am treated by other riders	34.8	30.1
How safe I feel using the service	50.0	40.2
How I am able to use the service during different kinds of weather How reliable the service is during different kinds of	78.8**	59.6**
weather	63.1	51.6
<u>Barriers to Fixed Route Transit – Fixed Route Specific</u> <i>The availability of fixed route public transportation</i>		
without advanced planning	71.2	63.1
Availability of public transportation when you need it	70.0	60.9
How often the service runs	81.5	75.8
How many transfers I need to take	62.5	57.3
How close the stop is to my home	54.7	48.7
The accessibility of the stops	60.6	56.8
The accessibility of the lifts or ramps	42.4**	28.3**
The reliability of the lifts or ramps	38.8*	27.1*
The announcements of stops	57.4	50.6
How mobility aids are accommodated	39.4	32.4
Drivers allowing service animals	18.4	15.2
Drivers understanding their responsibilities to people with disabilities	51.5	43.6
Drivers passing stops without picking up passengers with disabilities	42.4*	29.7*
How to use the service or to plan a route	56.7	46.2
The accessibility and safety of getting to/from stops	61.5*	48.6*
Access to help or emergency assistance	44.4***	24.0***

TABLE IVPUBLIC TRANSPORTATION BARRIERS

Reported Problems at Least Some of the Time on	Fixed Route and	d Paratransit
	<u>% of Latinx</u> <u>% of non-Latin</u>	
	Participants	White Participants
	(<i>N</i> =119)	(<i>N</i> =1,343)
How much the services cost	34.5	33.3
The time of day or day of the week I am traveling	69.4	63.4
Where the service runs	57.1	55.5
How reliable the service is	74.0	60.6
How flexible the service is	76.6	68.7
How much time it takes to get where I want to go	85.7**	70.0**
How easily I can find information on the service	55.3**	34.7**
How I am treated by drivers	34.7*	21.1*
How I am treated by other riders	10.4	10.0
How safe I feel using the service	28.6	20.7
How I am able to use the service during different kinds of		
weather	45.8	33.3
How reliable the service is during different kinds of		
weather	63.3**	44.0**
Barriers to Paratransit – Paratransit Specific		
The no-show policy	52.1***	28.7***
Making reservations	58.3	50.7
Missing the pickup window	56.3**	33.3**
Being removed from eligibility	16.7**	5.6**
The availability of door-to-door service	31.3	29.9
The availability of curb-to-curb service	25.0	25.8
How much time it takes for the service to arrive	87.8**	73.2**
Note: * p<0.05, ** p<0.01, ***p<0.001		

TABLE IVPUBLIC TRANSPORTATION BARRIERS

In terms of general transportation preferences, fewer Latinxs with disabilities reported

using a car as their main form of transportation to get from one place to another ($X^{2}[1,$

N=1460]=3.934, p=0.047), with only 37.8% of Latinx respondents reporting that a car was their main form of transportation and 47.3% of non-Latinx whites reporting the same. Relatedly, Latinxs with disabilities were more likely to have used public transportation in the past 12 months compared to their non-Latinx counterparts ($X^{2}[1, N=1,454]=7.046$, p=0.008), with 61.7% of Latinx respondents reporting that they had used fixed route transportation services within the past 12 months and only 48.8% of non-Latinx whites reporting the same." Thus, it appears that Latinxs with disabilities reported driving less and taking fixed route more than non-Latinx whites with disabilities.

a. **<u>Fixed route transportation barriers</u>**

In terms of barriers to accessing fixed route transportation, Latinxs with disabilities reported the following barriers as a problem (at least some of the time) more often than their non-Latinx counterparts: how much the service costs, how reliable the service is, how they are treated by drivers, using the service in different kinds of weather, accessibility of lifts and ramps, reliability of lifts and ramps, drivers passing stops without picking passengers up, accessibility and safety getting to stops, access to emergency assistance.

Economic considerations came into play for Latinxs with disabilities, who reported more often that the cost of public transportation is a concern ($X^2[1, N=702]=10.752$, p=0.001). Of Latinx respondents, 43.1% reported that cost was a problem at least some of the time and only 24.3% of non-Latinx whites reported the same.

The reliability of the fixed route transit system was also reported as a concern for Latinxs with disabilities ($X^{2}[1, N=702]=7.087$, p=0.008). Of the Latinx respondents, 66.2% reported that the system not being reliable was a problem at least some of the time and only 44.8% of non-Latinx whites reported the same.

Latinxs with disabilities reported instances of discrimination while riding on fixed route transportation more often than their non-Latinx counterparts. They reported that they had concerns about the way that they are treated by fixed route transit drivers ($X^2[1, N=706]=8.645$, p=0.003), with 50.0% of Latinx respondents reporting that this was a problem at least some of the time and only 32.0% of non-Latinx whites reporting the same. Latinxs with disabilities also reported that they have concerns about drivers passing them up at stops more often than their non-Latinx counterparts ($X^2[1, N=699]=4.532$, p=.033), with 42.4% of Latinx respondents reporting that this was a problem at least some of the time and only 29.7% of non-Latinx whites reporting the same.

In terms of safety, another issue reported concerned access to emergency assistance while riding on fixed route ($X^{2}[1, N=683]=12.411$, p=<.001). Of Latinx respondents, 44.4% reported that access to emergency assistance was a problem at least some of the time and only 24.0% of non-Latinx whites reported the same.

Transportation issues for this population did not just concern the transit vehicles and staff, they also concern the environment. When the weather was bad, Latinxs with disabilities seemed to be more affected than their non-Latinx counterparts when taking fixed route transit $(X^2[1, N=707]=9.300, p=0.002)$. Of the Latinx respondents, 78.8% reported that it was a problem for them to take fixed route transportation in all types of weather at least some of the time and only 59.6% of non-Latinx whites reported the same. Latinxs with disabilities also more often reported concerns about accessibility of the environment surrounding transit and being able to get to the stations and stops ($X^2[1, N=703]=3.957, p=.047$), with 61.5% of Latinx respondents reporting that this was a problem at least some of the time and only 48.6% of non-Latinx whites reporting the same.

Latinxs with disabilities reported that the (in)accessibility $(X^{2}[1, N=692]=5.734,$

p=0.017) and (un)reliability (X²[1, N=695]=4.118, p=0.042) of the lifts and ramps on fixed route transit vehicles was more of a problem for them compared to their non-Latinx counterparts. Forty-four point two percent of Latinx respondents reported that lack of accessibility of lifts and ramps was a problem at least some of the time and only 28.3% of non-Latinx whites reported the same. While 38.8% of Latinx respondents reported that a lack of reliability of the lifts and ramps was a problem at least some of the time and only 27.1% of non-Latinx whites reported the same.

Furthermore, another interesting result showed that Latinxs with disabilities were *more* likely than non-Latinx whites with disabilities to be enrolled in a discount program for transit $(X^2[1, N=1,045]=4.241, p=0.040)$, with 60.2% of Latinx respondents reporting that they were enrolled in a discount program and only 48.8% of non-Latinx whites reporting the same.

b. **Paratransit barriers**

First, more Latinxs with disabilities reported using paratransit services compared to non-Latinx whites with disabilities ($X^2[1, N=1,086]=7.026, p=0.008$), with 62.8% of Latinx respondents reporting that they have used paratransit services within the past 12 months and only 47.9% of non-Latinx whites reporting the same. Additionally, Latinxs with disabilities were more likely than non-Latinxs with disabilities to use paratransit as their exclusive form of transportation ($X^2[1, N=532]=4.420, p=0.036$), with 30.2% of Latinx respondents reporting that they use paratransit for all of their transportation needs and only 18.2% of non-Latinx whites reporting the same.

Overall, Latinxs with disabilities reported many barriers concerning their access to paratransit services that were more severe than those of non-Latinx whites with disabilities. In terms of barriers to accessing paratransit services, Latinxs with disabilities reported the following barriers as a problem (at least some of the time) more often than their non-Latinx counterparts: missing the pickup window, being removed from eligibility, problems with the no-show policy, how reliable the service is in different kinds of weather, how they are treated by drivers, how easily they can find information about the paratransit service, how much time it takes the service to arrive, and how much time it takes to get to where they need to go.

Many of the concerns reported about paratransit that were more of a barrier for Latinxs with disabilities compared to non-Latinx whites with disabilities centered on the paratransit system and its rules and regulations. Latinxs with disabilities worried about missing their pickup window ($X^2[1, N=517]=10.062$, p=0.002), with 56.3% of Latinx respondents reporting that this was a problem at least some of the time and only 33.3% of non-Latinx whites reporting the same. Furthermore, Latinxs with disabilities also worried more than their non-Latinx counterparts about being removed from ADA eligibility ($X^2[1, N=515]=8.696$, p=0.003), with 16.7% of Latinx respondents reporting that this was a problem at least some of the time and only 5.6% of non-Latinx whites reporting the same. Finally, Latinxs with disabilities reported more problems with the no-show policy compared to their non-Latinx counterparts ($X^2[1, N=515]=11.157$, p=0.001), with 52.1% of Latinx respondents reporting that this was a problem at least some of the ime and only 28.7% of non-Latinx whites reporting the same.

Similarly to fixed route, weather was an environmental concern reported more often as a problem by Latinxs with disabilities when riding paratransit. Sixty-three point three percent of Latinx respondents reported that the reliability of paratransit service in all kinds of weather was a problem at least some of the time and only 44.0% of non-Latinx whites reported the same ($X^{2}[1, N=517]=6.619, p=0.010$).

Also similar to the results for fixed route transit service, more Latinxs with disabilities reported that they had problems with the way that they were treated by paratransit drivers (X^{2} [1, N=519]=4.750, *p*=0.029), with 34.7% of Latinx respondents reporting that this was a problem at least some of the time and only 21.1% of non-Latinx whites reporting the same.

Latinxs with disabilities reported having a harder time finding information about the paratransit service compared to their non-Latinx counterparts ($X^2[1, N=519]=7.796$, p=0.005), with 55.3% of Latinx respondents reporting that this was a problem at least some of the time and only 34.7% of non-Latinx whites reporting the same.

Timing was a final issue that was reported moreso by Latinxs with disabilities. More Latinxs with disabilities than non-Latinxs with disabilities reported that they were unsatisfied with how much time it takes to get where they need to go on paratransit ($X^2[1, N=525]=5.404$, p=0.020), with 85.7% of Latinx respondents reporting that this was a problem at least some of the time and only 70.0% of non-Latinx whites reporting the same. Similarly, Latinxs were more unsatisfied with how much time it takes the paratransit service to arrive: ($X^2[1, N=522]=4.988$, p=0.026), with 87.8% of Latinx respondents reporting that this was a problem at least some of the time and only 73.2% of non-Latinx whites reporting the same.

3. **Research question 3**

Research question 3 asks: How do barriers to public transportation access affect the way that Latinxs with disabilities are able to participate in their communities? Participants were asked questions about their transportation options, and if they believed they had equal access to public transportation. A set of questions in the PARC transportation survey asked about community participation, specifically the following domains: school or work, health care, running errands, social and recreational events, and volunteerism. These statistics are reported in Table V.

LATINXS		
Reported Barriers at Least Some of the Time on Fixe	d Route and Pa	ratransit
	% of Latinx Participants	<u>% of non-</u> <u>Latinx</u> <u>White</u> <u>Participants</u>
	(<i>N</i> =119)	(<i>N</i> =1,343)
<u>General Barriers to Community Participation</u> Something is preventing me from using public		
transportation or from using public transportation as		
much as I would like	66.4	65.5
Problems with having the same access to public transit		
as others in my community	55.2	51.9
Problems accessing a different form of transportation if		
my usual way of traveling is not available	71.9*	56.0*
Barriers to Community Participation Using Fixed Route		
Getting to school or work	70.3***	46.6***
For healthcare appointments and other health needs	71.2**	52.8**
For running errands	68.7	57.5
For spending time with other people, socializing or doing		
things in my community for fun	75.8*	60.8*
Getting to places I volunteer	65.1***	40.3***
Barriers to Community Participation Using Paratransit		
Getting to school or work	36.8	32.5
For healthcare appointments and other health needs	35.1	37.3
For running errands	40.3	39.6
For spending time with other people, socializing or doing		
things in my community for fun	45.5	43.3
Getting to places I volunteer	32.1	32.9
Note: * p<0.05, ** p<0.01, ***p<0.001		

TABLE VBARRIERS TO COMMUNITY PARTICIPATION FOR LATINXS AND NON-
LATINXS

First, it appears that Latinxs with disabilities had fewer overall transportation options compared with non-Latinxs whites with disabilities. When it comes to needing a "plan B," Latinxs were more likely to have a problem finding a secondary form of transportation when their usual way of traveling is not available ($X^2[1, N=680]=5.974$, p=0.015). Of Latinx respondents, 71.9% reported that this was a problem at least some of the time and only 56.0% of non-Latinx whites reported the same. Perhaps contradictorily, Latinxs and their non-Latinx counterparts did not differ significantly in their perceived equality of access to public transportation services nor feeling like there was something preventing them from using public transportation or from using it as much as they would like.

a. Fixed route barriers and community participation

Overall, over half of Latinxs reported problems using fixed route to participate in their communities. Specifically, 70.3% of Latinx respondents reported that getting to school or work was a problem when using fixed route at least some of the time and only 46.6% of non-Latinx whites reported the same. Seventy-one point two percent of Latinx respondents reported that getting to health care appointments was a problem when using fixed route at least some of the time and only 52.8% of non-Latinx whites reported the same. Seventyfive point eight percent of Latinx respondents reported that getting to social events or spending time with friends was a problem when using fixed route at least some of the time and only 60.8% of non-Latinx whites reported the same. Of Latinx respondents, 65.1% reported that getting to places they volunteer using fixed route was a problem at least some of the time and only 40.3% of non-Latinx whites reported the same. Of Latinx respondents, 68.7% reported that using fixed route for running errands was a problem at least some of the time and only 40.3% whites reporting the same. There appeared to be some significant differences in the barriers to community participation experienced by Latinxs with disabilities compared to non-Latinx whites with disabilities when they use fixed route transportation. Particularly, using fixed route presented problems for Latinxs for getting to school or work ($X^2[1, N=671]=13.003$, p=<.001), for getting to health care appointments ($X^2[1, N=670]=8.125$, p=.004), for socializing or doing things for fun ($X^2[1, N=670]=5.693$, p=.017), and for getting to places they volunteer ($X^2[1, N=648]=14.221$, p=<.001). Using fixed route for running errands was the only domain where Latinxs did not significantly differ from non-Latinx whites, although they did report having problems more often.

b. Paratransit barriers and community participation

Interestingly, there were not the same statistically significant differences between Latinxs with disabilities and non-Latinx whites with disabilities in community participation when using paratransit. In fact, it appeared that both groups reported fewer barriers to community participation when they use paratransit services. Overall, only about one-third of Latinxs reported problems using paratransit to participate in their communities, similar to non-Latinx whites. Specifically, 36.8% of Latinx respondents reported that getting to school or work was a problem when using paratransit at least some of the time and 32.5% of non-Latinx whites reported the same. Thirty-five point one percent of Latinx respondents reported that getting to health care appointments was a problem when using paratransit at least some of the time and 37.3% of non-Latinx whites reported the same. For health care needs, Latinxs with disabilities actually reported *fewer* problems then their non-Latinx counterparts. Forty-five point five percent of Latinx respondents reported that getting to social events or spending time with friends was a problem when using paratransit at least some of the time and 43.3% of non-Latinx whites reported the same. Of Latinx respondents, 32.9% reported that getting to places they volunteer using paratransit was a problem at least some of the time and 32.1% of non-Latinx whites reported the same. Of Latinx respondents, 40.3% reported that using paratransit for running errands was a problem at least some of the time and 39.6% of non-Latinx whites reported the same.

B. <u>Part II Results</u>

Qualitative results from Part II appear in the following section. Results are organized based on research question and emerging themes. The discussion section will integrate these results into a unified theoretical model on transportation access and community participation for Latinxs with disabilities. The themes coding outline for these qualitative results, which describe how items were coded, can be found in the appendices.

1. **Research question 1**

Research question 1 asks: What are the barriers to public transportation access (both fixed route and paratransit) for Latinxs with disabilities?

The researcher used a modified socio-ecological model (Bronfenbrenner, 1989) to determine barriers at the following levels for both fixed route and paratransit: individual accessibility-related barriers, interpersonal barriers, systemic or organizational barriers, and environmental barriers. These categories were generated by the data and through discussion between the researcher and the co-facilitator.

a. **Fixed route barriers**

Overall, Latinxs with disabilities reported various barriers to their use of fixed route transportation. These barriers varied from general issues with the fixed route system that all users might experience (e.g., the bus arriving late, two buses arriving at once), issues

specific to the disability community (e.g., not being able to get to a bus stop because of environmental barriers, not being able to access the accessible seating area on a fixed route vehicle), and issues related to being Latinx (e.g., receiving comments from others about their ethnicity, not being able to communicate effectively with the bus driver). A summary of these barriers can be found in Table VI. Many of these barriers corresponded with the barriers identified in Part I of this study (e.g., interpersonal barriers encompass the survey's barriers of "how I am treated by drivers" and "how I am treated by other riders."

TABLE VI QUALITATIVE FINDINGS: BARRIERS TO FIXED ROUTE FOR LATINXS WITH DISABILITIES

Barriers to Fixed Route Transportation: Issues that participants have identified on the CTA buses, CTA L trains, Pace suburban buses, and the Metra trains. NOT while driving, while taking the door-to-door service, or on ride share

Individual/Accessibility-related Barriers: Issues or limitations related to one's disability or the (in)accessibility of fixed route public transportation for people with disabilities

Physical barriers: Barriers that someone with a physical disability might experience while on public transit

IDD-related barriers: Barriers that someone with an intellectual, developmental, or cognitive disability might experience while riding on public transit

Sensory-related barriers: Barriers that someone with a sensory-related disability might experience like someone who is blind or deaf or someone who is autistic and has sensitivities to different sensory experiences

Interpersonal Barriers: Barriers related to other people that one might encounter while taking fixed route public transit, including drivers and other passengers.

Transit employees: Issues related to interactions between customer and drivers, customer attendants, and other employees that work for the transit company on fixed

Other passengers: Barriers related to the interactions between customer and other passengers on fixed route transit

Third parties: Interpersonal issues related not to transit employees nor other passengers, but with the friends and family of the Latinx passenger with a disability or how transit barriers affect these third party individuals

<u>Systemic/Organizational Barriers:</u> Issues related to the way that the fixed route transportation is set up to work, issues at the organizational level of transportation

General fixed route system barriers: General issues that all people, not just people with disabilities or Latinxs might experience when taking fixed route public transit

Systemic issues that affect people with disabilities and Latinxs: Systemic issues on fixed route that disproportionally affect specifically people with disabilities and Latinxs

Affordability: Barriers related to how affordable the fixed route service is and how much the fixed route service costs

TABLE VI (continued)QUALITATIVE FINDINGS: BARRIERS TO FIXED ROUTE FOR LATINXS WITH
DISABILITIES

Environmental Barriers: Barriers related to the natural and built environment when riding fixed route public transportation, not the vehicles themselves.

The natural environment: Issues related to the natural, not human-built, environment surrounding transportation

The built environment: Issues related to the manmade structures that surround transit and that are used to access transit, like sidewalks, stations, and benches, not the vehicles themselves

1) <u>Individual/accessibility-related barriers to fixed route</u>

Because this study uses the social model of disability as a theoretical framework (Goodley, 2010; Oliver, 1996), the researcher was careful not to conflate individual disability-related barriers with issues related to the inaccessibility of transportation and transportation environments. However, since many of these issues will differ based on an individual's impairment or disability, the researcher decided to address accessibility-related issues specific to the disability community in this "individual" level of the socio-ecological model.

2) Individual-level: Physical barriers

Participants reported several physical barriers that they have experienced while riding on fixed route transportation. These barriers concern the physical accessibility of the buses and trains and may be of particular concern to those people with physical impairments such as wheelchair users, people with balance-related issues, people who use a cane to walk, and older adults. Participants reported issues or experiences that occurred on the fixed route vehicles, such as the driver stopping or driving too fast causing them to lose balance, or not being able to safely use the wheelchair securement area on the fixed route vehicles. One participant even told a story about how she acquired her disability because she was riding the bus: the driver stopped very fast, and she fell and hit her head.

Participants also reported barriers to transportation that were found at the fixed route stops and stations, for example the elevators at the train stations not working or being uninhabitable. One participant said, "I always go with my daughter [on the trains], and whenever there's the smell [of urine] on the elevator I say, 'I'm just going to take the stairs,' because of the smell." The discomfort that this participant felt caused them to change their travel plans.

Another participant talked about needing to travel with someone who could assist him with certain tasks related to his physical disability, which were often not able to be accommodated. He told the group about a time when he asked the CTA customer attendant if they could help secure his wheelchair and they told him no; he would have to have someone else do that for him. Now he said he travels with his young daughters who help out with his chair securement, but this is not always convenient for him or his daughters.

Some of these physical accessibility issues, like the previous example, are related to driver non-compliance of the ADA. For example, the driver does not help with mobility device securement, nor deploy the lift or ramp so a rider with a physical disability can ride. More about driver-related issues will be discussed later in the 'interpersonal barriers' section.

3) Individual-level: Sensory barriers

Other participants mentioned accessibility-related barriers related to sensory preferences. These barriers concerned issues on fixed route for people who are sensitive to lights or sound, people who are Deaf, or people who are blind. For some participants with sensory-related disabilities, the loud sounds on fixed route, the crowds of people, and the many smells were reported as bothersome. One parent of a child with autism talked about her child being bothered by the crowds and sounds on the buses in Chicago. So much so, that her child mentioned it to the doctor during an evaluation. "The other day I took my son to get an evaluation done," she told the group. "And the doctor asked him, "What's something that bothers you?" "The CTA," [he responded.] [She laughed,] "The CTA."

For participants with visual impairments, having functioning auditory stop announcements was important. Participants mentioned that often the audio stop announcements did not work or, more often, that the volume on the announcements was too low to be useful. One participant told a story about the stop announcements not working on his bus and the driver forgetting to call out his stop as requested. The participant was angry, both at the driver and at the administrators that allowed the bus to run with the broken audio system.

Not being able to bring a guide dog onto fixed route was reported to be a barrier for some people with visual impairments. One participant told a story about how he was told by the driver that he could not bring his service animal onto a bus.

I'm getting on [the train] and I go through the gates and the [transit employee] comes flying out... telling me, 'Hey, I need ID showing that that's a guide dog... I'll call the police.' I said, 'Hey, do you need my phone? You call the police, because this is a guide dog and I need to get someplace. I can't be fooling around with you.' (Participant A, personal communication, June 26, 2018)

The lack of knowledge of transit employees about the rights of riders with disabilities will be discussed further in the 'interpersonal barriers' section.

4) <u>Individual-level: IDD barriers</u>

Finally, participants with IDD reported some unique barriers to using fixed route for this community. Many of these comments came from parents of children with IDD and some from young adults with IDD themselves. Two themes that were commonly mentioned were *independence* and *safety*. Parents wanted their children to be able to get around independently, and young adults with IDD desired the same for themselves. However, fears about safety were never far behind comments about desiring independence. One mother explained, "[People with IDD] are the most vulnerable and the ones who are attacked the most... As a mom, one does a lot of things and it says, 'Okay, you go on the bus.' Because I want him to be independent, but then also there are other dangers there." Another mother echoed this sentiment. She said, "My son *can* be independent, but now I put myself in their shoes and I might think the same thing that you are thinking right now, that it wouldn't be that easy." Clearly the balance between safety and independence was salient here.

Getting lost was a common fear expressed among parents of children with IDD, and apparently this was also a fear for people with IDD themselves. Participants with IDD mentioned times when they were given inaccurate or incomplete information when taking fixed route, which led to them becoming confused about their route. Other participants mentioned feeling like they were not ready to take fixed route independently, or being afraid that if they did they would get lost. A few participants with IDD mentioned that although they might not be ready for independent travel on fixed route or they may be scared, their independence was important to them. One participant with IDD said confidently, "I have to figure it out on my own. I have to learn from [it] on my own." This echoes some of the parent sentiments of balancing safety and independence.

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5) **Interpersonal barriers to fixed route**

Another category of barriers that participants mentioned were barriers concerning interpersonal issues, specifically with the fixed route drivers/conductors, other passengers on fixed route, and even people that the Latinx with a disability might be travelling with. Some of these issues were already introduced in the previous section.

6) Interpersonal barriers: Transit employees

Many of the interpersonal issues that participants encountered related to transit employees such as drivers and customer service attendants. Participants mentioned that drivers would deny them access to accessibility features, such as the ramp or the accessible seating area, and that drivers act rudely toward them or ignore them. A participant gives a summary of some of the different ways that she had been treated poorly by bus drivers:

There are times when drivers are not careful with people with disabilities. They don't know if you can walk fast or not; they just pull you. It's happened to me. They closed the doors on me. Like, I hadn't even gotten on board and they had already closed the door. And one time the ramp went down for another women and my leg got trapped with the wheelchair, I mean, sometimes the drivers just aren't careful. (Participant B, personal communication, June 12, 2018)

Other participants spoke about another issue with bus drivers: they do not ask passengers to move from the accessible seating area when someone with a mobility device boards the bus. This theme also appears when talking about interpersonal issues with other passengers; other passengers do not move out of the accessible seating area when it is needed for a passenger with a disability.

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Another participant, who was a wheelchair user, talked about getting passed up by a bus driver while waiting at the bus stop. He told the group, "One time I waited an hour because the bus never came for me. When one finally stopped I said, 'I'm getting on,' but the driver... [said that] nobody wanted to stand up, and she didn't pick me up. 'There's no room,' she said." From the passenger's perspective, it seemed like the driver was lying to him when he said there was no space for the passenger with a disability. A similar experience also happened to the researcher when she was working with a Latinx client in a wheelchair during her role as travel trainer for the RTA, and she shared the account of that experience with some focus groups. None of the focus groups appeared surprised to hear about that occurrence.

Similarly, other participants talked about drivers ignoring them when they asked questions or requested help. One participant explained, "I ask the driver if he could do me the favor [of lowering the bus] but he acts like, 'I didn't hear you.' Like, 'I didn't understand you.' And this makes you feel bad. Because... for him it's something that's really easy and for me it's so high up."

While most of these interpersonal barriers with transit employees that were mentioned by participants involved an under-attentive driver, one participant mentioned that drivers can also be overly-accommodating, which this passenger still did not appreciate. This participant was blind and explained that when he walks onto the bus with his cane, drivers will often ask people to give up their seat for him. He would explain that he doesn't need to sit anywhere in particular, but the driver will insist, to which he would reply, "Leave me alone!"

Regardless if participants wanted the driver to be more or less involved in their transit experience, it was clear that there is a disconnect between what the drivers were doing and what Latinx riders with disabilities needed and preferred. Many participants made mention that the rude encounters from drivers could be due to racism or discrimination: because the participant is Latinx and the driver is not. One participant offered this summary: "If they see that you're Latino, they're not going to do it. Even if [the driver] is black." Participants from several different focus groups offered other evidence that non-Latinx drivers treated Latinxs more poorly than their own race. "If a black person, an African American like them gets on the bus, they make people get up, they stop the bus, they ask what the person needs." This theme will be explored more in-depth in the next research question that compares the experiences of Latinx and non-Latinx transportation riders with disabilities.

Other participants put the blame for these negative interpersonal interactions not on discrimination, but on a language barrier between the English-speaking driver and the Spanish-speaking Latinx passenger. One participant summed it up: "Yes, it's the problem, that we don't speak English." Clearly, language was an issue for Latinx transit riders with disabilities that will again be explored more fully in the next research question.

Although most of these issues tend to include bus drivers, one participant mentioned a negative experience involving a non-driver transit employee at a train station. He explained that he had quadriplegia and could not move his hands or fingers in order to use the machines to load money onto his train pass. He asked the customer attendant to help him use the machine and she told him no, that employees were not allowed to touch customers' money. The customer knew that this was not true, so he asked again. The employee said she would have to call her supervisor and ask. She picked up a phone and asked the question, but the participant did not hear anyone on the other end. She soon hung up and told him no, they were still not allowed to touch money. This is a similar theme to what participants are saying is happening with drivers; that they are not enforcing the rules appropriately.

Furthermore, many participants recognized that the problems they encountered tended to happen with city bus drivers, not suburban bus drivers or train conductors. They mentioned that transit workers in the suburbs were nicer and paid more attention to passengers. This was an interesting finding from both participants who lived in the city and participants who lived in the suburbs also.

7) Interpersonal barriers: Other passengers

Participants also mentioned interpersonal issues with other passengers on fixed route transportation. These themes appeared to center around other passengers being rude toward them, other passengers not respecting their accessibility needs, and also experiences of racism or discrimination from other passengers.

Many participants mentioned other passengers being rude to them in general. Participants attributed this to many things: other people being in a bad mood, American culture breeding a general sense of discontent, and people being in a hurry. But one thing was clear: many participants had experiences with other passengers who were not nice to them. For example, one participant told a story about someone who was smoking a cigarette on the bus near them, which was clearly prohibited, and who refused to stop after they were told the smoke was bothersome.

One particularly frequent occurrence that was mentioned was other passengers not moving out of the accessible seating area when it needed to be used by a person with a disability. This was mentioned in nearly every single focus group. A participant told the group: "People don't get up, and even if you tell them, they pretend they don't hear, and many times they even get mad and then you end up going in the back of the bus." This was a major theme among many focus groups, and not just for participants with physical impairments. Participants of many different impairment types talked about the unwillingness of other passengers to move and the unwillingness of transit personnel to intervene in order to give the space to someone who needed it. Furthermore, participants mentioned several encounters with passengers with small children in strollers who make claim to the accessible seating area and do not move when asked, which is a clear violation of transit policy.

Like participants with disabilities, parent participants also talked about how other passengers wouldn't move from the accessible seats when they needed to sit there with their child with a disability. Parent participants' stories reflected feeling shame and anxiety about bringing their children with disabilities onto the bus because of the negative comments other passengers would make about them.

Furthermore, participants mentioned some serious safety issues regarding other passengers on fixed route that make it scary or unsafe for them to use the transportation. One parent talked about how she regularly witnessed assaults, drug deals, cigarette sales to minors, and more. A participant with a physical disability said that her safety issues were so serious that she had decided to stop taking fixed route altogether. Another participant with a visual impairment told a story about being refusing to ride public transportation because of a time she was almost assaulted. A participant with IDD talked about how riding the bus can be dangerous for him. "It's dangerous. Some people ask for your money sometimes. People will take your stuff. People will stare, stare at you for a long time." It was unclear if these events have ever happened to this participant, but clearly the fear of it happening warranted mention. Clearly, public transportation can harbor some safety concerns for people with various disabilities.

Participants mentioned interpersonal issues with other passengers that were specific to being a passenger who is Latinx. One of these concerns was language; Latinx passengers could not always communicate with other passengers in Spanish to ask questions or advocate for their own needs. One participant explained, "I've stepped in a couple of times to translate because there are some people who, either they don't know English or they have trouble with it and stuff, or they can barely understand. There have been some problems with that." Another issue was discrimination based on the language you speak. A participant spoke about how she often feels discriminated against when speaking Spanish in public. "If you pay attention when you're someplace and you're speaking Spanish with your kids, [other people] are already looking at you the wrong way." Clearly there were some issues related to being specifically a Latinx fixed route user, and these will be explored further in the next research question.

8) Interpersonal barriers: Third parties

Finally, barriers experienced on fixed route transportation often had an effect that surpassed just the individual, but also affected other people in their life. One participant explained that whenever there is a problem with the bus scheduling and she runs late coming home, her parents worry about her; she needed to remember to contact her parents if she's running late. Other participants mentioned interpersonal barriers that affected people in their own parties: their families or friends, such as experiences of discrimination, ableism, or rude treatment from others. These issues not only affect the Latinx with a disability riding public transit, but also their support system.

9) Systemic or organizational barriers to fixed route

Participants in all the focus groups mentioned issues with the fixed route system or the way that the system was organized. These issues often caused them barriers to accessing public transportation. Barriers under this category include general fixed route issues, systemic issues that specifically affect Latinxs and people with disabilities, and issues related to affordability.

10) Systemic barriers: General fixed route issues

Systemic issues mentioned by participants included general problems or inconveniences that all riders, regardless of disability or ethnicity, often experience while using the system, such as the timing of the vehicles, the breadth of the routes, and coordinating fixed route service to one's schedule. In terms of general systemic or organizational barriers to fixed route use, participants mentioned a plethora of issues that plague fixed route users daily, regardless of if they were disabled or Latinx. Many of these issues even resonated with the researcher and co-facilitator, who are themselves avid users of the fixed route transit system in Chicago.

Participants mentioned the timing of buses being an issue. This was mentioned in most of the focus groups, but one participant summarized it well here: "We're waiting for the bus and someone says 'It's going to come in so-many minutes,' and then one comes to the bus stop and then none of them come [laughs]. And then, in few moments, three buses show up at the same time, all three come together, one behind the other." Participants also mentioned over-crowding of vehicles: that when the vehicles arrive there are too many people on them to be able to board comfortably. Also mentioned, of course, was the issue of transit vehicles arriving late or not getting them to their destination on time. All of these issues make it difficult for all users to access public transportation.

Participants mentioned that it was often difficult to plan trips using fixed route and coordinate them with their schedules. This process was often labeled as "stressful." One parent participant described the process she would have to go through to take public transportation to work each morning: "I had to get the train here on the red line at 4am, go to Rosemont, take the 6am bus from there... it's like, 'Wow.'" Another participant mentioned that she was so confused

about the train stops and schedules that it was just easier for her to drive. "It makes me confused that you have to get on one side, get off on another... so I generally drive, but I don't want to keep driving myself anymore." Sometimes the logistics of planning and executing a trip on fixed route were just too complicated for participants.

Suburban participants in particular mentioned some issues about the location of fixed route transit relative to where they lived. While some suburban participants had easy and convenient access to buses and trains, some did not. Some participants did not even have a bus stop or train station nearby their homes. Not living near a transit stop meant that some participants were not able to use fixed route at all, so clearly the location of stops for suburban participants was a barrier. This did not seem to be an issue for participants that lived in the city, where fixed route transportation is more abundant.

One parent participant brought up the point that the transportation systems here in the US are car-centric. Public transportation is not the most catered-to way to get around, especially for young people with disabilities and their families. She explained, "Many kids are just so used to taking the car, too, that then they don't want to get on a bus or they don't want to get on the Metra [train.]" This is a systematic issue that will be explored further on in this paper.

11) Systemic barriers: Specific barriers

Some barriers mentioned appeared to affect Latinxs and people with disabilities moreso than general riders. Participants mentioned that it was difficult to get information on fixed route for some Latinxs due to language and education. Many Latinxs were "misinformed" or just did not have access to the same information, especially written information in Spanish. Even when information was available in Spanish, one participant mentioned that the information is still not accessible to people who are not literate; this participant's aging mother with a disability was not able to read or write in any language, which she mentioned as a barrier to being able to use fixed route on her own.

12) Systemic barriers: Affordability

Finally, affordability was a commonly-mentioned theme among focus group participants. It appeared that affordability played a big role in the transportation choices of the participants. It also appeared that rising prices of fixed route were a barrier to using the service. One participant explained how he reacted when the fare of the suburban bus went up earlier that year. "Before it was \$2.25 and now it's \$2.50. It went up. And the [monthly and weekly] passes also went up. The passes for a month used to cost \$100 and it went up to \$105. Then the 8-day passes used to be \$25 and now they're \$30. They all went up." Another participant put it bluntly: "The prices have gone up, but the quality... I think it keeps going down." Affordability will continue to be explored with other transit options, including paratransit, in later parts of this paper.

13) Environmental barriers to fixed route

The last category of barriers to be explored in this section is barriers concerning the natural environment (e.g., the weather being a barrier to fixed route) and the built environment (e.g., the sidewalks leading to bus stops, the inaccessible structure of stops and stations).

14) <u>Environmental barriers: Natural environment</u>

Regarding the natural environment, many participants commented that the weather in Chicago made it difficult for them to get places. Participants mentioned the cold, the heat, the snow, the wind, and the rain as barriers that affected them in different ways, but overall made it harder for them to get around. A participant with a physical disability explained her barriers related to weather. "[For people who] use a wheelchair it's a little bit more harder... because they don't come and clean your streets or plow that area so the streets and sidewalks are not that dependable to use if you're using CTA or public transportation." The barriers in the natural environment do not only affect people with physical disabilities, however. One participant with a vision impairment explained, "When it's raining, or it's really cold, too much air, or when it's really windy, for us another important sense is hearing. When the wind is very strong or when it's raining really hard, it obstructs our ability to hear. So then it's difficult for us to be able to get around." Depending on the weather conditions, fixed route may not be an option for some people with certain disabilities.

Weather was often mentioned as a safety issue in regards to taking fixed route, and was also often mentioned as a barrier from someone being able to go anywhere at all. Many participants decided that, due to safety hazards created by the weather, it would be safer for them not to travel at all. A participant explained, "Many times it's not possible to use that transportation. And now more in the wintertime, because of the cold, because of the snow falling, that's the reason why I say that, for me, that's my way to say, 'no, I don't use it.'" Other participants who had a disability themselves echoed this sentiment above.

15) Environmental barriers: Built environment

Regarding the built environment, participants mentioned that their path of travel to the bus stop was often not accessible due to lack of sidewalks and shelters, dangerous street crossings, and lack of markers such as truncated domes for people with visual impairments. One participant talked about how crossing the street from her senior building to get to the bus stop was dangerous because of the traffic. She mentioned that there have been instances of people almost getting hit there and the residents begged the building and the city to do something about the crossing, but nothing had changed in the ten years she has lived there. "I think they just got used to it," she said of the changes not being made. One participant with a visual impairment talked about how inaccessible sidewalks can be a huge barrier to her. "I fell brutally into a pothole. My right leg. I had to be hospitalized." Another participant talked about the importance of bus shelters and their importance to passengers with disabilities to keep them sheltered from the sometimes dangerous natural environment. When the built environment is inaccessible it can pose danger for fixed route riders, especially riders with disabilities.

Another barrier related to the built environment were the neighborhoods and areas surrounding fixed route stops and stations. Many participants commented on the safety of these areas being of concern to them. One parent participant said that he worried about gangs nearby. Another parent said she would encounter people who were drunk or on drugs near the stations in her neighborhood. A participant with a disability talked about how the stations themselves were often desolate, making them unsafe: "There are train stations… that are very lonely. Almost no one is there and rarely do people get on, or they get off quickly and there is no one waiting there for the train. So that's where I feel that it's not safe." Clearly, environmental barriers were another factor that affected the safety of taking fixed route.

To summarize, it appeared that Latinxs with disabilities were experiencing barriers to fixed route transportation access due to accessibility-related, interpersonal, systemic and organizational, and environmental barriers. Some major themes within these barriers were: safety, discrimination, language, and weather.

b. **Paratransit barriers**

The barriers related to accessing and using paratransit transportation fit into the same categories as those related to using fixed route transportation. This is an important finding and will contribute to answering the second research question. Table VII summarizes some barriers to paratransit reported by focus group participants related to individual or accessibility-related issues, interpersonal issues, and systemic or organizational issues, and environmental issues. To introduce this section is a part of a conversation during one of the focus groups with Latinxs with disabilities: Moderator: "Now, I haven't heard a lot about paratransit. I haven't heard a lot about the vehicle that comes and picks you up at your door." Participant: "…Is this going to last three hours longer? Because if you wanna start on paratransit, whew!"

TABLE VII QUALITATIVE FINDINGS: BARRIERS TO PARATRANSIT FOR LATINXS WITH DISABILITIES

Problems with Paratransit: Issues that participants have identified on the ADA Paratransit service, the door-to-door transportation service specifically for people with disabilities who cannot take regular fixed route transportation some or all of the time (sometimes referred to as "Pace" because it is run by that company). This does NOT include barriers encountered while driving, on ride share, on school buses or other organizational-specific transportation, or on regular fixed route public transit)

<u>Individual/Accessibility-related Barriers:</u> Issues or limitations related to one's disability or the (in)accessibility of ADA Paratransit for people with disabilities

Interpersonal Barriers: Barriers related to other people that one might encounter while taking ADA Paratransit, including drivers, other passengers, and their own family and friends

- **Drivers:** Issues related to interactions between customer and drivers of ADA Paratransit vehicles (Not dispatchers, schedulers, or other employees that work for the ADA Paratransit company)
- **Dispatchers:** Issues related to interactions between customer and dispatchers and schedulers of ADA Paratransit rides (Not drivers of the ADA vehicles)
- **Other riders:** Issues related to interactions between the customer and other riders on the ADA vehicles (not drivers, dispatchers, or anyone that works for the transit company and not anyone in the rider's own party, such as their friends or family)

<u>Systemic/Organizational Barriers</u>: Issues related to the way that the ADA Paratransit system is set up to work, issues at the organizational level of ADA Paratransit

The paratransit system: Barriers related to the way that the ADA Paratransit service is set up to operate including pick-ups, drop-offs, scheduling, and taking a ride. Does not include becoming eligible for the service, paying for the service, or complaints

Systemic issues that affect Latinxs: Systemic issues on ADA Paratransit that disproportionally affect Latinxs, regardless of their disability

- **Timing:** Issues related to the time it takes to get somewhere, the time one is on the vehicle or the time the vehicle arrives
- **Routes:** Issues related to the routes that the vehicles take or where the vehicles are able to operate and travel
- Scheduling: Issues related to how the scheduling of the rides works, calling in to schedule, or scheduling multiple parts of one's trip that would not better fit under "timing" category

TABLE VII (continued) QUALITATIVE FINDINGS: BARRIERS TO PARATRANSIT FOR LATINXS WITH DISABILITIES

Affordability: Issues related to how affordable the ADA Paratransit service is, how much the ADA Paratransit service costs

- **Rules and eligibility:** Issues related to how one becomes eligible for the service and the rules that one must follow when they use the service, like no-shows and missing a ride
- Feedback and complaints: Issues that occur when filing a complaint or providing feedback about the system

Environmental Barriers: Barriers related to the natural and built environment when riding ADA Paratransit, not the vehicles themselves

- **The natural environment:** Issues related to the natural, not human-built, environment surrounding transportation
- **The built environment:** Issues related to the manmade structures that surround transit and that are used to access transit, like sidewalks, stations, and benches, not the vehicles themselves

1) Individual accessibility-related barriers to paratransit

Although paratransit is a service specifically designed for people

with disabilities to eliminate accessibility-related barriers that exist when using fixed route transportation, many participants still reported accessibility-related issues on the paratransit service. Making the appointment for the paratransit ride could be difficult for someone who is blind, Deaf, or someone with IDD. Particularly, participants mentioned that the paratransit ride could exacerbate existing physical impairments. One participant talked about how the paratransit ride caused her physical pain. "When you go to travel for two hours or three hours on the bus with such narrow seats, the backrest is uncomfortable, and you end up with a broken spine."

Furthermore, some parents mentioned that paratransit would still not be a safe alternate for their child with disability due to their child needing to travel alone on the service. It appeared that the paratransit service was still not accessible to all people with all types of disabilities.

2) Interpersonal barriers to paratransit

Interpersonal barriers are issues that relate to other people that one might encounter while taking paratransit, including drivers, dispatchers, and other passengers. These barriers were similar to those encountered on fixed route.

3) Interpersonal barriers: Drivers

Participants mentioned many interactions with paratransit drivers that were problematic. Many participants said that paratransit drivers were "rude," or "ignorant." One participant said, about the paratransit drivers, "I don't think they have a heart." Another participant described the drivers as "arrogant":

I've seen situations where the drivers... are so arrogant to the point that they feel like they're doing me a favor, and I don't see it that way. I see it as saying, 'Okay, I need the service and you need a job. If you don't want to do this, why are you doing it?' (Participant C, personal communication, April 11, 2018)

A few participants said that rude drivers were actually a systemic issue because of the way rides are scheduled or that, perhaps, the drivers do not get paid enough. Regardless of the reasons given, it was clear that participants agreed that the drivers' attitudes affected their paratransit experience.

Several participants recounted instances of unsafe behavior from their paratransit drivers. One participant with a visual impairment told about a time her paratransit driver was on the phone while driving. "You know I would hear them on their phones, and I'm like, 'you're driving.' Because I get panicky... And I don't think that's right, to be on their cell phone." Continuing with the theme of connecting the interpersonal with the systemic, participants often suggested more driver training and better enforcement of rules and regulations for these driver behaviors.

Participants sometimes attributed the paratransit driver's unacceptable behavior to discrimination, either based on a passenger's disability or ethnicity. One participant described a conversation he had with a paratransit driver that made him feel like a "second-class citizen."

I feel like they offend our dignity sometimes... In the end, the fact that you have a disability excuses everything that they do, like if they get there late or if they don't come at all. I have a job like anyone else, and I have told to the driver, 'If you arrive 5 minutes late or 10 minutes late to your job, [your company] did you apologize?' 'No, I get punished,' [the driver responds]. Then they don't believe that my company will also lower my salary and will punish me [if I'm late], too. (Participant D, personal communication, April 6, 2018)

Participants spoke about instances on paratransit, much like on fixed route, where drivers appeared to have discriminated against them based on their ethnicity. One participant talked about how the driver's tone immediately changed for her once the driver found out about her

"Hispanic last name." Another participant talked about how racism played a role in the quality of paratransit service she received. She asserted:

Yes, this racism exists because I have seen it. Because I am Hispanic.... That... makes me sad because someone needs help from these people that transport us and help us, but what is the help if they don't wait for you or they won't take you? (Participant E, personal communication, April 6, 2018)

Another participant described a conversation that he had with a Latinx paratransit driver that confirmed his suspicions about the drivers being racist. One time the participant had a Latinx paratransit driver. By the book, the driver is required to wait five minutes for the passenger if the passenger is not in sight. Many times, the participant said, the driver would not wait the full five minutes and just drive off without him. This Latinx driver waited. He thanked the driver for waiting. The driver responded, "'I was going to wait the five minutes for you, but if I had been an African American, I would have already left you.'" This was one of many explicit mentions of race and how race directly related to quality of paratransit service. More on this topic will be explored later in this paper.

Parent participants brought up another interpersonal issue on paratransit: that the drivers constantly changed, so that the driver that picked you up today may not be the one who picks you up tomorrow. Parents talked about how this failure for their child to build a personal, trusting relationship with the driver was hindering their independence and confidence in traveling.

One participant told the researcher after the focus group that she was sexually assaulted by a paratransit driver. She recounted an experience of being told sexually explicit things and then him touching her breast while fastening her safety belt. The researcher asked if she would feel comfortable filing a formal complaint about this experience and the participant said she would. The researcher offered her contact information to assist her in this matter, but the participant had not yet reached out by the time this paper was completed. Even though this story was shared after the focus group ended, the researcher thought it was important to share with the rest of this data. It also may show that some negative experiences on public transportation may not have even been shared during the focus groups.

4) Interpersonal barriers: Dispatchers

Interpersonal barriers involving paratransit dispatchers followed many of the same themes as those barriers involving paratransit drivers. Many participants said that dispatchers were "rude" or "impatient." One participant told a story about how when she called into the paratransit service, the dispatcher was having an inappropriate conversation. "I called one time to go to Chicago and the woman who was dispatching me a while back was talking to a friend about her boyfriend and what she had done with her boyfriend, and it left me saying to myself 'What a lack of respect!'" Many participants suggested disability training or sensitivity training for drivers and dispatchers alike as a suggestion to solve these reported issues.

The issue of discrimination based on Latinx ethnicity came up for paratransit dispatchers as well. One participant told a story about how he was treated poorly by a dispatcher and how he attributed the poor treatment to having a Latinx name. He called multiple times to find out the arrival time of his paratransit vehicle and they kept telling him it would be there sooner than it arrived. He said the reason why they did this was, "Because my name is Hispanic and it's not Jason Smith." While there was no evidence that he was being discriminated against strictly because of his ethnicity in this situation, the fact that he believed this is undoubtedly telling. Many of the issues that participants expressed about dispatchers included language as a barrier. Multiple participants in multiple focus groups mentioned being ignored or hung up on when they called and requested someone who spoke Spanish. One participant told the focus group: "Sometimes when I request Spanish, they hang up on me. They've hung up the call on me and I have to call three, four times, and they hang up when I tell them 'Spanish?'" A parent participant had a similar experience: "An experience like that happened to me... It was over the phone and they laughed at me for not expressing myself well in English." Clearly language was a barrier to Latinxs with disabilities when using the paratransit system and often resulted in rude treatment or discrimination.

Similar to parents wanting a more personable paratransit driver experience for their children, people with disabilities expressed a desire for the entire dispatching service for paratransit to be more personalized. One participant suggested, "But for them to have more communication with the client... I just feel that if I talk to somebody, somebody can hear me. I can speak with somebody, relate to somebody... I feel that I'm not talking to anybody, so nobody's listening."

5) <u>Interpersonal barriers: Other passengers</u>

Finally, participants mentioned interpersonal issues involving other riders on their paratransit vehicle. They mentioned that having too many people on the vehicles was an issue. One person summarized the sentiment like this: "I think they try to pack up, let's say, all the sardines together so we can hurry up and do it, you know?"

Along with this concern was the concern about the cleanliness of the paratransit vehicles and the safety of the passengers being in close quarters. One participant mentioned other passengers on the paratransit ride that smelled bad, which made for an unsatisfactory experience. Another participant mentioned riding next to sick passengers as being his most serious concern about paratransit.

Overall, like with fixed route, there were many concerns about interpersonal issues involving both passengers and drivers while riding on the paratransit service for Latinxs with disabilities.

6) Systemic or organizational barriers to paratransit

The bulk of the barriers related to paratransit fell in this category. And, as the participant mentioned in the beginning of this section, it would indeed take hours to recap all of the issues discussed regarding systemic and organizational barriers to paratransit during the focus groups. In case the reader is still not convinced that this service is fraught with problems, during a focus group, one parent participant hopelessly graveled, "What would they do to provide people with disabilities the service that they deserve?" The following sub-categories appear under systemic or organizational barriers: eligibility and sign-up, timing, scheduling, routes, feedback and complaints, and affordability.

7) Systemic barriers: Eligibility and sign-up

Eligibility and sign-up was a loaded theme. This theme included criticisms about and problems with the current eligibility criteria and sign up process and also the lack of information about signing up for and becoming eligibility for the service. First, there was an unbelievable amount of lack of knowledge about the paratransit service. In more than one focus group, the participants did not even know that a service like this existed! In one focus group, at the very end after talking about fixed route and paratransit for an hour and a half, one participant asked if paratransit was the same as Uber. The researcher was stunned that even after conversing about the topic for a long time, some participants were still not adequately informed about it. Participants themselves claimed to be "misinformed" and "ignorant" about paratransit. The reasons mentioned included language, discrimination, and lack of advocacy on behalf of Latinxs. A parent participant explained that lack of information was a general concern in the Latinx community, and it was due to both language and fear. She said, "I think that also because of language and also, like, if one doesn't know their rights as a Latino. Maybe we try to always see it as fear and that prevents you from doing things the way they should be done." Another participant admitted that she was indeed misinformed about many available services, including paratransit. She attributed this to both language and a political system that focuses on the informing people who speak English. She said,

Sincerely, I'm going to be frank with you... we are ignorant. We are not well informed... We don't have the information... Because I've paid attention to African Americans and Americans, and they have all the services, and the Hispanics, we don't know... because of language, or because we are not well informed, because I really see that. (Participant F, personal communication, May 26, 2018)

No matter the reason, Latinxs with disabilities clearly do not have all the information about the paratransit service and other transportation services.

Second, there was misinformation about how the service worked. One parent was not sure if her child with IDD would qualify for the service or if IDD was even a disability the service would consider (the researcher confirmed that it was). Another participant inquired into whether or not one needed a social security number to apply for the service (the researcher confirmed that one does not). Participants often made incorrect comments about how the service works. One participant said, "And then if you want to have transfers, it's the same thing. You gotta pay those transfers." The researcher knew from her role at the RTA that passengers should not be charged for transfers, so this could mean that the drivers are charging Latinx riders for transfers when they are not supposed to be.

Participants also spoke about discrimination during the application process to sign-up for the service. One participant recounted the experience he had signing up for the paratransit service where he felt he was discriminated against for being Latinx. He said,

I had to renew my pass a month and a half ago and I went... They didn't call me and I asked, 'Why didn't you call me?' 'I thought you would want someone who spoke Spanish.' 'I didn't tell you that.' But if I didn't ask, I would have stayed there, but when they saw that I was Hispanic, they thought that I needed someone who spoke Spanish... From the beginning, being Hispanic distinguishes you a lot. (Participant D, personal communication, April 6, 2018)

Finally, participants complained that the application process was too cumbersome and took too long. One participant explained the process to other participants and there were several time-consuming steps: several phone calls; long applications; an in-person interview; and several waiting periods. Coupled with the aforementioned language issues, the application for paratransit appeared to be a large amount of work.

8) Systemic barriers: Timing

Participants mentioned barriers related to timing, which included how long it took the paratransit service to arrive and how long riders were on the vehicle. These issues were probably the most commonly-stated problems with the paratransit system by participants. "It's always late!" and "You're in the van forever!" were exclamations uttered at almost every focus group, except the focus groups where not one participant knew about the service. Participants said that their vehicles frequently arrived 15-30 minutes after the scheduled pick-up time, but sometimes arrived even later. Waiting for the scheduled ride when it was running late was an issue for participants. "When the weather was really cold and you're outside waiting, waiting, waiting," one participant explained. "Then they don't show up so I'm like... walking back and forth trying to figure out like, okay are they coming? They're not coming. Go back inside the house."

Participants talked about how their trips took a long time to get them to their destination once they did arrive. A participant put it bluntly, "I hate [the paratransit]. One day I was in the van for at least three hours." Another participant explained that he is generally on the vehicles for a very long time: "Supposedly we have been told that we're not supposed to be on those vehicles for more than 90 minutes, but it happens often that we are." Another participant recounted her experience being on the vehicle for a long time.

I wouldn't come home sometimes 'til six, because... we're picking up this person, we're picking up this person, and I'm like, 'when am I next?' You know? They're taking forever, so by the time you know it, it would be six o'clock. That's a lot of hours, and it's dark, very dark. (Participant G, personal communication, April 27, 2018)

Other participants mentioned times when they spent so long in the vehicle that it was physically demanding on their body. More than one participant mentioned being on the vehicle so long that they often needed to use the restroom during their trip, or even wet themselves.

What really appeared to hit some nerves during the focus groups was a rule that stated that paratransit service can be up to twenty minutes late, but riders cannot be more than five minutes late. Participants knew this rule were a double standard and asserted so. One participant demanded, "And the question that I have, and I've never gotten an answer is: Why do they have five minutes to make you a no-show but they have fifty minutes to be late?" The riders clearly knew their rights, but still felt that they were taken advantage of.

9) Systemic barriers: Routes

Directly related to the timing issue is the issue of routing or where the vehicle would take someone before dropping them off at their destination. Not only would the person be on the vehicle for a long time, but they would travel to many different neighborhoods far from where they needed to go before getting dropped off. This conversation summed up well how participants felt about the paratransit routing: Participant 1: "Instead of taking me directly to my house-" Participant 2: "They take you throughout all of Chicago." Participant 1: "They take me throughout all of Chicago." Participant 2: "They give you a tour. [Laughs.]" This "tour" caused a lot of frustration for participants.

One participant told a story about when the paratransit vehicle took him all over different counties before dropping him off. He was visibly angry when telling the story. He got fed up, got in front of the vehicle and refused to move until the driver took him home: "I got out of the van and got in front of it and said, 'You're not going anywhere until you take me home!' And the driver told me, 'No, you have to get in,' or 'We're going to call the police.' I said, 'Call whomever you want, but I'm not moving anywhere.'" This participant was so angry that the vehicle was going to be headed the complete opposite way of his home, that he refused to get back in as a form of protest.

Adding to this issue is needing to transfer from one vehicle to another if the route crossed certain geographic boundaries. One participant explained how much of an inconvenience that issue was, and it made it more complicated for her to go on certain trips. She said,

If I wanna go from here to Blue Island... there's certain boundaries. That's what they tell me. I have to go and call the other [paratransit vehicle]. I think suburb to suburb they don't go. I'm suburb, so I can't go to another suburb....I don't think that shit's fair, but I guess that's how their boundaries is. (Participant G, personal communication, April 27, 2018)

Again, this is another situation where the participant was misinformed; paratransit vehicles in Chicago *do* travel from suburb to suburb, but perhaps she was never corrected or given wrong information. Regardless, having to transfer vehicles appeared to be an inconvenience for participants, and was clear evidence of issues with routing on paratransit.

10) Systemic barriers: Scheduling

Barriers related to scheduling involved issues related to how the scheduling of the rides works, calling in to schedule, or coordinating multiple parts of one's paratransit trip. Although the paratransit system is supposed to mimic the regular fixed route transportation hours and schedules, participants remarked that they often ended up waiting an excessive amount of time for a ride or are not able to schedule at a convenient time. One participant explained how inconvenient it is for him to schedule a ride on paratransit. "You say you want a ride at whatever time and they tell you, 'Sorry, we don't have that time. It's all full at that time.' ...If I ask for 2:00pm they say, 'No, give me another time.' 'How about 1:55pm?' 'No, sorry, we only have 4:00pm and that's it.'" It appeared that scheduling a ride was time-consuming and did not always fit with one's schedule, even as well as fixed route would.

A related issue to the scheduling system is the automated system that alerts a rider that their ride is coming. This conversation illustrated the shared frustration that participants had regarding being told they were getting picked up only to have to wait much longer until the vehicle actually arrived. Participant 1: "Because they tell you over the phone, through a computer, 'We are about to arrive' in English. Participant 2: "Generally for a half hour, 45 minutes they are about to arrive, but you're not!"

Adding to this scheduling issue is that vehicles will claim to have arrived but riders are not able to locate them or they are at a different area than the rider scheduled them to be at. One participant explained what happened one time when he was waiting for his ride and the driver was not where the dispatcher claimed. "They say, 'They're already in front of your house.' And I say, 'Where are they? I'm outside the place and I don't see them.' 'But they're already there!'" It appeared that not only was tardiness an issue, but also being told a different time and location than the driver was told.

Another related issue to scheduling was which company or carrier will pick one up. The current system in the Chicagoland area uses multiple companies that are contracted out as carriers. Each company has its own logo and name on the vehicle which makes them easy to identify. One participant explained that he used to be able to know ahead of time which carrier would be picking him up, but the system went through a change and now he is no longer able to identify the carrier ahead of time. This makes it more difficult to distinguish his vehicle, especially when there are other similar-looking vehicles waiting.

Furthermore, the system to call in and schedule a ride appeared to have some barriers. Above all, the automated system to schedule or confirm their ride was not bilingual and Spanishspeaking participants voiced their frustration with this.

Additionally, the system is designed to only allow scheduling of rides exactly one day ahead of time. This was frustrating for some participants who needed same-day scheduling or needed to make last-minutes changes to their ride schedule. One participant described this as a particularly serious flaw in the system and caused a lot of scheduling issues for his various appointments and activities.

My problem, for example with the door-to-door transportation, you have to schedule it a day before. But there are times when for some activities they let me know the same morning, and then there's no other option but to use Uber, use a taxi, because there's not going to be anyone like that who can give me a ride at the time I want. (Participant D, personal communication, April 6, 2018)

Another participant expressed her frustrated with the rigid scheduling system and how it often resulted in her waiting a long time.

Well if I want to get picked up and let's say I finish with my appointment and I'm like over an hour and a half... [I call and tell them,] 'I'm like I'm sitting here waiting can you see if somebody can pick me up? 'Oh no you have to wait 'til your set appointment.'

... They don't wanna send somebody to go get you. (Participant G, personal

communication, April 27, 2018)

This system appears to not be flexible enough to accommodate people with disabilities who often have their schedules change at the last minute.

11) Systemic barriers: Affordability

Affordability of the service was also an issue on paratransit, as it was for fixed route. The paratransit service costs more than fixed route, and unlike fixed route there are no discount programs for people with disabilities or based on income. Recently before these focus groups, the paratransit fare went up in the Chicagoland area. One participant claimed that the quality of the service even went down after the fare surge: "The fare went up and they didn't notify us that it was going to go up and the service is much worse after the increase in fare." The cost of the service was not affordable for everyone, and for some, cost was such a barrier that it prohibited them from using the paratransit service at all. One participant explained, "And then the fee went up, and I think it used to be three dollars and now it's more. All that adds up for me. I'm on a budget every month, so I can't afford doing those things. Now to go is one fee, to come back is another fee, and it's just too much." Cost appeared to be even more of a factor for paratransit use than it was for fixed route.

12) Systemic barriers: Feedback and complaints

Another systemic and organizational issue mentioned with the paratransit system was that participant felt that they were not able to effectively advocate or file complaints when the system didn't meet their needs. Participants mentioned that barriers to advocacy could be due to language. The complaint system, as one participant explained, was only available in English. "I went to talk to them on the phone again... there's no one who speaks Spanish to give the complaints to or to explain what happened... I spent around half an hour on the phone until they found someone to interpret for me."

Participants also identified some cultural reasons behind why they don't file more complaints when the service doesn't fit their needs. One participant mentioned that Latinxs are used to living in a "culture of oppression." He said,

Apart from language, being Latino, the culture. We come from countries where there is a lot of oppression. People with disabilities don't have resources. Programs and services for them don't exist. So we are in a country now where we believe we are fortunate that here we have the door-to-door transportation. It's a blessing. (Participant D, personal communication, April 6, 2018)

This participant suggested that instead of complaining about problems with the service, Latinxs should be thankful they have a system like this at all.

However, other participants challenged this idea and showed instead that they wanted to advocate and work to make the system better. Parent focus groups especially conversed a lot about defending their rights and advocating for themselves. A mother of a child with a disability put it this way: "I'm not bad. I'm just defending what's not right. Because it's true. It's not that someone is a bad person; they are just defending the rights that they know they have." Another participant said that he would exercise his advocacy rights even despite getting pushback from the agency. "I do, or at least pretend to, assert my rights. I don't demand more, but never less." Clearly there was not agreement among participants over the issue of advocacy; some had more issues exercising that right than others.

Barriers to advocacy might also be due to immigration or documentations status. When asked why Latinxs don't advocate more often, one participant explained, "Hispanics don't do that. Why? Due to problems with immigration, because we don't want to have trouble with the law." Not wanting to complain for fear of deportation was mentioned in more than one focus group. Participants also mentioned that they didn't want to complain because they wanted to keep using the service, even if it did have problems. "If I complain about it, like, okay, do you want it or not? You know, like, get over it, you know? I have to have it; I need it." Participants were afraid of not having the paratransit service more than they were afraid of the service not improving.

The following conversation also expressed the hopelessness that participant felt about giving feedback about the paratransit system: Participant 1: "And what's going to happen with

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that complaint? I've spent 25 years complaining and I've never seen any kind of result." Participant 2: "Yes, exactly, it's a waste of time."

When one participant went to file a complaint against a dispatcher, the dispatcher refused to give their name, so nothing could be recorded properly in order to make any changes. "I would complain, but they didn't listen," a participant said frankly. Another said, hopelessly, "So, this is not to insult you, and it's not to be disrespectful, but in reality, the fact is, what we're doing here [complaining] isn't going to matter at all."

One participant even claimed that he knew that the system was set up to suppress and punish riders who complain a lot. He said that people working in dispatch have admitted that they are not inclined to help them. He told the group, "So they say, 'Okay, this is a problematic person, we're not going to help them anymore." This statement reflects the frustration and helplessness that the participants experience when they feel like they cannot advocate or create change in the system that they view as problematic.

Overall, there was a general sentiment that participants did not complain because they did not have faith that complaining would lead to any change within the system. Even when participants did complain, they were often met with barriers. Many times, nothing ever happened with their complaints and things did not change.

13) Environmental barriers to paratransit

There were far fewer comments concerning environmental barriers on paratransit compared to fixed route during the focus groups. No participants mentioned any barriers concerning the natural environment, such as weather. One participant mentioned barriers regarding the built environment on paratransit. This participant explained the difficulty of accessing the paratransit service when living in a multi-story building. "Well the door-to-door is good but last year I lived on the second floor and there's a door bell. What I didn't like... they couldn't go up the steps; they'd just be at the bottom... And I would want them to come up." It appeared that the door-to-door design of the paratransit service did not eliminate all barriers related to inaccessible environments, especially for people with physical disabilities.

To summarize, it appears that Latinxs with disabilities have experienced barriers to paratransit access due to accessibility-related, interpersonal, systemic and organizational, and environmental barriers, just like they are with fixed route, although they experienced more barriers related to the system and organization and fewer problems related to the environment. Some major themes within these barriers were: safety, discrimination, language, affordability, and oppression.

2. <u>Research question 2</u>

Research question 2 asks: Are the barriers to public transportation access for Latinxs with disabilities different from the barriers to public transportation access for non-Latinx whites with disabilities? For this research question, focus group participants member-checked results from Part I of the study. Each focus group was presented with the same four results comparing Latinxs with disabilities to non-Latinxs whites with disabilities. These four results were chosen by the researcher, the co-facilitator, and members of the Latinx disability community to explore further in the focus groups. These four results and their applicable comments from focus group participants appear in this section.

During the focus groups, Latinxs were asked to member-check and discuss the quantitative results from Part I comparing public transportation barriers for Latinxs with disabilities and non-Latinx whites with disabilities. The results presented to all groups related to public transportation barriers were:

- 1) Latinxs with disabilities tend to be more satisfied with paratransit over fixed route transit compared to non-Latinx whites with disabilities.
- 2) Latinxs with disabilities reported more problems related to the way that they are treated by drivers compared to non-Latinx whites with disabilities.
- Latinxs with disabilities report more problems related to safety when riding on public transit compared to non-Latinx whites with disabilities.
- 4) Latinxs with disabilities report more problems related to the Paratransit system and scheduling compared to non-Latinx whites with disabilities.

Overall, participants agreed that the results found in Part I were valid.

a. Member checking question 1

Member checking question 1 was: "Latinxs prefer paratransit." This first finding proposed to participants was a bit controversial. First of all, it seemingly directly contradicted finding number 4 that Latinxs reported more issues with the paratransit system. Many participants initially disagreed that they would prefer a paratransit service that was fraught with timing, routing, and scheduling issues. Interestingly, these same participants that initially disagreed with the finding were also paratransit users themselves. One participant who disagreed with the finding admitted preferring the service in times of bad weather. Another participant who disagreed with the finding spent a good portion of the focus group trying to get another focus group member to sign up for the service! It appeared that there was indeed evidence to support this finding. Furthermore, the quantitative data also indicated that more Latinxs with disabilities reported using paratransit services compared to non-Latinx whites with disabilities and Latinxs with disabilities were more likely than non-Latinxs with disabilities to use paratransit as their exclusive form of transportation. In discussing this result, four major factors that contributed to transit mode choice emerged: affordability, safety, independence, and comfort/convenience.

In terms of affordability, many participants supported the idea that driving was expensive. When asked about some of the advantages of taking fixed route transportation, one participant responded, "Just the price, it's cheaper than driving a car. You pay once and it takes you where if have to go if it's far away. It takes longer, but it's fine; it's not that bad." Clearly there appeared to be a give-and-take with the fixed route (i.e., it's cheaper but it takes longer), but the price appeared to be an important factor. When discussing their ideal transportation system, many participants mentioned that they wanted something that would come and pick them up, but that also was affordable. When one participant was asked, "Would you want to take something like Uber?" He responded, "Yes, like Uber, but a lot of the time we don't have the money to pay for Uber." It appeared that transportation choices, being a vast as they are in the Chicagoland area, can be narrowed down solely based on affordability. If someone didn't have money to take one form, they were relegated to a different form. One participant put it bluntly: "I can't afford someone saying like, 'Oh, I get an Uber; I get a taxi.' It's expensive to get that. I have to deal with what I got."

Affordability was an important factor for Latinxs with disabilities choosing fixed route, but it also appeared to be a factor when they also chose to use paratransit. In Chicagoland, paratransit services cost more than the fixed route services, but paratransit costs much less than driving or taking a cab. When taking a cab is the alternate option, participants seemed to prefer paying less money for paratransit. One participant explained, "Sometimes when I don't have the money to buy the taxi I take [paratransit]." The choice for Latinxs with disabilities was not always fixed route or paratransit, but they also had other transportation options, including driving or taking a cab. When compared to these other options, paratransit was the more affordable choice.

Safety has been a topic heavily discussed already in this paper. Participants spoke about the criminal activity, the harassment, and the community safety issues that can occur when taking fixed route transportation. While paratransit was not free from safety concerns, it appeared that participants perceived paratransit to be a safer form of transportation than fixed route. Many participants mentioned that they could not even take fixed route due to safety concerns. "Oh, the bus stops. I can't use that. I'll get hit," one participant with a visual impairment explained. Another participant commented that despite its shortcomings, paratransit was her safest and most reliable choice because it got her to her destination. "At least with the door-to-door I'm safe and they will come and get me. Late or early, but they'll come to get me." A parent participant said something similar: paratransit is not perfect, but it's the safest choice for her child with a disability. "I think it's safer," she said. "Yes, maybe they're delayed, but I feel my child is better off there. It feels more comfortable than using public transit."

Another participant talked about safety issues related to weather on the fixed route as reasons for why people might prefer to take paratransit instead. "Because that door-to-door, it's pretty much for people with disabilities. The public transit, you have to wait through the weather, the heat, the winter, everything. And then with the door-to-door it's very different. You don't have to deal with the weather anymore." It appeared paratransit was a facilitator for getting around when the weather is less-than-ideal.

Furthermore, transit choice reflects one's level of independence. Many participants mentioned that they have people drive them places. Similarly, many parents mentioned driving their children with disabilities places they needed to go. Both groups mentioned that this was a

safer option than taking public transit. While some participants enjoyed getting a ride from others, they also recognized the hardship that might put on the person driving them. One participant said, "Our family members also have lives and we want to be independent. Or like, if I want to come, for example, here, for whatever reason, I need to be sure that I have a service I can use." Another participant in a different focus group shared the sentiment that he didn't want to inconvenience someone he cared about to get him places: "When I first acquired my disability I did have people drive me around everywhere. But once I got married I think that just changed, because of the fact that I guess it was just too much of a burden for my family to deal with two wheelchairs, with two people with disabilities." One participant said that his wife drove him everywhere he went, but also mused the idea of being able to go places without her. He joked, "The day that there's the Google Car, then I won't need to rely on my wife to get me places. I can have my own adventures without her knowing about them. [Laughs.]" It appeared that being independent and not burdening or having to rely on someone else to get around was important and this desire was reflected in their transportation choices.

Some participants did say that driving was their preferred form of transportation. Suburban participants said they preferred to drive when in the suburbs, where fixed route transportation does not run in all areas and does not run as often. During a focus group, two participants, one living in the suburbs and the other living in the city, discussed the options that they have living in the suburbs. They agreed that between the transit schedules and the locations of the stops, it would be easier to drive in the suburbs. Clearly when a form of transportation is not readily available to someone, they would not prefer to use it.

In the focus group with young adults with IDD, participants said that they liked getting a ride from their parents and family members. They enjoyed getting a ride from these people

because they were comfortable with them and they were not comfortable taking a form of transportation by themselves. While this was the majority of the group of people with IDD, not everyone with IDD in the study agreed that getting a ride was their preferred form of transportation, so some contradictory findings appear.

Independence was also an important factor for this group of participants in choosing paratransit. Paratransit was often reported as a more independent choice than relying on a ride from someone else. This conversation during a focus group with young adults with IDD illustrated one participant's desire to not burden his mother and instead be able to get around by himself. Participant: "If my mom is not able to drive, I prefer my own private transportation." Moderator: "Okay. So it would be the choice between your mom driving you and taking another form of transportation." Participant: "Yes." Moderator: "And which one do you think is better?" Participant: "CSS transportation." Moderator: "...Why is that better?" Participant: "Sometime faster. Sometime my mom not have drive a lot." Moderator: "Okay so you don't want your mom to have to drive you all the time?" Participant: "Yeah. Kinda stressful... for her." While this conversation was talking about the "CSS transportation" or a private transportation service provided by a social service agency, and not the paratransit service, it shares many traits with the paratransit service in that one does not have to rely on a friend or family member, the service picks them up, and it gets them to where they need to go.

Comfort and convenience were other related factors in choosing paratransit. It appeared that participants preferred paratransit in times of bad weather, like snow, rain, or very hot weather. Participants said that the weather could influence their transportation choices. When a participant was asked why he chose to take paratransit to the focus group, he responded: "Yes, for me, today, I took the paratransit, because I looked at the weather and they said that it was going to be raining the whole day and I said, 'Okay, then I'll take [paratransit.]'" Other participants said the same, that weather and comfort were important in their choice to take paratransit.

Another participant said that despite all the scheduling and routing issues, paratransit was still better and more comfortable than taking fixed route. One participant summed it up like this: "It seems logical that door-to-door, in spite of the imperfections that it has, is more convenient." In a nutshell, even though it's not a perfect system, the paratransit's convenience was a convincing factor for Latinxs with disabilities.

b. Member checking question 2

This was the most loaded and controversial finding for the participants. Member checking question 2 was: "Latinxs report being treated poorly by drivers." When presented this finding outright, many participants replied that this was not true: there were no differences between the way that Latinxs with disabilities and non-Latinx whites with disabilities were treated by drivers. Participants shared bad experiences with drivers, but instead attributed the driver's treatment of them to their *disability* and not their ethnicity. They specifically mentioned issues with ADA compliance: not assisting with their chair, not clearing the accessible seating area, not deploying the ramp, all issues that people with disabilities, and not specifically Latinxs, experience. When asked if drivers treat him any differently, one participant said that everyone gets treated poorly by drivers, not just Latinxs and not just people with disabilities. Later he continued,

It's a two-way street. That driver's dealing with traffic, and crazy people on the bus, and you've got to take that into consideration and you've gotta do your part by being patient and respectful and having the ability to distinguish 'Hey, is this discrimination, or is this

just life?" In other words, the drivers do treat people poorly, but they treat everyone the same. (Participant A, personal communication, June 26, 2018)

Another participant agreed that drivers treat them badly, but suggested that it might be because they are just not cut out for their job of working with the public or working with people with disabilities. "If you really don't have experience or you don't have patience to work with people, especially disabled people, this job is not for you." Other responses echoed that the drivers were not purposefully discriminating against Latinxs with disabilities; they were just uninformed about how to serve this population. While many participants agreed that fixed route and paratransit drivers could be mean or rude, some were hesitant to assert that this treatment was due to bad intentions on behalf of the driver.

One participant qualified the question, by challenging the use of the word "reported" or "reportaron" in Spanish. The researcher had meant "reported in the survey;" but participants had understood "reported to authorities" or "reported to a formal complaint line." Everyone in this focus group agreed that this was a misleading way to state the finding. After this focus group, the researcher was sure to add "reportaron en la encuesta" or "reported in the survey." However, some participants in these focus groups still initially denied poor treatment.

Despite remarks from participants that Latinxs were treated the same as their non-Latinx counterparts, the same participants who responded that this finding was not true also shared instances of being treated poorly by drivers, and instances of being treated poorly by drivers that they attributed to discrimination based on their being Latinx. After stating that Latinxs are not treated more poorly by drivers, one participant later asserted, "A person of color is treated much better than a Hispanic, because I've seen it." In this case "person of color" refers to African Americans and not Latinxs. So this means that even though they may have denied it in the

beginning, there was some agreement that Latinxs do experience discrimination from transit employees.

Although some participants initially responded that they did not agree that Latinxs with disabilities were treated more poorly than their non-Latinx counterparts, some did outright agree with this finding. One participant very clearly stated that he believed the mistreatment that Latinxs endure is because of their ethnicity and not their disability. He said, "Everything has to do with it [being Latinx]. Sometimes not so much with disability but rather the fact that we are Latinos. That's the way it is." Another participant was not so sure about how to parse out acts of discrimination based on ethnicity or race and acts of discrimination based on disability. Instead, he believed that it all compounded: "But aside from that, what you're talking about is double, because of the disability and because of being Latino." While it is impossible to separate racism from ableism many times, clearly Latinxs with disabilities are affected by discrimination based on their race.

One particularly power quote was from a Latinx woman with a disability who drew parallels with her experiences of discrimination on the bus to Rosa Parks'. She said,

I have a bus pass and free rides and [the card didn't register] and so a couple times the driver said, 'You have to get off my bus.' I felt so bad... I felt like crying. It was such a terrible feeling, you know? Like, embarrassing... I felt like Rosa Parks. I mean, really get off the bus because my bus pass didn't click. (Participant G, personal communication, April 27, 2018)

Some participants did not attribute poor treatment by drivers to outright racism; instead they attributed it to discrimination based on *language*. One participant explained, "For me, it's the language. I don't have a problem with that, but for some I hear a lot of the language that, 'Oh,

you're Latino, sorry. I can't help you.'" The same participant later said, "I just [speak to them in] English. I don't speak to them in Spanish. But they see my last name, and they think I don't speak English until they hear me. 'Oh you speak Spanish, yeah?'...But I don't think they just look at my last name and see and try to figure me out. They try to figure me out."

To further complicate this finding, participants mentioned that the driver's race often played a role in their treatment of Latinx riders. Many participants made comments about specifically black drivers who treated them poorly, but would qualify the statement with "T'm not racist, but..." One participant said, "I don't like to discriminate or talk about race, but the majority [of the drivers] are black and they just do not help." One parent participant told a story about a time when her Latinx son took the bus and she felt the black driver was singling him out because he was Latinx. She asked her son why he thought the bus driver was treating him differently and he answered, "'Because I was getting in the way.'" She told him, "'No, because you're Mexican, because you look Latino. A black kid could have gotten on the bus with everything and all smelling bad and he would not say anything to him, believe me. But because you look Latino he believed he could bring the attitude of 'Tm just gonna step over you...That's how they're derogatory.'"

One participant suggested that Latinxs are going through what Rosa Parks and African Americans went through decades ago from whites, but this time from African Americans. She said,

That's how I felt like when they told me to get off the bus a couple of times. Not all the time, but it happened to me a couple times... I became frightened and that's why I could see how the African Americans are protesting and all that about Rosa Parks because it happened to me a couple times. I'm Latin, I don't look black, but they do tell you to get

off and it's a racial thing... It's such an ugly feeling. Just a racial feeling. Like, if I were black would you let me stay, right? (Participant G, personal communication, April 27, 2018)

While many of these stories surfaced throughout many focus groups, participants were quick to remind each other that not *all* black drivers were rude or racist. One participant talked about a time when she saw a black driver going out of their way for a Latinx rider. "There was a black driver helping a Latino. The Latino was drunk. I don't think it was his job, but I'm sure he was doing it with pleasure." So while clearly race played a role in their experiences, participants tried to steer clear of generalizing.

Another issue interplaying with discrimination was stereotyping. Some participants felt that they were stereotyped by drivers as being more docile or agreeable, which then allowed drivers to pick on them more. One participant said,

I noticed this with a lot of drivers, they know who to pick on... they know who to talk nice to and bad to...I think people that look a little bit more convincing as a thug or whatnot, they'll just leave 'em alone because they know they're just going to come and retaliate with some kind of way. And other people are just like, they look so innocent that they're, 'Oh, this man ain't gonna do nothin'. He's just gonna probably huff and puff about it and sit in the back of the bus or something,' you know? (Participant A, personal communication, June 26, 2018)

A participant in a different focus group mentioned that Latinxs were often stereotyped as being passive, so they were often victims of crimes. She said, "Yes, I'd say that they put us more on our toes. I dunno. [Laughs.] It's probably because they say to themselves, 'These guys aren't going to defend themselves.'" Similarly, and more lightheartedly, this conversation also supported the

same claim: Moderator: "What criteria do you think they use to pick on people then?" Participant: "Whether they can beat 'em up."

At times it seemed that participants even believed that they deserved poor treatment from drivers because of their own disability. One participant said, "Because we have a disability, I feel like we don't have the right to say anything. You have to put up with things when you take this transportation, because we're doing you a favor." This harkens back to some of the themes discussed regarding advocacy and complaints in the paratransit barriers section.

One participant summed up these interpersonal issues poignantly. He said, "The human support is what is failing us... 'Cause, yeah, we get it: tires can get flat, cars can break down. The problem is that what is failing us is the human part." Overall, it appeared that Latinxs with disabilities have indeed experienced different treatment or discrimination compared to non-Latinx whites (and non-Latinxs of other races) with disabilities, which supports the findings from Part I.

c. Member checking question 3

Member checking question 3 was: "Latinxs report more safety issues." This finding was clearly confirmed by focus group participants, although their reasons varied. Safety was a theme that appeared in many ways throughout the focus groups. Some findings related to safety were already discussed when identifying Latinxs with disabilities' interpersonal barriers and environmental barriers to accessing fixed route and paratransit. Many participants had stories about safety-related incidents while riding on public transportation. One participant told the group about a time she was pickpocketed, another how he was robbed at the bus stop, and another about how he was assaulted. Even if someone did not personally experience a safety incident on public transportation, safety still appeared to be fresh in their minds. One participant said, "I'm always keeping a watchful eye to make sure nothing happens when I'm using public transit. So everything's okay for me." It appeared that safety was a big concern among Latinxs with disabilities while riding public transportation.

Some participants attributed safety issues to the areas in which Latinxs tend to reside in the Chicagoland area. When presented with this finding, one participant explained that it is likely due to "instances of robbery, gangs, bullets, violence" in these Latinx-dense areas.

Participants also harkened back to the finding about being treated differently by drivers and spoke about safety issues due to racism or discrimination, not just from drivers, but also in general in their communities. One participant stated, "Because you will be victim of hate crime if you're Latino sometimes. I may be insulted for being Latino." For the participants, discrimination for being Latinx directly related to speaking Spanish. Many participants talked about the discrimination they experienced when they spoke Spanish and how it could lead to safety issues, including being harassed. A participant said, "When you would speak only Spanish, everyone doesn't speak English, they think they're illegal immigrants… They tell you to go back to your country."

One participant talked about a time when she felt unsafe boarding a bus because in the past she had been threatened when her card didn't register. The driver was clearly stereotyping her, perhaps due to her disability or her Latinx identity. She told the group, "I don't tell them that [my card doesn't register] and I don't have no money, and I'm afraid the guy's gonna call the police on me or beat me up because they think I'm robbing him. Oh, it's a terrible feeling." The same participant shared a secret for avoiding this type of treatment: "I always bring a candy bar for the driver just to protect my life. Whenever get on the bus or [paratransit] or a cab, I always bring something for the cab driver, always... To know that I'm safe."

Continuing with the theme of discrimination on the basis of race or ethnicity, one participant mentioned an interesting story where Latinxs were the victims of unsafe behavior from African American riders. "We were heading over here and some black kids got on, some kids from the high school. Because we were Latino, they started to bully us. I already spoke a little bit of English, but because I didn't know the rules, I didn't want any problems." This story further complicated the issues of race and discrimination between Latinxs and African Americans that was a recurring theme in the focus groups.

Furthermore, not being able to speak the dominant language was reported as a safety concern. Participants reported that language barriers were connected to barriers to advocacy on public transportation, and thus connected to safety. A parent participant also noted the interplay between language and being able to effectively advocate, which affects one's safety. She said, "The language barrier that makes it so we cannot stand up for ourselves."

There were some issues mentioned that appeared to be of particular salience to the IDD community. Parent participants often spoke about fearing for their children's safety due to their child's lack of confidence and advocacy skills. They felt that their children, because of their disability, were an obvious target for crime. One parent told me his daughter was not prepared to defend herself against someone trying to take advantage of her. "For example," he explained, "if she's carrying her purse and some other person grabs something from her purse, she wouldn't say anything." Almost all of the participants with IDD confirmed that they themselves were concerned about safety issues when riding on public transportation, and mentioned some crimes that could happen to them. One participant with IDD told the group that he was afraid of being bullied by other passengers on public transportation "because I act weird." The IDD community appeared to have unique safety concerns due to their perceived vulnerability.

d. Member checking question 4

Member checking question 4 was: "Latinxs report more issues with the paratransit system." This finding was another that was clearly confirmed by focus group participants. The findings of research question 1 clearly illustrate the barriers that Latinxs with disabilities encounter when using or trying to use the paratransit service and those results will not be reiterated here.

To summarize, the most frustrating issues with the paratransit system appeared to be routing and timing issues. "And paratransit... it's like a Cracker Jack box," One participant summarized, cynically, "You don't know what's going to happen once you get in that vehicle. You may be held hostage because you might be going somewhere and they said 'Oh we got two pickups before we're taking you to where you're going."" One participant had a theory as to why the system might be set up to take a rider to many places before dropping them off: "That's the system that taxi drivers used or still use because they always make money," he hypothesized. "They are going to take the longest route to charge more, so it probably has to do with how much they make." This statement reflects the general distrust that Latinxs with disabilities expressed for the paratransit system, regardless if the system is actually set up this way.

Overall, participants did indeed confirm the four member checking questions presented to them, which, in turn, supports many of the results from Part I.

3. **Research question 3**

Research question 3 asks: How do these barriers to public transportation access affect the way that Latinxs with disabilities are able to participate in their communities? This question was asked directly to participants during the focus groups and other conversations related to using public transportation in order to participate in one's community also extraneously occurred throughout the focus groups. In order the fully answer this question about community participation and provide context, the researcher will also present descriptive information from thematic analysis about how the participants use public transportation in order to participate in their communities.

a. <u>Community participation themes</u>

First, Latinxs with disabilities reported using public transportation, both fixed route and paratransit, to participate in the communities in a number of ways. These manners of participating in one's community were categorized into the following themes: health care, work or school, errands, social or recreational, and social services. A summary of these themes can be found in Table VIII.

Participants often mentioned prioritizing one of these things over the other when transportation options were limited. For example, in homes with one car, participants mentioned that car priority went to the person that needed to work. Other participants prioritized their medical appointments. One participant explained, "I would go, more than anything, first to my appointments. Be on time for my appointments. I would visit my friends with more confidence, family members. But my doctor's appointments are priority for me, those appointments are first for me."

While many participants reported experiencing barriers to participating in their communities due to transportation issues, some reported that they did not have any barriers! One participant said, "Because of the blessing we have in Chicago, being a person who has lived in other cities and towns, and living in this area, I can handle myself between CTA and paratransit and the [taxi] system."

Other participants reported enjoying the public transportation experience. Some said that using public transportation in itself was a form of participating in their communities. One participant mentioned the social benefits he got from taking fixed route: "Sometimes you might meet new people on the bus. Like they wanna chat with you."

b. **Community participation barriers**

While some participants clearly expressed only positive experiences with participating in their communities, and did not report any barriers to community participation, most reported the opposite: they did experience barriers to participating analysis: missed appointments and opportunities, psychological barriers, inconvenience, and social and interpersonal barriers. A summary of these themes can be found in Table VIII.

TABLE VIII

QUALITATIVE FINDINGS: FACILITATORS AND BARRIERS TO COMMUNITY PARTICIPATION FOR LATINXS WITH DISABITIES

<u>Community Participation Barriers:</u> Identified barriers to community participation when using public transportation (both fixed route and ADA Paratransit) or issues or problems related to being able to participate in one's community using public transit.

Missed Appointments/Opportunities: Barriers to community participation that involve missing out on opportunities or missing appointments, etc. because of barriers to public transit (both fixed route and ADA Paratransit)

Psychological Consequences: The mental or psychological stress caused by barriers to public transportation barriers and barriers to community participation.

Scheduling/Timing Issues: Barriers to community participation associated with being inconvenienced by the timing or scheduling of public transit, but not necessarily missing out on appointments.

Social/Interpersonal Issues: Barriers to community participation associated with social or interpersonal life.

1) Missed appointments and opportunities

Many participants mentioned that the biggest barrier they

experience in terms of community participation due to problems with public transportation was missing out: missing out on appointments, missing out on social opportunities, and even missing work. After being asked what he would do if he was not able to get onto public transportation, one participant responded that that he wouldn't be able to get anywhere. "I couldn't go anywhere, because I don't drive, I don't ride a bike. I don't know anything."

One participant explained what she was not able to do when she experienced transportation issues, "I know that there are things that we cannot do because of transit. Like, I

want to make some arrangements in the house, and then I can't go buy something." Another participant talked about the things he wanted to do, but couldn't because he has no way to get around, "I want to learn Braille and I want to learn how to use a cane. I don't really know how to... I almost never go out anywhere."

This was not just the case for fixed route transportation, but for paratransit as well. One participant explained a situation that happened to her father on paratransit that caused him to miss his specialist appointment: "I remember that when my dad used [paratransit] that they would go to get him, but one time it didn't come and he also lost his appointment. Do you know that when you lose an appointment at the university, they schedule you in months? Months for specialists, they don't even schedule you. So it's a problem, yeah." Another participant explained why he no longer relied on paratransit to get him to work. "You know, paratransit will get you fired, by the way," he said. "For people that get jobs, I know this to be a fact. Paratransit is a good way to get you fired. When you need to be at work at nine, and you get there at 10:15, your boss usually doesn't understand what's involved with paratransit."

Some of these missed opportunities are related to weather. One participant mentioned that if the weather made it impossible for her to use fixed route, she was unable to make her appointments for the day. "I walk a long way to get to the bus stop," she explained. "If it's hot out, believe me, I get there with my tongue hanging out. Pretty tired. If it's cold I don't go out, because imagine how the weather is. And if there's a lot of snow, I fall. Something can happen on my way there. It's better if I don't go. Sometimes I postpone my appointments."

Other missed opportunities are related to one's level of independence in taking public transportation. Some participants relied on someone else to take them somewhere because they were not able to use public transportation to get to certain places. When asked about being able

to go places by himself, one participant responded: "I miss a lot. I almost don't go. There's no one to take me." Many times this other person is a spouse or family member, and if they cannot take the participant, the participant misses out on something.

Other missed opportunities were related to affordability and the cost of transportation. One participant explained how it got too expensive for her to take paratransit to her different classes and recreational activities, so she had to stop going to them. She said, "There was one that was offering me to go for swimming... I would've liked to go there, but I can't afford it... It adds up. I cannot afford so I can't go. I would love to but all that is just adding, adding, adding."

Participants mentioned the difficulties they had prioritizing which appointments they were going to make and which they would have to miss because of transportation constraints. One participant explained that he only used paratransit when he did not need to be somewhere at a specific time, but he would use it for a party or an occasion where the timing was more flexible. He said, "When I'm going to my friend's house to go drink and have a barbecue and I don't care about the time [I will use paratransit]. But I can't use them for something serious like a medical appointment or a work." Another participant explained that she did not go out for any social events because she had to prioritize her transportation for medical appointments.

I just don't go anywhere. If I have to go somewhere, I'll just go with family. They'll pick me up, drop me off... I get a ride because all that adds up. And then to get a taxi, it's expensive... So I just stay home, not do what I have to do... If I gotta go to therapy, I'm not gonna go to [other] places. (Participant G, personal communication, April 27, 2018)

Even after prioritizing which appointments to go to, sometimes the act of organizing and scheduling transportation was just too stressful. The same participant described being too exhausted after her classes to take transportation home:

I was very tired. So I had computer classes and I'm like forget it, and I wasn't gonna get into my computer... And then the Braille, the same thing... I dropped the Braille classes... because so much of the transportation time to go and come back also. (Participant G, personal communication, April 27, 2018)

2) **Psychological barriers**

While many participants said that they experiences missed appointments and opportunities due to transit barriers, some participants did say that they did *not* miss out on things because of transportation issues; however, it was often these same people who did not miss out that admitted they still felt stress or hopelessness when they needed to get somewhere in their communities. Many participants described the difficult psychological stress that they felt when they experiences barriers to transportation that affected their ability to participate in their community.

First, taking public transportation, as previously discussed, is often fraught with interpersonal issues. These issues have caused frustration and stress for the rider. One parent described this frustration: "We would be using the public transit and, yes, there are moments in which you get so frustrated you so much, that the driver gets frustrated, and other people get frustrated." Unexpected changes in transportation often resulted in a lot of stress. One participant explained that delayed rides or having to wait for transportation, "It causes me stress, headaches..." Another source of stress was not having adequate transportation options. One parent participant said: "It's stressful. I would like to use public transit more if it were more available in my area, but sometimes it can't be." "Stress" and "frustration" were commonly-uttered words during many parts of the focus groups.

Another participant went a bit beyond feeling stressed and referred to the public transportation experience as a "trauma." "For me, it was like a trauma," she said. "Still now, I've been scared to board a bus, because I say, 'I'm going to fall in this chair.' With the breaks I fly forward, and now I'm left traumatized that I can't board a bus with this chair because it scares me. That is a psychological trauma." Another participant talked about the severe psychological effects of not being able to participate fully in her community due to not having transportation. "Tve cried from feeling helpless," she said, emotionally. "From feeling frustrated, angry, sad and a whole bunch of feelings that I have to go there, and I can't go there. But what I do is I pick up the phone and talk to a bunch of people... to see if someone can come and get me because I have to go, because I won't be able to go alone."

For others, negative interpersonal experiences such as discrimination on public transportation exacerbated their current medical conditions and caused physical effects. One participant explained that she gets more frustrated with other people who are rude to her when her blood pressure is acting up. Another participant explained that discrimination, from public transportation personnel but also in general, affects her "physically and emotionally." She explained: "It affects me physically and emotionally. Emotionally, you feel bad, and feeling bad emotionally affects your whole body physically, and so in general, it's difficult."

3) <u>Timing and scheduling</u>

Similar to experiencing psychological barriers, several participants said that instead of missing out on appointments or opportunities, they were inconvenienced by the schedules or the process of their transportation options, which created barriers to their community participation. Many participants mentioned that their options were limited, so any issues or inconveniences they experienced hit them hard. Not driving was a commonlymentioned barrier to being able to get to different places or appointments. For example, one parent participant said that they prioritize their one car for her husband to get to work. If he works that day, they need to find a different way to get somewhere.

Another issue mentioned was that Latinxs with disabilities already have limited options for their appointments, particularly health care appointments, due to many non-transportationrelated barriers, that transportation is just one additional barrier for them to deal with. One participant explained the complicated situation her family was in due to limited options in many realms:

My mom comes here to the university for her appointments... because the university is the most recognized place for her, it has good medical specialists... I also like it because they have language interpretation and all of that... When it's possible I take her here in case of an emergency... When it's not, the ambulance will have to come to take her to a hospital from there. (Participant B, personal communication, June 12, 2018)

Because participants mentioned relying on the fixed route system that, as previously mentioned, regularly runs late, they often talked about having problems with their schedules in general. When transportation runs late, people are late to their appointments or, in this case, even their jobs: "There are times when it doesn't come on time... you get to work late," explained one participant. Another participant described the importance of fixed route keeping to their schedules because Latinxs with disabilities plan their scheduled around the fixed route.

The bus has to run on a schedule... because they also have stuff to do. And they have places to go and people to take and people have... to be at a certain time. So for us it is a necessity because it gets us where we need to go and it gets us to the time we need to be there. (Participant H, personal communication, June 26, 2018)

Another participant explained the "waste of time" waiting for fixed route can be and how that affected his daily life:

Most of the time that is lost is mainly the stress when you go to work or some appointment, when you go to the doctor. The time lost waiting for the bus is what makes you nervous, because you're going to be late... If the bus and the train take 20 minutes to go where you are going, by waiting for it you already lost two hours. Waiting for it, not even because I was on the road... it's a stress, when you're waiting for the bus that does not come and does not come, and counting the minutes because you have to arrive at a certain time. (Participant I, personal communication, March 30, 2018)

Another participant described all the effort she puts into planning how to get to and when to get to her doctor's appointments:

Basically, to me it's more about time. Like, for example, you have a meeting or a doctor's appointment... For that, let's say you have an appointment at ten... we have to wake up at like, seven, do all the stuff we need to do, try and get there before time because after that you have to wait to be called and all that other stuff. (Participant J, personal communication, June 26, 2018)

This participant sounded stressed out just describing her transit planning routine.

Another commonly-mentioned issue was the time it took them to do their trips on paratransit in particular. For a trip that by car would take 45 minutes, a participant explained that it would take four times that on paratransit. "To get to work," he explained, "I use the door-todoor and it takes 3 hours to get there and 3 hours to get home when I work in the office." The same participant later explained his method for getting transportation to the airport: he would need to leave six hours before his flight! He explained, "I request my transportation like 6 hours before my flight leaves to make sure that I'm going to arrive on time to the airport and to be there. Sometimes they take me there directly so then I spend like 5 hours there waiting for my flight to leave." Clearly this is an inconvenience and a waste of time for Latinxs with disabilities. Another participant summed it up this way: "They take you one way and another way and they make your life heavy in 6 hours, which should only be an hour and a half."

As illustrated here, one of the more frustrating inconveniences was not knowing if the ride would arrive late or not. The system is unpredictable. One participant sympathized that services like this might run late, but then suggested that the companies do a better job of letting riders know the schedules of the vehicles: "We're all human. There's traffic, there are accidents, things get delayed. I know. Already an hour or something, and they don't let you know, either. They don't call people to let them know."

One participant talked about how he believed that drivers took their time dropping people off on paratransit rides because they were people with disabilities who didn't have anywhere important to be and didn't know any better if they were late. This, he explained, was a form of discrimination.

They believe that we don't have a life, nor do we have responsibilities... Once it was my turn and a young kid was already on the vehicle. They took me, we picked up people, we dropped people off, and that boy was still there and he was picked up very early, and I say to the driver, 'You're keeping him here for many hours.' [The driver replied], 'Hey, he doesn't even say anything about it.' (Participant K, personal communication, April 6, 2018)

Clearly, timing and inconvenience can be at play with other identity-related issues.

Participants were not just inconvenienced by transit schedules and timing, but also by the system's rigidity. One participant talked about her effort taking fixed route to a food pantry and having to take all her bags with her:

I go to [a church] for the food pantry once a month, and if I have no money for the transportation or my card doesn't work or something, I walk with my cane. But I get on the bus coming back because I take the car to put my groceries in it, and man it's a big trip getting back. You know, it's really a trip. (Participant J, personal communication, June 26, 2018)

4) <u>Social and interpersonal barriers</u>

There were many barriers to community participation related to social or interpersonal realms. Many participants reported feeling disconnected from others in their communities because of transportation barriers. One participant said she even felt "trapped in her own house."

In the focus group with young adults with IDD, where only one of the participants took transportation independently, the participants mentioned being socially isolated from their peers and not hanging out with friends or going to social events regularly. When asked what she does socially, one participant mentioned that she stays home with her mom. Another participant in this group mentioned not being able to visit her boyfriend and having to wait for him to come visit her. Clearly transportation barriers limited many participants' social opportunities.

Participants mentioned that social conflicts could surface when they had to rely on someone else to take them somewhere when their transportation options were limited. Once participant explained the social issues that arose for him when asking someone for a ride when transportation didn't work out for him. "Most of my community of friends are in the same situation," he said, "They don't own cars or they're disabled. After a while, for me, it got very painful to feel like I was begging or asking for a favor." Another participant described another situation where he had to rely on someone for a ride and then felt like he had inconvenienced them, so he would rather just take public transportation, even if it's less convenient for him.

I'd rather go through [all the problems with taking fixed route] than asking people for favors for a ride. Because I've had experiences where they always tell you, 'Well, why didn't you tell me you needed to go there?' It's the same person who told me, 'Oh, I can't go there because I got to go, blah blah blah,' and it's like ...'Okay, it's cool. I know I won't be calling you for any favors.' (Participant A, personal communication, June 26, 2018)

Fears of burdening others also surfaced in another focus group. A participant described that when people try to help her out with transportation, she feels like she owes them.

Sometimes I'm waiting for the bus and someone in my building drives and goes 'Oh, I know her, let me go pick her up,' you know? And sometimes I don't like it because I won't have two or three dollars to give that person and... I don't want to feel like I'm begging, because I don't like getting anything for free. I like to pay for my service. (Participant L, personal communication, June 26, 2018)

Another barrier to community participation for Latinxs with disabilities related to the interpersonal was discrimination based on race or ethnicity. As previously revealed, discrimination from transit drivers clearly plays a role, but many participants argued that their experiences of discrimination went beyond just their experiences on public transportation. One participant argued that racism was a common experience among Latinxs in all realms of community life. "I see discrimination everywhere for Latinos with disabilities," she said. "This

small room about transportation is something, but it has to do with all layers of life. Transit is only a piece." Another participant's comment supported the broad effect that discrimination has on all facets of a Latinx's life: "Latinos... we are second. I'm speaking generally, the secondary ethnic race in all of the United States."

Many participants attributed the widespread discrimination of Latinxs to the current political climate in the US. One participant put it poignantly: "I believe that we are going through times now, Latinos, because of the situation that we have with the government. Many people sometimes feel that they have the right to insult Latinos, to treat us differently, because they view it as okay." Several participants mentioned current US President Donald Trump by name, saying that he was at least partially responsible for the uptick in racism against Latinxs in the US. Clearly the political climate has had an effect on Latinxs with disabilities.

Finally, safety was a theme that kept recurring, especially in relation to interpersonal interactions on transit, but even when talking about non-transportation-related experiences in one's community. As previously illustrated, safety appeared to be constantly on the minds of Latinxs with disabilities' when travelling out in the community. Many focus group participants mentioned that they found safety to be a barrier to travelling on public transportation, but another participant was quick to remind the focus group participants that safety issues can happen anywhere in the community. "Being robbed or pick pocketed at a bus stop has nothing to do with transit," he said. "Transit can't be responsible for that... I mean, you could get robbed in the alley. You can't say, 'Hey... it's the sanitation department that's responsible.'" The far-reaching breadth of safety issues for Latinxs with disabilities was further illustrated through talking about the particular dangerousness of neighborhoods in Chicago that house high Latinx populations.

Overall, public transportation access barriers can affect Latinxs with disabilities' ability to participate in their communities in several ways, especially due to missed appointments and opportunities, inconvenience, psychological effects, and interpersonal issues. Furthermore, community participation for Latinxs with disabilities may share some of the same barriers that make it more difficult for this same community to access public transportation, such as language, discrimination, and certain cultural values.

VI. PUTTING IT ALL TOGETHER

Based on the data presented, the following theoretical model has been developed. This model includes data from both Part I and Part II of the study and serves as a framework for future researchers to use for research on public transportation and community participation for Latinxs with disabilities.

Tables IX and X illustrate how the model on public transportation access barriers and community participation for Latinxs with disabilities was developed from the data in this study. These tables describe the process that the researcher used employing a grounded theory approach to develop the model. Themes and subthemes from the data, found in the results section, were theoretically coded to determine which over-arching moderating themes were related to each theme found through the initial analysis.

TABLE IXTHEORETICAL CODING OF FIXED ROUTE AND PARATRANSIT BARRIERS FOR
LATINXS WITH DISABILITIES

	Language	Discrimination	Culture	Documentation	SES
Individual/Accessibility					
<u>Barriers</u>					
Physical barriers	Х	Х			Х
IDD-related barriers	Х	Х	Х		
Sensory-related barriers	Х	Х			
Interpersonal Barriers					
Transit employees	Х	Х	Х		Х
Other passengers	Х	Х	Х	Х	Х
Third parties	Х		Х		Х
Systemic/Organizational					
<u>Barriers</u>					
General fixed route system	Х				Х
barriers					
Specific barriers	Х	Х	Х	Х	Х
Affordability			Х		Х
The paratransit system	Х	Х	Х	Х	Х
Rules and eligibility	Х	Х	Х	Х	Х
Feedback and complaints	Х	Х	Х	Х	
Environmental Barriers					
Natural environment			Х		Х
Built environment	Х	Х	Х		Х

TABLE X THEORETICAL CODING OF COMMUNITY PARTICIPATION BARRIERS FOR LATINXS WITH DISABILITIES

	Language	Discrimination	Culture	Documentation	SES
Community Participation Barriers					
Missed appointments/opportunities	Х	Х		Х	Х
Psychological consequences	Х	Х	Х	Х	
Scheduling/timing issues	Х		Х		Х
Social/interpersonal issues	Х	Х	Х	Х	Х

A. <u>A Model on Public Transportation Access, Barriers, and Community Participation</u>

Based on analysis of the data presented in this study using the socio-ecological model,

the following key factors have been identified affecting the relationship between the Latinx with

a disability and their access to public transportation (both fixed route and paratransit):

experiences of discrimination, documentation status, language, cultural contexts, and SES. Each of these key factors contains data at the following socio-ecological levels:

individual/accessibility; interpersonal; systemic/organizational; and environmental. Table IX shows how each theme specifically fit in with the key factors in the data for public transportation barriers. These key factors are interconnected in different ways.

1. Key factors

Language affects so many transportation-related factors for Latinxs with disabilities, from receiving information about transportation options, to being able to communicate with transit employees and other passengers, to one's ability to advocate within the

system. Language may be the most common factor that affects public transportation access for Latinxs with disabilities.

Discrimination toward Latinxs with disabilities can be experienced as both racism and ableism. People with disabilities of many races experience ableism through improper enforcement of ADA regulations and microaggressions towards people with disabilities. Latinxs with disabilities are often targets of racism and experience discrimination for the language they speak or appearing different. Furthermore, Latinxs with disabilities may experience acts of ableism that are fueled by racist intentions, so while all Latinxs with disabilities may not experience explicitly racist acts, the ableism they experience happens to them at higher rates than it does to non-Latinxs with disabilities.

Documentation status can affect not only Latinxs with disabilities eligibility for transportation programs, but also their confidence in advocating for changes in services, due to fear of being deported if they complain too much or if they fall out of favor with a providing agency.

SES affects Latinxs with disabilities' access to transportation in many ways. Primarily, it limits their transportation options based on affordability. SES also considers one's neighborhood, including the physical barriers in the environment, and the safety of the neighborhood one lives in. It is true that Chicago's neighborhoods tend to be segregated, and violence is more prominent in communities where people of color, including Latinxs, tend to reside.

The Latinx cultural context can affect Latinxs with disabilities' access to public transportation. The Latinx cultural context encourages transportation that is safe, personalized, social, and inclusive. Latinx cultural values are shaped by an emphasis on community, professionalism, and personalism, among others. These values may influence which type of transportation may be best in certain situations and may preclude a Latinx with a disability to choose one type of transportation over another.

2. <u>Transportation-specific factors</u>

It may be evident that major transportation-specific factors are missing from this model, especially at the level of barriers to public transportation. These transportation-specific factors might include systemic fixed route and paratransit issues, accessibility issues on public transportation, and knowledge about public transportation systems. While these factors surely do impact Latinxs' with disabilities access to public transportation, they were not included in this model because they are not specific to Latinxs with disabilities. Non-Latinx whites with disabilities, and even may non-disabled people could experience these barriers. Instead, the current model strives to focus on the Latinx-specific factors that can affect the relationship between a Latinx with a disability and some of these transportation-specific factors, which could include language, discrimination, cultural context, etc.

B. Hypothetical Model of Public Transportation and Community Participation

The following model has been inductively developed based on the results of the mixedmethods study presented here. Table X describes how each theme specifically fits in with the key factors in the data for community participation barriers. The relationship between public transportation access and community participation is influenced by the same factors as the relationship between the Latinx with a disability and public transportation access: documentation status, SES, language, discrimination, and cultural contexts. Table X describes how each theme specifically fit in with the key factors in the data.

Figure 1 shows the new proposed theoretical model that describes the relationship between Latinxs with disabilities, public transportation, and community participation. This model is exploratory and general, unlike a theory which is more explanatory and specific. Future research can certainly build upon this model, but it is useful enough to be implemented into transportation provision for Latinxs with disabilities.

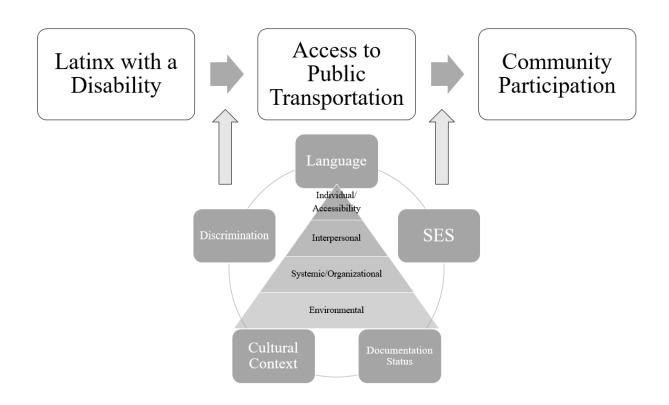


Figure 1: Model of Public Transportation Access and Community Participation for Latinxs

with Disabilities

VII. DISCUSSION

This section will discuss the results from parts I and II the study. It will synthesize the barriers that Latinxs with disabilities experience in accessing fixed route and paratransit public transportation and how these barriers to access impact their ability to participate in their communities.

In general, the results show that Latinxs with disabilities are experiencing barriers to accessing public transportation in a number of different realms (accessibility-related, interpersonal, systemic/organizational, and environmental), as revealed by using a socioeconomic lens to analyze the data. It is also clear from the data that many of these barriers are experienced disproportionally more often by Latinxs compared to their non-Latinx white counterparts. This is consistent with the scarce literature on the topic (Flores et al., 1998; Suarez-Balcazar et al., 2018).

Furthermore, these barriers are absolutely hindering Latinxs with disabilities' abilities to participate in their communities through causing them to miss out on appointments and opportunities, causing social and interpersonal distress, creating undue psychological stress, and disrupting their daily schedules. This is consistent with literature that shows that Latinxs report transportation-related barriers to medical, social, and civic activities (Graham et al., 2015; Sandoval & Jennings, 2012; Suarez-Balcazar et al., 2018).

A. Discussion of Barriers to Fixed Route and Paratransit Access

1. <u>Public transportation barriers for Latinxs with disabilities</u>

This section will discuss the results from Part I and Part II describing the barriers that Latinxs with disabilities experience on public transportation (both fixed route and paratransit). Fixed route and paratransit have been collapsed together in this section because participants reported problems in the same domains regardless of public transportation type. In Part I, more Latinxs with disabilities consistently reported experiencing problems some or more of the time with different domains related to fixed route and paratransit compared to non-Latinx whites with disabilities with one exception: the availability of curb-to-curb service. While only some of these differences were statistically significant, the sheer fact that more Latinxs with disabilities consistently reported problems in all domains compared to their non-Latinx counterparts warrants further qualitative exploration. The only topic Latinxs with disabilities did not report in Part I being more unsatisfied than non-Latinx whites with disabilities with was the availability of the curb-to-curb service. Whenever the differences between the door-to-door and the curb-to-curb service emerged in focus groups, it appeared that participants did not know there was a difference between the two or did not know a curb-to-curb service existed. As with many other pieces of information related to the paratransit system, Latinxs may be misinformed about what the curb-to-curb service is, and are not necessarily more or less satisfied with its availability. Overall, the results from Part I are consistent with the available literature on the topic, which says that Latinxs are more satisfied with transportation that is safe, reliable, and community-centered (Angel & Angel, 2015b) and prefer when transportation and information related to such transportation is available in their preferred language (Rodriguez-Galan & Falcón, 2009).

In Part II, notable differences between transportation types were that Latinxs with disabilities reported fewer environmental- and disability-related barriers and more systemic barriers on paratransit compared to fixed route; however, they still reported barriers in all domains. This section will also discuss why differences in public transportation access between Latinxs with disabilities and non-Latinx whites with disabilities were found in the following categories: disability and accessibility-related barriers; interpersonal barriers; systemic and organizational barriers; and environmental barriers, thus answering research questions 1 and 2.

a. **Disability and accessibility-related barriers**

There were clearly many barriers reported by Latinxs with disabilities related to accessibility of the public transportation. Significantly more Latinx survey respondents indicated that accessibility issues were a problem on fixed route transit compared to their non-Latinx counterparts, specifically physical accessibility barriers, such as lifts and ramps being reliable or available when needed. Focus group participants said that sometimes they do not have access to the physical accessibility features that they need when they need them and they mentioned drivers not putting down ramps for them and other passengers not moving from the accessible seating area when they need it. Although it wasn't captured in the survey, focus group participants mentioned feeling like paratransit was not always accessible to Latinxs with all types of disabilities due to its rigidity in timing and scheduling. Even on paratransit, which is meant to eliminate accessibility-related barriers, Latinxs with disabilities reported that there were concerns related to disability-related accessibility. The literature clearly states that these accessibilityrelated issues on fixed route and paratransit are already a problem for the disability community in general (Bezyak et al., 2017; Ing et al., 2014; Layton, 2012; NCD, 2015; Rosenbloom, 2007), but this study adds that there may be even more serious problems for specifically Latinxs with disabilities.

Focus group participants also reported barriers to transportation that might be salient for people with IDD, such as advocacy and safety-related issues. Reported instances of inaccessibility on public transportation can be directly related to language and discrimination, and many participants did draw this connection directly. Language barriers make it more difficult for Spanish-speaking Latinxs with disabilities to advocate for the accessible features that they need. Discrimination makes the instances that Latinxs with disabilities do not get the features they need a more likely occurrence. Drivers might ignore their requests or refuse to provide them with something they need if it inconveniences the driver. The existing literature on transportation for people with IDD does not currently particularly address the role of language barriers for this community in this context.

From a transit perspective, another likely hypothesis is that more problems occur on transportation in Latinx neighborhoods due to systemic and economic reasons. Bus garages in lower-SES neighborhoods, like the ones where Latinxs tend to live, might have older buses that need repairs to their accessibility features, making these features less likely to work properly when requested. Perhaps newer drivers or drivers that are not as acclaimed by customers are relegated to the areas that serve lower-SES riders or areas that are more dangerous, such as the areas where Latinxs tend to live. Latinxs in Chicago particularly experience disparities is SES due to rampant segregation in the city and the suburbs (Lee, 2009; US Census Bureau, 2016), so this hypothesis is not far-fetched.

b. **Interpersonal barriers**

Interpersonal barriers to public transportation were reported abundantly by Latinxs with disabilities, and these barriers related to interactions with transit employees, other passengers and people in their own party. Significantly more Latinx survey respondents reported issues related to the way they were treated by fixed route drivers and paratransit drivers than their non-Latinx counterparts, and specifically endorsed the issue of drivers passing stops without picking up passengers with disabilities. The survey did not inquire about negative interactions with paratransit dispatchers, but focus group participants pinpointed this, too, as a specific problem.

It has already been found in existing literature that people with disabilities in general tend to experience more negative attitudes and discrimination from transit employees than their nondisabled counterparts (Bezyak et al., 2017), but it seems that Latinxs with disabilities experience even more of this negative treatment and discrimination. Focus group participants supported this finding and cited discrimination- and language-related factors that contribute to this being more of an issue for Latinxs compared to non-Latinxs. Discrimination against Latinx riders is abundant and racism is clearly an issue for this community. Language may also foster opportunities for discrimination against Latinxs, but it also is a barrier for Spanish-speaking riders to be able to communicate with their drivers, leading to interpersonal conflicts. Literature is available supporting the level of discrimination and differential treatment experienced by Latinxs throughout the country (Brown & Lopez, 2013; Lopez, Gonzalez-Barrera, & Krogstad, 2018). A paper by Lopez et al. (2018) on perceived discrimination of Latinxs during the Trump presidency cites language and communication difficulties as a particularly worry among Latinxs living in the US. Specifically, in the context of Chicago and surrounding areas where all focus groups took place, Latinxs are 29% of the population and likely to be living in neighborhoods that are segregated (Lee, 2009; US Census Bureau, 2016).

There were some interesting comments mentioned during the focus groups about experiences of discrimination from specifically black drivers (of paratransit and fixed route). Many claims were made that black drivers in particular treat Latinxs poorly. While clearly it is not exclusively black drivers that were reported to discriminate or treat Latinxs poorly, this group was mentioned particularly. Whether or not discrimination against Latinxs occurs more often from a black driver than drivers of other races, the fact that Latinxs feel that discrimination occurs more from black drivers is worthy of a more nuanced exploration. Contextualizing this data from the study are some deep-seated conflicts between Latinxs and blacks in Chicago. Historically, both have experienced discrimination by the white majority, but there is evidence that members of the black community may harbor resentment toward Latinxs who they perceive as holding more social benefits and experiencing less racism than blacks (Alvarez, 1996; Reft, 2010). Many black Chicagoans also report fearing the increase in Latinx immigration to the Chicagoland area (Reft, 2010). On the other hand, there is evidence that, like the white majority, many Latinxs have historically harbored prejudice against blacks (Alvarez, 1996; Reft, 2010), so the race relations between blacks and Latinxs in Chicago certainly contextualize this finding.

Another factor adding to these interpersonal conflicts might be related to the Latinx cultural context, specifically preferences for personalism; some Latinxs might prefer to have a close interpersonal relationship and a clear path of communication with their fixed route driver, which is not encouraged by the dominant culture or the transit system's rigid organization (Zea et al., 1994). Furthermore, the value of professionalism also shapes Latinxs' interpersonal relationships with transit employees and may discourage Latinxs from resisting acts of discrimination from transit employees (Zea, Belgrave, Garcia, & Quezada, 1997; Zea et al., 1994).

Access to emergency assistance was another systemic issue endorsed by significantly more Latinx survey respondents. While this topic was not specifically mentioned by focus group participants, participants did mention safety being a major concern for them when on fixed route generally. Participants cited discrimination and lack of advocacy skills due to language as major factors related to safety, along with the neighborhoods in which Latinxs tend to live. These could be possible factors for the uptick in these concerns for Latinxs, which would correspond with existing literature about the safety of Latinxs in Chicago and throughout the country (Lee, 2009; Lopez et al., 2019). A focus on safety corresponds well with other themes in barriers that participants mentioned and can be tied to similar Latinx cultural values (Cohen, 2013; Zea et al., 1997; Zea et al., 1994). To summarize, there are real safety concerns for Latinxs in Chicago and throughout the country that are related to similar factors that affect their transportation access: SES, language, experiences of discrimination, cultural values, and likely documentation status.

A partner organization mentioned that transportation can affect one's social status. The organization cited that those who can access reliable transportation can keep good jobs, they are more dependable to others, and they can do more with their time compared to people that do not have access to reliable transportation or who encounter many barriers. This relates to existing research on people with disabilities and transportation, which cites more positive social attitudes and high quality social networks as advantages to reliable transportation options (Bascom & Christensen, 2017; Rosenbloom, 2007). Documentation status is also thought to complicate interpersonal issues, as well, as some participants reported feeling that others treated them differently because of their actual or perceived documentation status. This corresponds with literature on Latinxs and documentation status, specifically during the Donald Trump presidency (Lopez et al., 2018).

It is important to note that discrimination and other interpersonal issues were reported across the board on both types of public transportation. This is a pervasive and serious issue for Latinxs with disabilities. Language can also exacerbate interpersonal issues, especially since one cannot advocate well in the current transportation system if they do not speak English.

c. <u>Systemic and organizational barriers</u>

Significantly more Latinx survey respondents reported general issues regarding the public transportation system compared to their non-Latinx counterparts, specifically regarding the reliability and affordability of the fixed route service. Participants in the focus groups echoed these concerns, citing transit timing issues, bus bunching, and late transit vehicles as being problems for them. Participants did not mention any reasons why this might be more of a problem for Latinxs than non-Latinx whites; however, neighborhood and location-related factors could be at play. Participants mentioned that it takes cabs longer to get to their home because of where they live; a similar phenomenon could be occurring with fixed route transportation. Furthermore, as explained in the previous section, drivers in primarily-Latinx areas might be more inexperienced leading to more scheduling issues. Other systemic issues on fixed route could be due to the lack of information that Latinxs receive regarding the service, its schedule, or its operations. As discussed, language barriers might create barriers to accessing current and accurate information about the fixed route system. This has not been identified in the existing literature specifically for transportation-related information, but studies have shown that Latinxs report language barriers that prevent them from accessing information on health care (Barrio et al., 2008; Hayes-Bautista et al., 2012; Povenmire-Kirk, Lindstrom, & Bullis, 2010).

Significantly more Latinxs than non-Latinxs indicated in the survey that the cost of fixed route services was a concern. As shown by Latinxs with disabilities' transit mode preferences, affordability is a major factor for Latinxs with disabilities when choosing a preferred transportation option. This is not a surprise given that people with disabilities often make less money and are less likely to hold gainful employment compared to non-disabled people (Lubin & Deka, 2012). Additionally, Latinxs generally report lower SES than non-Latinx whites (Casas et al., 2004). If a transit option is not affordable, Latinxs with disabilities are relegated to a different form. It appears that fixed route is the most affordable option, followed by paratransit services. These services are clearly fraught with issues and barriers. More convenient options, like cabs, ride share, and driving, may not be affordable to Latinxs with disabilities, or may not be able to be used as often. So, Latinxs with disabilities need to prioritize using them only for certain trips. These economic constraints not only impact convenience, but also safety, because although private options such as cabs and share drive are seen as safer, they are more expensive.

Many of the preferences of Latinxs with disabilities were not reflected in the current transportation system. Latinxs with disabilities seemed to desire and prefer a more personalized and flexible transportation system (which corresponds with their cultural values of personalism and professionalism, as discussed earlier, e.g., Zea et al., 1997; Zea et al., 1994), and those values were not always prioritized in the current public transportation systems.

Significantly more Latinxs with disabilities to reported barriers related to paratransit eligibility and sign-up for the program. Specifically, Latinx survey respondents reported significantly more problems related to the no-show policy, missing the pick-up window and being removed from eligibility. These issues relate to the rigidity of the paratransit system that some participants mentioned during the focus groups. Participants expressed frustration that paratransit rides need to be set up one day ahead of time and if their schedules change, they are at the mercy of the system. Participants also expressed concern about the way they communicate with paratransit drivers and dispatchers. They felt that they need a more personalized form of communication when booking, cancelling, and confirming rides. While not specifically mentioned in this context, language could play a role in missing a paratransit ride. If a Spanishspeaking customer is not able to make their ride, they may not be able to effectively communicate that in the required time frame. Possibly this barrier could be affected by cultural context of Latinxs, who clearly indicated they wanted a personalized communication system rather than the current automated system. Language issues clearly play a role in missed paratransit pick-ups, as Spanish-speaking participants may not be able to effective communicate with the English-speaking driver of their vehicle. Finally, being removed from eligibility was a concern for Latinx survey respondents. This was a topic touched upon in the focus groups as many participants expressed hesitancy about being too critical of the paratransit system for fear that they would be denied service, or worse: deported. Documentation (or lack thereof) of Latinx riders may play a role in these fears. Latinx respondents also reported more issues related to finding information about the paratransit service. This was evident in the focus groups, as entire groups had not ever heard of the service and misinformation about eligibility and rules was rampant. Much of this misinformation is due to language barriers; a lot of the paratransit information is not available in Spanish and clearly not reaching Spanish-speaking potential customers. Studies have not been done on language affecting access to paratransit or other transportation information, but there are studies that confirm that Latinxs experience language barriers when accessing information in other realms, such as health care (Barrio et al., 2008; Hayes-Bautista et al., 2012; Povenmire-Kirk et al., 2010).

How much time it takes the service to arrive and how much time one spends on the paratransit vehicle were two issues that significantly more Latinxs indicated were a barrier for them on the survey compared to non-Latinx whites. Focus groups participants supported this finding and cited some discrimination-related and language factors that contribute to this being more of an issue for Latinxs compared to non-Latinxs. Drivers may not be accurately and effectively communicating pick-up and ride times with Spanish-speaking riders, or they might not be presenting this information in a personal way that may be preferable for Latinxs. Perhaps the non-Latinx drivers may be arriving later or taking longer for Latinx riders as a form of discrimination. Furthermore, the places that Latinxs with disabilities live may be more inaccessible for the paratransit service to get to and navigate in.

Like with fixed route transportation, Latinxs' values were not always reflected in the current paratransit system. Latinxs with disabilities desired and preferred a system that was more personalized and allowed for more monitoring than what the current system offers. Furthermore, the system for making paratransit complaints did not always correspond with what participants said they wanted or needed in order to effectively advocate. Finally, participants feared that their documentation status could affect their ability to get the service that they needed. All of these cultural issues come to play here.

d. Environmental barriers

Significantly more Latinxs than non-Latinxs whites reported barriers to public transportation in both the natural environment and the built environment in the national survey. Specifically, more Latinxs reported issues with the reliability of the fixed route and paratransit service during different kinds of weather and the accessibility and safety of getting to/from fixed route stops. Weather concerns were common during the focus groups, and many participants cited that they would use paratransit instead of fixed route during times of bad weather. Barriers to transportation related to weather are reported in the literature for people with disabilities (Bascom & Christensen, 2017), but these weather-related issues seem particularly salient for Latinxs in Chicago. It seemed that paratransit was actually a facilitator for Latinxs with disabilities in times of bad weather, but clearly bad weather was a general concern to transportation. It is not surprising that Chicagoans might have to endure all types of weather in order to get out in their communities. Latinxs with disabilities in other cities might have differing experiences for Chicagoans, thus resulting in this significant finding for the nationwide data. Furthermore, the survey data indicated that Latinxs with disabilities were more likely than their non-Latinx counterparts to experience barriers related to specifically the *reliability* of the paratransit service in all types of weather. Perhaps the unreliability of the service in general is a bigger issue than its unreliability in specific types of weather for riders in Chicago.

Many participants equated weather issues with safety concerns, claiming that traveling on fixed route and paratransit in bad weather was unsafe. There could be many factors contributing to more Latinxs endorsing this as a problem, including cultural preferences that discourage Latinxs from traveling alone and instead promote community and protection over one another (Cohen, 2013; Zea et al., 1997; Zea et al., 1994). Or perhaps Latinxs who have lived in Latin America are not used to the variable and extreme weather in Chicago and find it more difficult to navigate the natural environment there. A large percentage of Latinxs in Chicago were born in countries with tropical weather (Paral et al., 2014; US Census Bureau, 2016); therefore the Chicago winters could become extremely hard for people to move around and access transportation. The researcher spoke with a partner organization for this study and the organization confirmed that weather can be more of an issue for Latinxs with disabilities compared to their non-Latinx counterparts. They explained that Latinxs tend to be protective of each other and themselves in terms of the weather, so they might be less likely to venture out in times of bad weather, as illustrated in the focus groups. This organization also mentioned that

problems might occur that mix with language issues for Latinxs with disabilities. Latinxs with disabilities, in times of bad weather, must communicate more with transit employees, and if language is a barrier, the weather might keep them from doing an otherwise unproblematic trip.

Safety was an environmental issue introduced by participants across the board. The most common safety-related issue mentioned was weather, as previously discussed, in terms of the natural environment such as weather, but also the built environment and in the different neighborhoods that transit goes into. Safety issues also included crime and fear of gangs. Safety was also discussed in terms of one's ability to navigate independently in the built and natural environments. Focus group participants also mentioned how they preferred paratransit over fixed route because it helped them overcome barriers related to environmental safety. Safety was clearly important to these participants. This should come as no surprise, as according to the literature, the Latinx cultural context emphasizes safety in many ways (Zea et al., 1997; Zea et al., 1994).

While cultural contexts surely shape views of concepts such as safety, one cannot negate the true safety concerns that occur for the Latinx disability community. People with disabilities in general are more likely to be victims of a crime than their non-disabled counterparts (Bureau of Justice, 2017). Similarly, Latinxs are more likely than their white counterparts to be victims of crime (Bureau of Justice, 2017). For Latinxs with disabilities in particular, language issues and fear of documentation problems may discourage them from reporting such crimes. During the focus groups for this study, a focus group participant told the researcher after the focus group ended about an experience she had where she was sexually assaulted on a paratransit vehicle. She said she did not know how to report the incident and the researcher walked her through the process. This is evidence of the compounding barriers that affect the safety of Latinxs with disabilities every day. Experiences like this validate Latinxs' safety concerns and make their fears about safety appear quite justified.

Environmental issues related to getting to and from transit stops was also discussed in the focus groups. This could be more of an issue for Latinxs due to the areas in which Latinxs live not being kept up to ADA standards due to lower SES residents living here. Furthermore, transit mode choice may have an influence here: if Latinxs cannot afford a mode of transportation that avoids environmental barriers (such as driving or taking a cab) these environmental barriers are more salient to them. This complements existing research on community participation for the disability community (e.g., Hammel et al., 2015), but uncovers that these barriers might be magnified for Latinxs with disabilities due to additional factors. A study by Kaplan and colleagues (2001) found that a Latinx neighborhood in Chicago was plagued by environmental accessibility concerns, and such reports of environmental inaccessibility are all too commonplace for the Latinx disability community.

Overall, many of the issues experienced and reported by Latinxs with disabilities on fixed route can be explained, at least partially, by looking at five variables: SES (including income and location); language; documentation status; discrimination; and cultural contexts (including personalism and professionalism).

2. <u>Possible facilitators to public transportation barriers</u>

While barriers were the focus of this study, participants also talked about advantages to fixed route transportation and paratransit, and they mentioned some ways to facilitate their access to public transportation.

Many of the advantages of public transportation that participants identified came by comparison to other forms of transportation: public transportation is cheaper than driving or parking, it is not as tiring as driving, or it allows one to have more self-determination about their schedule. Many participants mentioned enjoying the social aspect of public transportation and being able to enjoy travel on public transportation.

Participants gave suggestions on how to improve paratransit and fixed route access, which will be further explored later in this paper. Participants gave many suggestions on how to make public transportation more linguistically accessible, to improve enforcement of regulations on public transportation, and to make public transportation more flexible and inclusive.

Participants also talked about coming together as one unified Latinx community in order to combat both racism and ableism, and forming a powerful united front to demand accessibility changes in public transportation. They expressed a desire for the acceptance of understanding of disability-related needs within their Latinx community. This acceptance would empower the community to realize the suggested changes that they developed. Perhaps this task can be examined using Block, Balcazar and Keys (2002)'s empowerment framework. Block et al. (2002)'s empowerment framework theorizes that the amount of control that a minority community has over certain aspects of their environments can explain the systematic inequalities that they face. By working together to promote awareness and empowerment as a minority group, the group can create systemic change to challenge inequality. While there are obvious differences between this model and Block et al.'s, the empowerment framework would be a beneficial lens for Latinxs with disabilities to use in order to encourage Latinxs with disabilities to mobilize and come together on transportation-related issues of inequality.

B. How Barriers to Public Transportation Impact Community Participation

Latinxs with disabilities are clearly using public transportation to participate in their communities. Latinxs with disabilities vary in the ways that they participate and the ways that

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they use transportation in order to do so. They also vary in the levels to which they participate, with some Latinxs with disabilities participating quite a bit and others not participating very much.

1. Overview of community participation for Latinxs with disabilities

The focus groups did a good job of capturing the breadth of ways that Latinxs with disabilities use public transportation to participate in their communities. Latinxs with disabilities are using public transportation to get to health care appointments, work or school, social and recreational events, to run errands, and to access social services. Social services was one important category that was mentioned many times by Latinxs with disabilities in the focus groups, but that was not captured by the survey. Social services included community-based organizations (such as the study's partner organizations), church, research participation, disability-related events, the YMCA, and the food pantry. This appears to be a domain of community participation that is particularly important to Latinxs with disabilities and warrants inclusion in future surveys about community participation.

2. <u>Transportation and barriers to community participation</u>

While many Latinxs with disabilities reported that they did not miss out on participating in their communities due to transportation barriers, barriers to community participation for Latinxs with disabilities related to transportation still exist.

a. Language

Language was commonly-mentioned barrier to participants' community participation. Language affects many aspects of transportation and community participation. First, it affects the information that one is able to collect on transportation (and other) options. If information is not available in one's language, they might miss out on an opportunity. This was one difference noted between the Spanish and the English language focus groups; the focus groups done in English had participants that appeared more well-informed of available services and appeared to be more well-connected with different organizations and services in their communities.

Language also affects one's ability to advocate. This has been established in the literature on advocacy for Latinx parents of children with IDD (e.g., Cohen, 2013). Even though many of the Latinxs with disabilities in the study knew that the service they were receiving was subpar, they were not able to effectively complain or advocate in Spanish. Thus, Latinxs are not able to get the same treatment on public transportation and are consequently not able to participate in their communities as fully due to the transportation barriers that ensue.

b. **Discrimination**

Again, the experiences of discrimination described by Latinxs with disabilities were very serious and nearly unbelievable to the white and apparently able-bodied researcher. Experiences of discrimination appear to affect every part of a Latinx with a disability's life. Ableism or discrimination based on one's disability was the most commonly mentioned form of discrimination, but also racism, or discrimination based on apparent race or ethnicity, was very commonly reported. Some Latinxs with disabilities also reported receiving discriminating comments when they spoke Spanish in public. These results correspond with results from a research survey from the Pew Research Center that shows that almost half of Latinxs in the US report being discriminated against for their ethnicity or the language that they speak (Brown & Lopez, 2013). Furthermore, this study illustrates an increase in these sentiments in the past two years, since current US President Donald Trump came into office (Lopez et al., 2018). These results fit well with results found in other research with the Latinx community, not just Latinxs with disabilities.

Ableism and racism often interplayed with each other. For example, a driver might think a Spanish-speaking rider won't be able to call and complain if their ride is late, so they take advantage of that lapse in communication and don't arrive on time. Or a driver might pretend not to hear a rider with an accent request the ramp so they do not deploy it. Many actions that appear to be ableist can be triggered instead by racism. Participants mentioned that these experiences of discrimination add up, and they don't just happen on transportation.

The interaction of racism and ableism can be best understood using Borderlands theory. As described earlier in this paper, Borderlands theory is an interdisciplinary framework conceptualized by Mexican-American author Gloria Anzaldúa which describes the sentiment of owning competing identities (Anzaldúa, 1987). In this case, those competing identities are disability identity and Latinx identity, along with any other identities an individual might hold. These identities are related to each other in multi-directional, individualized, and contextdependent ways. There is no formula that describes how these two identities interact, but rather their relationship is dynamic and additive. Borderlands theory helps describe the dynamic relationship Latinxs with disabilities have with their intersecting identities and how these intersecting identities impact the relationship between the Latinx disability community and barriers to public transportation access. Borderlands theory is similar to intersectionality theory developed by Crenshaw (1989) which shows how dominant structures and institutions uniquely and additively marginalize people with multiple minority identities. Borderlands theory, though, adds onto intersectionality. It is Latinx-centric and focuses more on hybridity and duality of identities rather than multiplicity of marginalization. The two theories can both simultaneously

add perspective to the compounding and co-existing barriers that Latinxs with disabilities face on public transportation or when desiring to participate in their communities.

Another theory that might expand the analysis of the ableism-racism relationship for Latinxs with disabilities is internalized oppression. Internalized oppression is when minority communities fall victim to the discriminatory and stigmatic assumptions made about them by the majority (Pyke, 2010). This may be causing Latinxs with disabilities to assume that their voices will not be heard or taken seriously. Furthermore, many Latinxs can hold ableist ideologies and many disabled people can hold racist ideologies, so when these competing identities come into contact with one another, as described in Borderlands theory, Latinxs with disabilities may have difficulties finding support for their own self-empowerment. This can also lead to something called "advocacy fatigue," a phrase coined by Griffin Basas (2015), where a minority community experiences a strain on resources through their repeated exposure to systemic inequalities and oppression. Latinxs with disabilities, although quite vocally willing to stand up for their rights, often do not resist when faced with repeated adversity. They feel angry and frustrated when they are not able to participate, but instead of working harder to make changes, overcome with hopelessness that their efforts will make a difference, they resist advocating for change.

c. <u>Cultural context</u>

Latinxs mentioned some barriers and preferences that coincide with commonly-cited values found in a Latinx cultural context. First, Latinxs with disabilities tended to prefer more personalized services that involved social interaction and the opportunity for twoway communication. They mentioned preferring services like Uber that allowed you to track and call your driver (though they wished Uber was more affordable!) and they liked social service transportation services that they already had built a trusting relationship with. This is consistent with Latinx values of familism and personalism (Zea et al., 1997; Zea et al., 1994).

Latinxs with disabilities often put a high priority on safety, especially the safety of their family members, and particularly the safety of their family members or children with IDD. This may be a manifestation of paternalism. While not exclusive to the Latinx community, paternalism can particularly affect the transportation choices of this community and cause someone to prefer a safer and more familiar form of transportation.

Finally, there was evidence of Latinxs with disabilities' valuing of professionalism. Many focus group participants appreciated enforcement of rules and top-down monitoring and evaluation of transportation systems. Their suggestions were often tailored to systemic-level solutions to problems, and they expected systemic-level changes based on their suggestions.

Some focus group participants said that Latinxs with disabilities might be less likely to advocate and complain compared to their non-Latinx counterparts due to cultural differences, although this did not correspond with the findings of the focus groups as a whole. The results from this study show that Latinxs are not less likely to advocate, but instead language and discrimination are the barriers keeping their advocacy from being effective. Participants also mentioned that Latinxs who are undocumented might be afraid to voice criticisms of systems and services in the US for fears of having the services taken away or themselves getting deported. This is a more realistic explanation for Latinxs with disabilities not complaining about their services, but it only affects a portion of Latinxs with disabilities in the US. This is consistent with the literature which posits that Latinos with disabilities in general, are less likely to feel a sense of entitlement therefore less likely to advocate for their rights (Suarez-Balcazar et al., 2013).

A desire for independence (and its opposing-counterpart interdependence) plays a role in the relationship between public transportation access and community participation for Latinxs with disabilities, but this relationship is complicated and influenced by conflicting values. The cultural context in the US prioritizes independence and self-determination, including in one's ability to get out in their community by themselves. In this vein, many participants mentioned wanting to be able to do things on their own and make their own autonomous decisions on what they were going to do. But others responded that they would prefer to travel in a group of people that they are comfortable with to places that they are familiar with. Furthermore, parents of children with disabilities grappled with the pros and cons of their child with a disability having more independence in their communities, with the trade-off of independence being safety. These results were in line with results from a study by Angell and Solomon (2018) who showed that Latinx parents of children with autism simultaneously feared for their children's safety and desired to bolster their independence. Much of this conversation is fueled by two cultural values: familism and paternalism. Both of these values encourage keeping one's family members safe and with other trusted family members. These values may clash with the American values of independence, but the disability community in the US instead values *interdependence*, the reliance of community members on each other in order to thrive. This value is particularly important as it may bridge the disability and Latinx communities.

d. Socio-economic status

Closely related to cultural contexts as barriers to community participation is SES. SES can relate to many issues that impact the relationship between public transportation access and community participation for Latinxs with disabilities including the affordability of different transit choices, the areas where Latinxs with disabilities live, the provision of transportation in Latinx-populated areas, and it can impact the community services that Latinxs choose to access in their communities. Latinxs with disabilities clearly use affordability to guide many of their transit choices, and some transit options are precluded due to their cost. This can obviously lead to barriers to community participation if someone is relegated to a more inconvenient form of transportation because of cost.

The areas in which Latinxs tend to live, especially in Chicago, tend to receive fewer public services or services of lower quality (Escarce & Kapur, 2006). Furthermore, Latinxs often report feeling isolated from other non-Latinx communities in their urban area (Lee, 2009). This can impact not only transportation provision in these areas, but also the types of community services that Latinxs with disabilities choose transportation to participate in. Cost and location guide many choices related to community participation.

e. **Documentation status**

Documentation status, or whether or not someone is a legal resident of the US, impacts the Latinx community in many ways. Documentation status may affect if someone is eligible for transportation-related programs. Documentation status may also impact the types of community services and programs that someone is eligible for, thus shrinking the pool of available community services someone is able to access.

Similar to their perception of discrimination, participants reported that they feel that they are often judged by others in their community based on their documentation status. This often makes for an unsatisfactory experience out in their communities and also limits the places that Latinxs with disabilities feel comfortable traveling to.

3. Transportation facilitators to community participation

As previously described when discussing the relationship between Latinxs with disabilities and public transportation barriers, Block et al.'s framework could be a facilitator to solving the social issues that relate to barriers to public transportation and community participation for Latinxs with disabilities by encouraging this community to challenge the status quo that is at the root of their oppression (Block, Balcazar, & Keys, 2001). It appears that if the Latinx and disability communities mobilize together, they can work toward eliminating some barriers to community participation through tacking their shared transportation barriers.

An interesting finding from the quantitative data indicates that Latinxs with disabilities experience significantly more barriers to participating in their communities compared to non-Latinx whites with disabilities when they use fixed route. However, these differences are not significant when both groups use paratransit. It appears that paratransit may be a way to even the playing field and eliminate some community participation disparities for Latinxs with disabilities (although more Latinxs did report experiencing barriers using paratransit, just not *significantly* more).

There are several reasons why this may be the case. Weather-related barriers can be minimized using paratransit. Latinxs with disabilities reported this to be a particular barrier when using both fixed route and paratransit, but focus group participants spoke about the way that paratransit can eliminate weather-related barriers in order to get them where they need to go. Paratransit also caters to cultural preferences of the Latinx community. It is a more personalized and a safer service than fixed route, which better aligns with the Latinx cultural values of personalism and paternalism (Zea et al., 1997; Zea et al., 1994); parents especially were interested in using the service for their children with IDD because they thought it was a safe

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option for them. Furthermore, there are gender differences observed in Latinx immigrants (not necessarily with disabilities). Interestingly, these studies show that Latina women immigrants are more likely to report difficulties with transportation and are less likely to drive than their male counterparts (Matsuo, 2016). If this is the case for Latinxs with disabilities, paratransit may help bridge this gender gap. Finally, paratransit is also more affordable: not compared to fixed route, but compared to the alternative options of driving and taking a cab, which makes it more accessible to Latinxs with disabilities that are on a budget. Latinxs with disabilities are able to use paratransit for rides that would otherwise have to be done by car, but more affordably. With that said, the paratransit service is by no means perfect, especially for Latinxs that experience discrimination based on their language and ethnicity, cannot access information about the service in Spanish, and experience systemic and organizational barriers related to the timing, scheduling, and routing of the service.

Regardless of why, it appears that paratransit is a mode of transportation that must be looked at more closely with Latinxs with disabilities. Paratransit, and services like it, can be a facilitator to community participation for this group. Focus group participants mentioned their satisfaction with services similar to paratransit, which pick up and drop off a person with a disability and help them avoid environmental barriers. These other services, like school bus transportation and private social service transportation, were also well-liked by the Latinx disability community and should also be explored further. It is important to note that there are many private transportation services available to people with disabilities to get to medical appointments, but many require enrollment in Medicaid, which requires documentation and thus may not be available to many Latinxs with disabilities who are not documented. Furthermore, these services can only be used with medical appointments, which is only one piece of community participation for Latinxs with disabilities (Friedman & Rizzolo, 2016). More flexible route transportation services should be made available with the needs of the Latinx disability community in mind.

It seems that Latinxs with IDD themselves report fewer issues with community participation, but it seems like they are actually participating less. Their participation is already narrowed down for them based on if they can get there or not. Furthermore, the places that they go to are only places that accommodate Latinxs with disabilities already, and likely not places that are not as accommodating based on linguistic, cultural, and accessibility-related preferences. Their perspective may be based off of places they can already get to and things they can already do, thus giving them a sense of greater satisfaction.

C. <u>Limitations</u>

1. Limitations with design

This study is a broad, grounded-theory driven analysis of public transportation for Latinxs with disabilities. It was designed to create a working model regarding public transportation for Latinxs with disabilities. The biggest limitation of this data is that its scope is far-reaching instead of specific; the model derived from this study does is not able to capture the nuances that every Latinx with a disability might experience when getting around their community, thus why it is not called a "theory." Furthermore, this study has not been able to describe some of the details as to how Latinxs with disabilities interact with public transportation and their communities. This study and its model are clearly exploratory and invite further research.

Likewise, the design of this study does not allow it to be generalized to all areas. Part I of the study used a national data set whose participants were obtained through snowball sampling.

It is not nationally-representative. Part II of this study was conducted only in Chicago, IL and its surrounding suburbs. Furthermore, Part II also implemented snowball sampling that may lead to a sampling bias of Latinxs who are connected to services and primarily Spanish-speaking. There was also an absence of rural perspectives in this paper, since recruitment was done in urban and suburban areas. Finally, in the PARC transportation survey there was a notable difference in sample sizes between the Latinx sample and not non-Latinx white sample. While this did not appear to affect the validity of the statistical tests, it is also not representative of the US population, where Latinxs represent 17.8% according to the US Census Bureau (2017).

Self-identification was used for the inclusion criteria of both parts I and II. While the researcher hoped that self-identification (instead of putting the burden of proof of an identity on the individual) would increase participation by the desired participant sample, it may have also resulted in non-qualifying individuals participating in the research. In fact, there was suspicion from the researcher and co-facilitator that there were some Latinxs without disabilities who actually self-identified as disabled in order to participate in the focus groups. While the researcher does not condone non-disabled people's voices being used to speak for the disability community, these individuals who may not have had disabilities were accepted by their communities to join them alongside disabled Latinxs in these focus groups. This warrants a reifying way to look at the disability identity from a Latinx lens; perhaps this identity does include family members and caregivers of people with disabilities in line with the Latinx cultural values of familism and community.

Likewise, the Deaf focus group participants at first did not identify as disabled. When told that they would have to be "a person with a disability" in order to participate, they corrected the researcher and co-facilitator saying that they were "Deaf, not disabled." The researcher explained that some Deaf people also identify as disabled in certain situations. They seemed to be confused by this. Another participant explained to them that Deaf people can participate, too, they just need to *claim* to be disabled for the purposes of the research. Neither the researcher nor the co-facilitator debated this, and the Deaf participants agreed to "be disabled" and participate. This warrants further discussion on the inclusion of "Deaf" as an identity separate from disability in inclusion criteria in research with the disability community.

In terms of sampling, the Latinx sample in the quantitative portion of the study was about 8.1% of total participants. This is lower than the US national percentage of 18.1% measured by the US Census in 2016 (US Census Bureau, 2016). Clearly, despite efforts to recruit Latinx participants for the PARC transportation survey, a representative sample of Latinxs was not recruited. A further exploration of demographic information may uncover limitations in generalizability of the results of this part of the study.

Similarly to self-identification, self-report was used to capture the participants' thoughts, opinions, feelings, and experiences. The researcher relied on accurate and full self-report in both Part I and Part II. A limitation of self-report is that a participant's experiences are filtered through their words. Participants may not express their experiences in a way that accurately reflects what happened to them. Participants can also choose not to self-disclose. In which case, the researcher does not know that an experience happened to them.

Similarly, there are pros and cons to using the two types of data collection methods that the researcher chose. Focus groups in particular allow conversation about a topic, but since focus groups are a group discussion, some participants may choose not to disclose certain information or experiences in front of a group. This happened during one focus group and then the participant later approached the researcher alone to talk about a particularly sensitive experience. On the other hand, online surveys allow for anonymity in responses, but do not allow for elaboration and may not offer the breadth of options that might be expressed in a more open-ended environment like a focus group.

This study was not able to capture many demographic variables that affect transportation access, such as immigration status, many components of SES, acculturation, and impairment type. These variables might be important to collect in future research to help develop an inductive theory on public transportation and community participation for Latinxs with disabilities.

The participants in both Part I and Part II of the study were recruited using snowball sampling with the help of different disability-related organizations. This creates a sampling bias toward participants who are already connected with programs and services. The actual picture of transportation for Latinxs with disabilities might look different for those who do not have ties to community organizations.

Finally, there were some limitations with how the author used different theoretical perspectives in the study. The theoretical perspectives highlighted in this paper were the social model of disability, the socio-ecological model, and Borderlands theory. The social model of disability grounded the study's aims and analysis because the barriers identified through the qualitative analyses were environmental, attitudinal, or social instead of relating directly to the individual's impairment or bodily differences (Goodley, 2010). However, the social model did not provide enough of a guide to use specifically with the Latinx disability community; it identified that outside environmental factors are important, but did not identify specifically which ones. The socio-ecological model guided the analyses by encouraging the emergence of the four levels of barriers experienced by Latinxs with disabilities (Bronfenbrenner, 1989);

however, this model did fall short in explaining all the factors involved and the author had to go beyond the socio-ecological to identify Latinx-specific barriers to public transportation and community participation, which arose by the use of thematic analysis guided by grounded theory. Borderlands theory also proved a useful theoretical approach for this particular study, as it was able to bridge many gaps between Latinx-specific experiences and barriers and disability ones (Anzaldúa, 1987). However, the researcher could have gone further with this theory's utility and future research should certainly implement it as a theoretical tool.

2. Limitations with rigor

There were some limitations related to the rigor of the data, or how well the data reflects the actual experiences of the Latinx community. First, data was analyzed in the language in which it was produced. This means that Spanish responses were analyzed in Spanish and English responses were analyzed in English. Not all data was analyzed in the same language, which may lead to differences in the way that themes were created and data was categorized.

Second, the Latinx co-facilitator was not present for three of the ten focus groups. These included two focus groups in English and one in Spanish. However, the co-facilitator read and analyzed the focus group transcripts and was de-briefed regarding the missed focus groups with the researcher.

Third, an inter-rater reliability score was not calculated for thematic analysis of the qualitative data. This was decided due to the study's grounded theory approach, which instead encourages engagement with the data and constant comparison of new thematic trends to existing data. Instead of a reliability score, theme and subtheme categorization was actually changed in order to accommodate the reliability rater's thematic categorizations.

D. Subjectivity and Personal Reflection

Qualitative research methods are ways of doing research that value subjective, personal experiences. In a constructivist approach to qualitative research, like the one employed in Part II of this study, the researcher does not claim to be an unbiased observer. Subjectivity plays a role in qualitative research done from this perspective. All data collected through interviewing, including through focus groups, is subjectively filtered through the respondent and again through the interviewer, so it is important for the researcher to disclose his or her subjectivity and biases. Subjectivity is particularly valued by Disability Studies researchers, many of whom have begun to embrace qualitative research approaches in order to capture more subjective, nuanced experiences, beliefs and concepts related to disability (Barnes, 2010).

The researcher is a white PhD student at UIC, fluent in Spanish. Outside of her studies, she works full-time for the RTA, a public organization that provides financial oversight, funding, and planning for the public transportation services in the Chicagoland area. Her role at the Regional Transportation Authority (RTA) is a mobility outreach coordinator. In this role she provides community outreach on services and programs related to the RTA transportation systems to people with disabilities and older adults, including Latinxs with disabilities and Latinx older adults. She has held this role for over six years. The researcher does not have authority to change public transportation policies, but her experiences in this position have helped her discover the barriers related to public transportation and community participation that people with disabilities and especially people of color with disabilities experience. She has always been eager to share these barriers and possible solutions to alleviating them with her colleagues at RTA.

The researcher has been involved in other research projects with the Latinx community in Chicago. She previously worked for four years as the coordinator of a project on parent education for Latinx parents of children with developmental disabilities in Chicago as well as a project with the autism community in Bogotá, Colombia. While she has many years' experience working with this community, she is not bicultural and she is not a native Spanish speaker.

The researcher identifies as a person with multiple disabilities. She is a person with mental disability, as she lives with anxiety and depression, and additionally she grew up with a facial difference. Her lived experience of disability influences her perspectives on disability research, as does her engagement in a Disability Studies PhD program for which this research study is a dissertation project. While her disability is not always apparent, she also has personal relationships with apparently-disabled friends, family members, and colleagues.

The researcher shares many traits with her participant sample: she speaks English and Spanish and identifies as a person with a disability. She does not, however, share a cultural identity of being Latinx. Because of this, she recruited a Latinx co-facilitator, Latinx reliability coders, and communicates regularly with Latinx members of her partner organizations in order to ensure that her interpretation of data is influenced by voices that are ethnically Latinx since she cannot authentically claim that identity.

The researcher has worked in the transportation field for many years, and she is also a rider of the public transit systems in Chicago and the surrounding suburbs. Her career perspective gives her insight into policy and organizational development in transportation-related fields, but she recognizes that this insight is much different from the user experience of transit. With this said, though her work at the RTA, she has built many relationships with the Latinx disability community with users of the public transportation system in Chicago. In fact, many focus group participants knew the researcher because of her role at RTA. At first, the researcher

was afraid this would make the participants wary of criticizing the system, but instead she was offered a lot of trust that she could make changes because of her professional role.

Overall, the researcher believes that disclosing her multiple identities will help the reader understand the filter through which the study's data has travelled.

VIII. IMPLICATIONS

Overall, this study aspires to contribute to a better understanding of public transportation among Latinxs with disabilities and will help to determine policies and provisions that will help increase community participation among Latinxs with disabilities.

A. Significance

Because transportation for Latinxs with disabilities is a highly under-studied research topic, the goals of this research are general rather than specific. It is the researcher's hope that this work influences additional, more particular research into the topic of interest. The biggest hurdle to research on public transportation for Latinxs with disabilities has been the general dismissal and de-prioritization of public transportation research funding; American society is increasingly car-dominated in their policies, infrastructures, and priorities. Furthermore, Latinxs with disabilities are affected by the de-prioritization of public transportation in the policy arena, and are additionally affected by structures and policies that discriminate against their preferred language and cultural contexts. We already know that Latinxs use public transportation over driving personal vehicles more often than whites do (Tal & Handy, 2010). Because these communal travel choices have been hegemonized by the increasingly privatized choices of the car-dominant, able-bodied, white majority, Latinxs with disabilities are being marginalized through funding cuts to public transportation services. This leads Latinxs (and especially Latinxs with disabilities) to become further isolated, and they continually face lack of access to resources (Angel & Angel, 2015a). In order to address the issues entangled with community participation of Latinxs with disabilities, we need the disability community and the Latinx community to work together to increase access for these intersecting identities. This research does just that.

This research uncovers a need to overhaul the paratransit system. Judging from data from the PARC transportation survey, this overhaul may need to happen in entire nation, but definitely changes should be implemented specifically in the paratransit system in the Chicagoland area. It appears that this system is taking advantage of people with disabilities and offering them a subpar transportation. While these issues are certainly being exacerbated by the lack of public transportation funding, unconventional solutions to the paratransit problem must be explored.

Racism exists for Latinxs at very high rates. It is doubtful that this problem is isolated just on public transportation. Oftentimes this racism is based on aspects other than actual race and instead surname, country of origin, and preferred language. For Latinxs with disabilities in particular, this racism can often look like ableism (e.g., a driver refusing to put down a ramp, a conductor refusing to secure a wheelchair, another passenger ignoring a customer who asks for assistance). But these instances are happening to Latinx people with disabilities more often than their non-Latinx white counterparts. This was perhaps the most striking observation for the white, non-Latinx researcher. Racism is a very real and very stressful experience for Latinxs.

B. <u>Planned Dissemination</u>

This study was performed by the researcher for the purpose of fulfilling the dissertation requirement of her doctoral dissertation. Other scholarly, peer-reviewed works will likely develop from this study. She plans on sharing the results of this study with colleagues at the RTA and other transportation-related organizations in the Chicagoland area. She also desires to write non-academic reports on the topic of transportation and community participation for Latinxs with disabilities to share with disability-related community organizations. Such reports would be disseminated with policy makers, transportation experts and other stakeholders who could affect change. During the focus groups, the author asked participants for suggestions on how these results could be disseminated, both to transportation providers and also within the disability community. Participants appeared to be enthusiastic and eager to give these suggestions. As one focus group participant phrased it, referencing the food and refreshments available at the focus group: "We all have to eat at home. We don't have to come here to eat. We came here because we want to fix the problem."

Participants suggested holding meetings with members of the Latinx disability community to present the data found in this study, in Spanish of course, and allow the community to continue to ask questions and give input for solutions. Many groups suggested this. They appreciated the personal aspects of the focus groups, so it makes sense that something in-person that allows a back-and-forth conversation would be a good fit for the focus group participations.

Participants also suggested using the ties this project already formed with community organizations to help disseminate the information. Many of the participants already have ties with several Latinx and disability organizations whom they trust and with whom they already regularly keep in touch with. It has been illustrated in other studies that in order to serve marginalized groups, such as Latinxs and people with disabilities, researchers must build trusting relationships with their communities, allow them to participate and contribute to the process, and promote their goals and values (Magaña, 2000). Holding a meetings at community sites would be particularly helpful and convenient in order to spread information, especially since the researchers have gained the trust of these organizations through their engagement with them in this project. Some focus group participants suggested that the Latinx disability community transit providers and transit policy decision makers hold a joint meeting, such as a town hall in order to help spread the information in this study and in order to further share their experiences using transit. This face-to-face communication may further influence policy and transportation provision as well.

On the other end of the spectrum is the less-personal, but still effective, use of social media, including Facebook, to disseminate the study results. Many participants mentioned using Facebook or other social media outlets to get information about disability-related interventions and organizations, so posting the results on Facebook in easy-to-follow, simple language, and in Spanish would be helpful. Furthermore, an info sheet could be created and shared it through the Facebook pages of partner community organizations. This would complement many of the participants' preferred modes of information transfer.

Participants also suggested getting political with the results of this study. Contacting politicians is not just a way to change policies, but also a way to spread information. The researchers have considered partnering with disability political organizations such as Americans Disabled Attendant Programs Today (ADAPT) to highlight Latinx-centered issues within the community. Furthermore, they could partner with Latinx-centered organizations such as the National Day Laborer Organizing Network (NDLON) to try to get them to focus on disability-related issues. While Latinx and disability don't often cross the same political paths, this study could bridge the gap between these two overlapping communities. Other participants offered to contact specific aldermen and mayors (of Chicago and the surrounding suburbs) to get out the results of this study. Participants mentioned that they would like to share the results of this study with politicians that represent the Latinx communities in Chicago.

Finally, some participants suggested that the researcher go to the press with the results of this study. The researcher fully intends to publish the results of this study in local news outlets, such as the newsletters of partner organizations. She also hopes to work toward getting recognition of this project from Univision, the local Spanish-language news station.

In summary, the hope for this project is that the Latinx community is involved in the dissemination and use of the data developed from this study. While the researcher hopes to follow their suggestions for dissemination of this data, she will also rely on the Latinx disability community to help put forth an effort to spread this information and keep the body of knowledge in transportation for Latinxs with disabilities growing.

1. **Impact on transportation provision**

Transportation is an important facilitator to community participation for Latinxs with disabilities. It is the author's hope that the findings from this study influence the way that transportation is provided to Latinxs with disabilities. During the focus groups, the author asked participations for suggestions on how to use the results of this study to impact the Latinx disability community. Participants responded with several practical interventions that could be implemented, including suggestions to improve the fixed route and paratransit systems, increasing disability-related and linguistic accessibility, and better equipping the community to use public transportation to participate in their communities

For fixed route provision, the focus groups suggested driver training, creating more accessible transit vehicles, and providing more information about fixed route programs in Spanish. Driver training was a suggestion brought up by many groups. Their specific suggestions varied from disability simulation training for drivers, to cultural competence training, to surprise monitoring of driver behaviors. All of these suggestions could be implemented into already existing training programs for fixed route drivers. Furthermore, since the interpersonal issues on fixed route aren't solely with drivers, but with other passengers, participants suggested also providing disability awareness information to passengers as well. Many fixed route services have newsletters that could focus on disability-related topics in order to meet this objective.

Universal accessibility of transit vehicles was another suggestions brought up by the focus group participants. They varied in what universal accessibility would look like, from having separate cars for different accessibility needs to creating all cars and vehicles to broader accessibility standards, and also incorporating sensory accessibility into fixed route vehicles. Either way, it is clear that the inaccessibility needs to be improved. The groups also mentioned that providing better lines of communication between transit agencies and the Latinx disability community is crucial. Of course, groups suggested proving more info about transit in Spanish. Furthermore, some groups requested a more personalized approach by transit agencies, such as providing a direct line (in English and Spanish) to talk with transit employees in Spanish and ask questions. This would increase the flow of information to the Latinx disability community and might also increase their capacity to advocate and record complaints. Just providing already existing information and services in Spanish would likely go a long way for transit agencies in terms of connecting with this community.

For the provision of paratransit, participants suggested some similar improvements such as driver training, monitoring of the system and, and more options for Spanish-speakers to communicate with paratransit workers and get the info they need in their preferred language. They also made some suggestions to the way that paratransit is provided that would improve the system for Latinxs with disabilities. One suggestion was to make the entire system more flexible. Currently, the paratransit system in Chicago operates on a call-in scheduling system where the individual needs to call in one day in advance to schedule. They are then picked up by a vehicle that may travel to several destinations (which the rider does not know in advance) before they arrive where they need to go. Participants suggested creating a more on-demand paratransit system that might operate like ride share services, where the person can request a vehicle right before they need a ride and be informed of all stops it will take. If they cannot create this system, participants at the very least requested more transparency with the routing systems, because they are clearly not happy with the routes the vehicles currently take and the time it takes them to arrive using the service. Similarly, participants requested a more personal connection to the paratransit drivers and schedulers. They said they would like a way to communicate directly with the driver to see how far away they are, and a way to be informed about any scheduling changes. This could even be done using phone technology. Participants mentioned that these are tools available when taking fixed route (vehicle tracking and set scheduling), so they may be easy to implement on paratransit. Finally, participants suggested that drivers should have the requirement to use the service themselves. Since paratransit is a service exclusively for people with disabilities, drivers may not know what the entire process of eligibility, booking a ride, and using the service entails.

The community could benefit from several suggestions from the focus groups. Several focus groups mentioned informative seminars on public transportation options in Spanish in order to inform the Latinx community about transportation programs for people with disabilities. This would tackle the issue that Latinxs are often not informed of services or misinformed about services that could benefit them due to the information not being available in their language. Similarly, one group suggested advocacy training for people with disabilities in order to better advocate for their rights on public transportation. In the same vein, another group suggested

travel training for people with disabilities to prepare them for travel on fixed route buses and trains.

One group of parents brought up a different suggestion: developing an identification system for people with disabilities to wear while taking transit. This identification system would be worn like a bracelet or a necklace and it would electronically alert transit personnel of the needs of a passenger, such as the accessible seating area, help with directions, or communication barriers. It could also serve as a tracker for parents to track their children. Although the parents sold this as a good advocacy tool, frankly, the researchers were wary of this suggestion because it seems to stem from paternalism and protectiveness that the disability community in the US often rejects. However, after discussing the suggestion with some focus groups of people with disabilities, the Latinxs with disabilities seemed to accept it and agree that it was a good idea. The researchers were surprised by this outlook, but they believe that it fits with the Latinx cultural values of professionalism, paternalism, and familism. This is evidence that Latinx values may often clash with the values of the non-Latinx white-led disability community and suggests that we must make room for non-dominant disability-related perspectives that can capture the nuances of other cultures, including those of the Latinx community.

Another way that this research can practically intervene with transportation provision for Latinxs with disabilities is by serving as a blueprint for cultural competence training for transportation agencies. When implementing practical interventions for Latinxs with disabilities, it is important for providers to work toward cultural competence. This has been shown in a number of studies with Latinxs with disabilities (e.g., Lopez et al., 2012; Magaña, 2000; Parish et al., 2012). Implementing some kind of cultural competence training at a system level might reduce some of the discrimination that Latinxs with disabilities appear to be experiencing.

2. Impact on policy

The findings from this study have the potential to impact transportation policy for people with disabilities and people of color. During the focus groups, the author asked participations for suggestions on how to use the results of this study to impact the Latinx disability community. Participants responded with several ideas on how to impact transportation and disability policy. Many of the suggestions participants gave to improve transportation provision for Latinxs with disabilities could be tackled at the policy level, such as mandatory driver training and system monitoring.

One helpful suggestion from multiple focus groups focused on the monitoring of ADA compliance for drivers of fixed route and paratransit at regular intervals. A participant in one of the focus group offered specific ideas for implementing an incentive-based reward system for drivers (of fixed route and paratransit) in order to positively impact their attitude and performance, and another participant suggested paying drivers better salaries in general to incentivize better attitudes. While driver actions are individual, they could be influenced on a broader systemic level by these incentives. If there was a stronger focus on compliance and creating monitoring and compliance programs formally, many of the issues related to drivers could be solved more effectively.

In order to tackle many of the language-related barriers that Latinxs experience, mandatory translation of fixed route and paratransit information into Spanish and other common languages could be mandated by policy. Hiring a certain percentage of bilingual staff could also be mandated.

Another option that should be explored and was touched upon in several of the focus groups is partnering with social service organizations for Latinxs with disabilities in order to provide transportation services to and from their programs. The focus group of young Latinx adults with IDD were very enthusiastic about the "pink bus" that took them to and from the organization that the focus groups were conducted at. Furthermore, parents talked about the importance of having organization-specific transportation options for their kids with disabilities. However, groups of Latinxs with disabilities brought up the freedom, flexibility, and independence that using the regular fixed route transportation brings them, and organizationspecific transportation does not allow the same freedom or flexibility since it only goes to places where the organization hosts activities. So while increasing funding for the provision of organization-specific transportation is important, it should not overshadow opportunities to improve public transportation.

Finally, many of the identified issues with the public transportation system could be ameliorated by increasing the available funding for these services. As mentioned in this paper's literature review, the cost of providing public transportation increased 32% to 53% between 2004 and 2009 and funding for public transportation only increased by 27% in the same time period (Lubin & Deka, 2012). Also as previously mentioned, because of the high reliance of people with disabilities and ethnic minorities on public transportation, these funding cuts are affecting Latinxs with disabilities at a disproportional rate. Policymakers should consider the high price these cuts have on this population and consider broader economic solutions that value the Latinx disability community and their reliance on public transportation.

The theoretical framework of this paper intentionally encourages use of the social model of disability and other theories garnered from this study in more practical and political arenas, such as re-shaping the interpretation of the ADA. The goals of the ADA center on social inclusion: equality of opportunity, full participation, independent living, and economic selfsufficiency. While the ADA stems from a disability studies-centric philosophical orientation (the social model of disability), compared to academic fields like disability studies, the ADA's theories are quite pragmatic and cater more toward policymakers rather than taking a philosophical approach. The social model and other theoretical blueprints that come out of this research study show great potential in influencing future policy related to transportation and community access for Latinxs with disabilities. Future research may explore the potential role of other theories such as internalized oppression and borderlands theory (Anzaldúa, 1987; Pyke, 2010).

The author of this study is in an effective position to influence public transportation policy as an employee of the RTA in Chicago. She hopes not only to produce academic work, but also collaborate with disability and Latinx community activist organizations to determine the best way for the results of this study to reach both community members and grassroots organizations in order to influence both disability and transportation policy. The researcher made her role at the RTA clear to participants during the focus groups. Some participants even knew the researcher from her role as a mobility outreach coordinator where she provided them information session on public transportation in Spanish. It was clear in many of the groups that with this role comes the power and responsibility to influence transportation policy.

While the participants felt their power to create change was limited, they believed sharing their experiences with an employee of the transit organization would make a bigger difference tan what they could create on their own.

C. <u>Future Research Goals</u>

Clearly, more research is needed on the topic of transportation and community participation with Latinx community. This study focused on public transportation because of its particular importance to the disability and Latinx communities, but future research should not silo itself here; instead future research should examine how other forms of transportation interact with public transportation options for Latinxs with disabilities, because Latinxs with disabilities clearly use other forms of transportation as well.

Future research on transportation for Latinxs with disabilities should consider transportation contexts in other US cities. Each city is a microcosm of transportation options and interactions, and one cannot generalize the results of this study or other studies done in only one location. There are many nuances to consider when transferring research from one geographical location to another and researchers should take care to identify the differences that must be noted to transfer this research somewhere else.

Future research might consider collecting more and different demographic and identity variables from Latinxs with disabilities. Some variables to consider are: impairment type; immigration status; acculturation in the US; and factors related to SES like income and household size. These variables would allow for a more distinct discussion on how identity and demographics play into transportation access.

Finally, the Latinx cultural context played a big role in this research and clearly affects transportation access and community participation for Latinxs with disabilities in many varied ways. Latinx cultural values should be further parsed out, along with the roles they play specifically for Latinxs with disabilities and how they can be added to the larger study of disability in the US.

D. Concluding Thoughts

While there are clearly many barriers experienced by Latinxs with disabilities on public transportation, interventions and changes that are made in that system must also go beyond just

transportation. Latinxs with disabilities have many intersecting needs related to transportation and community participation: health care, education, employment, social services, social events, etc. Any changes made to the public transportation system should reach beyond and influence these different realms of the lives of Latinxs with disabilities.

The best suggestion on how to make a difference in public transportation and community participation for Latinxs with disabilities came from a participant with a disability in one of the focus groups. He said, "The point is not what we want; the point is how far do you have access or are talking to someone to start to develop a solution. Because you told us, 'What do you want or how far do we want?' The point is: how far can *you* go? How far can *you* go to help us?" As a researcher, especially one who is white, educated, and appears able-bodied, I have the responsibility to create transformative change with this research. With the blessing of the community, I send this dissertation as the beginning of a long journey to fight for better public transportation and more inclusive community participation for Latinxs with disabilities.

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APPENDICES

APPENDIX A

PARC Transportation Survey – English

Q1 Transportation Access and Experiences Survey A Program of the ADA Participation Action Research Consortium (ADA-PARC)

Q2 Consent Form for Human Participants in Research University of Northern Colorado Project Title: Transportation Access and Experiences Researchers: Jill Bezyak, Ph.D., CRC, Human Rehabilitative Services Phone Number: 970-351-1585 jill.bezyak@unco.edu You are being asked to participate in a research study investigating the accessibility of public transportation for people with disabilities. This study is being conducted through collaboration with the ADA Participation Action Research Consortium (ADA PARC) and ADA National Network. The purpose is to improve understanding of the accessibility of public transportation and use this information to make improvements as needed at regional and national levels. The study will examine the experience of public transportation from the perspective of people with disabilities across the nation. Completion of the 50 question online survey will take approximately 10-15 minutes of your time. Almost all of the questions are multiple choice format with some questions asking you to provide basic demographic information. All information obtained from this survey will be used to improve understanding and access to public transportation for people with disabilities.

Q3 All data from this project will be protected with state-of-the-art technology, and confidentiality will be protected by de-identifying all the data collected. Data will also be stored on a computer with password protection known only to the researchers. Only group data will be included in reports of the results, and individuals will not be identified. No risks are anticipated with your participation in this project, and no direct benefits to you are likely to result. Although, it is hopeful that the information will lead to improved accessibility of public transportation for people with disabilities. Participation is voluntary. You may decide not to participate in this study, and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above and having had an opportunity to ask any questions, please complete the survey below if you would like to participate in this research. By completing the survey, it will be assumed that you have consented to participate in this study. Please print a copy of this form for future reference. If you have any concerns about your selection or treatment as a research participant, please contact the Sponsored Programs and Academic Research Center, Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1907. Sincerely, Jill Bezyak, Ph.D., CRC Associate Professor University of Northern Colorado

Q4 Transportation Access and Experiences Survey A Program of the ADA Participation Action Research Consortium (ADA-PARC) We appreciate your willingness to participate in this survey. We are excited to learn more about public transportation for people with disabilities. Please answer the questions that follow based only on your personal experiences as a person with a disability.

Q5	Section 1: Transportation	This section is about how you get around.

Q6 1a. What is the main way you usually get from one place to another? Please select one option.

- 1. Fixed route public bus (Fixed route means public transit services where buses or other vehicles run on regular, pre-determined, pre-scheduled routes, with no variation.) (1)
- ADA public paratransit services (ADA Public Paratransit services are a requirement of all public entities operating a fixed route system. ADA Public Paratransit services are typically a shared ride, curb-tocurb service that must be scheduled in advance.) (2)
- 3. Public transit agency subsidized taxi services (3)
- 4. Other community-based transit services (for example, social or human service agency or volunteer services from a local organization such as a religious organization or other community organization) (4)
- 5. Ride with others (5)
- 6. Rideshare (e.g. Uber or Lyft) (6)
- 7. Taxi or hired driver (7)
- 8. Personal vehicle (my own car) (8)
- 9. Commuter rail/light rail (12)
- 10. Bicycle (9)
- 11. Walk or roll (10)
- 12. Other (please describe): (11)

Q7 1b. In the past 12 months, how often has the availability of transportation to get where you need to in your community been a problem for you?

13. Never (1)
 14. Rarely (2)
 15. Sometimes (3)
 16. Usually (4)
 17. Always (5)

Q8 Section 2: Public Transportation This section is about public transportation. Public transportation includes shared passenger transport service which is available for use by the general public (for example, city buses that run on fixed routes) and ADA public paratransit services that provide door-to-door or curb-to-curb service.

Q9 2a. Do you feel like you have the same access to public transportation as others in your community?

Q10 Please explain your answer:

Q11 2b. How would you rate your overall understanding of your rights and responsibilities in regard to access to public transportation under the Americans with Disabilities Act?

- 20. No understanding (1)
- 21. Limited understanding (2)
- 22. Some understanding (3)
- 23. Fairly good understanding (4)
- 24. Very good understanding (5)

Q12 2ca. In the past 12 months, have you used public transportation?

- 25. Yes (1)
- 26. No (2)

Display This Question:

If In the past 12 months, have you used public transportation? Yes Is Selected:

Q13 2cb. Are you currently using disability discount programs for public transportation?

27. Yes (1) 28. No (2)

Q15 2d. Is there anything preventing you from using public transportation, or from using public transportation as much as you would like?

29. Yes (1) 30. No (2)

Display This Question If Yes Is Selected:

Q16 You indicated that something is preventing you from using public transportation, or from using public transportation as much as you would like. Please explain your answer:

Q17 Section 3: Public Transportation in Your Community This section is about your use of public transportation in your community.

Q18 3a. In your community, what types of public transportation do you use? Please select all that apply.

- □ Fixed route public buses (Fixed route means public transit services where buses or other vehicles run on regular, pre-determined, pre-scheduled routes, with no variation.) (1)
- □ Subway (4)
- □ Commuter rail/light rail (5)
- □ ADA public paratransit services (ADA Public Paratransit services are a requirement of all public entities operating a fixed route system. ADA Public Paratransit services are typically a shared ride, curb-to-curb service that must be scheduled in advance.) (2)
- □ Other (please describe): (3) _____

Q19 3b. In the past 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular, pre-determined, pre-scheduled routes, with no variation.

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular Yes Is Selected:

Q20 3c. In the past 12 months in your community, how often has each of the following been a problem for you?

	Never (1)	Rarely (2)	Sometimes (3)	Usually (4)	Always (5)
How much the services cost (Q23_1)					
How often the service runs (Q23_2)					
Where the service runs (Q23_3)					
How reliable the service is (Q23_4)					
How much time it takes to get where I want to go (Q23_5)					
How many transfers I need to take (Q23_6)					
How close the stop is to my home (Q23_7)					
The time of day or day of the week I am traveling (Q23_8)					

	Never (1)	Rarely (2)	Sometimes (3)	Usually (4)	Always (5)
Access to a different form of transportation if my usual way of traveling is not available (Q20_1)					
The availability of fixed route public transportation for getting to school or work (Q20_2)					
The availability of fixed route public transportation for healthcare appointments and other health needs (Q20_3)					
The availability of fixed route public transportation for running errands (Q20_4)					
The availability of fixed route public transportation for spending time with other people, socializing or doing things in my community for fun (Q20_5)					
The availability of fixed route public transportation for getting to places I volunteer (Q20_6)					
The availability of fixed route public transportation spontaneously without advanced planning (Q20_7)					

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular Yes Is Selected:

Q21 3d. In the past 12 months in your community, how often has the availability of fixed route public transportation when you need it been a problem for you?

33. Never (1)
34. Rarely (2)
35. Sometimes (3)
36. Usually (4)
37. Always (5)

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular, p Yes Is Selected:

Q22 3e. In the past 12 months in your community, how would you rate your experience with fixed route public transportation?

38. Poor (1)
39. Fair (2)
40. Good (3)
41. Very good (4)
42. Excellent (5)

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular Yes Is Selected:

Q23 3fa. In the past 12 months in your community, how often has each of the following been a problem for you in using fixed route public transportation?

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular, Yes Is Selected:

Q24 3fb. In the past 12 months in your community, how often has each of the following been a problem for you in using fixed route public transportation?

	Never (1)	Rarely (2)	Sometimes (3)	Usually (4)	Always (5)
How easily I can find information on public transportation options and how to use the service (Q24_1) How I am treated by drivers (Q24_2)					
How I am treated by other riders (Q24_3)					
How safe I feel using the service (Q24_4)					
How I am able to use the service during different kinds of weather (Q24_5)					
How reliable the service is during different kinds of weather (Q24_6)					

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular Yes Is Selected:

Q25 3ga. In the past 12 months in your community, how often has each of the following been a problem for you in using fixed route public transportation?

	Never (1)	Rarely (2)	Sometimes (3)	Usually (4)	Always (5)
The accessibility of the stops for people with disabilities (Q25_1)					
The accessibility of the lifts or ramps for people with disabilities (Q25_2)					
The reliability of the lifts or ramps (Q25_3)					
The announcements of stops and routes (Q25_4)					
How mobility aids (such as wheelchairs, scooters and walkers) are accommodated for people with disabilities (Q25_5)					
Drivers allowing service animals (Q25_6)					

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular, Yes Is Selected:

Q26 3gb. In the past 12 months in your community, how often has each of the following been a problem for you in using fixed route public transportation?

	Never (1)	Rarely (2)	Sometimes (3)	Usually (4)	Always (5)
Drivers understanding their responsibilities to people with disabilities (Q26_1)					
Drivers passing stops without picking up passengers with disabilities (Q26_2)					
The accessibility of easy to use information on how to use the service or to plan a route (in person at the station or online) for people with disabilities (Q26_3)					
The accessibility for people with disabilities and safety of getting to/from stops to your house (Q26_4)					
Access to help or emergency assistance while using service if needed (Q26_5)					

Q27 Section 4: ADA Public Paratransit This section is about ADA public paratransit services. ADA Public Paratransit services are a requirement of all public entities operating a fixed route system. ADA Public Paratransit services are typically a shared ride, curb-to-curb service that must be scheduled in advance.

Q28 4a. Are ADA public paratransit services available in your community?

128. Yes (1)
129. No (2)
130. I don't know (3)
131.

If No Is Selected, Then Skip To End of Block

If I don't know Is Selected, Then Skip To End of Block

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	Never (1)	Rarely (2)	Sometimes (3)	Usually (4)	Always (5)
The availability of ADA public paratransit services for getting to school or work (Q29_1)					
The availability of ADA public paratransit services for healthcare appointments and other health needs (Q29_2)					
The availability of ADA public paratransit services for running errands (Q29_3)					
The availability of ADA public paratransit services for spending time with other people, socializing or doing things in my community for fun (Q29_4)					
The availability of ADA public paratransit services for getting to places I volunteer (Q29_5)					

Q29 4b.	In the past 12 months,	how often has each of the following been a problem for you?
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Q30 4c. In the past 12 months, how often has the availability of ADA public paratransit services when you need it been a problem for you?

157. Never (1)
 158. Rarely (2)
 159. Sometimes (3)
 160. Usually (4)
 161. Always (5)

Display This Question: If 2bc. In the past 12 months, have you used public transportation in Wake County, North Carolina? Yes Is Not Selected

Q31 4d. In the past 12 months in your community, have you used ADA public paratransit services?

162. Yes (1) 163. No (2)

If No Is Selected, Then Skip To End of Block

Display This Question If 4d. In the last 12 months in your community, have you used ADA public paratransit services? Yes Is Selected

Q32 4e. In the past 12 months in your community, how would you rate your experience with ADA public paratransit?

Poor (1)
 Fair (2)
 Good (3)
 Very good (4)
 Excellent (5)

Display This Question: If 4d. In the last 12 months in your community, have you used ADA public paratransit services? Yes Is Selected

Q33 4fa. In the past 12 months in your community, how often has each of the following been a problem for you in using ADA public paratransit services?

	Never (1)	Rarely (2)	Sometimes (3)	Usually (4)	Always (5)
How much the services cost (Q33_1)					
The time of day or day of the week I am traveling (Q33_2)					
Where the service runs (Q33_3)					
The availability of door-to-door service (Q33_4)					
The availability of curb-to-curb service (Q33_5)					
How reliable the service is (Q33_6)					
How flexible the service is (Q33_7)					
How much time it takes for the service to arrive (Q33_8)					
How much time it takes to get where I want to go (Q33_9)					
How easily I can find information on options and how to use the service (Q33_10)					

Display This Question: If 4d. In the last 12 months in your community, have you used ADA public paratransit services? Yes Is Selected

Q34 4fb. In the past 12 months in your community, how often has each of the following been a problem for you in using ADA public paratransit services?

	Never (1)	Rarely (2)	Sometimes (3)	Usually (4)	Always (5)
How I am treated by drivers (Q34_1)					
How I am treated by other riders (Q34_2)					
How safe I feel using the service (Q34_3)					
How I am able to use the service during different kinds of weather (Q34_4)					
How reliable the service is during different kinds of weather (Q34_5)					
The no-show policy (Q34_6)					
Making reservations (Q34_7)					
Missing the pickup window (Q34_8)					
Being removed from eligibility (Q34_9)					

Display This Question If 4d. In the last 12 months in Wake County, have you used ADA public paratransit services?... Yes Is Selected

Or 4d. In the last 12 months in your community, have you used ADA public paratransit services? Yes Is Selected:

Q35 4g. Do you use ADA public paratransit services for all your transportation needs?

264. Yes (1) 265. No (2)

If No Is Selected, Then Skip To End of Block

Q36 Why do you not use fixed-route service for some of your travel? Fixed route means public transit services where buses or other vehicles run on regular, pre-determined, pre-scheduled routes, with no variation.

Q37 Would you like to use a fixed-route service for some of your travel? Fixed route means public transit services where buses or other vehicles run on regular, pre-determined, pre-scheduled routes, with no variation.

Q38 Section 5: Demographic Information

Q39 5a. What is your gender?

268. Male (1)269. Female (2)270. Other (3)

Q40 5b. What year were you born in?

240

APPENDIX A (continued)

Q41 5c. What is your race?

- □ American Indian or Alaska Native (1)
- \Box Asian (2)
- □ Black or African American (3)
- □ Native Hawaiian or Other Pacific Islander (4)
- \Box White (5)
- □ Other (please write in): (6) _____
- \Box Do not wish to say (7)

Q42 5d. Are you Hispanic, Latino/a, or Spanish Origin?

- 271. Yes (1)272. No (2)
- 273. Do not wish to say (3)

Q43 5e. What is the highest level of education you have completed?

- 274. Less than high school (1)
- 275. High school diploma or GED (2)
- 276. Some college or Associate's degree (3)
- 277. Bachelor's degree (4)
- 278. Graduate or professional degree (5)
- 279. Other (please specify): (6) _____
- Q44 5f. What is your employment status?
 - 280. Unemployed/Not looking for work (1)
 - 281. Unemployed/Looking for work (2)
 - 282. Part time employed (3)
 - 283. Full time employed (4)
 - 284. Self-employed (5)
 - 285. Student (6)
 - 286. Homemaker (7)
 - 287. Retired (8)

Q45 5g. Do you have a disability?

Display This Question:

If 5g. Do you have a disability? Yes Is Selected

Q46 5h. Do you have any of the following disabilities or long-lasting health conditions? Please select as many as needed.

- □ Mobility or other physical disability (1)
- □ Blindness or other vision loss (2)
- Deaf or other hearing loss (3)
- □ Speech or communication difficulties (4)
- □ Autism Spectrum Disorder (6)
- Cognitive disability (e.g. brain injury or learning disability) (7)
- □ Intellectual disability (This used to be called MR or mental retardation.) (8)
- Psychiatric disability/mental health conditions (e.g. depression, anxiety, schizophrenia, etc.)
 (9)
- □ Ongoing chronic health condition (e.g. diabetes, obesity, arthritis, etc.) (10)
- □ Other (Please describe.) (11) _____
- $\Box \quad \text{Do not wish to say (5)}$

Q47 5i. Are you deaf or do you have serious difficulty hearing?

290.	Yes (1)
291.	No (2)

Q48 5j. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

292. Yes (1)293. No (2)

Q49 5k. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

294. Yes (1)295. No (2)

Q50 51. Do you have serious difficulty walking or climbing stairs?

296. Yes (1)297. No (2)

Q51 5m. Do you use any of the following mobility aids?

298.	Cane, crutch, or walker (1)
299.	Manual wheelchair (2)
300.	Power wheelchair (3)
301.	None (4)

Q52 5n. Do you have difficulty dressing or bathing?

302. Yes (1)303. No (2)

Q53 50. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

304. Yes (1)305. No (2)

Q54 5p. In what city do you live?

Q55 5q. In what state do you live?

Q56 5r. What is your zip code?

Q57 5s. What is the nearest intersection to where you live? Providing the two streets that cross nearest to where you live allows us to know how close people live to fixed-route transportation stops.

Q58 5t. What is your annual household income?

306.	Less than \$12,400 (1)
307.	Between \$12,400 - \$24,000 (2)
308.	Between \$24,001 - \$40,000 (3)
309.	Between \$40,001 - \$74,000 (4)
310.	Between \$74,001 - \$100,000 (5)
311.	More than \$100,000 (6)
312.	Do not wish to say (7)

Q59 5u. Do you receive money from Social Security (SSI or SSDI)?

- 313. Yes (1)
- 314. No (2)

Q85 How did you learn about this survey?

- 315. ADA Center (1)
- 316. Center for Independent Living (2)
- 317. Facebook (5)
- 318. Twitter (6)
- 319. Listserv of a specific organization (Please provide the name of the organization.) (3) _____
- 320. Newsletter of a specific organization (Please provide the name of the organization.) (4) _____
- 321. Other (Please provide.) (7)

APPENDIX B

PARC Transportation Survey - Spanish

Q1 Encuesta sobre el Acceso y la Experiencia de Transporte

Un Programa del Consorcio de la Investigación sobre la Acción para la Participación de la ADA (ADA-PARC)

Q4 Encuesta sobre el Acceso y la Experiencia de Transporte

Un Programa del Consorcio de la Investigación sobre la Acción para la Participación de la ADA (ADA-PARC)

Agradecemos su voluntad de participar en esta encuesta. Estamos muy contentos de aprender más sobre el transporte público para personas con discapacidad. Por favor, responda las siguientes preguntas basándose solo en sus experiencias personales como persona con discapacidad.

Q5 Sección 1: Transporte Esta sección trata sobre la forma en que usted se traslada.

Q6 1a. ¿Cuál es el principal medio de transporte que utiliza habitualmente para trasladarse de un lugar a otro?

Por favor, seleccione una de las siguientes opciones.

- 322. Autobús público de ruta fija (Ruta Fija se refiere a un servicio de transporte público donde los autobuses u otros vehículos circulan en rutas regulares, predeterminadas y previstas, sin variaciones).
- 323. Servicios de paratránsito público de la ADA (los servicios de Paratránsito Público de la ADA son un requerimiento para todas las entidades públicas que operan un sistema de ruta fija. Los servicios de Paratránsito Público de la ADA normalmente son un servicio de traslado de puerta a puerta compartido que debe ser programado de forma anticipada).
- 324. Servicios de taxi subsidiados por la agencia de transporte público.
- 325. Otros servicios de transporte comunitario (por ejemplo, agencia de servicio social o humanos servicios voluntarios de una organización

local como una organización religiosa u otra organización comunitaria).

- 326. Trasladarse con otros.
- 327. Desplazamiento compartido (por ejemplo, servicio Uber o Lyft)
- 328. Taxi o conductor contratado
- 329. Vehículo personal (mi propio vehículo)
- 330. Tren de cercanías/metro ligero
- 331. Bicicleta
- 332. Caminar o ir en silla de ruedas
- 333. Otro (por favor, especifique:)

Q7 1b. En los últimos 12 meses, ¿con qué frecuencia la disponibilidad de transporte para trasladarse a donde usted necesite ha representado un problema para usted?

- 334. Nunca
- 335. Rara vez
- 336. Aveces
- 337. Generalmente
- 338. Siempre

Q8

Sección 2: Transporte Público

Esta sección trata sobre el transporte público.

El Transporte Público incluye el servicio de transporte compartido de pasajeros, el cual está disponible para ser utilizado por el público en general (por ejemplo, autobuses urbanos que circulan en rutas fijas) y los servicios de paratránsito público de la ADA que ofrece servicios puerta a puerta.

Q9 2a. ¿Siente usted que tiene el mismo acceso al transporte público que otras personas en su comunidad?

339. Sí340. No

Q10 Por favor, explique su respuesta:

Q11 2b. ¿Cómo clasificaría usted la comprensión general de sus derechos y responsabilidades en relación con el transporte público bajo la Ley para Estadounidenses con Discapacidades?

- 341. Total falta de comprensión
- 342. Comprensión limitada
- 343. Cierto grado de comprensión
- 344. Comprensión aceptable
- 345. Muy buena comprensión

Q12 2ca. En los últimos 12 meses, ¿ha utilizado algún medio de transporte público?

346. Sí347. No

Display This Question:

If In the past 12 months, have you used public transportation? Yes Is Selected:

Q13 2cb. ¿Actualmente utiliza programas de descuento por discapacidad para el transporte público?

348. Sí349. No

Q15 2d. ¿Existe algo que le impida usar el transporte público, o usar el transporte público con la frecuencia que usted desearía?

350. Sí351. No

Display This Question If Yes Is Selected:

Q16 Usted indicó que algo le impide usar el transporte público, o usar el transporte público con la frecuencia que usted desearía.

Por favor, explique su respuesta:

Q17 Sección 3: El Transporte Público en Su Comunidad

Esta sección trata del uso que usted hace del transporte público en su comunidad.

Q18 3a. En su comunidad, ¿qué tipos de transporte público utiliza?

Por favor, seleccione todas las opciones que apliquen.

- Autobús público de ruta fija (*Ruta Fija* se refiere a un servicio de transporte público en donde los autobuses u otros vehículos circulan en rutas regulares, predeterminadas y previstas, sin variaciones.)
- Metro
- Tren de cercanías/metro ligero
- Servicios de paratránsito público de la ADA (los servicios *de Paratránsito Público de la ADA* son un requerimiento para todas las entidades públicas que operan un sistema de ruta fija. Los servicios de Paratránsito Público de la ADA normalmente son un servicio de traslado de puerta a puerta compartido que debe ser programado de forma anticipada).
- Otro (Por favor, especifique):

Q19 3b. En los últimos 12 meses, ¿ha utilizado el transporte público de ruta fija en su comunidad?

Ruta Fija se refiere a un servicio de transporte público donde los autobuses u otros vehículos circulan en rutas regulares, predeterminadas y previstas, sin variaciones.

352. Sí353. No

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular Yes Is Selected:

Q20 3c. En los últimos 12 meses, ¿con qué frecuencia cada una de las siguientes opciones

ha representado un problema para usted en su comunidad?

	Nunca	Rara vez	Aveces	Generalmente	Siempre
Acceso a diferentes medios de transporte si no está disponible la forma de desplazamiento habitual					
La disponibilidad del transporte público de ruta fija para ir a la escuela o al trabajo					
La disponibilidad del transporte público de ruta fija para ir a la escuela o al trabajo					
La disponibilidad del transporte público de ruta fija para realizar sus diligencias					
La disponibilidad del transporte público para pasar tiempo con otras personas, socializar o hacer cosas en mi comunidad por diversión					
La disponibilidad del transporte público para ir a lugares en donde hago actividades como voluntario					
La disponibilidad de tomar el transporte público espontáneamente, sin planear en avanzado					

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular Yes Is Selected:

Q21 3d. En los últimos 12 meses, ¿con qué frecuencia la disponibilidad de transporte público de ruta fija ha representado un problema para usted cada vez que lo necesita en su comunidad?

- 389. Nunca
- 390. Rara vez
- 391. Aveces
- 392. Generalmente
- 393. Siempre

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular, p Yes Is Selected:

Q22 3e. En los últimos 12 meses, ¿cómo clasificaría su experiencia con el transporte público de ruta fija en su comunidad?

394. Deficiente395. Aceptable396. Buena397. Muy buena398. Excelente

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular Yes Is Selected:

Q23 3fa. En los últimos 12 meses, ¿con qué frecuencia cada una de las siguientes opciones ha representado un problema para usted en su comunidad?

	Nunca	Rara vez	Aveces	Generalmente	Siempre
Los costos del servicio					
La frecuencia con que funciona el servicio					
La dirección hacia donde funciona el servicio					
La confiabilidad del servicio					
El tiempo que toma llegar a donde quiero ir					
La cantidad de transferencias que de hacer					
La distancia de la parada a mi casa					
La hora del día o el día de la semana en que me traslado					

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular, Yes Is Selected:

Q24 3fb. En los últimos 12 meses, ¿con qué frecuencia cada una de las siguientes opciones ha representado un problema para usted en su comunidad?

	Nunca	Rara vez	Aveces	Generalmente	Siempre
La facilidad con que puedo recibir información sobre las opciones de transporte público y la forma de usar el servicio					
La forma en que me tratan los conductores					
La forma en que me tratan otros pasajeros					
La seguridad que siento al usar el servicio					
La forma en que soy capaz de utilizar el servicio bajo diferentes tipos de clima					
La confiabilidad del servicio bajo diferentes tipos de clima					

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular Yes Is Selected:

Q25 3ga. En los últimos 12 meses, ¿con qué frecuencia cada una de las siguientes opciones ha representado un problema para usted en su comunidad?

	Nunca	Rara vez	Aveces	Generalmente	Siempre
La accesibilidad de las paradas para personas con discapacidad					
La accesibilidad de los elevadores o las rampas para personas con discapacidad					
La confiabilidad de los elevadores o las rampas					
Los avisos de parada y rutas					
La forma en que la ayuda de movilidad (como sillas de ruedas, motonetas y andadoras) es incorporada para personas con discapacidad					
Los conductores que permiten el uso de animales de servicio					

Display This Question If 3b. In the last 12 months in your community, have you used fixed route public transportation? Fixed route means public transit services where buses or other vehicles run on regular, Yes Is Selected:

Q26 3gb. En los últimos 12 meses, ¿con qué frecuencia cada una de las siguientes opciones ha representado un problema para usted en su comunidad?

	Nunca	Rara vez	Aveces	Generalmente	Siempre
Los conductores comprenden sus responsabilidades respecto a las personas con discapacidad					
Los conductores pasan por alto las paradas sin recoger a los pasajeros con discapacidad					
La accesibilidad a la información de fácil manejo sobre la manera de utilizar el servicio o planificar una ruta (personalmente en la estación o en línea) para personas con discapacidad					
La accesibilidad para personas con discapacidad y la seguridad de ir desde la parada a su casa y viceversa					
Acceso para la ayuda o asistencia de emergencia mientras utiliza el servicio, si fuese necesario					

Q27 Sección 4: Paratránsito Público de la ADA

Esta sección trata sobre los servicios de paratránsito público de la ADA.

Los servicios de paratránsito público de la ADA son un requerimiento para todas las entidades públicas que operan un sistema de ruta fija. Los servicios de Paratránsito Público de la ADA normalmente son un servicio de traslado de puerta a puerta compartido que debe ser programado de forma anticipada.

Q28 4a. ¿Se encuentran los servicios de paratránsito público de la ADA disponibles en su comunidad?

499. Sí500. No501. No lo sé502.

If No Is Selected, Then Skip To End of Block

If I don't know Is Selected, Then Skip To End of Block

Q29 4b En los últimos 12 meses, ¿con qué frecuencia cada una de las siguientes opciones ha

representado un problema para usted en su comunidad?

	Nunca	Rara vez	Aveces	Generalmente	Siempre
La disponibilidad los servicios de paratránsito público para ir a la escuela o al trabajo					
La disponibilidad los servicios de paratránsito público para ir a la escuela o al trabajo					
La disponibilidad los servicios de paratránsito público para realizar sus diligencias					
La disponibilidad los servicios de paratránsito público para pasar tiempo con otras personas, socializar o hacer cosas en mi comunidad por diversión					
La disponibilidad los servicios de paratránsito público para ir a lugares en donde hago actividades como voluntario					
La disponibilidad de los servicios de paratránsito público espontáneamente, sin planear en avanzado					

Q30 4c. En los últimos 12 meses, ¿con qué frecuencia la disponibilidad del servicio de paratránsito público de la ADA ha representado un problema para usted cada vez que lo necesita?

503. Nunca504. Rara vez505. Aveces506. Generalmente507. Siempre

Display This Question: If 2bc. In the past 12 months, have you used public transportation in Wake County, North Carolina? Yes Is Not Selected

Q31 4d. En los últimos 12 meses, ¿ha utilizado los servicios de paratránsito público de la ADA en su comunidad?

508. Sí

509. No

If No Is Selected, Then Skip To End of Block

Display This Question If 4d. In the last 12 months in your community, have you used ADA public paratransit services? Yes Is Selected

Q32 4e. En los últimos 12 meses, ¿cómo clasificaría su experiencia con el servicio de paratránsito público de la ADA?

- 510. Deficiente
- 511. Aceptable
- 512. Buena
- 513. Muy buena
- 514. Excelente

Display This Question: If 4d. In the last 12 months in your community, have you used ADA public paratransit services? Yes Is Selected

Q33 4fa. En los últimos 12 meses, ¿con qué frecuencia cada una de las siguientes opciones ha representado un problema para usted en su comunidad respecto al uso de servicios de paratránsito público de la ADA?

	Nunca	Rara vez	Aveces	Generalmente	Siempre
Los costos del servicio					
La frecuencia con que funciona el servicio					
La dirección hacia donde funciona el servicio					
La confiabilidad del servicio					
El tiempo que toma llegar a donde quiero ir					
La cantidad de transferencias que de hacer					
La distancia de la parada a mi casa					
La hora del día o el día de la semana en que me traslado					

Display This Question: If 4d. In the last 12 months in your community, have you used ADA public paratransit services? Yes Is Selected

Q34 4fb. En los últimos 12 meses, ¿con qué frecuencia cada una de las siguientes opciones ha representado un problema para usted en su comunidad respecto al uso de servicios de paratránsito público de la ADA?

	Nunca	Rara vez	Aveces	Generalmente	Siempre
La forma en que me tratan los conductores					
La forma en que me tratan otros pasajeros					
La seguridad que siento al usar el servicio					
La forma en que soy capaz de utilizar el servicio bajo diferentes tipos de clima					
La política de ausencia					
Realización de reservaciones					
Omisión de la ventana de recogida					
Descarte de la elegibilidad					

Display This Question If 4d. In the last 12 months in Wake County, have you used ADA public paratransit services?... Yes Is Selected

Or 4d. In the last 12 months in your community, have you used ADA public paratransit services? Yes Is Selected:

Q35 4g. ¿Utiliza usted los servicios de paratránsito público de la ADA para todas sus necesidades de transporte?

595. Sí

596. No

If No Is Selected, Then Skip To End of Block

Q36 ¿Por qué no utiliza usted el servicio de ruta fija para algunos de sus traslados?

Ruta Fija se refiere a un servicio de transporte público en donde los autobuses u otros vehículos circulan en rutas regulares, predeterminadas y previstas, sin variaciones.

Q37 ¿Quisiera utilizar el servicio de ruta fija para algunos de sus traslados?

Ruta Fija se refiere a un servicio de transporte público en donde los autobuses u otros vehículos circulan en rutas regulares, predeterminadas y previstas, sin variaciones.

597. Sí

598. No

Q38 Sección 5: Información Demográfica

Q39 5a. ¿Cuál es su género?

- 599. Masculino
- 600. Feminino
- 601. Otro

Q40 5b. ¿En qué año nació?

Q41 5c. ¿Cuál es su raza?

- Indígena Estadounidense o Nativo de Alaska
- Asiático
- Negro o Afroamericano
- □ Nativo de Hawái u otra Isla del Pacífico
- Blanco
- □ Otro (por favor, especifique:)
- □ No deseo mencionarlo

Q42 5d. ¿Es usted de origen hispánico, latino o español?

- 602. Sí603. No604. No deseo mencionarlo
- Q43 5e. ¿Cuál es el grado de educación más alto que ha completado?
 - 605. Inferior a la escuela secundaria
 - 606. Con diploma de escuela secundaria o título equivalente
 - 607. Algún título universitario o técnico universitario
 - 608. Título de licenciado
 - 609. Título de grado o título profesional
 - 610. Otro (por favor, especifique:)

Q44 5f. ¿Cuál es su estado laboral?

Unemployed/Not looking for work (1)

- 611. Desempleado/No estoy en busca de trabajo
- 612. Desempleado/Estoy en busca de trabajo
- 613. Empleado a tiempo parcial
- 614. Empleado a tiempo completo
- 615. Empleado independiente
- 616. Estudiante
- 617. Ama de casa
- 618. Jubilado

Q45 5g. ¿Tiene usted alguna discapacidad?

619. Sí

620. No

Display This Question:

If 5g. Do you have a disability? Yes Is Selected

Q46 5h. ¿Tiene usted alguna de las siguientes discapacidades o condiciones de salud?

Por favor, seleccione todas las opciones que apliquen.

- Discapacidad física
- □ Ciego
- □ Sordo
- Dificultades con la lengua o la comunicación
- □ Transtorno del Espectro Autista
- Discapacidad cognitiva
- Discapacidad intelectual/del desarrollo
- Discapacidad siquiátrica
- Condición crónica
- □ Otro (por favor, especifique:)_____
- □ No deseo mencionarlo

Q47 5i. ¿Es usted sordo o presenta serias dificultades para oír?

621. Sí622. No

Q48 5j. ¿Es usted ciego o presenta serias dificultades para ver, incluso cuando usa lentes?

623. Sí624. No

Q49 5k. Debido a una condición física, mental o emocional, ¿tiene usted serias dificultades para concentrarse, recordar o tomar decisiones?

625. Sí626. No

Q50 51. ¿Tiene dificultades serias para caminar o subir escaleras? 627. Sí 628. No 629. Q52 5n. ¿Tiene dificultades para vestirse o bañarse? 630. Sí 631. No

Q53 50. Debido a una condición física, mental o emocional, ¿tiene usted dificultades para hacer diligencias por sí solo, tales como ir al consultorio del doctor o ir de compras?

632. Sí633. No

Q54 5p. ¿En qué ciudad vive?

Q55 5q. ¿En qué estado vive?

Q56 5r. ¿Cuál es su código postal?

Q57 5s. ¿Cuál es la intersección más cercana al sitio donde vive? Al indicar las dos calles más cercanas al sitio donde vive, nos permitirá saber qué tan cerca vive la gente de las paradas de transporte de ruta fija.

Q58 5t. ¿Cuál es su ingreso familiar anual?

- 634. Menos de \$ 12.400
 635. Entre \$12.400 \$24.000
 636. Entre \$24.001 \$40.000
 637. Entre \$40.001 \$74.000
 638. Entre \$74.001 \$100.000
- 639. Más de \$ 100.000
- 640. No deseo mencionarlo
- Q59 5u. ¿Recibe usted dinero por parte del Seguridad Social (SSI o SSDI)?
 - 641. Sí
 - 642. No

APPENDIX C

PARC Transportation Survey Recruitment Announcement - English

Hello!

My name is Joy Hammel, and I am working with the ADA Participation Action Research Consortium (ADA-PARC) to conduct a survey of accessibility to public transportation for people with disabilities. The ADA-PARC is a collaborative research project of seven Americans with Disabilities Act (ADA) Regional Centers (PIs: Lex Frieden and Joy Hammel). This project focuses on community living, community participation & work/economic participation disparities of people with disabilities (For more information, visit the website: <u>www.adaparc.org</u>). We would like to improve our understanding on transportation access of people with disabilities and use this information to make improvements at regional and national levels.

As a result of your strong connections with disability communities across the nation, we would like the assistance of the ADA National Network in distributing this survey. If each of the regional centers could send a personalized invitation to complete the survey to their listservs, affiliates, etc., we are likely to achieve a high response rate and capture personal experiences related to public transportation from across the nation.

Please use the invitation letter below to share the survey throughout your region. You are welcome to personalize the invitation as you would like, which will likely encourage greater participation. Please send out the invitation as soon as possible. We are excited to begin this project.

-----Invitation Letter -----

Hello and thank you for taking the time to read this email!

We would like to invite you to participate in a national survey titled, Transportation Access and Experiences, which is designed to improve understanding of accessibility of public transportation for people with disabilities. This survey is being conducted by the ADA Participation Action Research Consortium (ADA-PARC), a collaborative research project of seven Americans with Disabilities Act (ADA) Regional Centers (PIs: Lex Frieden and Joy Hammel). This project focuses on community living, community participation & work/economic participation disparities of people with disabilities (For more information, visit the website: www.adaparc.org). We would like to improve our understanding on transportation access of people with disabilities and use this information to make improvements at regional and national levels.

We are very interested in receiving as many responses as possible from people with disabilities based on their personal experiences with public transportation. Please feel free to share the survey with potentially interested entities. The results will serve as crucial evidence to support improvements to accessible transportation. Please use the link below to access and complete the

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APPENDIX C (continued)

survey. If you have any questions or comments regarding this survey, please contact Joy Hammel at hammel@uic.edu.

(Insert survey link here: _____)

Also please be informed that we are happy to assist you to take the survey over phone, if internet access is an issue for you or you prefer to complete it verbally. You can call the research team at 312-996-9655 if you would like to take the survey over phone. If you would like to complete the survey by phone in Spanish, please contact Ancel Montenelli at 312-413-1439. Please mention that you are calling about the ADA transportation survey.

Sincerely, Joy Hammel, PhD, OTR/L

APPENDIX D

PARC Transportation Survey Recruitment Announcement - Spanish

Saludos!

Mi nombre es Joy Hammel y estoy trabajando con el Consorcio de la Investigación sobre la Acción para la Participación de la ADA (siglas en inglés ADA-PARC) para realizar un estudio de la accesibilidad al transporte público para personas con discapacidad. La ADA-PARC es un proyecto colaborativo de investigación que colabora con siete Centros Regionales de la Ley para americanos con Discapacidades (siglas en inglés ADA) (Investigadores Principales: Lex Frieden y Joy Hammel). Este proyecto el cual se enfocan en la vida en la comunidad, la participación comunitaria, el trabajo / desigualdades de participación económica de las personas con discapacidad (Para obtener más información, visite el sitio web: www.adaparc.org). Nos gustaría mejorar nuestro entendimiento sobre el acceso al transporte de personas con discapacidad y utilizar esta información para hacer mejoras a nivel regional y nacional.

Como resultado de sus fuertes conexiones con las comunidades de discapacidad en todo el país, nos gustaría disponer de la asistencia de la Red Nacional de la ADA en la distribución de esta encuesta. Si cada uno de los centros regionales pudiese enviar una invitación personalizada para completar la encuesta a sus listas de contactos, afiliados, etc., es probable que podamos lograr un alto porcentaje de respuesta y de igual manera obtener experiencias personales relacionadas con el transporte público en todo el país.

Por favor utilice la carta de invitación abajo para compartir la encuesta a través de su región. Se le motiva a que usted personalice la invitación como usted considere más conveniente, lo que probablemente contribuya a fomentar una mayor participación. Por favor enviar la invitación tan pronto como sea posible. Estamos muy entusiasmados de iniciar este proyecto.

-----Invitation Letter -----

Saludos y Gracias por tomarse el tiempo de leer este correo electrónico.

Nos gustaría invitarle a participar en una encuesta nacional titulada, Acceso y Experiencia de Transporte, el cual está diseñada para mejorar la comprensión de la accesibilidad del transporte público para personas con discapacidad. Esta encuesta está siendo realizada por el Consorcio de la Investigación sobre la Acción para la Participación de la ADA (siglas en inglés ADA-PARC), un proyecto colaborativo de investigación que colabora con siete Centros Regionales de la Ley para americanos con Discapacidades (ADA) (Investigadores Principales: Lex Frieden y Joy Hammel). Este proyecto el cual se enfocan en la vida en la comunidad, la participación comunitaria, el trabajo / desigualdades de participación económica de las personas con discapacidad (Para obtener más información, visite el sitio web: www.adaparc.org). Nos gustaría mejorar nuestro entendimiento sobre el acceso al transporte de personas con discapacidad y utilizar esta información para hacer mejoras a nivel regional y nacional.

Estamos muy interesados en recibir tantas respuestas como sea posible de las personas con discapacidad en base a sus experiencias personales con el transporte público. Siéntase en libertad

de compartir la encuesta con entidades potencialmente interesadas. Los resultados servirán como evidencia clave para mejoras al transporte accesible. Utilice el siguiente enlace para acceder y completar la encuesta. Si usted tiene alguna pregunta o comentario acerca de esta encuesta, por favor, póngase en contacto con Joy Hammel a su correo electrónico hammel@uic.edu.

(Agregue el enlace de la encuesta aquí: _____)

También deseamos informarle que estamos en la disposición de ayudarle a participar en la encuesta vía teléfono si así lo prefiere, especialmente si el acceso a Internet es un problema para usted o usted prefiere completar la encuesta verbalmente. Puede llamar a nuestro equipo de investigación al 312-996-9655 si desea realizar la encuesta por teléfono. Si desea completar la encuesta por teléfono en español, por favor póngase en contacto con el Sr. Ancel Montenelli al 312-413-1439. Y Por favor, haga mención que usted está llamando acerca de la encuesta de transporte ADA.

APPENDIX E

Focus Group Recruitment Announcement - English

Are you a Latino/a with a disability? Are you a Latino/a parent of a child with a disability? Are you familiar with the public transportation services in your area? We want to hear from you!

What is the research study about?

The research study is about public transportation and community participation for Latinos with disabilities. We want to know how you get around your communities, what kinds of issues you face when using public transportation, and how public transportation affects how you connect with other people and services. This study is being conducted through the University of Illinois at Chicago (UIC) (protocol # 2018-0169).

Who is eligible for the study?

- People who are 18 years of age or over
- People who self-identify as a person who is Latina/o, Hispanic, or Chicana/o.
- People who self-identify as a person with a disability or a chronic health

condition OR be the parent of a child with a disability or a chronic health condition - People who are familiar with public transportation options (fixed route or

Paratransit) in their area

What will participants have to do?

Participants will participate in a group discussion called a focus group. You will talk with 4-6 other participants about your experiences with public transportation. Focus groups will be conducted in Spanish and English. Focus groups will last about two hours long and will take place in a public location near Chicago and the surrounding suburbs. Refreshments will be provided during the focus groups. Accommodations will be provided upon request. The focus groups will be audio-recorded.

What do I get for participating?

Participants will receive \$25.00 for their participation in the focus group.

Contact the primary investigator Kristen Salkas, MS for more



information:



Institute for Research on Race and Public Policy

Research that Makes a Difference

U.S. Department of Transportation

Federal Highway Administration

Email: ksalka2@uic.edu

Phone: 708-870-4787

APPENDIX F

Focus Group Recruitment Announcement - Spanish

¿Es usted un/a latino/a con una discapacidad? ¿Es usted un padre latino de un hijo/a con una discapacidad? ¿Está familiarizado/a con los servicios del transporte público en su área? ¡Queremos escuchar de usted!

¿De qué trata el estudio de investigación?

El estudio de investigación trata sobre el transporte público y el acceso a la comunidad para los latinos con discapacidades. Queremos averiguar cómo se desplazan dentro de su comunidad, que problemas se encuentran cuando usan el transporte público y como el transporte público les afecta en la manera de conectar con otras personas y servicios. Este estudio se está llevando a cabo a través de la Universidad de Illinois en Chicago (UIC) (protocolo # 2018-0169).

¿Quién es elegible para el estudio?

- Personas que tienen 18 años de edad o más

- Personas que se identifica como latino/a, hispano/a, chicano/a y/o son de un país latinoamericano

- Personas que se identifican como personas con una discapacidad o una enfermedad crónica O son padres/madres de un niño con una discapacidad o una enfermedad crónica

- Personas que están familiarizadas con el transporte público (ruta fija o puerta-apuerta) en su comunidad

¿Qué tendrán que hacer los participantes?

Los participantes serán parte de un discurso grupal llamado grupo de enfoque. Los participantes hablarán con otras 3 a 6 personas participantes sobre sus experiencias usando el transporte público. Los grupos de enfoque se realizan en inglés y español. Los grupos de enfoque durarán aproximadamente 2 horas y tendrán lugar en locales públicos cerca de Chicago, IL. Se proveerán alimentos durante los grupos. Se proveerán acomodaciones si son solicitados por anticipado. Se grabará el audio de este grupo de enfoque.

¿Qué recibirá por mi participación?

Los participantes recibirán \$25.00 por su participación en el grupo de enfoque.



Institute for Research on Race and Public Policy Research that Makes a Difference Comuníquese con la investigadora, Kristen Salkas, MS para más información: U.S. Department of Transportation Federal Highway

Administration

Teléfono: 708-870-4787 Correo electrónico: ksalka2@uic.edu

APPENDIX G

PARC Transportation Survey Informed Consent - English

Consent Form for Human Participants in Research

University of Northern Colorado

Project Title: Transportation Access and Experiences

Researchers: Jill Bezyak, Ph.D., CRC, Human Rehabilitative Services

Phone Number: 970-351-1585

jill.bezyak@unco.edu

You are being asked to participate in a research study investigating the accessibility of public transportation for people with disabilities. This study is being conducted through collaboration with the ADA Participation Action Research Consortium (ADA PARC) and ADA National Network. The purpose is to improve understanding of the accessibility of public transportation and use this information to make improvements as needed at regional and national levels. The study will examine the experience of public transportation from the perspective of people with disabilities across the nation.

Completion of the 50 question online survey will take approximately 10-15 minutes of your time. Almost all of the questions are multiple choice format with some questions asking you to provide basic demographic information. All information obtained from this survey will be used to improve understanding and access to public transportation for people with disabilities.

All data from this project will be protected with state-of-the-art technology, and confidentiality will be protected by de-identifying all the data collected. Data will also be stored on a computer with password protection known only to the researchers. Only group data will be included in reports of the results, and individuals will not be identified.

No risks are anticipated with your participation in this project, and no direct benefits to you are likely to result. Although, it is hopeful that the information will lead to improved accessibility of public transportation for people with disabilities.

Participation is voluntary. You may decide not to participate in this study, and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled.

Having read the above and having had an opportunity to ask any questions, please complete the survey below if you would like to participate in this research.

By completing the survey, it will be assumed that you have consented to participate in this study. Please print a copy of this form for future reference. If you have any concerns about your selection or treatment as a research participant, please contact the Sponsored Programs and Academic Research Center, Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1907.

Sincerely,

Jill Bezyak, Ph.D., CRC

Associate Professor

University of Northern Colorado

APPENDIX H

PARC Transportation Survey Informed Consent – Spanish Formulario de Consentimiento para los Participantes Humanos en la Investigación Universidad del Norte de Colorado

Título del Proyecto: Acceso y Experiencia de Transporte Investigadores: Jill Bezyak, Ph.D., CRC, Servicio de Rehabilitación Humana Número de teléfono: 970-351-1585 jill.bezyak@unco.edu

Se le ha solicitado participar en un estudio de investigación que analiza la accesibilidad al transporte público para personas con discapacidad. Este estudio se realiza en colaboración con el Consorcio de la Investigación sobre la Acción para la Participación de la ADA (ADA PARC) y la Red Nacional de la ADA. El objetivo de esta encuesta es aumentar el conocimiento sobre la accesibilidad al transporte público y usar dicha información para hacer mejoras a nivel regional y nacional, según se requiera. El estudio analizará la experiencia del transporte público desde la perspectiva de las personas con discapacidad en toda la nación

Responder las 50 preguntas de la encuesta solo requerirá de 10 a 15 minutos de su tiempo. Casi todas las preguntas son de selección múltiple. Algunas preguntas requerirán que proporcione información demográfica. Toda la información obtenida a través de esta encuesta será utilizada para mejorar el conocimiento y el acceso al transporte público para personas con discapacidad.

APPENDIX H (continued)

Todos los datos de este proyecto estarán protegidos con tecnología de vanguardia. También, se mantendrá la confidencialidad a través de la desidentificación de toda la información recolectada. Los datos serán almacenados en una computadora protegida por contraseña, la cual estará únicamente bajo el dominio de los investigadores. Solo los grupos de datos serán incluidos en informes de resultados, y los individuos no serán identificados:

No se anticipa ningún riesgo que derive de su participación en este proyecto, y no recibirá ningún beneficio a cambio de dicha participación. Aunque, se espera que la información propicie una mejora en la accesibilidad del transporte público para personas con discapacidad.

La participación es voluntaria. Usted puede decidir participar en este estudio y, una vez iniciada su participación, puede decidir suspenderla y retirarse en cualquier momento. Su decisión será respetada y no causará la pérdida de algún beneficio del cual usted disfruta.

Habiendo leído lo expuesto anteriormente, y habiendo tenido la oportunidad de realizar cualquier pregunta; por favor, proceda a completar la siguiente encuesta si desea participar en esta investigación.

Al completar esta encuesta, se asumirá que usted ha dado su consentimiento para participar en este estudio. Por favor, imprima una copia de este formulario para futuras referencias. Si tiene alguna duda sobre su selección o el tratamiento como participante de la investigación; por favor, contacte a los Programas Auspiciados y al Centro de Investigación Académica, Kepner Hall, Universidad del Norte de Colorado Greeley, CO 80639; 970-351-1907. Atentamente,

Jill Bezyak, Ph.D., Profesor Asociado CRC

APPENDIX H (continued)

Universidad del Norte de Colorado

APPENDIX I

Phone Screener – English

		Participant ID:
Name:		
Address:		
Email:		
Preferred language:		
Parent? Yes	No	
Info left in message:		

Focus Group scheduled for:

APPENDIX I (continued)

Hello, my name is ______ and I'm a researcher with the study titled "Public Transit Access and Community Participation for Latinos with Disabilities" at the University of Illinois at Chicago. You responded to our ad indicating that you are interested in participating in a focus group about transportation. I wanted to give you a little more information about the focus group, to check to see if you are eligible to participate, and to answer any questions you might have. Do you have five minutes to talk about the focus group?

If no, best time to call back: _____

If yes, Great! This focus group is part of a research study being done by graduate student Kristen Salkas through the University of Illinois at Chicago. Participants will take part in a group discussion called a focus group. In the focus group participants will talk with 3-6 other participants about their experiences on public transportation. The other participants are, like you, *Latinos with disabilities/Latino parents of children with* disabilities, including buses, trains, and ADA Paratransit.

First, we want to make sure you fit the eligibility requirements:

1. Are you over the age of 18? YES NO

2. Do you identify as a person with a disability or a chronic health condition? YES NO

- OR Are you a parent of a child with a disability? YES NO
- 3. Do you identify as Latino/a (Hispanic/Chicana/o, Mestiza/o)? YES NO
- 4. Do you have familiarity with public transportation? YES NO

If no to any, **I'm sorry, you don't meet the requirements for this study. We will contact you if we have another opportunity available to you in the future.**

If yes to all, Great, you meet all the requirements! Let me tell you more about the study.

During this focus group we will be discussing different topics related to the ways that you as a *Latino/a with a disability/Latino parent of a child with a disability* get around on public transportation and the ways that you use transportation to participate in your community. We will also be discussing the results of a study that was done on public transportation for people with disabilities to gain insight into why Latinos with disabilities responded in certain ways.

APPENDIX I (continued)

The focus groups will last about 2 hours and will take place in different public places around Chicago. Refreshments will be provided. You will receive \$25.00 for your participation.

The focus groups will be audio-recorded. We will ask that you sign a consent form indicating that you understand the procedures of the focus group and the privacy expectations.

Do you have any questions about the focus group? (Answer questions as best as you can)

We will be hosting _____ focus groups in your area: (List locations and times). Which of these will work out best for you?

1 st choice:	
2 nd choice:	:
3 rd choice:	

Will you need any accommodations in order to participate in the focus group?

- ASL interpretation or CART services?
- Braille, large print, or electronic copies?
- Personal Attendant or Parent? (you may bring one along, but they may not participate)
- Chemical-free environment?
- Other?

What is a good way to remind you about the focus group? We will send a reminder one week before and one day before the scheduled focus group with the time and location.

Text message Phone call Email

Latino families come from many different places. What would you say is your family's country of origin?

Anything else you'd like us to consider in order to make your participation easier?

APPENDIX I (continued)

Thank you for your interest in the focus group. I look forward to seeing you for the discussion on (date/time).

APPENDIX J

sh

			Participant II
Name:			
Phone number:			
Email:			
Location:			
Preferred language:		Spanish	
Parent? Yes	No		
Info left in message:			

Focus Group scheduled for: _____

APPENDIX J (continued)

Hola, mi nombre es ______ y soy investigador(a) para el estudio llamado "Acceso al transporte público y la participación comunitaria para latinos con discapacidades" en la Universidad de Illinois en Chicago. Usted respondió a nuestro anuncio indicando que está interesado en participar en un grupo de enfoque sobre el transporte. Quería darle un poco más de información sobre el grupo de enfoque, verificar su elegibilidad para participar, y responder a cualquier pregunta que pueda tener. ¿Tiene cinco minutos para hablar sobre el grupo de enfoque?

Si no, mejor momento para devolver la llamada:

If yes, ;Muy bien! Estos grupos de enfoques son parte de un estudio de investigación conducido por estudiante graduada Kristen Salkas parte en la Universidad de Illinois en Chicago. Los participantes participarán en una discusión grupal llamada grupo de enfoque. En un grupo de enfoque, los participantes hablarán con otras 3 a 6 personas participantes sobre sus experiencias usando el transporte público. Los otros participantes son, como usted, *latino/as con discapacidades/padres de niños con discapacidades*.

Primero, queremos asegurarnos de que usted cumpla con los requisitos de elegibilidad:

1. ¿Tiene 18 años o más? SI NO

2. ¿Se identifica como una persona con una discapacidad o una condición de salud crónica? SI NO

- O ¿es padre de un niño con una discapacidad? SI NO
- 3. ¿Se identifica como latino/a (hispano/a, chicana/o, mestiza/o)? SI NO
- 4. ¿Está familiarizado/a con el transporte público? SI NO

If no to any, **Lo siento, pero no cumple con los requisitos para este estudio. Nos comunicaremos con usted si tenemos otra oportunidad disponible para usted en el futuro.**

If yes to all, **¡Bueno, usted cumple con todos los requisitos! Déjame contarle más sobre el estudio.**

Durante este grupo de enfoque, discutiremos diferentes temas relacionados con las maneras en las ustedes como *los latinos con discapacidades / padres latinos con niños con discapacidades* se desplazan usando transporte público y las formas en que usan el transporte para participar en sus comunidades. También discutiremos los resultados de una encuesta sobre el transporte público para personas con discapacidades para obtener una idea de por qué los latinos con discapacidades respondieron de cierta manera.

APPENDIX J (continued)

Los grupos de enfoque durarán aproximadamente 2 horas y tendrán lugar en diferentes locales públicos cerca de Chicago, IL. Se proveerán alimentos durante los grupos. Recibirá \$25.00 por su participación.

Se grabará el audio de este grupo de enfoque. Le pediremos que firme un documento de consentimiento que indique que comprende los procedimientos del grupo de enfoque y las expectativas de privacidad.

¿Tiene alguna pregunta sobre el grupo de enfoque? (Answer questions as best as you can)

Organizaremos _____ grupos de enfoque en su área: (List locations and times). ¿Cuál de estos funcionará mejor para usted?

1st choice: _____ 2nd choice: 3rd choice: _____

¿Necesitará alguna acomodación para participar en el grupo de enfoque?

- ¿Interpretación de lenguaje de señas o servicios de CART?

- ¿Braille, letra grande, o copias electrónicas?

- ¿Asistente personal o padre? (Puede llevar uno, pero no pueden participar)
- ¿Ambiente libre de químicos?
- -;Otra?_

¿Cuál es una buena manera de recordarle sobre el grupo de enfoque? Le enviaremos un recordatorio una semana antes y un día antes del grupo de enfoque programado con la hora y la ubicación de la cita.

Mensaje de texto Llamada telefónica Email

Las familias latinas provienen de muchos lugares diferentes. ¿Cuál dirías que es el país de origen de tu familia?

¿Algo más que le gustaría que consideremos para facilitar su participación?

APPENDIX J (continued)

Gracias por su interés en el grupo de enfoque. Espero verle para el grupo de enfoque en (fecha / hora).

APPENDIX K

Focus Group Informed Consent - English

The University of Illinois at Chicago Research Information and Consent/Permission for Participation in a Focus Group Public Transit Access and Community Participation for Latinos with Disabilities

You are being asked to participate in a focus group as part of a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Kristen Salkas, MS		
Department and Institution:	University of Illinois at Chicago (UIC)	
	Department of Disability and Human Development	
Address and Contact Information:	1640 Roosevelt Rd., Chicago IL 60608	
Phone: 708-870-4787		

Why am I being asked?

You are being asked to be a subject in a research study that will explore barriers to public transportation access and how these barriers may affect community participation for Latinos with disabilities.

Your participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future dealings with UIC. If you decide to participate, you are free to withdraw at any time without affecting your relationship with the University of Illinois at Chicago (UIC) or any other community organization associated with this research.

Approximately 70 participants may be involved in this research.

What is the purpose of this research?

This research study will explore public transportation access and community participation for Latinos with disabilities. We have found interesting findings from a previous study on public transportation and community access for people with disabilities nationwide. We would like suggestions from the Latino disability community about how these findings may affect community participation for this group. This study is being done through the University of Illinois at Chicago (UIC) (protocol #: 2018-0169). This study is being funded through the US Department of Transportation's Dwight D. Eisenhower Transportation Fellowship Program (grant #: 693JJ31845019) and the Institute for Research on Race and Public Policy at UIC.

APPENDIX K (continued)

What procedures are involved?

Participants will participate in a group discussion called a focus group. Participants will talk with 4-6 other participants about their experiences using public transportation. Focus groups will be conducted in both English and Spanish. The focus groups last approximately two hours and will take place in publicly-accessible locations near Chicago, IL and the surrounding suburbs. Refreshments and snacks will be provided during focus groups. The focus group will be audio-recorded.

What are the potential risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. The focus group may include discussion of sensitive issues such as your experience as a person with a disability or your experience as a Latino. You do not have to discuss anything that makes you feel uncomfortable.

Another risk of this research is a loss of privacy (revealing to others that you are taking part in this study) or confidentiality (revealing information about you to others to whom you have not given permission to see this information). All study staff are trained in the importance of confidentiality to protect you from this risk. Furthermore, we will discuss with all focus group participants the importance of upholding privacy and confidentiality before, during, and after the focus group discussions.

Are there benefits to taking part in the research?

Taking part in this research study may not benefit you personally. Our goal is to share experiences of public transportation for Latinos with disabilities. We hope that the information learned from this study will benefit you and other Latinos with disabilities in the future.

What other options are there?

You have the option to not participate in this study without any consequences.

What about privacy and confidentiality?

The people who will know that you are a participant in this research study are members of the research team and other people in the focus group. Otherwise personal information about you will only be disclosed if necessary to protect your rights or welfare or if required by law. Although everyone in the focus group will be asked to respect others' privacy, privacy and confidentiality cannot be guaranteed.

Study information which identifies you and the consent form signed by you may be looked at and/or copied for checking up on the research by: UIC Office for the Protection of Research Subjects (OPRS) and State of Illinois Auditors.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

APPENDIX K (continued)

To protect your confidentiality, we will not record your name on any of the documents associated with the research study or the focus group. Instead, only an identifying number will be used. In presentations, publications, and other dissemination of the study results, we will use a *pseudonym* or a fake name instead of your real name.

Audio-recordings will be stored on a secured electronic drive maintained by the primary investigator, Kristen Salkas. Access will be limited to her and research staff only. Ms. Salkas will also maintain a file with your contact information: your name, address, phone number and study ID number which will be stored in a locked file cabinet in her office. The audio-recordings and your contact information will be destroyed at the end of the study period. Forms that do not include identifying information and the audio transcriptions (which will not include any direct identifiers like your name) will be kept in locked files indefinitely.

What are the costs for participating in this research?

There are no costs to you for participating in this research.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will receive \$25.00 in cash after completing the focus group.

Can I withdraw or be removed from the study?

If you decide to participate, you are free to withdraw your consent or permission and discontinue participation at any time without penalty.

The Researchers also have the right to stop your participation in this study without your consent if they believe it is in your best interest or determine that you are not eligible for the study.

Who should I contact if I have questions?

Contact the principal investigator, Kristen Salkas at 708-870-4787 or email address: <u>ksalka2@uic.edu</u> or the faculty adviser Yolanda Suarez-Balcazar at 312-413-0117 or email address: ysuarez@uic.edu

- if you have any questions about this study or your part in it
- if you have questions, concerns or complaints about the research.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at <u>uicirb@uic.edu</u>.

APPENDIX K (continued)

Consent/Permission to audio-record (please initial):

_____I agree to allow the researchers to audio-record me and other participant during the focus group. I understand that what I say during the focus group will not be connected to my name or my other personal information.

_____I do <u>not</u> agree to allow the researchers to audio-record me during the focus group. I understand that I cannot participate in the focus group or the research study.

Signature of Participant

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

Signature of Participant

Date

Printed Name of Participant

APPENDIX L

Focus Group Informed Consent - Spanish

Universidad de Illinois en Chicago Información y consentimiento de participación en un grupo de enfoque Acceso al transporte público y la participación comunitaria para latinos con discapacidades

Se le ha pedido que participe en un grupo de enfoque como parte de un estudio de investigación. Los investigadores tienen la obligación de suministrarle un documento de consentimiento como el que tiene en sus manos para informarle en qué consiste el estudio de investigación, explicarle que toda su participación es voluntaria, describir los riesgos y ventajas de participar, y ayudarle a tomar una decisión informada. No dude en consultar con los investigadores por cualquier duda que pueda tener.

Nombre y cargo del investigador principal:	Kristen Salkas, MS
Departamento e Instituto:	University of Illinois at Chicago (UIC)
	Department of Disability and Human Development
Dirección e información de contacto:	1640 Roosevelt Rd., Chicago IL 60608
	Teléfono: 708-870-4787

¿Por qué se me pide participar?

Se le ha pedido a usted que participe como sujeto en un estudio de investigación el cual quiere explorar las barreras al acceso al transporte público y como afectan a la participación comunitaria de personas latinas con discapacidades.

Su participación en este estudio de investigación es voluntaria. Tanto si decide participar como si no, su relación actual o futura con la Universidad de Illinois en Chicago no se verá afectada por dicha decisión. Si decide participar, es libre de retirarse en cualquier momento sin que ello afecte a dicha relación o su relación con cualquier otra organización comunitaria relacionada con este estudio.

Aproximadamente 70 participantes participaran en este estudio de investigación en la área de Chicago, IL.

¿Cuál es el objetivo de esta investigación?

El estudio de investigación trata sobre el transporte público y el acceso a la comunidad para los latinos con discapacidades. Hemos encontrado información interesante de otra investigación sobre transportación para personas con discapacidades y queremos sugerencias de la comunidad latina para explorar el por qué encontramos esos resultados y el efecto que tiene esta información en la manera en que los latinos con discapacidades participan en sus comunidades. Este estudio se está llevando a cabo a través de la Universidad de Illinois en Chicago (UIC) (protocolo # 2018-0169). Los fondos para este estudio son provistos por la beca universitaria para transportación de Dwight D. Eisenhower del Departamento de Transportación de los estados

APPENDIX L (continued)

unidos (número de beca: 693JJ31845019) y el Instituto para Investigaciones de Raza y la Política Pública en UIC.

¿Qué procedimientos integran el estudio?

Los participantes participarán en una discusión grupal llamada un grupo de enfoque. Participantes hablarán con otras 3-6 personas latinas con discapacidades sobre sus experiencias usando el transporte público. Los grupos de enfoque serán facilitados en inglés y español. Los grupos de enfoque durarán aproximadamente 2 horas y tendrán lugar en locaciones públicas cerca de Chicago, IL. Se provendrán alimentos durante los grupos. Se grabará el audio de este grupo de enfoque.

¿Cuáles son los posibles riesgos y molestias?

A nuestro leal saber y entender, las cosas que usted tendrá que hacer no acarrean un riesgo o daño mayor que el habitual de la vida cotidiana. El grupo de enfoque puede incluir una discusión de temas sensibles como su experiencia como persona latina o persona con discapacidad. Usted no tiene que discutir nada que lo haga sentir incómodo.

Un riesgo de esta investigación es la pérdida de privacidad (el poner en conocimiento de terceros que usted está participando en este estudio) o de la confidencialidad (la divulgación de información sobre usted a terceros que no cuentan con su permiso para ver esta información). Todo personal del estudio está entrenado en la importancia de la confidencialidad para protegerla a usted de este riesgo. Además, se les notificarán a todos los miembros del grupo de enfoque de las expectativas de privacidad y confidencialidad antes de, durante, y después de la discusión.

¿Cuáles son los beneficios de participar en el estudio de investigación?

Al tomar parte en este estudio de investigación a lo mejor no tendrá un beneficio a usted personalmente. Nuestro objetivo es compartir experiencias para añadir al cuerpo de investigación sobre el tema de transporte para personas latinas con discapacidades. Esperamos que la información que aprendamos de este estudio beneficie no solo a usted u otras personas latinas con discapacidades en el futuro.

¿Qué otras opciones existen?

Usted tiene la opción de no participar en el estudio sin consecuencias.

¿Cómo se tratará la privacidad y la confidencialidad?

Las personas con conocimiento de su participación como sujeto en la investigación son los miembros del equipo de investigación y los otros miembros de su grupo de enfoque. Por lo demás, la información sobre usted únicamente se divulgará a terceras personas con su permiso por escrito, o si fuera necesario para proteger sus derechos o bienestar, o en cumplimiento de la ley. Aunque pedimos respeto para la privacidad y confidencialidad de todos los participantes del grupo de enfoque, no podemos garantizar la privacidad y confidencialidad en todas maneras.

APPENDIX L (continued)

Datos del estudio que le identifican individualmente y el documento de consentimiento firmado por usted serán examinados o copiados para analizar la investigación por: UIC Oficina para la Protección de los Seres Humanos en la Investigación (OPRS) y Status of Illinois Auditores.

En el caso en que los resultados de la investigación se publiquen o comenten en congresos, no se incluirá ninguna información que pudiera revelar su identidad.

Para proteger su confidencialidad, nosotros no notaremos su nombre en ninguno de los documentos asociados con el estudio o con el grupo de enfoque. En vez de ello, solamente se usará un número de identificación. En publicaciones o presentaciones sobre los resultados del estudio, usaremos un *pseudonombre* o un nombre inventado en vez de su nombre real.

Las audio-grabaciones serán almacenados en una unidad electrónica protegida mantenida por la investigadora primaria, Srta. Salkas. El acceso será limitado a ella y personal del estudio nada más. La Srta. Salkas también mantendrá un archivo con su información de contacto: su nombre, dirección, número de teléfono y número de identificación del estudio en una cabineta cerrada en la oficina de la investigadora primaria. Su información de contacto y las audio-grabaciones serán destruidas al final del período de estudio. Formas que no incluyan información de identificación y las transcripciones de audio (que no incluirá identificadores directos como su nombre) serán mantenidas bajo llave indefinidamente.

¿Cuáles son los costos de participar en esta investigación? No hay costos para usted por participar en esta investigación.

<u>¿Se me reembolsarán algunos de mis gastos o se me pagará por mi participación en este estudio</u> <u>de investigación?</u> Pagibirá \$25.00 después de completer el grupo de enfogue

Recibirá \$25.00 después de completar el grupo de enfoque.

¿Puedo retirarme o ser eliminado del estudio?

Si decide participar, es libre de retirar su consentimiento y dejar de participar en cualquier momento sin ninguna penalización.

Los investigadores tienen también derecho a interrumpir su participación en este estudio sin su consentimiento si creen que es lo más conveniente para usted o si determinan que usted no es elegible para el estudio.

En el caso de que usted se retire o de que se le pida que abandone el estudio, seguirá siendo compensado tal como se ha descrito anteriormente.

¿A quién debo contactar si tengo preguntas?

Póngase en contacto con la investigadora principal, Kristen Salkas, llamando al 708-870-4787 o por correo electrónico: <u>ksalka2@uic.edu</u> o la consejera de la facultad Yolanda Suarez-Balcazar llamando al 312-413-0117 o por correo electrónico: ysuarez@uic.edu

- si tiene preguntas acerca de este estudio o de su participación en él,
- si tiene preguntas, preocupaciones o quejas sobre la investigación.

APPENDIX L (continued)

¿Cuáles son mis derechos como sujeto de investigación?

Si cree que usted o su hijo/a no ha sido tratado de acuerdo con las descripciones de este documento, o si tiene preguntas sobre sus derechos como sujeto de investigación, incluyendo preguntas, preocupaciones o quejas, o para darnos su opinión, puede llamar a la Oficina para la Protección de los Seres Humanos en la Investigación (OPRS, Office for the Protection of Research Subjects) al 312-996-1711 o 1-866-789-6215 (llamada gratuita) o enviar un mensaje por correo electrónico a la OPRS a <u>uicirb@uic.edu</u>.

Recuerde:

Su participación en esta investigación es voluntaria. Su decisión sobre su participación no afectará a su relación actual o futura con la universidad. Si decide participar, es libre de retirarse en cualquier momento sin que ello afecte a dicha relación.

Consentimiento/ Permiso de audio-grabación (por favor marque con sus iniciales):

____Estoy de acuerdo en permitir a los investigadores audio-grabarme durante el grupo de enfoque. Entiendo que la grabación no será compartida con nadie fuera del estudio. Entiendo que lo que digo durante el grupo de enfoque no será conectado con mi nombre u otra información personal.

_____No estoy de acuerdo en permitir a los investigadores grabarme durante el grupo de enfoque. Entiendo que no puedo participar en el grupo de enfioque ni en el estudio.

Firma del sujeto o del representante legalmente autorizado

He leído (o alguien me ha leído) la información anterior. He tenido oportunidad de hacer preguntas, y éstas se han contestado a mi entera satisfacción. Acepto participar en esta investigación. Se me entregará una copia de este documento firmado y fechado.

Firma

Fecha

Nombre en letra de imprenta

APPENDIX M

Focus Group Guide - English

INTRODUCTION

Welcome to this focus group on transportation and community participation for Latinos with disabilities. My name is Kristen Salkas and I will be your group moderator. First, some housekeeping. Please help yourself to snacks and coffee while I talk about what we will be doing today. Feel free to get up and move around if it will make you more comfortable. Bathrooms can be found (fill in here). This focus group will last about two hours. There will be 12 total questions, including an icebreaker question.

During this focus group, we will be discussing different topics related to the ways that you as **Latinos with disabilities/ Latino parents of children with disabilities** get around on public transportation and the ways that you use transportation to participate in your communities. The people in this room may **have different disabilities/ have children with different disabilities**, so we want to hear about the ways that your experiences differ or are the same as others'. We will also be discussing the results of a survey that was done on transportation for people with disabilities to gain insight into why Latinos with disabilities responded in certain ways. The information we discuss today will be used for academic presentations, publications and hopefully influence the way that transportation is provided to Latinos with disabilities.

A focus group is a group interview. I want to hear everyone's thoughts and opinions on the topic of transportation and getting around your community. Feel free to respond to one another as well as to the questions themselves. There are no right or wrong answers. I want to hear from *you*. My job as the moderator is to pose the questions, to listen, to make sure that all voices are heard and to make sure that we stay on track in terms of time.

Before we begin, I want talk about the consent form that you received upon arrival. This form talks about the privacy and confidentiality expectations we have for everyone in this group, including myself. This form must be signed in order to participate in the focus group. I can summarize the form now.

- We ask that everyone respect the opinions of others. Please try to make this an open and inviting space for discussion; do not to interrupt each other and let everyone have a turn to speak.
- Privacy is very important. Please don't share the names of others in this focus group with those outside of the group. I, the researcher, may use the information we talk about in academic papers. If I quote something that you said, I will not use your name. Instead, I will give you a fake name called a pseudonym so no one will trace the quote back to you.
- This focus group will be audio recorded. The audio recording is used so that the researcher has a record of all the valuable information being discussed during this focus group. We will destroy the recordings at the end of the study.

APPENDIX M (continued)

- You will receive \$25.00 after the focus groups ends as compensation for your participation today. Your time and your expertise is valuable to researchers, so we want you to receive something in return for coming and sharing your experiences with us.
- If you have any questions, I will give you the opportunity to ask them before we begin. Additionally, my contact information and the contact information for the Office of Protection of Research Subjects who approved this study is on your copy of the consent form in case you need to follow-up on anything we discussed today.
- Finally, your participation in the focus group is completely voluntary. You can stop participating at any time without consequence.

I want to thank all of you who have joined us for this focus group. Your time and opinions are important and valuable, and I appreciate you being here today.

Are there any questions before we begin?

ICEBREAKER

Let's begin with introducing ourselves. I'll begin. My name is Kristen Salkas. I am a PhD student at the University of Illinois at Chicago and I developed this study on transportation and community participation for Latinos with disabilities as part of my dissertation project. I have worked with the Latino disability community for 5 years. I am not Latina. I am a person with disabilities. I use the public transportation frequently in Chicago and where I live in Homewood, IL. I work for the Regional Transportation Authority where I do community outreach to older adults and people with disabilities on the different programs and services that are available on public transit.

Who wants to continue?

(Go around until everyone has introduced themselves)

(Turn on audio recorders)

PART I: Transportation and Community Participation

1.Let's begin the discussion. Many people get around in different ways. Some people walk, some people drive, some get a ride from others, some people use public transit, and some people use paratransit. What are some ways that you get around your communities?

1a. **Have you ever used the public transit services?** By public transit I mean the public buses and trains that run in your area, such as the CTA buses and trains, the Pace buses, and the Metra trains. If not, why not? If so, what is the experience like?

APPENDIX M (continued)

1b. **Have you ever used the paratransit services**? Paratransit is the service for people with disabilities that comes and picks you up, like the Pace curb-to-curb service. If not, why not? If so, what is the experience like?

2.Let's focus on public transit and paratransit. Some people might use them to get to doctor's appointments, or to work or school, or to spend time with friends and family. What are some things that you use these forms of public transportation to get to?

PART II: Transportation Barriers

- 3.Now I want to talk about the problems that you might experience when you're using public transportation. What are some issues that you have when using or when trying to use public transit and paratransit?
- 4. What types of things are you not able to do or not able to do as often as you'd like because of transportation barriers?
- 5. What would the perfect transportation system look like to you? What would you do and where would you go if you could use the perfect system?

PART III: Member Checking

6.I'd like to share with you the results of a survey that was done on public transportation for people with disabilities throughout the country. We compared the responses of Latinos with disabilities to the responses of non-Latino whites with disabilities. We found some interesting ways that the responses from Latinos differed from the responses from non-Latinos.

I have a sheet here so you can follow along with the results. For each result we found, I'd like for you to talk about the following questions:

- Do you agree with the results? Why or why not?

- How do you think these problems affect the ways that Latinos with disabilities are able to go out and participate in their communities?

3a. Latinos with disabilities tend to be more satisfied with paratransit over public transit compared to non-Latino whites with disabilities.

APPENDIX M (continued)

- 3b. Latinos with disabilities reported more problems related to the way that they are treated by drivers compared to non-Latino whites with disabilities.
- 3c. Latinos with disabilities report more problems related to safety when riding on public transit compared to non-Latino whites with disabilities.
- 3d. Latinos with disabilities report more problems related to the paratransit system and scheduling compared to non-Latino whites with disabilities.

PART IV: Conclusion

7.What should we do with the results of this study? How should we present or share this data so that it benefits the Latino disability community?

8.Is there anything else you'd like to add on the topic of transportation and community participation?

This concludes the focus group. Thank you for your participation. Your responses are very much valued and appreciated.

APPENDIX N

Focus Group Guide - Spanish

INTRODUCCIÓN

Bienvenido a este grupo de enfoque sobre transporte y participación comunitaria para latinos con discapacidades. Mi nombre es Kristen Salkas y seré su moderadora. Primero, algo de información básica: por favor, siéntense libres de tomar la comida y el café mientras hablo de lo que haremos hoy. No duden en levantarse y moverse si eso les hace sentir más cómodos. Los baños se pueden encontrar (**fill in here**). Este grupo de enfoque durará aproximadamente dos horas. Habrá 12 preguntas en total, incluida una pregunta para 'romper el hielo.'

Durante este grupo de enfoque, discutiremos diferentes temas relacionados con las maneras en las ustedes como **los latinos con discapacidades / padres latinos con niños con discapacidades** se desplazan usando transporte público y las formas en que usan el transporte para participar en sus comunidades. Las personas en este salón pueden **tener diferentes discapacidades / tener niños con diferentes discapacidades**, por lo que queremos escuchar acerca de la manera en que sus experiencias difieren o son las mismas que las de los demás. También discutiremos los resultados de una encuesta que se realizó sobre el transporte para personas con discapacidades para obtener una idea de por qué los latinos con discapacidades respondieron de cierta manera. La información que discutiremos hoy se usará para presentaciones académicas, publicaciones y, con suerte, influirá en cómo se proporciona el transporte a los latinos con discapacidades.

Un grupo de enfoque es una entrevista de grupo. Quiero escuchar los pensamientos y opiniones de todos sobre el tema del transporte y cómo moverse por su comunidad. Siéntense libres de responder el uno al otro y a las preguntas mismas. No hay respuestas correctas o incorrectas. Quiero saber de ti. Mi trabajo como moderadora es plantear las preguntas, escuchar, asegurarme de que se escuchen todas las voces y hacer un seguimiento del tiempo.

Antes de comenzar, quiero hablar sobre el documento de consentimiento que recibió al llegar. Este documento habla sobre las expectativas de privacidad y confidencialidad que tenemos para todos en este grupo, incluyendo yo misma. Este documento debe estar firmado para poder participar en el grupo de enfoque. Les resumo el contenido del documento:

- Pedimos que todos respeten las opiniones de los demás. Intentamos que este espacio sea un espacio abierto y atractivo para la discusión; no se podrá interrumpir y que todos tendrán un turno para hablar.

- La privacidad es muy importante. No se compartirán los nombres de otros en este grupo de enfoque con los que están fuera del grupo. Yo, como la investigadora, puedo usar la información de la que hablamos en documentos académicos. Si cito algo de lo que digan, no usaré sus nombres. En lugar de eso, daré un nombre falso llamado un *seudónimo* para que nadie sepa su identidad.

APPENDIX N (continued)

- Se grabará el audio de este grupo de enfoque. La grabación se utiliza para que la investigadora tenga un registro de toda la información valiosa que se discuta durante este grupo de enfoque. Destruiremos las grabaciones al final del estudio.

- Todos recibirán \$25.00 después del final del grupo de enfoque como compensación por su participación de hoy. Su tiempo y sus experiencias son valiosas para la investigadora, por lo que queremos que reciba algo a cambio de venir y compartir sus experiencias con nosotros.

- Si tienen alguna pregunta, les daré la oportunidad de preguntar antes de comenzar. Además, mi información de contacto y la información de contacto de la Oficina de Protección de Asuntos de Investigación que aprobó este estudio se encuentran en su copia del documento de consentimiento en caso de que necesite hacer un seguimiento de cualquier tema que discutiremos hoy.

- Finalmente, su participación en el grupo de enfoque es completamente voluntaria. Pueden dejar de participar en cualquier momento sin consecuencias.

Quiero agradecerles a todos ustedes que se hayan unido a nosotros para este grupo de enfoque. Su tiempo y sus opiniones son importantes y valiosas, y les agradezco que estén aquí hoy.

¿Hay alguna pregunta antes de comenzar?

ROMPEHIELOS

Comencemos por presentarnos a nosotros mismos. Yo comenzaré. Mi nombre es Kristen Salkas. Soy estudiante de doctorado en la Universidad de Illinois en Chicago y desarrollé este estudio sobre transporte y participación comunitaria para latinos con discapacidades como parte de mi proyecto de disertación. He trabajado con la comunidad de latinos con discapacidades por 5 años. No soy latina, pero sí soy una persona con discapacidades. Utilizo el transporte público frecuentemente en Chicago y donde vivo en Homewood, IL. Trabajo para la Autoridad de Transporte Regional donde hago alcance comunitario para adultos mayores y personas con discapacidades en los diferentes programas y servicios que están disponibles en el transporte público.

¿Quién quiere continuar? (Go around until everyone has introduced themselves) (Turn on audio recorders)

PARTE I: Transporte y Participación Comunitaria

1. Comencemos la discusión. Mucha gente se mueve de diferentes maneras. Algunas personas caminan, algunas personas conducen, otras se llevan de otras personas en carro, algunas usan el transporte público y otras usan el servicio puerta-a-puerta. ¿Cuáles son algunas de las formas en las que se mueven por sus comunidades?

APPENDIX N (continued)

1a. **¿Alguna vez ha usado los servicios de transporte público**? El transporte público se refiere a los autobuses y trenes públicos en su área, como los autobuses y trenes CTA, los autobuses Pace y los trenes Metra. ¿Si no, porque no? Si es así, ¿cómo fue la experiencia?

1b. ¿Alguna vez ha usado los servicios del servicio puerta-a-puerta? El servicio puerta-apuerta también se llama el "Paratransit" o el "Pace" y es el servicio para personas con discapacidades que viene y le recoge. ¿Si no, porque no? Si es así, ¿cómo fue la experiencia?

2. Enfoquémonos en el transporte público y el servicio puerta-a-puerta. Algunas personas pueden usarlas para ir a citas con el médico, o para trabajar o estudiar, o para pasar tiempo con amigos y familiares. ¿Cuáles son algunas de las cosas para las que usan estas formas de transporte público?

PARTE II: Barreras del Transporte

3. Ahora quiero hablar sobre los problemas que pueden haber al usar el transporte público. ¿Cuáles son algunos de los problemas que tiene al usar o al tratar de usar el transporte público y el servicio puerta-a-puerta?

4. ¿Qué tipos de cosas no pueden hacer debido a las barreras de transporte?

5. ¿Cuál sería el sistema de transporte perfecto para usted? ¿Qué haría y a dónde iría si pudiera usar el sistema perfecto?

PARTE III: Cheque de miembros

6. Me gustaría compartir con ustedes los resultados de una encuesta que se realizó sobre el transporte público para personas con discapacidades en todo el país. Comparamos las respuestas de los latinos con discapacidades con las respuestas de las personas de raza blanca con discapacidades que no son latinas. Encontramos algunos resultados interesantes de en las cuales, algunas respuestas de los latinos.

Tengo una hoja aquí para que pueda seguir con los resultados. Por cada resultado que encontramos, me gustaría que hablaran sobre las siguientes preguntas:

- ¿Están de acuerdo con los resultados? ¿Por qué sí o por qué no?

- ¿Cómo creen que estos problemas afectan las maneras en que los latinos con discapacidades pueden participar en sus comunidades?

APPENDIX N (continued)

3a. Los latinos con discapacidades están más satisfechos con el servicio puerta-apuerta que con el transporte público en comparación con los no latinos con discapacidades.

3b. Los latinos con discapacidades reportaron más problemas relacionados con la forma en que son tratados por los conductores en comparación con los no latinos con discapacidades.

3c. Los latinos con discapacidades reportaron más problemas relacionados con la seguridad cuando usan el transporte público en comparación con los no latinos con discapacidades.

3d. Los latinos con discapacidades reportaron más problemas relacionados con el sistema del servicio puerta-a-puerta en comparación con los no latinos con discapacidades.

PARTE IV: Conclusión

7. **¿Qué deberíamos hacer con los resultados de este estudio?** ¿Cómo deberíamos presentar o compartir esta información para que beneficie a la comunidad latina con discapacidades?

8. ¿Hay algo más que quiera agregar sobre el tema del transporte y la participación comunitaria?

Esto concluye el grupo de enfoque. Gracias por su participación. Sus respuestas son muy importantes y valiosas.

APPENDIX O

Fact Sheet – English

Latinos with Disabilities and Transportation Focus Group

Fact Sheet

These are some of the results of a survey that was done on transportation for people with disabilities throughout the country.

For each result we found, I'd like for you to talk about the following questions:

- Do you agree with the results? Why or why not?

- How do you think these problems affect the ways that Latinos with disabilities are able to go out and participate in their communities?

- 1. Latinos with disabilities tend to be more satisfied with Paratransit over public transit compared to non-Latino whites with disabilities.
- 2. Latinos with disabilities reported more problems related to the way that they are treated by drivers compared to non-Latino whites with disabilities.
- 3. Latinos with disabilities report more problems related to safety when riding on public transit compared to non-Latino whites with disabilities.
- 4. Latinos with disabilities report more problems related to the Paratransit system and scheduling compared to non-Latino whites with disabilities.

APPENDIX P

Fact Sheet – Spanish

Grupo de Enfoque para Latinos con Discapacidades Sobre el Transporte

Hoja de Información

Aquí están los resultados de una encuesta que se realizó sobre el transporte público para personas con discapacidades en todo el país.

Por cada resultado que encontramos, me gustaría que hablaran sobre las siguientes preguntas:

- ¿Están de acuerdo con los resultados? ¿Por qué sí o por qué no?
- ¿Cómo creen que estos problemas afectan las maneras en que los latinos con discapacidades pueden participar en sus comunidades?

- 1. Los latinos con discapacidades están más satisfechos con el servicio puerta-a-puerta que con el transporte público en comparación con los no latinos con discapacidades.
- 2. Los latinos con discapacidades reportaron más problemas relacionados con la forma en que son tratados por los conductores en comparación con los no latinos con discapacidades.
- 3. Los latinos con discapacidades reportaron más problemas relacionados con la seguridad cuando usan el transporte público en comparación con los no latinos con discapacidades.
- 4. Los latinos con discapacidades reportaron más problemas relacionados con el sistema del servicio

APPENDIX P (continued)

puerta-a-puerta en comparación con los no latinos con discapacidades.

APPENDIX Q

IRB Exemption Letter

Exemption Granted

February 21, 2018

Kristen Salkas Disability and Human Development 1757 Cedar Rd Homewood, IL 60430 Phone: (312) 413-1837

RE: Research Protocol # 2018-0169 "Public Transit Access and Community Participation for Latinxs with Disabilities"

PAF#:	Not applicable, 00409288
Grant/Contract No:	Not applicable, 693JJ31845019
Grant/Contract Title:	Institute for Research on Race and Public Policy Dissertation
	Research Grant, Dwight David Eisenhower Transportation
	Fellowship Program
Sponsors:	Institute for Research on Race and Public Policy, U. S. Department
	of Transportation Federal Highway Administration

Dear Ms. Salkas:

Your Claim of Exemption was reviewed on February 21, 2018 and it was determined that you research meets the criteria for exemption. You may now begin your research.

Your research may be conducted at Achieving Independence & Mobility Ctr for Independent Living, Progress Center-Center for Independent Living, and UIC with adult subjects.

The specific exemption category under 45 CFR 46.101(b) is:

2 Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:(i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

APPENDIX Q (continued)

- 6	rease note the reason of this submission.				
	Receipt Date	Submission Type	Review Process	Review Date	Review Action
	02/07/2018	Initial Review	Exempt	02/16/2018	Modifications
					Required
	02/21/2018	Response To	Exempt	02/21/2018	Approved
		Modifications			

Please note the Review History of this submission:

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

- 1. <u>Amendments</u> You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.
- 2. <u>Record Keeping</u> You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.
- 3. <u>Final Report</u> When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).
- 4. <u>Information for Human Subjects</u> UIC Policy requires investigators to provide information about the research protocol to subjects and to obtain their permission prior to their participating in the research. The information about the research protocol should be presented to subjects in writing or orally from a written script. <u>When appropriate</u>, the following information must be provided to all research subjects participating in exempt studies:
 - a. The researchers affiliation; UIC, JBVMAC or other institutions,
 - b. The purpose of the research,
 - c. The extent of the subject's involvement and an explanation of the procedures to be followed,
 - d. Whether the information being collected will be used for any purposes other than the proposed research,
 - e. A description of the procedures to protect the privacy of subjects and the confidentiality of the research information and data,
 - f. Description of any reasonable foreseeable risks,
 - g. Description of anticipated benefit,
 - h. A statement that participation is voluntary and subjects can refuse to participate or can stop at any time,

APPENDIX Q (continued)

- i. A statement that the researcher is available to answer any questions that the subject may have and which includes the name and phone number of the investigator(s).
- j. A statement that the UIC IRB/OPRS or JBVMAC Patient Advocate Office is available if there are questions about subject's rights, which includes the appropriate phone numbers.

Please be sure to:

f. \rightarrow Use your research protocol number (2018-0169) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS office at (312) 996-1711 or me at (312) 996-2014.

Sincerely, Sandra Costello Assistant Director, IRB # 7 Office for the Protection of Research Subjects

cc: Tamar Heller, Disability and Human Development, M/C 626 Yolanda Suarez-Balcazar (faculty advisor), Occupational Therapy, M/C 811

APPENDIX R

IR Ammendment Letter

Exemption Determination Amendment to Research Protocol – Exempt Review UIC Amendment #1

April 2, 2018

Kristen Salkas Disability and Human Development 1757 Cedar Rd Homewood, IL 60430 Phone: (312) 413-1837

RE: Protocol # 2018-0169 "Public Transit Access and Community Participation for Latinxs with Disabilities"

Dear Kristen Salkas:

• The OPRS staff/members of Institutional Review Board (IRB) #7 have reviewed this amendment to your research and have determined that your amended research continues to meet the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b)].

The specific exemption category under 45 CFR 46.101(b) is: 2

Exemption Period:	April 2, 2018 – April 2, 2021
Performance Site:	UIC
Recruitment Sites:	Achieving Independence & Mobility Center for
	Independent Living; Progress Center - Center for Independent
	Living; Community Support Services (Cicero, IL)
Subject Population:	Adult (18+ years) subjects only
Number of Subjects:	70

• You may now implement the amendment in your research.

Please note the following information about your approved amendment:

Amendment Approval Date: April 2, 2018

Amendment:

Summary: UIC Amendment #1: Adding an additional non-UIC Performance Site. That site is Community Support Services located at 5416 West 25th St in Cicero, IL. This organization services people with various disabilities in the Chicagoland area. The organization does not exclusively serve Latinxs, but the location is located in a primarily Latinx neighborhood. The location in Cicero specifically provides day program services to young adults with disabilities. This site will be hosting the research activity of focus groups for Latinxs with disabilities on the topic of transportation and community participation.

APPENDIX R (continued)

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

- 1. <u>Amendments</u> You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.
- 2. <u>Record Keeping</u> You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.
- 3. <u>Final Report</u> When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).
- 4. Information for Human Subjects UIC Policy requires investigators to provide information about the research to subjects and to obtain their permission prior to their participating in the research. The information about the research should be presented to subjects as detailed in the research protocol, application and supporting documents.

Please be sure to use your research protocol number (2018-0169) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711.

Sincerely, Charles W. Hoehne, B.S., C.I.P. Assistant Director, IRB #7 Office for the Protection of Research Subjects

cc: Tamar Heller, Yolanda Suarez-Balcazar VITA

Kristen Salkas

1757 Cedar Rd, Homewood, IL 60430 • 708-870-4787 • Kristen.Salkas@gmail.com

EDUCATION:

- Ph.D. Disability Studies (Expected 2019) University of Illinois at Chicago 2013—Present Dissertation: Public transportation access and community participation for Latinxs with disabilities • Chair: Yolanda Suarez-Balcazar
- M.S. Disability and Human Development University of Illinois at Chicago 2011–2013

Thesis: *Exploring how spirituality impacts conceptualizations of and feelings about disability* • Chair: Carol J. Gill

B.S. Psychology • B.A. Spanish Language and Literature • Loyola University Chicago • 2006—2009 • magna cum laude

Thesis: Head Start preschoolers' individual characteristics, family demographics and child care contexts: A comparison of CSRP and FACES • Mentor: Christine P. Li-Grining

LANGUAGE SKILLS: Fully proficient in Spanish — Study abroad in Alcalá de Henares, Spain in 2008

PROFESSIONAL WORK EXPERIENCE:

Regional Transportation Authority of Northeast Illinois • Chicago, IL

2011—Present

2008-2010

Mobility Outreach Coordinator • 2015—Present

• Coordinating community outreach efforts for people with disabilities and older adults on RTA programs and services

Mobility Management Outreach Specialist • 2014-2015

• Community outreach worker for people with disabilities and older adults on RTA programs and services

Travel Trainer • 2011–2014

• Performed travel training on RTA transportation for people with various disabilities and older adults

Latinxs with Disabilities and Transportation Project • Principal Investigator • Chicago, IL 2018

• Designing and implementing a mixed-methods research study to investigate public transit access and community participation for Latinxs with disabilities in the Chicagoland area

University of Illinois at Chicago, Cultural Contexts Lab • Project Coordinator • Chicago, IL 2013–2018

• Designing and implementing a peer health worker model in a research initiative designed to educate Latino parents of children with autism about available therapeutic approaches and other services

Loyola University Chicago • Research Assistant • Chicago, IL

• Research assistant for a longitudinal study on families of adolescents with spina bifida

PEER REVIEWED PUBLICATIONS:

- Magaña, S. M., Moreno Angarita, M., Salkas, K., & Tejada-Hughes, M. (accepted). Adapting a parent education program from north to south. *Disability and the Global South*.
- Salkas, K., Magaña, S. M., Marques, I., & Mirza, M. (2016). Spirituality in Latino families of children with autism spectrum disorders. *Journal of Family Social Work, 19*(1), 38-55.
- Salkas, K., & Gill, C. J. (2016). Exploring how Christians and atheists deal with issues related to disability. *Journal of Religion and Disability*, 20(3), 190-202.

BOOK CHAPTERS:

• Salkas, K. (2018). Disability and religion, spirituality. In T. Heller, S. Parker Harris, C. Gill, & R. Gould (Eds.), *Disability in American Life: An Encyclopedia of Concepts, Policies, and Controversies*. Santa Barbara, CA: ABC-CLIO.

OTHER MEDIA:

• Rosen, D., Barbee, F., **Salkas, K.**, Blair, S., Burton, R., Daly, B., McClain, J., VanDekreke, M., & Chamberlain, L. (2017). *RTA Mobility Management Video Series: Options for Travel Independence*.

PRESENTATIONS:

- Salkas, K. (2018). Public transportation for Latinxs with disabilities. Oral paper presented at the Annual Conference of the Association of Travel Instruction, San Diego, CA, August 2018.
- Torres, L., Pérez, K., **Salkas, K.**, & V, L. (2018). A needs assessment survey for Latinxs with disabilities. Oral paper presented with the symposium "Nada Sobre Nosotrxs sin Nosotrxs: Addressing the Needs of Latinxs with Disabilities through Intersectional Educational Research." at the annual conference for the American Educational Research Association, New York, NY, April 2018.
- Magaña, S. M., Tejada-Hughes, M., **Salkas, K.**, & Moreno, M. (2018). Parents taking action in Colombia. Oral paper presented at the Symposium "Latino interventions" at the Gatlinburg Symposium, Davis, CA, April 2018.
- Pérez, K., Hernández, M., **Salkas, K.**, & Vanik, L. (2017). Panel discussion: "Needs and self-identification of Latinxs with disabilities in the U.S.". Oral paper presented at the annual conference for the Association of University Centers on Disability, Washington, DC, November 2017.
- Salkas, K. (2017). Perfecting our travel training interview skills. Oral paper presented at the Annual Conference of the Association of Travel Instruction, Austin, TX, August 2017.
- Magaña, S. M., **Salkas, K.**, Moreno, M., Tejada-Hughes, M. (2017). Adapting and testing a parent education program in Colombia. Poster presented at the International Meeting for Autism Research, San Francisco, CA, May, 2017.
- Salkas, K. (2016). How are we making a difference? Evaluating travel training success. Oral paper presented at the Annual Conference of the Association of Travel Instruction, Saint Paul, MN, August 2016.
- Salkas, K., Magaña, S. M., & Garcia-Rodriguez, M. (2016). Adapting an autism education program for Latino families in Colombia. Poster presented at the Empowering Latinxs with Disabilities Conference, Chicago, IL, May, 2016.
- Salkas, K. (2015). Travel Training: Offering Options for Travel Independence. Oral paper presented at the Illinois Statewide Transition Conference, Chicago, IL, October 2015.
- Salkas, K. (2015). Using a peer education model in travel training. Oral paper presented at the Annual Conference of the Association of Travel Instruction, Boston, MA, August 2015.
- Salkas, K., & Gill, C. J. (2015). Exploring how spirituality impacts conceptualizations of and feelings about disability. Poster presented at the Annual Conference of the Society for Disability Studies, Atlanta, GA, June, 2015.
- Salkas, K., Marques, I., & Magaña, S.M. (2015). Spirituality in Latino families of children with autism spectrum disorders. Poster presented at the International Meeting for Autism Research, Salt Lake City, UT, May, 2015.

- Magaña, S.M., **Salkas, K.**, & Li, H. (2015). The impact of a health education program on older Latina mothers of adults with intellectual and developmental disabilities (IDD). Oral paper presented at the Annual Conference of the Society for Social Work and Research, New Orleans, LA, January, 2015.
- Johnson, A., & Salkas, K. (2014). Panel discussion: "Cultural competency and travel training." Oral paper presented at the Annual Conference of the Association of Travel Instruction, Portland, OR, August 2014.
- Salkas, K. (2014). RTA transportation: Accessibility options and brainstorming for the future. Oral paper presented at the University of Illinois at Chicago Disability Studies Student Council Student Scholar Symposium, Chicago, IL, April 2014.
- Salkas, K. (2013). Ideology of disability in travel training practice. Oral paper presented at the Annual Conference of the Association of Travel Instruction, Chicago, IL, August 2013.
- Salkas, K.M., & Floyd, F.J. (2011). Challenges in assessing quality of life for adolescents and young adults with intellectual disability. Presented with the Symposium "Transition into Adulthood: Diverse Family Perspectives" at the Gatlinburg Symposium, San Antonio, TX, March 2011.
- Salkas, K., Devine, K., Holmbeck, G.N., McLone, D.G., Zebracki, K. (2010). Functional math, quality of life, and independent living skills in young adults with spina bifida. Poster presented at the 2010 Annual Conference for the Midwest Psychological Association, Chicago, IL, April 2010.
- Salkas, K., Li-Grining, C.P., Raver, C.C. (2010). Head Start preschoolers' individual characteristics, family demographics and child care contexts: A comparison of CSRP and FACES. Poster presented at the 2010 Annual Conference for the Midwest Psychological Association, Chicago, IL, April 2010.
- Wasserman, R., Devine, K., Holmbeck, G., Gershenson, L., **Salkas, K.,** & Bienz, L. (2009). Timeline for transfer of responsibility: A comparison study of families of children with and without spina bifida. Poster presented at the Midwest Conference on Pediatric Psychology, Kansas City, MO, April 2009.

INVITED TALKS & KEYNOTES:

- Salkas, K. (2018). La seguridad comunitaria. Oral paper presented at a staff training at the Centro Ann Sullivan de Peru, Lima, Peru, September 2018.
- Salkas, K. (2016). Tratamientos basados en evidencia para niños con autismo. Oral paper presented at the Autismo, Pautas de Crianza y Estrategias de Comunicación Conference, Bogotá, Colombia, January 2016.
- Salkas, K. (2014). Using the RTA's accessible system and services. Keynote address at the Illinois Association for Education and Rehabilitation for the Blind and Visually Impaired Vision Conference, Schaumburg, IL, February 2014.

PROFESSIONAL DESIGNATIONS:

- The Progress Center for Independent Living Board Member, 2018—Present
- Association of Travel Instruction Treasurer, 2017—Present Member, 2013—Present
- National Coalition for Latinxs with Disabilities Founding Member 2016—Present Research Chair, 2016—2018
- Society for Disability Studies Student Member 2014—Present
- International Society for Autism Research Student Member 2014—2015
- UIC Disability Studies Student Council Member, 2011—Present Student Life Chair, 2012—2013
- Phi Beta Kappa Inductee 2010

EDITORIAL EXPERIENCE:

- Journal Reviewer Journal of Spirituality in Mental Health, 2018
- Journal Reviewer Disability Studies Quarterly, 2018
- Journal Reviewer International Journal of Developmental Disabilities, 2016
- Journal Reviewer Journal of Family Social Work, 2015

SCHOLARSHIPS, FELLOWSHIPS & GRANTS:

- Carlos Drazen Memorial Research Scholarship \$1,000 2018
- Dwight David Eisenhower Transportation Research Fellowship \$11,500 2017
- Institute for Research on Race and Public Policy Dissertation Research Grant \$1,000 2017
- Rush University Women's Board Scholarship \$1,000 2010
- Loyola University Chicago Damen Scholarship \$12,000/year 2006-2009

AWARDS & HONORS:

- Disability and Human Development Departmental Travel Awards \$250, \$500 2018
- Disability and Human Development Departmental Travel Award \$500 2017
- Regional Transportation Authority Performance-Based Annual Bonus \$250 2016
- Regional Transportation Authority Top Employee Annual Review 2015
- Society for Disability Studies Student Presenter Award \$150 2015
- Disability and Human Development Departmental Travel Award \$350 2015
- University of Illinois Research in Diversity Travel Award \$600 2015
- University of Illinois Board of Trustees Tuition Waiver 2012 & 2016
- Loyola University Chicago, Departmental Honors, Psychology 2009

VOLUNTEER EXPERIENCE:

- Centro Ann Sullivan de Peru Transit professional volunteer for a disability organization in Lima, Peru 2018
- Chicago Area Mountain Bikers Mountain biking trail clean-up and repair 2018—Present
- **Dare2Tri Race Volunteer** Race organizer and sighted guide for a group that supports paratriathletes 2013–2016
- **Best Buddies Loyola University** Social skills training with adults with intellectual disability 2009—2010
- Rush University Medical Center Volunteer Services Department Office manager, patient transport 2008–2010
- Rush University Medical Center Child Life Department Organized activities for inpatient children 2009