Analysis of the Non-Driving Mobility Needs of People with Disabilities

Final Report

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15. Abstract

This report presents the findings and conclusions of a multi-methodology investigation into the transportation-related needs and barriers facing people with disabilities (PWD). Data collection consisted of a nationwide survey, with participant recruitment assisted by a variety of disability advocacy groups, and follow-on interviews conducted with a subset of survey respondents. The goals of the project included identification and prioritization of specific barriers and transportation needs facing individuals with a variety of types of disabilities, including those who have more than one type of disability. We identified several high-priority needs for each disability type, including structural barriers to movement for people with physical disabilities, sensory barriers that can preclude people with perceptual disabilities from accessing needed information, and informational barriers to travel for people with intellectual and developmental disabilities. Overall, we determined that the needs of the PWD community are extraordinarily varied and heterogeneous, and that members of this community should be meaningfully involved in the development of future transportation modalities and technology.

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EXECUTIVE SUMMARY

This study was conducted to enable better understanding of the mobility-related needs and barriers facing people with disabilities (PWD) in the United States. PWD face a variety of challenges in non-driving transportation, whether by a personal means of locomotion (including on foot and using a wheelchair or other assistive device(s)) or when using public transportation or paratransit. The needs and barriers encountered by PWD were expected to be distinct across disability category, including for people with physical, perceptual, and/or intellectual/learning disabilities as well as related disabilities. More data on specific needs and barriers facing the wide range of PWD are needed to prioritize countermeasures and improve transportation assistance options. The present study utilized a multimodal approach to quantify these needs, including a nationwide survey of people with a range of disabilities and detailed follow-up interviews with a subset of this survey sample.

The nationwide survey was conducted via the internet, with recruitment assisted by a wide variety of disability advocacy and educational groups across the country. 160 participants ages 18-81 responded, with the majority of respondents being white (91%) and female (68%), and between the ages of 36 and 65 (58%). Participants reported having a wide range of disabilities, with 77% reporting having physical disabilities, 26% having sensory disabilities, 13% intellectual/developmental disabilities, and 40% having multiple disabilities. Of the people with physical disabilities, 86% reported using some form of mobility device such as a wheelchair or walker. Participants reported using a variety of means of transportation, with riding in a car being most prevalent and using a bicycle being the least prevalent. Surprisingly, relatively few people reported using public transit, with less than 20% reporting using it a few times a month or more. Most participants reported traveling outside their homes at least a few times per month, with more than half reporting traveling a few times a week or more for errands.

Participants reported a wide variety of barriers to transportation. Many participants reported some difficulty with public transit, particularly people with sensory disabilities and IDD, for

whom obtaining and understanding information was a challenge. People with physical disabilities reported challenges traversing physically difficult areas (including broken/slippery sidewalks), and entering and exiting transit vehicles. In general, people found it hard to get where they need to go using public transportation.

A follow-up series of interviews provided more in-depth and nuanced information about transportation challenges. Here, participants discussed specific challenges they encounter when traveling, including transportation modality, structural concerns, and technology usage. Participants remained skeptical about public transit, citing a number of physical, informational, and scheduling challenges to this being an acceptable form of transportation. Paratransit was somewhat endorsed, but has its own challenges including limited scheduling and overcrowding. Numerous structural concerns were noted, particularly for people with disabilities, including issues with sidewalk and ramp integrity and weather-related issues (for example, lack of snow plowing at curb cuts). Participants also discussed their experiences with technology, including existing navigation apps, along with what features and functions could best improve their transportation experience.

Overall, this study provided significant insight into the broad range of challenges facing PWD as they traverse the built environment. These people represent a heterogeneous population with diverse functional impairments living in a wide range of areas, with different access to public transportation and paratransit. The findings of this project underline that technology and transportation advancement must be done with significant input from the disability community, and with consideration of the wide range of voices within this community. Only then can equity be ensured in our future transportation environment.

DESCRIPTION OF PROBLEM

People with disabilities (PWD) face a variety of challenges in navigating the built environment in their everyday lives. These include people with physical impairments ranging from chronic pain to the use of wheelchairs, walkers, and other assistive devices, people with perceptual disabilities such as hearing or vision deficits, and people with intellectual and developmental disabilities (IDD) such as autism spectrum disorder (ASD) and Down's syndrome. For people with any of these types of disabilities, including the many individuals that fall into multiple categories, there is a need for solutions to assist their locomotion through the world. This assistance may take one or more of several forms, such as navigational aids, personalized route selection, and/or methods of information presentation.

For people with physical disabilities with limited mobility or who require the use of assistive devices, everyday features such as stairs, curbs, and hills may prove a serious or even insurmountable challenge to locomotion. This is especially true when these are compounded in an outdoor environment with inclement weather such as rain or snow that decreases surface friction. The mobility barriers for people with physical disabilities are likely to vary with the specific type of disability and the type of assistive device(s) used; for example, someone with a cane may be able to step off a sidewalk or over a tree root, while a person in a wheelchair may not be able to accomplish either. People with perceptual disabilities such as low vision or a hearing impairment may face overlapping barriers with people who have physical disabilities (e.g. dealing with physical obstructions), but may have distinct challenges such as wayfinding and localizing hazards and traffic. Infrastructure features such as tactile walking surface indicators (TWSIs) and curb cuts are designed to assist people with low vision, but they may be inconsistently or inappropriately implemented.

Accessibility is an equally important consideration for individuals with IDD. Although individuals with IDD may also face challenges with mobility, primary barriers to travel can include limited literacy and numeracy (e.g. inability to encode information from signage or

determine distance), sensory concerns (e.g. overly loud routes, overly bright signage or landmarks), and speed of information processing (e.g. taking time to understand traffic signals or directions). These barriers to access have been labeled pace, complexity, and literacy (Yalon-Chamovitz, 2009). Thus, people with IDD may face challenges of both travel and information processing, simplicity of directions and signage, and demands on cognitive interpretation of written letters and numbers. Currently, some road signals are more accessible for people with intellectual disabilities – for example, crosswalk signals that include countdown mechanisms rather than just unlabeled flashing – but these accommodations are not universal. Wayfinding supports are needed to identify where such accommodations are present. Additionally, although individuals with IDD are increasingly adopting mobile devices, usage rates remain far lower than in the general population (e.g. Bryen et al., 2007). This gap in usage has been partially attributed to the lack of accessible apps and features of smartphones (Igual et al., 2013). Thus, any technological development to assist individuals with IDD needs to not only identify accessible routes, but also present such information in an accessible way.

Because of these persistent and varying needs, it is necessary to develop navigation solutions that can take individual needs and requirements into account when creating walking or multimodal routes through and between cities. Such individualized solutions could allow unprecedented mobility opportunities and affordances for people who have traditionally faced significant obstacles. The goal of this project was to conduct a thorough needs analysis of the transportation-related needs of people with physical and/or cognitive disabilities. This project is related to the ongoing CATM project "Vulnerable Road User Mobility Assistance Platform" (VRU-MAP), which is focused on the development of an application platform to support the mobility needs of people with physical disabilities, and is in part intended to provide that project with a theoretical foundation for prioritization of user needs. Here, the involvement of faculty and students from Virginia Tech's Department of Human Development, who bring expertise in the field of Disability Studies, enabled a stricter focus

and deeper dive into the identification and specification of transportation needs of the larger community with disabilities.

The conclusions of this project will serve not only to support the VRU-MAP project, but to function as a standalone document that will enable other researchers, policymakers, and research bodies, such as the USDOT's Accessible Transportation Technologies Research Initiative (ATTRI), to gain further insight into the mobility needs of people with a wide range of disabilities. Similar analyses have been performed previously (e.g. Pierce, Plapper & Rizek, 2016); however, these have been somewhat limited in scope and had some limitations including reliance on remote group discussions.

APPROACH AND METHODOLOGY

The study utilized a two-prong approach to identify the mobility-related needs and barriers of PWD. First, we conducted a nationwide online survey to examine barriers to transportation and navigation for PWD. Data were collected via REDCap, a secure online data-capture platform (Harris et al., 2009). Participants provided information on demographics and current transportation modalities and experiences, and used sliding scales to indicate how much of a problem various scenarios were for them. Participants were identified with the assistance of a variety of disability organizations across the United States. Organizations at the state and local level agreed to share the survey with their members, resulting in a diverse, national sample. After the survey, we conducted follow-up interviews with a subset of respondents to gain more in-depth information about their needs and barriers. All protocols were approved by the Virginia Tech Institutional Review Board.

Procedures

Online Survey

Survey Initiation

In order to gather perspectives from individuals with a wide variety of disabilities and experiences, nearly 200 national, state, and local disabilities organizations across the United

States were contacted to help disseminate the survey (full list in Appendix A: List of Contacted Organizations). Of the groups and associations we contacted, approximately 10% agreed to share the survey information with their members. Links to the survey, along with instructions and eligibility criteria were shared with potential participants through email listservs and websites administered by these organizations. Potential respondents could click the link to the survey, which would take them to an introductory page. This introductory page directed participants to consent/assent screens as appropriate, or to an exit page thanking them for their interest if they were younger than 18 (text in Appendix B: Survey Welcome Screen).

Consent/Assent

Survey respondents were required to be over the age of 18 to participate; potential participants who indicated that they were under 18 were thanked for their interest and dismissed from participation. Participants were then directed to the appropriate consent or assent forms. As participants were a vulnerable population, potential participants who were over 18 were asked to indicate if they had the legal capacity to consent; if they did not, they were directed to an assent page and a permission page to be completed by their legal guardians. Consent, permission, and/or assent, as necessary, were required before participants could access the survey questions. All forms are presented in Appendix C: Consent, Assent, and Guardian Permission forms. The survey itself took 15-20 minutes to complete; a complete version of the survey is located in Appendix D: Survey.

Survey Components

The survey was created to obtain information on travel habits and perceived barriers to travel of PWD. The survey consisted of five sections: travel habits, general trouble when traveling, barriers with public transportation, barriers with other transportation, and demographics. These are described here, with the full text of the survey presented in Appendix D: Survey.

Demographics

First, participants were asked to indicate any and all types of disability they had (intellectual/developmental, learning, physical, psychiatric, sensory, communication, and/or other). For each type of disability that the respondent endorsed, they were provided with an additional list of diagnoses for more detail (e.g. if they indicated "learning disability," they were asked if they had ADHD, dyslexia, specific language impairment, language processing disorder, nonverbal learning disability, or other). They also provided information on age, gender, race, education, living arrangements, job status, and socioeconomic status.

Travel Habits

Using a six-point Likert-like scale (0 = never or almost never to 5 = daily), participants indicated how frequently they used each of the following types of transportation to get around outside their home: car (as driver), car (as passenger), bike, personal mobility equipment/on foot, public transportation, or other. If participants indicated "other," they were asked to describe the additional means of transportation. Then, using a seven-point scale (0 = never or almost never to 6 = more than once per day), participants were asked how frequently they left the house for each of the following activities: work/school, socialization, errands, and other.

General Trouble when Traveling

Participants used a five-point scale (0 = never or rarely to 4 = every time, plus an option for "does not apply to me") to indicate how frequently they have trouble getting around outside the home in the following situations: as a pedestrian or on a bike, while using public transportation, and while driving. Participants responded to each item twice – once regarding traveling to places they have been to or visit often, and once regarding traveling to a new place.

Barriers Using Public Transportation

Participants were asked if they use public transportation. If they responded "yes," they were taken to a series of questions regarding their perceived challenges with public transportation. Participants used a sliding scale (0-100) to indicate how much of a problem each of the following situations were for them when using public transportation: feeling safe, getting on or off the vehicle, understanding how to use the transportation (e.g. how to pay or what route to take), being able to go where they need to go, taking care of personal needs (e.g. finding a bathroom), and other people staring or treating them differently.

Barriers Using Other Transportation

Like the public transportation section, the barriers with general travel used 0-100 sliding scales. Participants were asked how much trouble they had with each of the following: route being too steep, route is not smooth, route is slippery, route is too narrow, getting across the street before the signal changes, getting onto or off the sidewalk, getting into or out of buildings, finding out what street they are on, figuring out which entrance to use, following directions for how to get around, route is too crowded, route is too noisy, bright or smelly, and knowing when or where it is OK to move (e.g. when to cross the street or where people are allowed to walk).

Follow-Up Interview

Interview Initiation

After completing the survey, participants were given the option to share their contact information to potentially participate in a follow-up interview. This information was provided via a separate link that was not connected to their survey responses. A total of 30 participants provided their contact information, and all were emailed or called to determine their interest in participating in an interview. Of those contacted, 15 agreed to participate in the follow-up interview, but three of those who agreed withdrew after schedule conflicts, resulting in a final sample size of 12.

Interview Conduct

Follow-up interviews were conducted by medium of the participant's choosing – phone calls, video chat, or email responses. Ten individuals participated via a phone interview, and one each participated via video chat and email response. Interviews were conducted by the third author and a team of undergraduate researchers, with at least two people (the third author and at least one undergraduate assistant) present for each interview to assist with note-taking and clarification.

The follow-up interview was semi-structured, with researchers asking participants about the nature of their disability; how their disability impacts travel; their use of public transportation, travel services, and navigation apps (e.g., Google Maps, Waze, etc.); their positive and negative experiences when traveling; and what they think would help improve their travel and navigation experiences. Participants who expressed interest (e.g., provided their contact information after the survey in a separate link) were contacted via email to ascertain their continued willingness to be interviewed. Interviews were scheduled at the participant's convenience, and were conducted via phone or video chat. All interviews were audio-recorded and transcribed verbatim by members of the research team. Interviews took between 20 and 40 minutes.

Data Analyses

Survey Data

Quantitative data analyses were conducted for survey data. These analyses included descriptive statistics, one-way ANOVAs comparing reported difficulty amongst all types of disability, and t-tests comparing level of reported difficulty by gender and presence/absence of a given type of disability. Pearson product-moment correlations assessed relationships between reported difficulty and total number of disabilities endorsed. Because of the large number of comparisons, the alpha level was set at .01.

Interview Data

Qualitative analysis for interview data was conducted using content analysis (Sandelowski, 2000). A total of 32 initial codes were derived using Braun and Clarke's (2006) stages of thematic analysis, and codes were then combined into six themes: 1) benefits of travel options, 2) challenges of travel options, 3) structural challenges, 4) personal adaptations, 5) functionality of navigation apps, and 6) non-essential travel considerations. Each statement from a participant could fall under more than one code, if necessary. Two team members read over all transcripts separately for coding, then met to talk through discrepancies until 100% consensus was reached.

FINDINGS, CONCLUSIONS, RECOMMENDATIONS

Survey Results

Demographics

The survey sample included 160 adults with a range of disabilities and ages, with participants ranging from 18 to 81 years (mean = 51.8, *SD* = 16.1). The majority of respondents were white (91.3%; *n* = 146) and female (68.1%; *n* = 109). The breakdown of age by gender are summarized in Table 1.

Table 1 Age and Gender of Participants

Age	Male	Female	No Answer	Total
18-21	2 (1.3%)	4 (2.5%)	0 (0%)	**6 (3.8%)**
22-35	9 (5.6%)	14 (8.8%)	0 (0%)	**23 (14.4%)**
36-50	15 (9.4%)	20 (12.5%)	1 (0.6%)	**36 (22.5%)**
51-65	16 (10.0%)	40 (25%)	0 (0%)	**56 (35%)**
66+	4 (2.5%)	25 (15.6%)	1 (0.6%)	**30 (18.8%)**
No Answer	0 (0%)	6 (3.8%)	3 (1.9%)	**9 (5.6%)**
Total	**46 (28.8%)**	**109 (68.1%)**	**5 (3.1%)**	**160 (100%)**

Table 2 breaks down participation by race and ethnicity; note that these do not sum to 100% as participants could indicate that they belonged to more than one racial category. The large majority (91.3%) of participants identified as White/Caucasian.

Table 2 Race and Ethnicity of Participants

Race	Count (%)
Hispanic or Latino	4 (2.5%)
American Indian or Alaska Native	2 (1.3%)
Asian	5 (3.1%)
Black or African American	5 (3.1%)
Native Hawaiian or other Pacific Islander	2 (1.3%)
White/Caucasian	146 (91.3%)
Other/Decline to answer	6 (3.8%)
Multiracial	7 (4.4%)
Total	**160**

Table 3 displays the living environment of respondents. While about 41% lived in urban environments, over half lived in suburban or rural areas. This residential heterogeneity is important as it serves as a reminder that solutions developed for urban areas may not be readily available to a large proportion of PWD.

Table 3 Living Environment of Participants

Living Environment	Count (%)
Urban	66 (41.3%)
Suburban	58 (36.3%)
Rural	35 (21.9%)
No Answer	1 (0.6%)
Total	**160**

A breakdown of employment by age is displayed in Table 4**Error! Not a valid bookmark self-reference.**. Note that 60% of respondents were unemployed, a much higher proportion than in the general population, which reinforces that solutions to mobility problems should not assume that users have discretionary income available.

Table 4 Age and Employment Status of Participants

Age	Employed/School	Unemployed	No Answer	Total
18-21	0 (0%)	6 (3.8%)	0 (0%)	**6 (3.8%)**
22-35	13 (8.1%)	10 (6.3%)	0 (0%)	**23 (14.4%)**
36-50	22 (13.8%)	13 (8.1%)	1 (0.6%)	**36 (22.5%)**
51-65	17 (10.6%)	39 (24.4%)	0 (0%)	**56 (35%)**
66+	4 (2.5%)	25 (15.6%)	1 (0.6%)	**30 (18.8%)**
No Answer	2 (1.3%)	3 (1.9%)	4 (2.5%)	**9 (5.6%)**
Total	**58 (36.3%)**	**96 (60%)**	**6 (3.8%)**	**160 (100%)**

Disabilities

Participants were asked to indicate what disability/disabilities they had from a list of common disability categories. In addition, disabilities that were not listed could be entered under the appropriate category. This allowed respondents to provide comprehensive information regarding specific disabilities and mitigating tools used in conjunction with disabilities. For example, individuals suffering from physical disabilities may use powered scooters or walkers for mobility. A large majority of participants reported having a physical disability (76.9%; n = 123), and roughly a quarter of participants reported having a sensory disability (26.3%; n = 42). Two-fifths of the participants (40.0%; n = 64) reported having more than one disability category. The full breakdown of included disabilities is detailed in Table 5.

Table 5 Count of Disability Types

Disability Type	N	%
Intellectual /Developmental (IDD)	22	13.8%
Learning (LD)	12	7.5%
Physical (Phys)	123	76.9%
Psychiatric (Psyc)	22	13.8%
Sensory (Sens)	42	26.3%
Communication (Comm)	17	10.6%
Other (Oth)	29	18.1%
Multiple Disabilities	**64**	**40.0%**

To identify the relationships of reported disabilities, Table 6 displays the correlations of disability types within individuals. The most common comorbid disabilities were IDD with communication as well as sensory with communication disabilities.

Table 6 Correlation of Comorbid Disabilities (* indicates significance at $p<0.05$)

	IDD	LD	Phys	Psyc	Sens	Comm	Other
IDD	-	0.16*	-0.17*	0.05	0.09	0.33*	0.05
LD	0.16*	-	-0.13	0.23*	0.1	0.06	-0.01
Phys	-0.17*	-0.13	-	0	-0.08	0.1	-0.13
Psyc	0.05	0.23	0	-	0.13	0.04	-0.05
Sensory	0.09	0.1	-0.08	0.13	-	0.26*	0.01
Communication	0.33*	0.06	0.1	0.04	0.26*	-	0.21*
Other	0.05	-0.01	-0.13	-0.05	0.01	0.21*	-

Specific disabilities within the seven main categories of disabilities were identified to obtain additional information from the individuals on potential mobility issues as they relate to disabilities.

Table 7 describes further counts of disabilities among participants. Physical disabilities capture proxy information related to the specific disability, namely, mobility aides that assist the respondent due to some unnamed physical constraints.

Table 7 Counts of Specific Disabilities among Disability Categories

Disability Type	N	%
Intellectual /Developmental	**22**	**13.8%**
Autism	7	4.4%
Down syndrome	2	1.3%
Williams syndrome	1	0.6%
Prader-Willi syndrome	1	0.6%
Other (please describe)	11	6.9%
Learning	**12**	**7.5%**
ADHD	9	5.6%
Dyslexia	3	1.9%
Specific language impairment	3	1.9%
Language processing disorder	3	1.9%
Nonverbal learning disability	3	1.9%
Other (please describe)	2	1.3%
Physical	**123**	**76.9%**
Manual wheelchair	34	21.3%
Power wheelchair	41	25.6%
Walker	36	22.5%
Cane	42	26.3%
Other (please describe)	27	16.9%
None	22	13.8%
Psychiatric	**22**	**13.8%**
Depression	19	11.9%
Anxiety	17	10.6%
Bipolar Disorder	4	2.5%
Schizophrenia	1	0.6%
Other (please describe)	3	1.9%
Sensory	**42**	**26.3%**
Blindness	11	6.9%
Deafness	10	6.3%
Sensitivity to noise	19	11.9%
Sensitivity to light	15	9.4%
Other (please describe)	15	9.4%
Communication	**17**	**10.6%**
Other	**29**	**18.1%**
Multiple Disabilities	**64**	**40.0%**

Transportation Modalities

Participants were asked about the frequency of use for different transportation modalities; these results are summarized in Figure 1. The majority of participants (59.4%, n = 95) reported using mobility equipment at least a few times per week, with 21.9% (n = 35) of survey respondents not needing or using mobility equipment for getting around. Almost half of the participants (46.3%; n = 74) drove using a personal vehicle at least a few times per week, while most of the remaining participants (41.8%; n = 67) reported never driving a personal vehicle. Participants reported higher rates of car use as a passenger, in which only 9.4% (n = 15) of people reporting never or almost never being a passenger in a car. Nearly half of participants reported using public transportation at some point (44.4%, n = 71), though only a small sample uses it at least a few times a week (10.0%, n = 16).

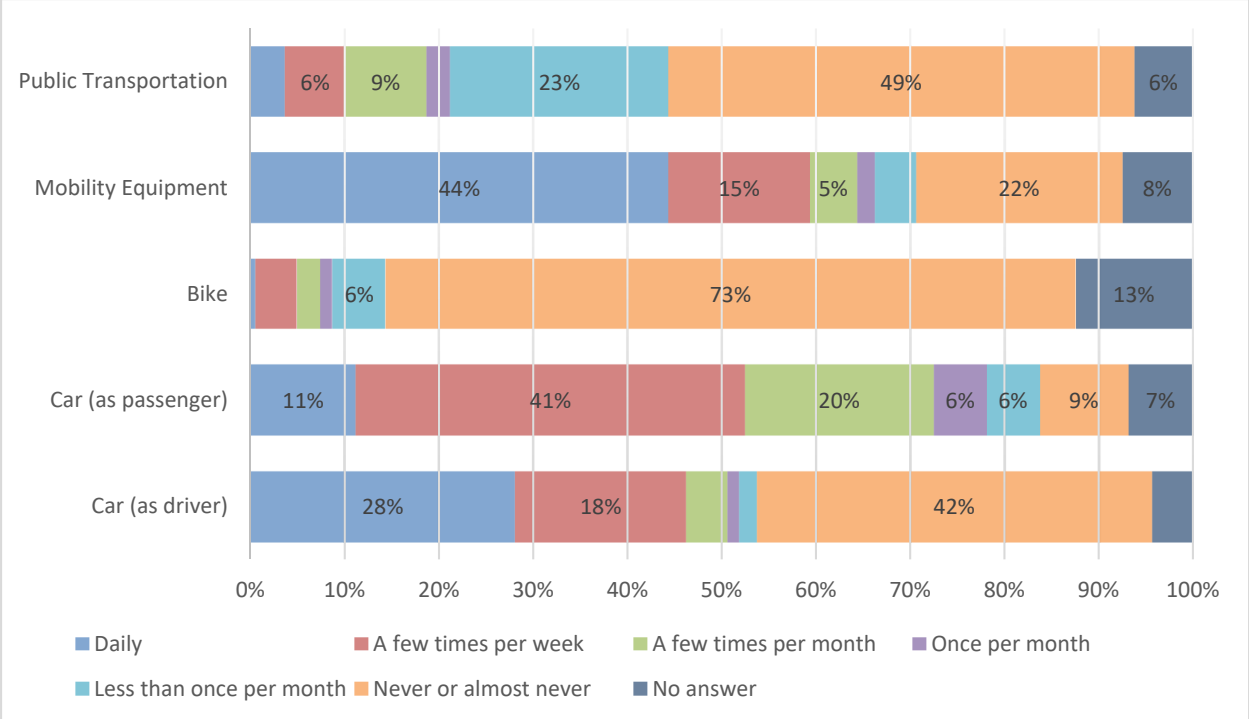

Figure 1. Frequency of use by transportation modality.

Transportation modalities were then categorized by frequency of use for only participants with some form of physical disability (n = 123; Figure 2) and/or sensory disability (n=42; Figure 3). As noted above in *Table 6*, participants did not frequently have both physical and sensory disabilities as they had other types of comorbid disabilities. Despite this, there are many similarities in the transportation modalities used as well as the frequency of utilization.

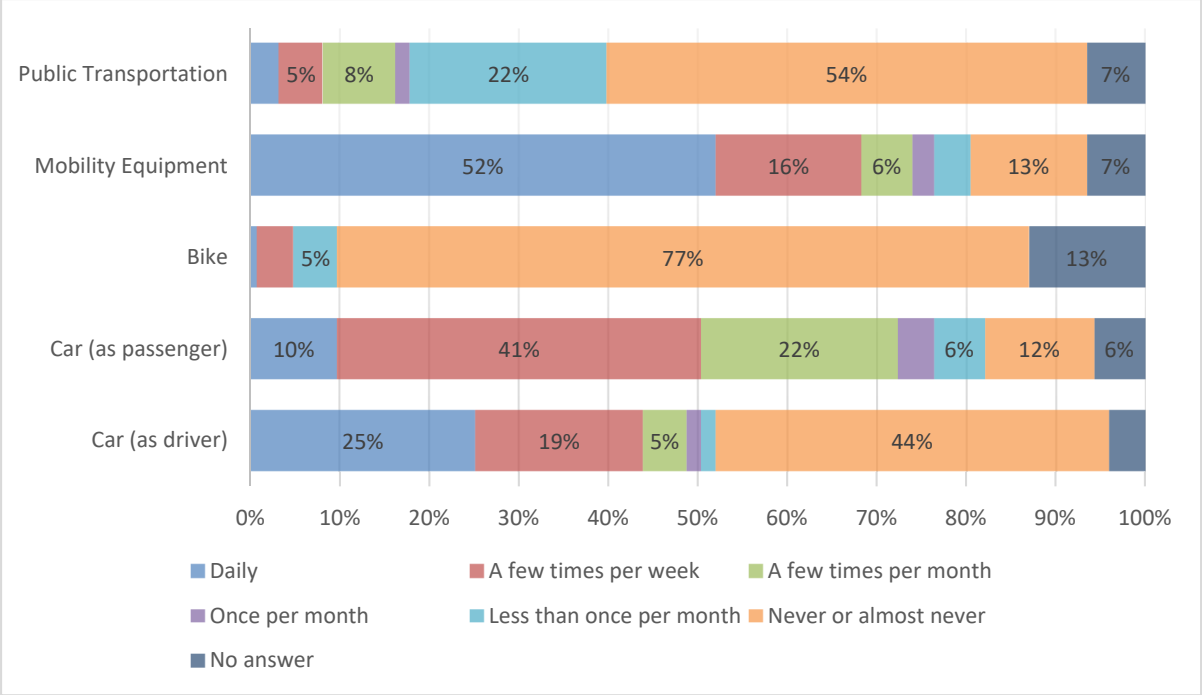

Figure 2. Transportation breakdown for people with physical disabilities only. Values <5% are not reported for clarity.

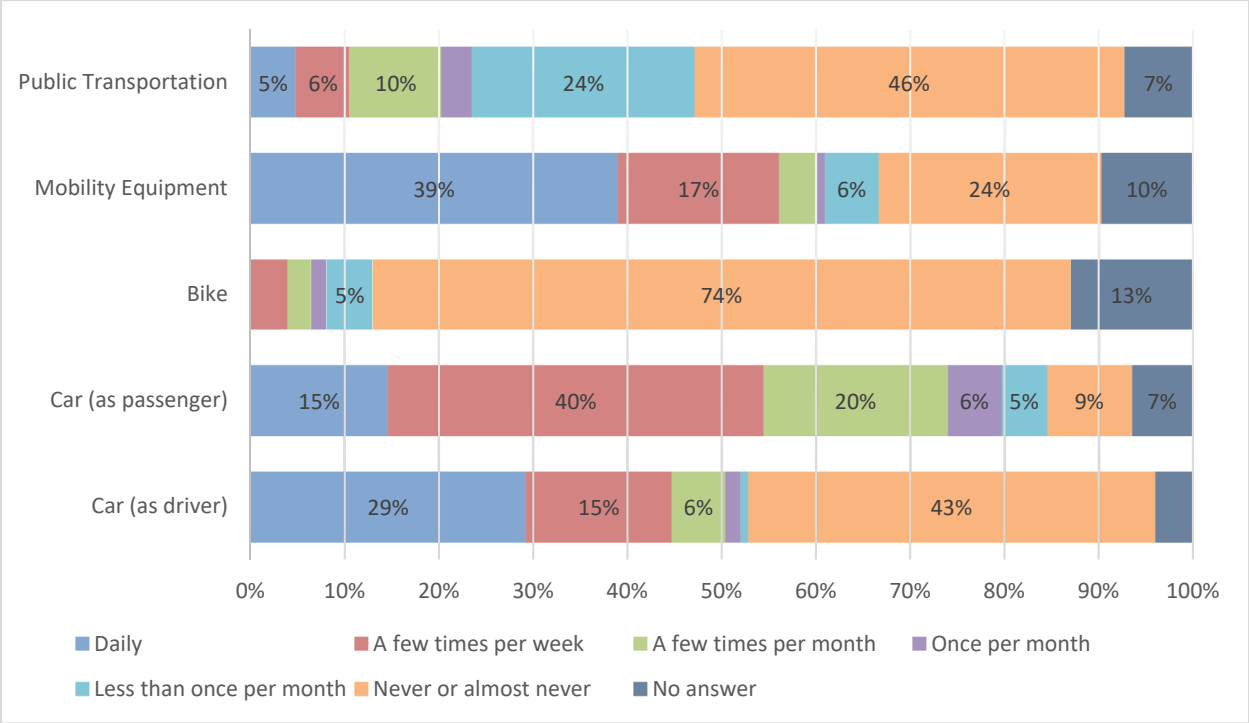

Figure 3. Transportation breakdown for people with sensory disabilities only.Values <5% are not reported for clarity.

Respondents identified how often they would leave their home and for what functional purposes; these values are reported in Figure 4. Participants traveled at least a few times per month nearly equally for work or school, socialization, and errands. The most frequent responses for the 'other' category included church, doctors' appointments, physical therapy, and exercise-related traveling.

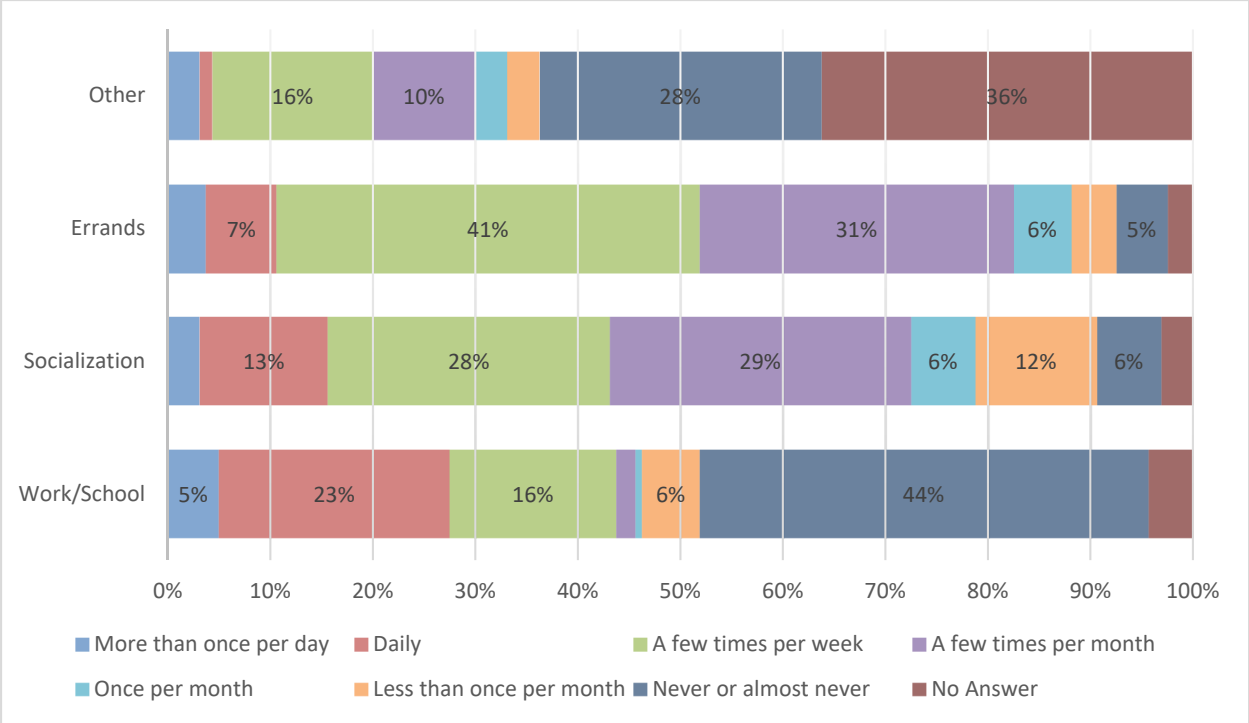

Figure 4. Frequency of travel by purpose. Values <5% are not reported for clarity.

Barriers to Public Transportation Use

Of those that use public transportation (n = 51; Figure 5), participants' reported largest barrier was getting where they needed to go (e.g., public transportation routes covering places that the participants needed to go; mean = 46.2, *SD* = 36.0), while the least-recognized barrier was being treated differently (mean = 23.7, *SD* = 29.7), on a scale of '0'(not much of a problem) to '100'(a very serious problem). However, all reported barriers had wide variability, with standard deviations ranging from 29.7 to 36.6 and all ranges of responses covering 0-100, suggesting substantial variance in experiences among participants. Figure 5 displays means and standard errors of the six listed barrier categories using public transportation for all participants, with additional means detailed for individuals with the each of the two most common disability types, physical and sensory disabilities.

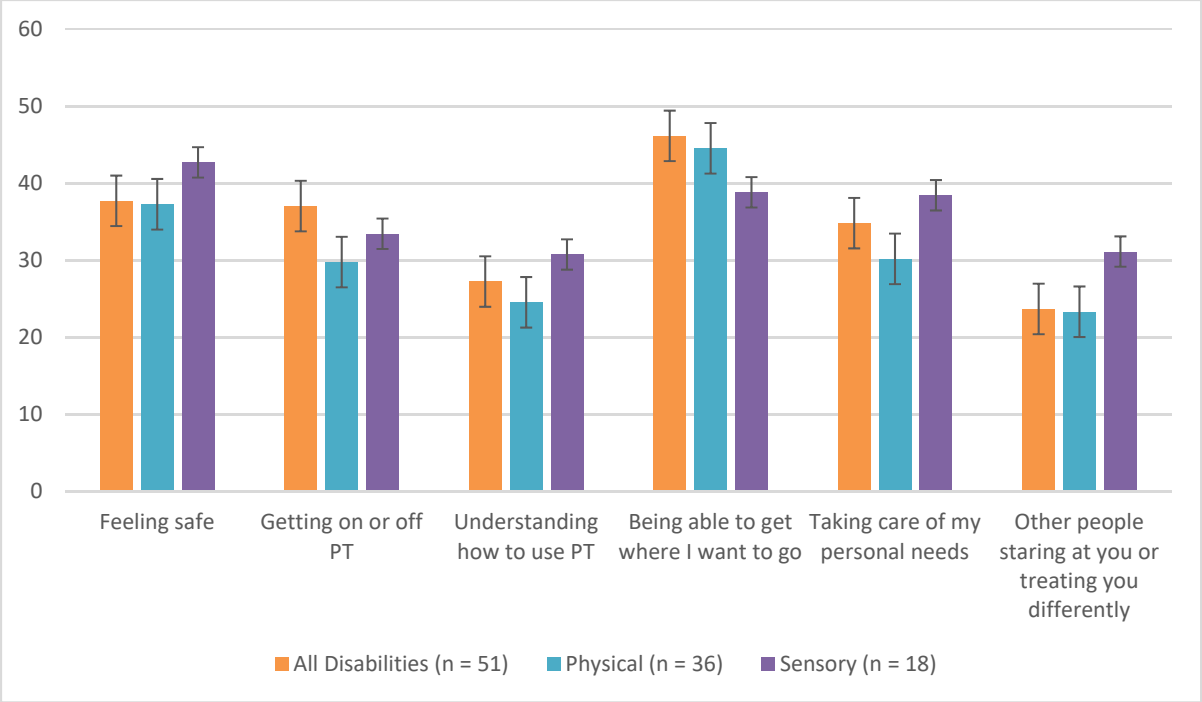

Figure 5. Barriers faced by those who use public transportation.

The second scale utilized in the survey measured barriers using transportation other than public transportation modalities. This scale was created to reflect a number of issues that individuals may experience. This scale (Appendix D; Items 7(i) through 7(xiv)) had high internal reliability (Cronbach's alpha = 0.90). Further, two factors were identified using principal components analysis with Varimax rotation, one relating to *physical traversal of route elements*, the second related to *informational and environmental route elements*. The items within each factor are presented in *Table 8.*

Table 8 Factor Label and Item Loadings on Two Factors of the Barriers Using Other Transportation Measure

Factor 1: Physical Traversal	Factor 2: Informational and Environmental
Route is too steep or at a difficult angle	Route isn't smooth
Route is slippery	Figuring out what street you're on
Route is damaged or not usable	Figuring out which entrance to go to
Route is too narrow	Following directions for how to get around
Getting across the street before the signal changes	Route is too crowded
Getting onto or off the sidewalk	Route is too noisy, bright, or smelly
Getting into or out of buildings with ease	Knowing when or where it is OK to move

Similar to public navigation, all navigation-related challenges that were presented to participants (Figure 6) shared moderate severity averages (range from 19.3 "knowing when or where it is OK to move" to 48.6 "route isn't smooth") and large standard deviations (range from 28.0 to 36.2). These challenges are listed, with averages and standard errors, in Figure 7, for all participants, as well as for each category of participants with physical and sensory disabilities.

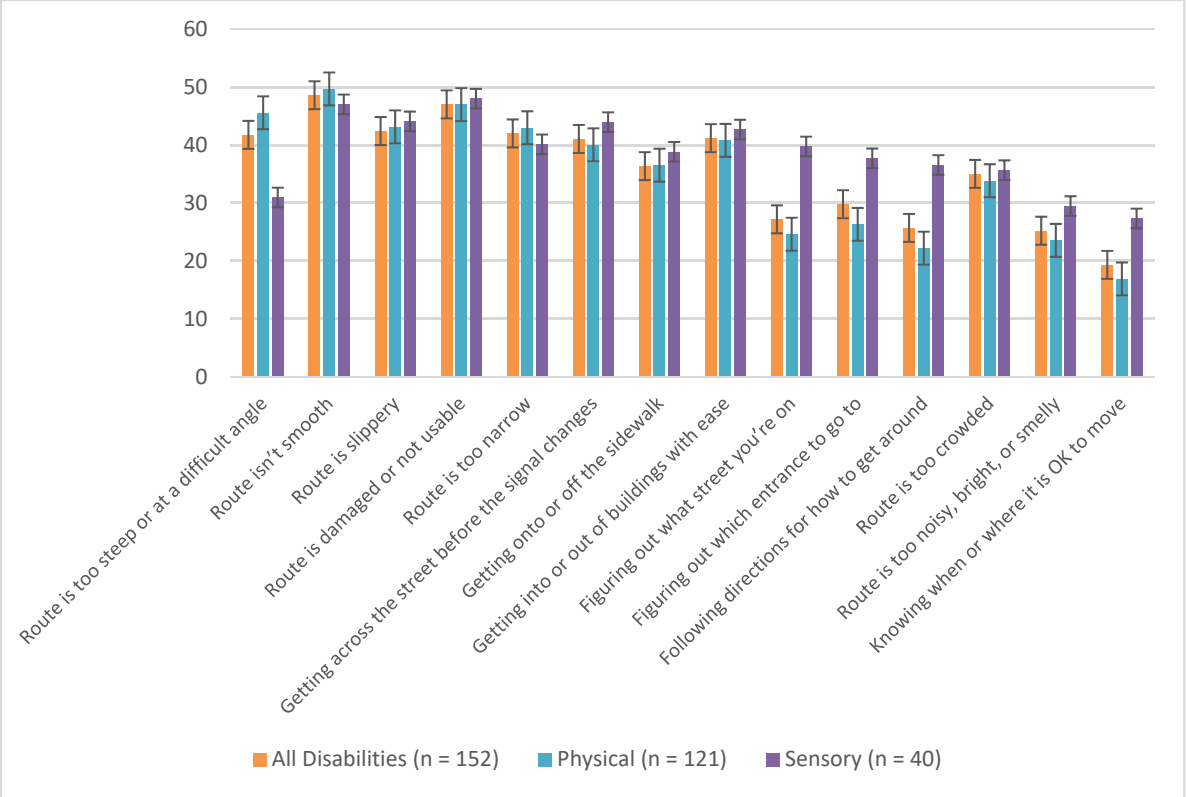

Figure 6. General challenges facing navigation.

Participants with sensory (but not comorbid with physical) disabilities reported higher difficulties ($t = 2.48$, $p = 0.015$) with the informational and environmental route elements than individuals with physical (but not comorbid with sensory) disabilities. However, when factoring age as a covariate, results were nonsignificant ($F = 2.408$, $p > 0.05$). This finding suggests that younger individuals with sensory disabilities have more difficulties with informational and environmental route elements than older individuals (for example, individuals 35 and younger averaged "difficulty following directions" 52.2 on average, where older individuals averaged 37.6). An element of experience may temper difficulties or barriers faced for those with sensory disabilities. This pattern did not hold for individuals with other disability types.

A correlational matrix (Table 9) outlines select relationships between demographics (age, education level), barriers to navigations (public transportation, physical traversal, informational and environmental), frequency of transportation modality (car as driver, car as passenger, bike, mobility equipment, public transportation), and frequency of travel purpose (work or school, socialization, errands). A number of interesting observations are present. First, individuals who had difficulty with some aspect of navigation likely had difficulties with other facets of navigation. For example, individuals with difficulties with public transportation had higher difficulty with the informational or environmental aspects of travel ($r = 0.607$, $p < 0.05$). Second, younger individuals were not only more likely to travel to work or school more often, but also to travel for socialization purposes and utilize public transportation as well as a car as a passenger. These younger individuals also reported having a higher number of disabilities across categories ($r = -0.303$, $p < 0.05$), which is reflective of the sample in which older individuals have physical disabilities at a higher rate than younger individuals (69.2% in 35 years or younger versus 84.9% in 36 and older). Likely because of this, older participants reported higher difficulties of physical traversal ($r = 0.263$, $p < 0.05$). Third, individuals who drive a car reported more frequent travel for all purposes. These individuals also had higher levels of education and fewer physical difficulties traveling.

Table 9 Correlational Matrix Among Demographics, Barriers, and Travel Modalities

	Total Disability Categories	Age	Highest Education	Public Trans Difficulties	Physical Traversal Difficulties	Inf Env Difficulties	Car as Driver	Car as Psngr	Bike	Mob Eqpmt	Pub Tran	Work or School	Social.	Errands
Total Disability Categories	1													
Age	-.303*	1												
Highest Education	-.224*	.345*	1											
Public Trans Difficulties	.184	.055	.139	1										
Physical Traversal Difficulties	.081	.263*	.011	.515*	1									
Inf Env Difficulties	.033	.045	.040	.607*	.241*	1								
Car as Driver	-.095	.135	.262*	.204	.174*	.135	1							
Car as Psngr	-.044	.250*	.225*	.112	.072	.076	.193*	1						
Bike	-.017	.133	.067	.144	.185*	.061	.178*	.077	1					
Mob Eqpmt	-.041	.111	.022	.079	.269*	.010	.158	.026	.186*	1				
Pub Tran	.029	.193*	.017	.217	.150	.060	.044	.093	.409*	.099	1			
Work or School	-.050	.456*	.030	.309*	.297*	.008	.259*	.213*	.255*	.204*	.329*	1		
Social.	-.117	.199*	.100	.379*	.162*	.046	.160*	.321*	.153	.042	.239*	.333*	1	
Errands	-.009	.115	.049	.329*	.219*	.008	.440*	.145	.230*	.003	.181*	.241*	.559*	1

Further exploration by type of disability yielded some clear distinctions. Individuals with physical disabilities reported more difficulties with the physical traversal of navigation (t = 4.034, $p < 0.001$), but fewer difficulties with the informational and environmental aspect (t = -1.991, $p < 0.050$). Generally, these individuals felt comfortable with the cognitive navigation, that is, following directions and knowing where they are, as compared to those individuals without physical disabilities. On the contrary, individuals with learning disabilities reported significantly fewer difficulties with physical traversal than individuals without learning disabilities (t = 2.504, $p < 0.050$). This relationship is further demonstrated by the slight negative correlation (r = -0.130) between learning and physical disabilities.

Individuals with sensory disabilities reported significantly higher difficulties using public transportation than individuals without sensory disabilities (t = 2.734, $p < 0.050$). An investigation into specific facets revealed that these individuals with sensory disabilities reported feeling less safe (t = 2.438), having more issues getting on or off public transportation (t = 3.149), and not having personal needs met (t = 3.987) than individuals without sensory issues (all $p < 0.050$). Understanding how to use public transportation, being able to get to their destination, and being treated differently were not significantly different for these individuals. This finding suggests an awareness of operational navigation, but a lack of obtaining necessary information or having basic needs met. For example, a transit bus stop may have multiple bus routes present, but buses may not be equipped with voice-announced route designations that assist blind individuals in getting on the correct bus. Similarly, detailing which bus stop is next along the route may not occur, or buses equipped with automated voice may be too quiet to hear consistently.

Survey Conclusions

There was wide variability in the challenges reported, with answers to each challenge ranging from 0-100 and sizeable standard deviations. This indicates substantial individual differences in transportation and navigation experiences. Further, although no individual challenge was rated higher than 50 (the midpoint of the scale) on average, there are still substantial numbers of PWD who experience high levels of difficulty with each presented situation.

Follow-Up Interview Results

Follow-up interviews were conducted with 12 participants who responded to the survey and were willing and able to engage in a telephone, video chat, or email interview to engage in more in-depth discussion with research personnel. Interview results were analyzed qualitatively by extracting important themes from discussions.

Thematic Findings

Transportation Modality Considerations

Although participants in more metropolitan areas generally had access to public transportation, none discussed any benefits to general public transit. If public transportation isn't *paratransit* (or similar), it was not generally seen as helpful or useful to PWD. Common drawbacks to public transportation included lack of stop accessibility; limited schedules, times, and accessible information; driver limitations (including inability to provide assistance to riders with disabilities or help during medical emergencies); and regional variations in services.

Paratransit was seen in a more positive light; however, it also has drawbacks, as it requires prior planning, can take significantly longer, may have a limited schedule or availability, and may have inaccuracies that can affect service or timing. Rideshare services were mentioned as an alternative, but these services have limitations for PWD including physical accessibility (particularly for wheelchairs) and availability of information (e.g. route options and cost) for people with low vision.

Participants also discussed travel beyond local transit, including flying for both work and leisure. One important take-home here was that PWD should be afforded the same leisure and travel options as the non-disabled population, which is an area that is not often focused upon in studies of equity and transportation.

Structural Challenges

Participants identified a number of structural challenges to mobility. These included perpetual issues, such as lack of building ramps, missing curb cuts, and poorly-maintained sidewalks, weather-related issues, such as snow being plowed over curb cuts or into accessible parking spaces, and driver behaviors including disregarding crosswalks and

parking improperly to block vehicle ramp access. Participants reported a variety of personal adaptations, including memorizing the layout of stores, modifying their travel timing to maximize the likelihood of finding parking, and bringing along a portable ramp to ease access.

Technology Usage

Participants reported utilizing a variety of popular navigation apps, including Google Maps, Waze, and Apple Maps. For general navigation for people without vision impairments, these often provide useful information, but they generally do not provide any functionality specific to PWD, including locations of accessible parking spots, warnings about missing, uneven, or broken sidewalks, etc. Specific apps designed for PWD were mentioned by several participants, including *Be My Eyes*[1] that enlists the help of volunteers to identify relevant information (e.g. street signs) through a user's smartphone camera and *Parking Mobility*[2] that provides information about accessible parking as well as enabling users to report vehicles that violate accessible parking space rules.

Participants also discussed ways in which future technologies could help remove or bypass barriers to transportation. These included better indicators of accessible parking; structural indicators and warnings such as ways to avoid steps, steep or broken routes, and crossing signals with button input; destination-specific information such as accessibility and temperature information; ways to contact industries for accessibility and traveler information; and usability preferences for technology itself including customizability and high-contrast display options.

Representative Quotes

Beyond thematic analyses, representative quotes were extracted from interviews to illustrate salient points. Here we present a variety of these quotes to help contextualize some of the information presented above:

[1] http://www.bemyeyes.com
[2] http://www.parkingmobility.com

- "Since I have become wheelchair-bound, it has been so difficult flying... I can't get through to these airlines [about] what kind of help I need." (P11, female, hypokalemic periodic paralysis)
- "I talk about it often in 'the economy of steps' - I need to plan my routes pretty carefully and safely." (P12, male, left side weakness resulting from hemorrhagic stroke)
- "[Paratransit] dropped me off 45 minutes from where I was supposed to be[...]They also dropped me off five places down at my neighbor's[...] it was pouring down rain." (P3, female, optic dysplasia)

Interview Conclusions

The follow-on interviews provided more detail and context to support the findings of the survey. These interviews demonstrate how important it is to hear individual voices within the disability community, in particular their generation of barriers and ideas that may not have been considered during development of a fixed-response survey.

General Conclusions

In conclusion, this study provided a large-scale, multi-modality investigation into the mobility-related challenges and barriers facing people with a wide range of disabilities, including physical, perceptual, intellectual & developmental, and a mix of these. This provided an unprecedented opportunity to identify the scope and scale of the issues PWD face when traveling locally or afar. The results of this study stand alone as a valuable contribution to the state of knowledge on transportation and PWD, and additionally support the development of an ongoing CATM project developing a navigation platform for PWD.

Participants in this study had a wide range of disabilities, including physical (77%), sensory (26%), and IDD (14%); 40% of participants had more than one disability. Significant numbers of people with IDD or sensory disabilities reported also having communicative disabilities. Participants reported using a variety of means of transportation, with riding in a car being most prevalent and using a bicycle being the least prevalent. Surprisingly, relatively few people reported using public transit, with less than 20% using it a few times a

month or more. Most participants reported traveling outside their homes at least a few times per month, with more than half reporting traveling a few times a week or more for errands.

Survey questions focused on the barriers facing PWD when traveling. At a high level, a wide and heterogeneous range of general challenges face PWD. Respondents rated many of these as moderately to severely challenging, including route surface characteristics, building entrance/egress, and route information availability, which is particularly challenging for people with sensory disabilities. People with physical disabilities tended to report more difficulty with the physical aspects of navigation, such as traversing broken or slippery surfaces, while people with sensory disabilities had more difficulty with informational aspects of travel.

The highest-rated barrier to public transportation use was "*Being able to get where I want to go*." People with sensory disabilities tended to have higher difficulty using public transit in general, but also particularly with feeling less safe, having more issues embarking and disembarking, and having issues with getting personal needs met. Interestingly, participants who reported difficulty with some aspects of transportation tended to list difficulty with others, suggesting that there may not be simple answers to overcoming transportation barriers for some PWD. Older adults were more likely to have physical disabilities, which correlated with higher difficulty in physically traversing the environment.

A follow-up series of interviews provided more in-depth and nuanced information about transportation challenges. Here, participants discussed specific challenges they encounter when traveling, including transportation modality, structural concerns, and technology usage. Participants remained skeptical about public transit, citing a number of physical, informational, and scheduling challenges to this being an acceptable form of transportation. Paratransit was somewhat endorsed, but has its own challenges including limited scheduling and overcrowding. Numerous structural concerns were noted, particularly for people with disabilities, including issues with sidewalk and ramp integrity and weather-related issues (for example, lack of snow plowing at curb cuts). Participants also discussed their experiences with technology, including existing navigation apps, along with what features and functions could best improve their transportation experience. Particularly notable was just how

important it is that technology be specific to the wide variety of needs experienced by this varied group of users.

Overall, for people with physical disabilities, the highest priority difficulty was their significantly greater trouble with physically demanding routes (steep, slippery, etc.). In this case, key to overcoming this barrier is either improvement of the physical structure of the environment – a worthy long term goal, but optimistic in the short term – and/or the development of tools that can help users bypass particularly demanding or impassable aspects of routes. People with perceptual disabilities reported greater trouble meeting their personal needs when using public transportation, and indeed tended to have report difficulty with public transportation in general than people with other types of disabilities. This is somewhat surprising given the physical challenges surrounding entrance into and egress from public transportation vehicles, and strongly supports that the informational needs of travelers with disabilities must be addressed in a way that supports all users. Relatedly, people with IDD reported greater trouble following directions and knowing when or where it is ok to move, further indication that transportation-related information must be presented both multi-modally but also in ways that can support the needs of people with intellectual disabilities. For example, designers of transportation system maps and schedules may work with disability advocates to make these more easily interpretable to a broad audience of users; in agreement with the principles of Universal Design, such modifications could benefit the user base as a whole.

To conclude, this study found that there is an extremely varied and heterogeneous set of transportation-related challenges and barriers facing PWD, all of which must be considered when developing future transportation systems and technology. Input from a wide range of stakeholders with disabilities is absolutely essential when developing transportation-related technology, protocols, tools, or policies. Individuals with different types of disability have very different experiences, so when trying to promote inclusivity and access, researchers, designers, and policymakers need to work with the disability community to create the most inclusive systems possible. There is a significant amount of variance in what people need, what difficulties they experience and where, and how - and how often - they use varying

modalities of travel. Although this project was able to capture overarching generalizations, the ultimate reality is that individuals with disabilities have very specific and often unique combinations of needs and challenges that warrant a platform that can capture these individualized needs by allowing them to focus on what is important to them, and to enable them to overcome very personal barriers.

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APPENDIX A: LIST OF CONTACTED ORGANIZATIONS

Organization	Location	Organization	Location
ARC- Richmond, Chapter 22	Halifax, VA	Here and Now Project	Sumner, WA
A Step Toward Hope	Nationwide	Homebridge	San Francisco, CA
Acess Living	Chicago,IL	HOPE after Brain Injury	Arlington, TX
ADAPT-Community Network	New York, NY	IncludeNYC	New York, NY
Adaptive Sports Foundation	Windham, NY	Independent Living Resource Center of San Francisco	San Francisco, CA
Adelante Development Center	Albuquerque, NM	Iowa Paraluzed Veterans of America	Urbandale, IA
Adult Loss of Hearing Association	Tucson, AZ	Jewish Family & Career Services	Atlanta, GA
Adult Services at the Asperger/Autism Network	Watertown, MA	Just People, Inc.	Nocross, GA
Adult Services at the Asperger/Autism Network	Watertown, MA	Learning Disabilities Association of New York State	Kenmore, NY
Advocacy Center of Louisiana	New Orleans, LA	Liberty Resources	Syracuse, NY
Alaska Brain Injury Network	Anchorage, AK	Lighthouse for the Blind and Visually Impaired	San Francisco, CA
Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell)	Washington, DC	Little people of America-District 2	NJ, NY & PA
ALS Association	Washington , DC	Lone Star Paralysis Foundation	Austin, TX
ALS Association- DC/MD/VA Chapter	Rockville, MD	Mental Health Association of San Francisco	San Francisco, CA
American Association on Developmental and Intellectual Disabilities	Washington, DC	Michael Feger Paralysis Association	Shelbyville, KY
American Council of the Blind	Alexandria, VA	Minnesota Brain Injury Alliance	Roseville, MN

American Foundation for the Blind (AFB)	1401 South Clark Street, Suite 730 Arlington VA 22202	Multiple Sclerosis Association of America	Cherry Hill, NJ
Amputee Association of Maine	Falmouth, ME	Muscular Dystrophy Association	Chicago, IL
Amputee Coalition	Knoxville, TN	Muscular Dystrophy Association- NC Chapter	Greensboro, NC
Arthiritis Foundation- California Chapter	Los Angeles,CA	Muscular Dystrophy Family Foundation	Carmel, IN
Asperger Syndrome & High Functioning Autism Association	New York, NY	Muscular Dystrophy Family Foundation	Carmel, IN
Autism Society of Greater Orlando	Orlando, FL	National Center for Learning Disabilities	New York, NY
Autism Speaks- Atlanta, GA	900 Circle 75 Parkway, Suite 445 Atlanta, GA 30339	National Down Syndrome Society- HQ	8 E 41st street New York, NY
Autism Speaks- Boston, MA	85 Devonshire Street, 9th Floor Boston, MA 02109	National Institute or Neurological Disorders and Stroke	Bethesda, MD
Autism Speaks- Charlotte, NC	601 E. 5th Street, Suite 120 Charlotte, NC 28202	National Multiple Sclerosis Society	New York, NY
Autism Speaks- Florida	557 N. Wymore Road, Bldg. A, Suite 101 Maitland, FL 32751	National Multiple Sclerosis Society- Greater New England chapter	Waltham, MA
Autism Speaks -New York	1 East 33rd Street 4th Floor New York, NY 10016	National Multiple Sclerosis Society- New York City- Southern New York chapter	New York, NY

Autism Speaks- Princeton, NJ	1060 State Road, 2nd Floor Princeton, NJ 08540	National Multiple Sclerosis Society- Northern California chapter	San Francisco, CA
Bosma Enterprises	Indianapolis, IN	National Multiple Sclerosis Society-Virgina/West Virginia chapter	Glenn Allen, VA
Brain Injury Alliance of Arizona	Phoenix, AZ	National Organization on Disability	New York, NY
Brain Injury Alliance of Colorado	Denver, CO	Nebraska Center for the Blind and Visually Impaired	Lincoln, NE
Brain Injury Alliance of Connecticut	Windsor, CT	New York State Chapter of American Association of Orthotists and Prosthetists	Schenectady, NY
Brain Injury Alliance of Idaho	Boise, ID	Noble	Indianapolis, IN
Brain Injury Alliance of Iowa	Urbandale, IA	NRV Disability Resource Center	Christiansburg, VA
Brain Injury Alliance of Kentucky	Louisville, KY	Office for People with Developmental Disabilities	Albany, NY
Brain Injury Alliance of Nebraska	Lincoln, NE	Paralyzed Veterans of America	Washington, DC
Brain Injury Alliance of Oregon	Molalla,OR	Paralyzed Veterans of America: Central Florida Chapter	Sanford, FL
Brain Injury Alliance of Utah	Murray, UT	Paralyzed Veterans of America: Kentucky-Indiana Chapter	Jeffersonville, IN
Brain Injury Alliance of Washington	Seattle, WA	Paralyzed Veterans of America: Northwest Chapter	Burien, WA
Brain Injury Alliance of Wisconsin	Madison, WI	Paraquad	St.Louis, MO
Brain Injury Alliance of Wyoming	Casper, WY	People with Disabilites Foundation	507 Polk Street, Suite 430 San Francisco, CA
Brain Injury Association of America	Vienna, VA	Periodic Paralysis Association	New York, NY
Brain Injury Association of America-Virginia chapter	Richmond, VA	Prader Wili Syndrome Association-Wisconsin	Menasha, WI

Brain Injury Association of California	Bakersfield, CA	Prader-Wili Alliance of New York	New York, NY
Brain Injury Association of Delaware	Dover, DE	Resources for Human Development	Philadelphia, PA
Brain Injury Association of Florida	Tallahassee, FL	Resources for Human Development-Rhode Island	Pawtucket,RI
Brain Injury Association of Georgia	Atlanta, GA	Special Olympics	Washington D.C.
Brain Injury Association of Illinois	Chicago, IL	Spina Bifida Advocates of Washington State	Colbert, WA
Brain Injury Association of Indiana	Indianapolis, IN	Spina Bifida Associatio of the Carolinas	Indian Trail, NC
Brain Injury Association of Kansas and Greater Kansas	Overland Park, KS	Spina Bifida Association of Alabama	Gadsden, AL
Brain Injury Association of Maryland	Baltimore, MD	Spina Bifida Association of Colorado	Denver, CO
Brain Injury Association of Massachusetts	Westborough, MA	Spina Bifida Resource Network	Flemington, NJ
Brain Injury Association of Michigan	Brighton,MI	Spinal Cord Injury Association of Illinois	Palos Heights, IL
Brain Injury Association of Mississipi	Jackson,MS	Spinal Rap - Northwest Ohio chapter	Maumee, OH
Brain Injury Association of Missouri	Saint Louis, MO	Stroke Association	Centennial, CO
Brain Injury Association of New York State	Albany, NY	Support for families of children with disabilities	San Francisco, CA
Brain Injury Association of North Carolina	Raleigh, NC	Texas Brain Injury Alliance	Austin, TX
Brain Injury Association of Oklahoma	Tulsa, OK	The Arc of Texas	Austin, TX
Brain Injury Association of Pennsylvania	Carlisle, PA	The Arc- Richmond, VA // Chapter #20	2147 Staples Mill Rd Richmond, VA 23230
Brain Injury Association of Rhode Island	East Providence,RI	The Arc- Richmond, VA // Chapter #21	Roanoke, VA
Brain Injury Association of South Carolina	Columbia, SC	The Arc- Richmond, VA // Chapter #22	Halifax, VA

Brain Injury Association of Tennessee	Nashville, TN	The Arc- Richmond, VA // Chapter #23	3600 Saunders Ave Richmond, VA 232287
Brain Injury Association of Vermont	Waterbury,VT	The Arc- The New River Valley, VA	Blacksburg VA, 24060
California Autism Foundation	4075 Lakeside Drive Richmond, California 94806	The Arc- West Virginia // Chapter #413	Clarksburg, WV 26302
California DeafBlind Services	San Francisco, CA	The Arc-San Francisco	San Francisco, CA
Center for Independence of the disabled	New York, NY	The Brain Injury Alliance of South Dakota	Sioux Falls, SD
Coalition of Texans with Disabilities	Austin, TX	The Greater Kansas City Spinal Cord Injury Association	Kansas City, MO
Crossroads of Western Iowa	Council Bluffs, IA	The New Jersey Institute for Disabilities	Edison, NJ
Cystic Fibrosis Foundation	Bethesda, MD	The Virginia Association of the Deafblind	Ashland,VA
Cystic Fibrosis Foundation - Virginia chapter	Richmond, VA	The WOW Center	Miami, FL
Cystic Fibrosis Foundation-Tennessee Chapter	Nashville, TN	Through the Looking Glass	Berkeley, CA
Cystic Fibrosis Foundation-Texas Chapter	Dallas, TX	Toolworks	San Francisco, CA
Dare2Tri	Chicago, IL	Tourette Asisociation of America-Southern California Chapter	Los Angeles,CA
Deaf Initiative in Technology	Rochester, NY	Travis Roy Foundation	Boston, MA
Disability Rights Wisconsin	Madison, WI	Travis Roy Foundation	Boston, MA
Disabled American Veterans	Cold Spring, KY	UCP- Central Minneosota	St. Augusta, MN
Disabled American Veterans-Roanoke branch	Salem, VA	United Cerebral Palsy Association of Greater Indiana	Indianapolis, IN
District of Columbia Speech-Language-Hearing Association	Washington, DC	United Cerebral Palsy Association-Oregon	Portland, OR

Down Syndrome Association of Central Floria	Winterpark, FL	United Cerebral Palsy Foundation	1825 K st. NW Suite 600 Washington, D.C.
Down Syndrome Association of Los Angeles	Van Nuys, CA	United Cerebral Palsy of the Golden Gate	Oakland, CA
Dreamscape Foundation	Naples, FL	United Spinal Association	Kew Garden, NY
Easterseals	141 W Jackson Boulevard; 1400A Chicago, IL	United Spinal Association-Connecticut Chapter	Wallingford, CT
Emerge	Columbia, MD	United Spinal Association of Virginia	Richmond, VA
ENDependence	Arlington, VA	United Spinal Association-Boston Chapter	Woburn, MA
Epilepsy Organization	Landover, MD	United Spinal Association-Iowa Chapter	Cambridge, Iowa
Epilepsy Organization-Virginia chapter	Charlottesville, VA	University of Iowa REACH (Realizing Educational and Career Hopes)	University of Iowa.
Florida Lyme Disease Association	Jacksonville Beach,Florida	Upstate Cerebral Palsy	Utica, NY
Florida Spinal Cord Injury Resource Center	Tampa, FL	Valey Center of the Deaf	Phoenix, AZ
Foundations for Independence - Cerebral Palsy of Utah	South Jordan, UT	Valley Center for the Blind	Fresno,CA
Frazer Center	Atlanta, GA	Virginia Board for People with Disabilities	Richmond, VA
Gigi's Playhouse	Hoffman Estates, IL	Washington State Association of the Deaf	Puyyalup, WA
Golden Gate Regional Center	San Francisco, CA	Williams Syndrome Association- New York Metropolitan Region	NYC, NY
Hearing and Speech Center of Northern California	San Francisco, CA	Wounded Warrior Project	Jacksonville, FL
Helping Hands for the disabled of NYC	Astoria.NY	Wounded Warrior Project-Washington DC chapter	Washington, DC

APPENDIX B: SURVEY WELCOME SCREEN

Thank you for your interest in our study. This study was developed by researchers at Virginia Tech and the Virginia Tech Transportation Institute. We are trying to learn about the experiences and needs of people with disabilities when they travel. We want to make it easier for people with disabilities to move through the world. To learn more about the survey and then decide if you want to answer the questions, please click one of the following options:

[The following are clickable buttons]

I am over the age of 18 and have the legal capacity to provide consent

Links to page with consent form information

I am over the age of 18. I have a legal guardian that must provide permission before I can engage in research activities

Links to page with permission information, which then leads to page with assent information

I am the legal guardian of a ward over the age of 18 who does not have the legal capacity to provide consent.

Links to page with permission information, which then leads to page with assent information

I am younger than 18

Links to page thanking them for interest but saying they cannot participate

APPENDIX C: CONSENT, ASSENT, AND GUARDIAN PERMISSION FORMS

Virginia Polytechnic Institute and State University

Consent Form for Participants in Research Projects Involving Human Subjects

Title of Project: Analysis of the Non-Driving Mobility Needs of People with Disabilities

Investigators: Carolyn Shivers, Ph.D. shivercm@vt.edu/ (540) 231-5434

Justin Owens, Ph.D. jowens@vtti.vt.edu / (540) 231-1010

I. The Purpose of this Research

We are doing this study to learn more about how people with disabilities travel. We want to see what challenges people with disabilities face as they travel outside their home. This study will be used to find ways to help people travel safely.

We plan to gather data from 300 people with disabilities, age 18 and up.

II. Procedures

This study uses an online survey of approximately 40 questions to gather information from individuals about how they travel and what kinds of challenges and barriers they encounter

when traveling. You will complete the survey about your own experiences traveling and navigating around your community. It will take you up to 20 minutes to complete the survey.

III. Risks

There is very little risk involved in this study. The minimal risks include possible minor discomfort from expressing your opinions. You are free to skip any question that you are uncomfortable answering.

IV. Benefits

While there are no direct benefits to you, your answers will help us better understand how to support individuals with disabilities as they navigate around their communities.

No promise or guarantee of benefits has been made to encourage you to participate.

V. Extent of Anonymity and Confidentiality

At the end of the survey, you will be offered the choice to share your contact information (name, email address, and/or phone number) if you would like to be contacted for a follow-up interview. This is entirely voluntary, and the contact information will be provided through a separate link. Personal information will not be connected in any way to survey responses. All survey materials that you complete will be identified by a code number, not by name, and stored in a secure electronic database. Your responses will be made available in an online database for use by other researchers for future projects, but they will be anonymous and not associated with your name or other information that can be used to identify you.

The Virginia Tech (VT) Institutional Review Board (IRB) may view the study's data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research.

VI. Compensation

There is no compensation provided for participation in this study.

VII. Freedom to Withdraw

It is important for you to know that you are free to withdraw from this study at any time without penalty. You are free not to answer any questions without penalty.

VIII. Subject's Responsibilities

You have the following responsibilities:

Complete the online survey, with questions about your experience traveling and navigating around your community, including barriers or challenges experienced.

IX. Questions or Concerns

Should you have any questions about this study, you may contact one of the research investigators whose contact information is included at the beginning of this document.

Should you have any questions or concerns about the study's conduct or your rights as a research participant, or need to report a research-related injury or event, you may contact: Virginia Tech Institutional Review Board for the Protection of Human Subjects

Telephone: (540) 231-3732

Email: irb@vt.edu

X. Consent

I have read the Consent Form and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent to participate in this study:

[will have checkbox here to enable survey initiation]

Virginia Polytechnic Institute and State University

Assent of Participants in Investigative Projects

Title of Project: Analysis of the Non-Driving Mobility Needs of People with Disabilities

Investigators: Carolyn Shivers, Ph.D. shivercm@vt.edu/ (540) 231-5434

Justin Owens, Ph.D. jowens@vtti.vt.edu / (540) 231-1010

I. What This Study is About

We are doing this study to learn more about how people with disabilities travel. We want to see what challenges people with disabilities face as they travel outside their home. This study will be used to find ways to help people travel safely.

II. Why You Qualify for this Study

You qualify for this study because you have a disability, and you are at least 18 years old.

III. Voluntary Participation

Your participation in this study is your choice. You can decide if you want to complete the online survey, with no pressure from others.

IV. Study Procedures

For this study, you will fill out an online survey of about 40 questions, which should take about 20 minutes. After you finish the survey, you will be taken to a separate survey and will have the option of providing your contact information, if you would like us to contact you in the future with more questions about your travel experiences.

Your participation in the study will be confidential, meaning that no one will know which answers are yours.

V. Potential Benefits and Risks

Your insight into your experiences as a person with a disability will help us understand how to make traveling safer and easier for people with disabilities. We will use the information you provide, along with the information from other people, to help create tools to support people with disabilities when they travel. Your answers will be made available in an online database for use by other researchers for future projects, but they will not associated with your name or other information that can be used to identify you.

There is very little risk involved in this study. The minimal risks include possible minor discomfort from expressing your opinions. You are free to skip any question that you are uncomfortable answering.

VI. Questions

We are happy to discuss any questions with you that you might have. You can email or call any of the investigators at any time during the study, including before you decide if you want to participate, or even after you have finished the survey. Your parent or guardian has also received information about this study, and is available to discuss the study more.

VII. Extent of Anonymity and Confidentiality

The data gathered in this experiment will be confidential. The questionnaire does not collect any identifying information. However, after participating you may enter your contact information in a separate questionnaire. There will be no link between your answers on the

survey and your contact information should you choose to provide your information. The data from this study will be stored at the Virginia Tech Transportation Institute.

It is possible that the Institutional Review Board (IRB) may view this study's collected data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research. Access to the data will be under the supervision of the research team.

VIII. Withdrawing from the Study

You may withdraw from study at any time if you change your mind about participating. You may also withdraw after talking with your parent(s) or guardian about the study.

IX. Participant's Assent

I have read this Assent Form and conditions of this project. I have had all my questions answered. By checking "Yes" below, I acknowledge that I voluntary agree to participate in this study:

[will have checkbox here to enable survey initiation]

Virginia Polytechnic Institute and State University

Permission of Legal Guardians for Participants in Research Projects Involving Human Subjects

Title of Project: Analysis of the Non-Driving Mobility Needs of People with Disabilities

Investigators: Carolyn Shivers, Ph.D. shivercm@vt.edu / (540) 231-5434

Justin Owens, Ph.D. jowens@vtti.vt.edu / (540) 231-1010

I. The Purpose of this Research

We are doing this study to learn more about how people with disabilities travel. We want to see what challenges people with disabilities face as they travel outside their home. This study will be used to find ways to help people travel safely.

We plan to gather data from 300 people with disabilities, age 18 and up.

II. Procedures

This study uses an online survey of approximately 40 questions to gather information from individuals about how they travel and what kinds of challenges and barriers they encounter when traveling. Your child or ward will complete the survey with your help. You can help them read the questions and explain what they mean, but the answers should reflect their

experience traveling, not yours .We estimate that it will take your child or ward up to 20 minutes to complete the survey.

III. Risks

There are no foreseen physical risks to your child or ward for participating in this project.

Your child or ward may answer questions about challenges or difficult events, which could bring up negative emotions or memories. Your child or ward does not have to answer any question that he or she chooses not to answer on the online survey.

IV. Benefits

While there are no direct benefits to your child or ward, his or her answers will help us better understand how to support individuals with disabilities as they navigate around their communities.

No promise or guarantee of benefits has been made to encourage your child or ward to participate.

V. Extent of Anonymity and Confidentiality

At the end of the survey, your child or ward will be offered the choice to share their contact information (name, email address, and/or phone number) if they would like to be contacted for a follow-up interview. This is entirely voluntary, and the contact information will be provided through a separate link. Personal information will not be connected in any way to survey responses. All survey materials that your child or ward completes will be identified by

a code number, not by name, and stored in a secure electronic database. Your child's or ward's responses will be made available in an online database for use by other researchers for future projects, but they will be anonymous and not associated with his/her name or other information that can be used to identify him/her.

The Virginia Tech (VT) Institutional Review Board (IRB) may view the study's data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research.

VI. Compensation

There is no compensation provided for participation in this study.

VII. Freedom to Withdraw

It is important for you and your child or ward to know that he or she is free to withdraw from this study at any time without penalty. He or she is free not to answer any questions without penalty.

VIII. Subject's Responsibilities

I voluntarily give permission for my child or ward to participate in this study. He or she has the following responsibilities for participation:

Complete the online survey, with questions about his or her experience traveling and navigating around his or her community, including barriers or challenges experienced.

IX. Questions or Concerns

Should you, your child or ward have any questions about this study, you may contact one of the research investigators whose contact information is included at the beginning of this document.

Should you have any questions or concerns about the study's conduct or your child's or ward 's rights as a research participant, or need to report a research-related injury or event, you may contact:

Virginia Tech Institutional Review Board for the Protection of Human Subjects

Telephone: (540) 231-3732

Email: irb@vt.edu

X. Guardian's Permission

I have read the Permission Form and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary permission for my child or ward to participate in this study:

[will have checkbox here to enable survey initiation]

APPENDIX D: SURVEY

Please answer the following questions about yourself.

1. How often do you use the following ways of getting around outside your home?

   a. Car, as driver

   b. Car, as passenger

   c. Bike

   d. Personal mobility equipment (wheelchair, walker) or on foot

   e. Public transportation (bus, shuttle, train, subway)

   f. Other

Answer options (matrix):

   i. Daily

   ii. A few times per week

   iii. A few times per month

   iv. Once per month

   v. Less than once per month

   vi. Never or almost never

2. How often do you leave your home for:

   a. Work/School

   b. Socialization

   c. Errands (such as shopping)

   d. Other (please specify)

Answer options (matrix):

i. More than once per day

ii. Daily

iii. A few times per week

iv. A few times per month

v. Once per month

vi. Less than once per month

vii. Never or almost never

3. Do you use public transportation?

Yes/No [radio button]

If Yes -

4. When you use public transportation, how much of a problem are the following issues?

Response Options [slider, with additional anchors]: 0 = Not much of a problem to 10 = A very serious problem

a. Feeling safe

b. Getting on or off (for example: high steps, uneven surfaces, ramps)

c. Understanding how to use (for example: how to know which stop to get off at, how to pay)

d. Being able to get where I want to go (for example: how close to your home or destination the bus or train stops are)

e. Taking care of my personal needs (for example: finding a bathroom, food or environmental allergies, ability to take care of your medical needs while in a vehicle or at a station, etc.)

f. Other people staring at you or treating you differently (for example: the driver or other passengers)

5. How often do you have trouble getting around outside your home when going somewhere you have been to or visit often?

a. As a pedestrian (wheelchair, on foot) or on a bike

b. Using public transportation

c. While driving

Answer options (matrix)

i. Every time
ii. Most of the time
iii. Often
iv. Sometimes
v. Never or rarely
vi. Does not apply to me

6. How often do you have trouble getting around outside your home when going to a new place?

a. As a pedestrian (wheelchair, on foot) or on a bike

b. Using public transportation

c. While driving

Answer options (matrix)

i. Every time
ii. Most of the time
iii. Often
iv. Sometimes
v. Never or rarely
vi. Does not apply to me

7. How much of a problem do you have with any of the following when getting around outside your home?

Response Options [slider, with additional anchors]: 0 = Not much of a problem to 10 = A very serious problem

i. Route is **too steep or at a difficult angle** (Example: It's hard for me to get up or down hills)
ii. Route **isn't smooth** (Example: Bumps, cracks, or tree roots make it difficult to walk)
iii. Route **is slippery**
iv. Route **is damaged or not usable** (Example: Construction or weather damage)
v. Route **is too narrow** (Example: Sidewalk is very skinny or there are things in the way)
vi. Getting **across the street before the signal changes** (Example: "Walk" sign goes off before you can get across)
vii. Getting **onto or off the sidewalk** (Example: The curb is too high or not slanted)
viii. Getting **into or out of buildings with ease** (Example: Too many stairs or doors don't open easily).
ix. Figuring out **what street** you're on (Example: Hard to read signs or no signs around)
x. Figuring out **which entrance** to go to (Example: Hard to tell which building or door is the right one)
xi. **Following directions** for how to get around (Example: I don't understand what the directions are telling me)
xii. Route is **too crowded** (Example: A lot of people too close together)
xiii. Route is **too noisy, bright, or smelly** (Example: too many noises, too many bright signs or lights, too many bad smells)
xiv. **Knowing when or where it is OK to move** (for example: when to cross the street or where are people are allowed to walk)

8. What types of disability do you have? Please check all that apply. [checkboxes w/branching]

a. Intellectual/developmental disability (for example: Down syndrome, autism, global developmental delay)
    i. If checked: Please check all that apply
        1. Autism
        2. Down syndrome
        3. Williams syndrome
        4. Prader-willi syndrome

5. Other (please describe)

b. Learning disability (for example: ADHD, dyslexia)
    i. If checked: Please check all that apply
        1. ADHD
        2. Dyslexia
        3. Specific language impairment
        4. Language processing disorder
        5. Nonverbal learning disability
        6. Other (please describe)
c. Physical disability (for example: difficulty walking or standing, limited endurance)
    i. If checked: What type of assistive devices do you require?
        1. Manual wheelchair
        2. Power wheelchair
        3. Walker
        4. Cane
        5. Other (please describe)
        6. None
d. Psychiatric disability (for example: depression, anxiety, schizophrenia)
    i. If checked: Please check all that apply
        1. Depression
        2. Anxiety
        3. Bipolar Disorder
        4. Schizophrenia
        5. Other (please describe)
e. Sensory disability (for example: blindness, deafness, sensitivity to noise or lights)
    i. If checked: Please check all that apply
        1. Blindness
        2. Deafness
        3. Sensitivity to noise
        4. Sensitivity to light
        5. Other (please describe)
f. Communication disability (for example: difficulty speaking)
g. Other (please describe)

9. How old are you? [text box]

10. Are you a: [radio button]

Male

Female

Other

11. What is your race/ethnicity (please check all that apply): [checkboxes]

Hispanic or Latino

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or other Pacific Islander

White

Other

12. What state do you live in? [dropdown]

13. How would you describe the area where you live: [radio button]

Big city (lots of buildings, lots of people, lots of traffic)

Medium-sized city (some buildings, people, and traffic)

Suburbs (smaller neighborhood close to a big or medium city)

Small town (local traffic, not any big buildings like skyscrapers)

Country (very little traffic, wide open spaces, fewer people and buildings)

14. Are you still in school? [radio button]

Yes - No

If yes: In high school

In college

In a graduate program

15. How long did you go to school? [radio button]

I went to high school, but didn't graduate

I have a high school diploma, certificate, or GED

I went to college, but didn't graduate

I have 2-year degree from college

I have a 4-year degree from college

I have a graduate degree (Master's, doctorate, etc.)

16. What are your current living arrangements? Check all that apply [checkbox]

Roommate(s)/friends

Alone/ Independently

With family (parents, siblings, grandparents, etc.)

With a partner (spouse, girlfriend/boyfriend)

Supported living (with assistants or staff)

Residential living

Other (please describe)

17. Do you have a job? [radio button]

Yes No

If yes: Full-time

Part-time

Seasonal

18. How would you describe your socio-economic status: [radio button]

Lower class

Lower middle class

Middle class

Upper middle class

Upper class

APPENDIX E: PUBLICATIONS, PRESENTATIONS, POSTERS RESULTING FROM THIS PROJECT:

Owens, J.M., Miller, A., & Shivers, C. (2019). *Project Overview: Analysis of the Non-Driving Needs of People with Disabilities.* Talk presented at 3rd Annual CATM Symposium, Daytona Beach, FL.

Shivers, C., Owens, J.M., & Miller, A. (2018). *Project Update: Analysis of the Non-Driving Needs of People with Disabilities.* Talk presented at 2nd Annual CATM Symposium, Blacksburg, VA.