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MTI MINETA TRANSPORTATION INSTITUTE

# Understanding the Safety and Usability of Personal Vehicles for Non-Driving Individuals with Disabilities and their Families/Care Providers

Anil R. Kumar, PhD
Hannah Bowman

# Mineta Transportation Institute

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Report 22-49

# Understanding the Safety and Usability of Personal Vehicles for Non-Driving Individuals with Disabilities and their Families/Care Providers

October 2022

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| **16. Abstract**<br>The connections between shared personal vehicles of individuals with disabilities (IWDs) and their household family members play an important role in the mobility, overall health, and well-being of all involved actors, yet this topic remains mostly overlooked within publicly available research. Families that include a non-driving IWD are more likely to be low-income, and often struggle with the costs of operating a family car but, due to insufficient public transportation options, they own vehicles despite their prohibitive cost. This exploratory study utilized the Systems Engineering Initiative for Patient Safety (SEIPS) model, a framework focused on assessing the interplaying sociotechnical factors that contribute toward work-systems to gain a holistic understanding of the factors that influence household vehicles, safety, and a sense of well-being for non-driving IWDs and their household family members. A combined effort of surveys, interviews, qualitative coding, and statistical analysis (including one-way ANOVA) revealed a series of influential factors, including: (1) slow bureaucratic processes for vehicle funding; (2) error-prone modifications including lift and tie-downs; (3) miscommunications between IWDs and family members; and (4) residential area development and subsequent social support. Findings highlight the need for improved access to government funding, more reliable modification equipment, and interior vehicle designs that consider better social integration for IWDs. | | | |
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# Introduction

## 1.1 Background

Radical changes are happening in the commercial vehicle industry, including the introduction of autonomous vehicles on the road, and cars that are digitally connected to the outside world. This automotive sector paradigm shift raises questions regarding which populations, and whose unique needs, ought to be considered when creating and refining such vehicles. One population that has been proposed to gain a great benefit from up-and-coming technologies is non-driving individuals with disabilities (IWDs). This benefit has been proposed because of the structural limitations imposed by traditional personal vehicles, and personnel requirements such as care providers (e.g., nurses) and/or family members needed for travel (Brewer & Kameswaran, 2018; Bennett et al., 2019). Though contemporary and future technologies may greatly improve the transport methods of IWDs, there is little public-facing foundational research on the work-system dynamics available. This prevents an intimate understanding of what journeys are like in general with these contemporary technologies and, more specifically, what kinds of challenges and benefits arise in trips taken by IWDs in their personal vehicles (Kett et al., 2020).

Taking a big-picture approach to conceiving the journey of IWDs alongside their family members and non-relative care providers (e.g., in-home support, nurses) in personal vehicles is essential, yet ambitious, due to the complex and interconnected sociotechnical systems associated with individuals with disabilities' transportation (Bascom et al., 2017). To move across a geographical space, an IWD may require specialized procedures and tools such as lifts for entering and exiting the vehicle, as well as the continued care of the IWD by family members and/or care providers while the vehicle is in motion (Henderson et al., 2008). With such complex systems in place, concerns for the safety and well-being of all involved stakeholders arise.

Pre-existing literature pertaining to non-driving IWDs and shared personal vehicles is sparse, scattered across disciplines, and has largely focused on the driving patterns and socioeconomic challenges of the noted populations (Brumbaugh, 2018; NCD, 2017). Families that include an IWD are more likely to be low-income, and often struggle with the costs of operating a family car. Households that can purchase a vehicle often share it across members, with modifications for the IWD made by untrained family members, thus posing a safety risk for all inside of the vehicle (Batavia & Beulaurior, 2001; Di Stefano, 2019). Additional research has concluded that though personal vehicles are of great expense, they are a valuable tool for households with an IWD, helping family members maintain independence, and offering some financial security (Jansuwan et al., 2013). Given the importance of personal vehicles for households with non-driving IWDs, the noted safety risks, and the potential for current and future technologies to better serve the aforementioned actors, it is essential to address the research gap that exists with respect to understanding the work-systems of personal vehicles for these largely overlooked persons including the family members, non-relative care providers of IWD, and non-driving IWDS.

# 2. Literature Review

## 2.1 Method

To gain an understanding of vehicle safety for non-driving IWDs and their family members, the SEIPS (Carayon et al., 2006, Holden et. al, 2013; Carayon et al. 2020) framework was used. the involvement of human factors in vehicle design. Participants were recruited, and literature review following the PRISMA-P method (Moher et al., 2016) was done. A systematic search for relevant records was performed using Google Scholar, Scorpus, Microsoft Academic, and OneSearch.

- For vehicle accessibility, the keyword "vehicle modifications" was searched in conjunction with "disabilities", "non-driving", "accessibility", and "family".
- For the SEIPS framework, "SEIPS" was searched in conjunction with "healthcare", "home", "vehicles", and "history of".
- For human factors in vehicle design, "human factors" was searched in conjunction with "history of vehicles", "autonomous vehicles", "future vehicles", and "vehicle design".
- For recruiting IWDs, "recruiting participants with disabilities" was searched in conjunction with "best practices", "history", and "surveys and interviews".

The search yielded a total of 1,258 records, with 68 duplicates removed. Materials were included if they: (1) pertained to vehicle accessibility or figures pertaining to IWDs and vehicles/driving; (2) SEIPS in healthcare; (3) human factors design. Two additional inclusionary factors were used: (1) records published between 1996–2021; and (2) if records were from government/academic sources. Records were excluded if they were from predatory journals or were published before 1996. A total of 1,233 records total were removed. Twenty-nine articles were accepted into this review: eighteen from quantitative sources; and eleven from qualitative sources.

This review of twenty-nine articles is organized as follows. First, some background on the role of Human Factors/Ergonomics in the healthcare setting is presented, with particular focus on perspectives pertaining to healthcare spaces. The review then considers the challenges faced by non-driving IWDs and their families, and the need for more research on the aforementioned topic. The role of Human Factors/Ergonomics (HF/E) in the automotive sector is then briefly discussed, to contextualize why this field, with its extensive background in healthcare, is equipped to help fill in current gaps of understanding concerning the personal vehicles used by families to transport non-driving IWDs.

## 2.2 Human Factors/Ergonomics in Healthcare

HF/E in healthcare has expanded beyond the hospital and into non-clinical home healthcare settings for individuals with medical needs. Applying an HF/E lens to home environments has provided an in-depth look into the complex, often sub-optimal work-systems provided by largely untrained family members (Carayon et al., 2014). Such research has delivered insights into the interactions of interconnected elements of patient care, including care providers and tools, thus helping to better pinpoint patient/care provider safety issues and overall care outcomes (Doutcheva et al., 2019). To gain a macro-perspective on care settings away from conventional clinical spaces, it is imperative to consider spaces in addition to the home that those with medical needs and their care providers occupy. The analysis of work-systems of personal vehicles of non-driving IWDs and their families/care providers as a non-clinical health space is yet to be addressed either more widely in publicly available research, or in healthcare.

## 2.3 Transporting Non-Driving IWDs

Given that stable access to personal vehicles for IWDs and their families reduces social marginalization, while contributing to a sense of well-being and independence, a holistic and in-depth understanding of vehicle work-systems is a critical social need (Jansuwan et al. 2013; Power, 2016; Weinrich et al., 2018). Furthermore, when discussing IWDs, it is important to note that they constitute a sizable portion of the U.S. population—the U.S. Census Bureau has reported that approximately 8 percent of individuals ages five to twenty years, 19.2 percent of those ages twenty-one to sixty-four years, and 41.9 percent of persons aged sixty-five and over had some level of disability, further highlighting the importance of accessibility research for commercial vehicles (Steinmetz, 2006). As previously noted, issues concerning personal vehicles of IWDs and their families have often been overlooked. Thus there is still much to be understood in this sub-field of commercial vehicle manufacturing. Indeed, the personal vehicle has been addressed as a means to access healthcare and as a potential transportation solution for IWDs, but the journey, or the sociotechnical system, associated with the personal vehicle is still largely unaddressed in the research (Kett et al., 2019).

Although personal vehicles are an important tool for IWDs and their families, the aforementioned population's transportation needs have largely been studied only with regard to public transit, and the concomitant higher-than-average poverty rates in the population of interest (Brumbaugh, 2018; Bezyak et al., 2017, Weinrich et al., 2018). As a result of significant physical barriers, widespread obstacles to the use of mass transport systems, and the pervasiveness of *transit deserts*, or public transportation insufficiency, owning a personal vehicle is imperative for many IWDs and household family members despite the prohibitive cost of vehicle ownership (Jiao et al., 2013; Bascom & Christensen, 2017). According to the U.S. Department of Transportation, the prevalence of personal vehicles as a primary method of transportation for households with IWDs is approximately 61 percent (Brumbaugh, 2018). Further research has concluded that the

overwhelming majority of those with disabilities are passengers, as opposed to drivers, within family vehicles, with some needing extensive assistance to leave the house (Rosenbloom, 2007).

Personal vehicles used to transport IWDs are often shared between non-disabled household family members as a means to ensure transportation for all individuals within the home. A vehicle modified for an IWD can cost between $20,000 to $80,000, due to the cost of specialized equipment and rehabilitation specialists (NHTSA, n.d.). Modifications are frequently made by unqualified individuals such as family members, compromising the safety of the vehicle for all riders (Batavia & Beulaurior, 2001; Di Stefano, 2019). The National Highway and Travel Safety Administration noted that a mere half-inch adjustment to a van's floor can impact a driver's ability to see the road, thus stressing the critical need for professional vehicle fitting (NHTSA, n.d.).

## 2.4 Human Factors in the Automotive Industry and Beyond

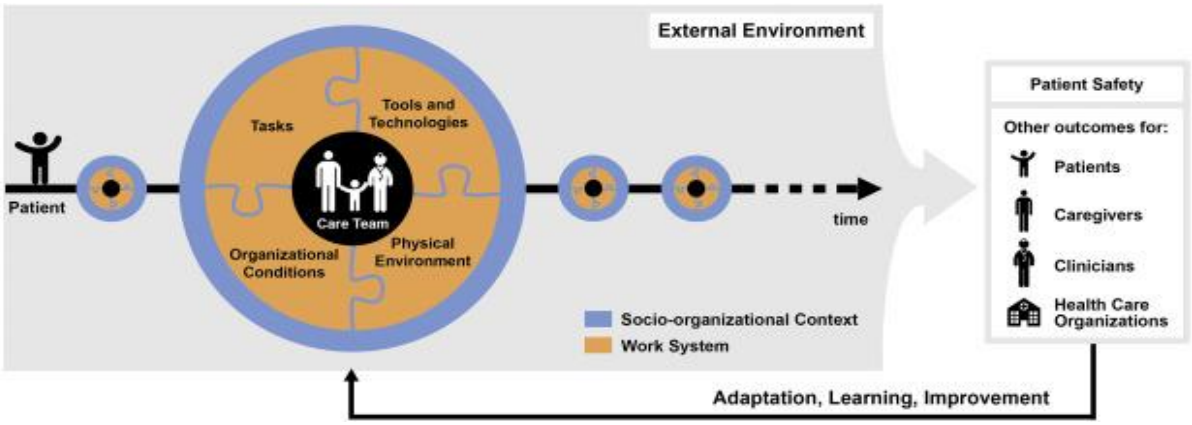
HF/E has an extensive history of being affiliated with automotive safety, starting with the design of controls for primary driving tasks (steering wheel, brakes) in the early 20th century (Akamatsu et al., 2013). Contemporary research has evolved to mirror the increasingly digitized world, including themes such as autonomous vehicles, and the integration of digital infotainment systems—all studied with safety as a cornerstone (Akamatsu et al., 2013). In the automotive field, HF/E in healthcare has expanded and shifted its focus to reflect the times. As previously noted, healthcare was once confined within the walls of hospitals and care homes, but with increased demand for home healthcare, HF/E has slowly become concerned with the personal homes of those in need of care, their family members, and care providers (Fathollahi-Fard et al., 2019).

## 2.5 Using the SEIPS Model for Vehicles

The Systems Engineering Initiative for Patient Safety (SEIPS) model is a prevalent macroergonomic framework within HF/E that provides a means to understand the work-systems of those in need of care and their care-providers (Carayon et al., 2006, Holden et. al, 2013; Carayon et al. 2020). SEIPS has gone through a series of revisions as it continues to evolve with the attitudes and outlooks of sociotechnical systems in healthcare. In the original SEIPS framework, the model imposed the need to consider the patient and their interactions within the healthcare work-systems—stressing the safety and well-being of all as a key outcome measure (Carayon et al., 2006). In the updated SEIPS 2.0 model, caregiver outcomes were considered alongside that of the patient, and interconnected components, such as tools/technologies and the external environment, were included as part of the interconnected web of patient care (Holden et al., 2013; Carayon et al., 2020). The patient journey, or movement between organizations, was added to SEIPS 3.0 (Fig. 1), given the increased focus on differing healthcare settings (Carayon et al., 2020).The use of the SEIPS model in non-clinical health spaces where patients reside, including those with personal vehicles, is yet to be understood. With that said, it may be possible to develop a codebook using the categories from the SEIPS framework, specifically the categories of work-systems (task, tools and technologies, organization conditions, and physical environment), and external environments,

for qualitative analysis to be conducted in the current study. Similarly, the questions posed in the surveys and interviews can be adapted to the SEIPS categories. Fig. 1.

Figure 1. SEIPS 3.0 Model




Note: Adapted from Beleffi E., Mosconi P., and Sheridan S. (2021) "The Patient Journey" in Donaldson L., Ricciardi W., Sheridan S., and Tartaglia R. (eds.) Textbook of Patient Safety and Clinical Risk Management. Springer, Cham.

## 2.6 The Need for Commercial Vehicle Accessibility Studies

With sub-fields nestled within both healthcare and automotive, HF/E is uniquely positioned to synthesize theory and frameworks, enabling it to capture insights regarding the work-systems of personal vehicles, and involved actors, from a holistic perspective. Given the lack of publicly available literature on the aforementioned topic, the documented safety issues, and the rapid emergence of up-and-coming automotive technologies, it is essential that the welfare of the aforementioned populations be considered by the automotive industry. Novel applications of HF/E frameworks such as that of the healthcare-centered SEIPS model (Carayon et al., 2006, Holden et. al, 2013; Carayon et al. 2020) may help provide long-overdue insights into existing research.

## 2.7 Recruiting IWDs for Research

It is imperative to note that the challenges of recruiting IWDs partially explain the knowledge gaps in vehicle accessibility research. Although about 20 percent of the US population has at least one disability (Stevens et al., 2016), IWDs are difficult to recruit for research due to feelings of mistrust by participants with disabilities toward researchers, time and resource constraints of research projects, and inaccessible research materials for participants.

Within a research context, IWDs have historically been subjected both to exploitation, and to the charity model—a paradigm in which disability is perceived as tragic and unwanted (Clifton, 2020). Upon distributing a structured survey to individuals from an array of marginalized communities,

Smirnoff et al. (2018) discovered that only about one out of four survey recipients responded—the lowest response rate of all populations surveyed. The additional time and resources needed to appeal to ethics boards for working within the disability community, a population regarded as vulnerable (Banas et al., 2019; Carey & Griffiths, 2017), along with the time and resources needed to ensure participants have accessible accommodations, has created branches of research that operate on a fundamentally slower timeline than that of the broader population.

To address the prevalence of mistrust, methods for gaining wider acceptance in the disability community have been sought. Alongside calls for more intuitive accommodations and respect toward IWDs, studies have demonstrated that the snowball sampling method has been a helpful tool for gaining a better working relationship between researchers and the disability community (Sadler et al., 2010; Lee & Spratling, 2019).

# 3. Rationale and Objectives

## 3.1 Rationale

Although personal vehicles play an important role for non-driving IWDs and their household family members, the sociotechnical factors that influence the journey and work-systems have largely been underrepresented in the literature. Such gaps in knowledge may cause critical oversights in the safety and well-being of the aforementioned population, their household family members, and non-related caregivers. With the rapid emergence of new technologies in the commercial automotive industry, filling-in gaps in knowledge will help ensure that the needs of these people are advocated for and represented with future designs and technologies.

## 3.2 Objectives

This exploratory research aimed to better understand how the sociotechnical elements of work-systems impact the personal vehicle safety of non-driving IWDs, their household family members, and non-related caregivers. The study has been designed for the results to be used to inform future product designs, lending to the safety and well-being of disabled individuals and others, while calling attention to the need for more widespread research in the field of accessible vehicles.

# 4. Methods and Procedures

## 4.1 Participants

Three cohorts were studied to understand vehicle accessibility from multiple perspectives. The first cohort was non-driving IWDs whose main mode of transportation was a private family vehicle. The second cohort was family members who live with a non-driving IWD, and the third party was paid non-relative care providers who had at least one non-driving IWD client. Care providers were asked to focus on one client for both interview and survey responses. Each participant was presumed to be from a separate care case/household due to the risk of exposing confidential information of previously identified individuals.

## 4.2 Inclusionary Sampling Factors

All three cohorts were eighteen or older, and were able to communicate in English. Further inclusionary criteria were as follows:

- For IWDs: have one or more self-reported physical disabilities, and use a private vehicle as the primary mode of transportation.
- For family members: live with a family member who is non-driving and has one or more physical and/or intellectual disabilities, and drive/ride in a vehicle that transports the family member with one or more disabilities.
- For the non-related care provider: have a non-driving client with one or more disabilities, and partake in the process of loading their client in and out of the vehicle and/or transporting their client.

## 4.3 Exclusionary Sampling Factors

Potential study participants were excluded if they were unable to communicate in English and/or were younger than eighteen. Furthermore, recruits were excluded if they were not part of one of the three identified cohorts. For the non-driving IWD group, participants were excluded if they identified as having an intellectual disability (e.g., autism spectrum disorder, social communication disorder) due to resource constraints for potential accommodations.

## 4.4 Study Consent and Confidentiality

For the survey, recruits were presented with a consent form that required them to click an "agree" button to enter the survey (see the Survey Consent Form in Appendix A). Those who clicked "disagree" were redirected out of the survey. For the interview, recruits were emailed a consent

information sheet at least twenty-four hours in advance, with their verbal consent recorded at the start of the interview session.

To ensure participant confidentiality, no names or related identifiers were collected from surveys or interviews. All identifiers voluntarily disclosed by participants were immediately redacted from transcripts and imported survey data. Participants who took the survey were asked to voluntarily provide their telephone number and/or email address if they were interested in being interviewed for the study, and were asked for their email address to be entered into the Visa gift-card raffle.

All recordings (both video and audio), notes, and data from surveys were uploaded to a secure Google Drive folder and an encrypted USB drive, accessible only to the researchers. A Google Sheets document was created that listed the email addresses of participants to enable gift card payment by administration at the Mineta Transportation Institute (the governing body of the US Department of Transportation grant).

## 4.5 Materials

The materials for the data collection and analysis of this study were as follows:

- A 13" Apple MacBook Pro for video conferencing, communicating with participants, and a platform for data analysis.
- Qualtrics for hosting surveys.
- Zoom video conferencing for conducting interviews virtually with participants.
- Google Suite as a secure cloud storage platform for data drop-off/storage/retrieval, word processing, storing and cleaning data (Sheets), and communicating with participants and independent living facilities (for recruitment).
- Otter.ai for transcribing recorded interviews.
- Encrypted INNÔPLUS Secure Flash Drive 256-bit 32 GB for storing transcripts and hosting NVivo locally.
- NVivo 1.4.1 for coding transcribed interviews.
- SPSS 25, Python 3.7, and Excel (2016) for statistical analysis.

## 4.6 Study Design

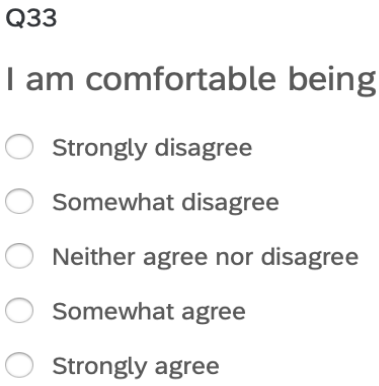
### 4.6.1 Data Collection Methods

#### 4.6.1.1 Surveys

A web-based survey (see Appendix A) was distributed to all three cohorts, with research candidates recruited via community-based organization websites / newsletters, Craigslist, and social media websites/apps (Twitter, Reddit, and Facebook). As previously noted, recruiting from these cohorts is particularly challenging in healthcare studies (Holden et al., 2015). Thus, a convenience sample for the survey of sixty total survey entries was targeted (twenty non-driving individuals with disabilities, twenty family members, twenty caregivers) over a span of two and a half months.

To create an accessible survey, the Qualtrics "Check Survey Accessibility" testing tool was used alongside a study of literature on creating accessible web-based surveys. Survey modifications included turning Likert scale questions into vertical radio buttons since they are more screen-reader friendly than matrix tables and the use of plain text while avoiding rank order questions and graphic sliders (Berton et al., 2020).

Figure 2. A Vertical Likert Scale Question to Help with Screen Reader Accessibility




Upon agreeing to the conditions outlined in the survey consent form, participants were directed to self-identify as either a member of one of the three cohorts, or "other". Those who did not identify as a member of the cohorts of interest were directed out of the survey. Participants who identified as a member of one of the three cohorts of interest were presented with a consent form, and then channeled into the surveys for their respective groups (see surveys for individuals with disabilities and Family Member/Care Provider in Appendices D and E respectively).

Each of the surveys aimed to capture demographic data and insights related to the work-systems and sentiments of each respective cohort per the categories that are a part of the SEIPS model (Carayon et al., 2006, Holden et. al, 2013; Carayon et al. 2020). Furthermore, survey questions

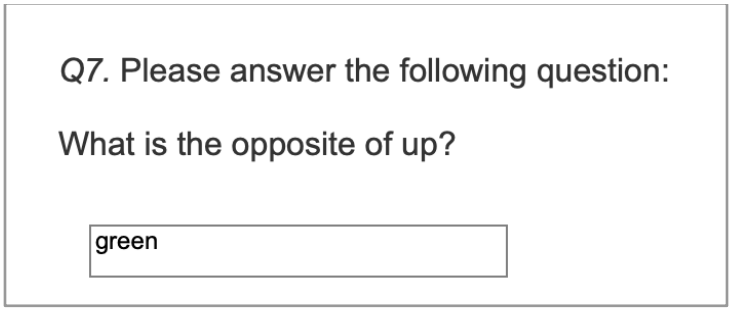
inspired by Di Stefano et al. (2019) were intended to understand participants' current vehicle modifications, and sentiments toward their modifications. Surveys were anticipated to be completed in fifteen minutes or less. The original compensation plan was to give participants a $5 Visa gift card for completing the survey. In order to avoid false positives and ballot stuffing, the compensation method was changed to a random draw to win one of sixteen $25 Visa gift cards. Prize promotion laws in California stipulate that prizes cannot be conditioned upon a minimum number of entries, thus a separate Google Forms website was included in the consent form to allow for interested parties who did not participate in the survey to be entered into the drawing. The email addresses of those who responded to the survey, or did not but wished to be entered into the drawing, were aggregated into a single document, in which a unique number ID between 1-100 was assigned to each email address. Winners were chosen using a random number generator and notified via email.

Survey data was downloaded into an Excel file for the cleaning and removal of identifiers. Duplicate and straight-lined responses, along with nonsensical answers in open-ended questions (e.g., irrelevant answers, gibberish language) were removed.

#### 4.6.1.2 MTurk

Due to low survey enrollment rates, Amazon's Mechanical Turk (MTurk), a crowdsourcing platform that pays workers to perform individual tasks remotely, was added to solicit additional survey responses. Given that MTurk workers are not generalizable with respect to health status and behaviors (Walters et al., 2018), a two-minute, six-question screener was developed to identify MTurk workers who fit into one of the study's three cohorts (see MTurk Screener in Appendix H). Popular CAPTCHA tools can be used to ensure that survey bots are inaccessible for IWDs (Hollier et al., 2019), therefore an open-ended question ("what is the opposite of up?") was included in the screener, since bots are prone to providing nonsensical answers to open-ended questions and perform poorly on logic-based questions (Klopfenstein et al., 2017; Latah, 2020). MTurk workers who completed the survey were paid $0.35 for their total time.

Figure 3. A CAPTCHA-like Question that has Been Answered, Presumably by a Bot, in Amazon's Mechanical Turk Platform.



To further reduce the prevalence of survey bots and limit low-quality workers, the screener was restricted to MTurk workers with a Human Intelligence Task (HIT) approval rate greater than or equal to 98 percent, per the recommendation of Ipsen et al. (2021). Furthermore, the study's aim was to capture the nuances of transportation and disability in the United States, therefore MTurk workers' locations were restricted. To prevent false positives on the screener, the title of the screener included language intended to catch the attention of those in the disability community, but was kept vague enough so as not to fully reveal the screener's goal (titled "Vehicle Accessibility Screener"). Small screener trial-runs discovered a disproportionate number of respondents who would fit into the cohorts, so the title was changed to "Vehicle Accessibility Questionnaire", and within the questionnaire, MTurk workers were informed that they would be paid regardless of their answers.

As a means to continuously test data quality, the updated screener was distributed over one week to between twenty and thirty participants at a time (with 155 total participants). Survey batches were opened between 8:00 a.m. and 4:00 p.m. Pacific Standard Time to accommodate workers' varying time zones. MTurk workers who fit cohort criteria were provided a "qualification", or granted access, to the full consent form and survey based on their worker ID numbers. The surveys were identical to those distributed to participants recruited outside of MTurk, but with the addition of attention/bot checks. It was decided that three attention-check questions were to be included to identify the presence of non-human respondents. If a bot could accurately answer each attention-check question, it would exceed the boundaries of the 3-sigma distribution, thus leaving a 0.3% probability that respondents who passed attention checks would be bots. Those who passed attention checks were paid $3.75 for filling out the survey. Attention-check questions were:

1) *The bot test is simple, when asked if you're a bot, please enter 'I am not a bot' in the text box. Are you a bot?* _____

2) *Five plus seven equals twelve. Tick "this applies to me" if twelve is correct.*

3) *What year were you born? [The first question of the survey asks participants for their age; thus, this question is designed as both an attention check for humans, and a logic check for bots (Buchanan & Scofield, 2018).]*

#### 4.6.1.3 Interviews

One-hour semi-structured interviews were conducted with all of the three cohorts over Zoom teleconferencing software (See Interview Questions in Appendix H). Participants were recruited through project surveys, and through the snowball sampling method. Questions posed to participants were centered around their vehicles and vehicle modifications, along with elements of the SEIPS framework including environment and work-systems (Carayon et al., 2006, Holden et. al, 2013; Carayon et al. 2020). The study anticipated conducting interviews with fifteen to twenty

participants over a span of two and a half months. Participants were paid a $50 Visa gift card for their time. Interviews will be transcribed and coded for further analysis.

#### 4.6.1.4 Infeasibility of Vehicle Schematics and Video Tours

Due to the COVID-19 pandemic, all interactions with participants were remote. As such, in-person ride-alongs and assessments of participants' vehicles as an ethnographic space were not feasible. To replicate the aforementioned interactions in a digital space, participants who were scheduled to interview were asked beforehand to provide signed consent, and either upload a schematic, or record a video of the vehicle of interest. Given the many opportunities to see license plates and other identifiers in videos, to uphold client confidentiality, care providers were permitted to upload a schematic only per the oral consent of their client(s). A prompt was emailed to participants to help guide their schematics and tours (see Video Tour and Schematic Drawing prompts in Appendices F and G respectively). The prompt helped participants note vehicle modifications, seating arrangements, and vehicle entrance points. Once completed, the documents were to be uploaded to a Google Forms website.

Individuals in disability communities expressed in communication that the COVID-19 pandemic had left their already vulnerable population overwhelmed. Studies looking at the impact of the COVID-19 pandemic on IWDs noted its profound negative impact on social services, employment, and the interpersonal relationships for the aforementioned community (Lebrasseur et al., 2021; Rosenblum, 2020). As a result of these communications with disability communities, it was decided to suggest vehicle schematics/video tours as supplementary materials to participants, and not a necessary method for the research. Those who chose not to provide additional materials were asked during interviews to note their vehicle make, model, and year, and provide full descriptions of vehicle modifications, seating arrangements, and vehicle entrance points. Participants' vehicle descriptions were then visually overlaid by researchers.

### 4.6.2 Analysis Methods

#### 4.6.2.1 Quantitative Data Analysis

Contrary to convention, in this study, experimental units (participants) were not recruited to test one or all combinations of treatment levels. Rather, participants already have/use/perform a specific treatment level (such as a type of car, modification made, type of disability). Thus the design of experiment closely resembled a nested design. More specifically, as there are two or more factors, the experiment qualified as having a completely randomized design. The surveys were designed to capture preexisting factors and treatment levels (see surveys for IWDs and Family Member/Care Provider in Appendices D and E respectively). It must be noted that randomization and replication were difficult due to selection bias in recruiting experimental units with a certain treatment level. With sample size and the type of testing chosen, the aim was to overcome this limitation.

**Independent Variables:** Age, gender, development of residency (e.g., rural, city), type of disability (for IWD), relation to IWD (for family members), income, and employment.

**Dependent Variables:** All five-point Likert-scale questions (ranging from strongly disagree to strongly agree) designed to measure the comfort, safety, and ease of use for vehicles and modifications were measured against the aforementioned independent variables. Example questions to be used as dependent variables posed to participants were as follows:

*I feel safe entering and exiting my vehicle.*

*I feel physically comfortable sitting in my vehicle.*

*I feel I can travel anywhere in my vehicle.*

**Outcomes**

Outcomes defined for this study were: comfort, safety, and ease of use for vehicles and modifications based on statistical analysis.

**Statistical Analysis**

Given the small sample size (n = 35), the unavailability of normality information for population distribution, and the imbalance in the replication of treatment levels, nonparametric testing was used for comparing responses from the two cohorts. Owing to the difference in response rates between cohorts, a Wilcoxon signed-rank test was performed to understand the difference in sentiments between the two cohorts. Furthermore, a simple linear regression test was conducted to study the correlation between the safety level (from Likert-style questions,) and independent variables such as age and income. This was performed by taking an equal-weight average to the scaled responses, and running them individually. Lastly, a one-way ANOVA was used as a means to study the influence of demographic factors (e.g., gender, development-level of residence, income) on dependent variables (Likert-style questions). Due to the small sample size, we are accepting $p \leq 0.15$ and $W^2 \leq 0.15$ while reporting correlation along with the aforementioned values as a holistic means to analyze statistical significance (Amrhein et al., 2019; Halsey, 2019; McShane et al., 2019).

4.6.2.2 Qualitative Data Analysis

The qualitative elements of this research were designed to better understand the behaviors, attitudes, and feelings of participants. Data was collected and systematically analyzed through the following methods:

1) All interviews were transferred to text format by the use of transcription (Otter.ai) and word processing (Google Docs) software.

2) Identifiers (e.g., names of individuals, names of workplaces) were redacted from transcripts.

3) Transcriptions were cleaned of misinterpretations, repeats, and related errors as a result of AI-based transcription software.

4) Once cleaned, data was hand-coded using NVivo software. A codebook of 24 codes and 11 sub-codes was created in NVivo using categories from the SEIPS framework (Carayon et al., 2006, Holden et. al, 2013; Carayon et al. 2020) to form deductive codes, along with deductive codes created through interview transcripts and open-ended survey responses (see Code Key in Appendix K). A total of three outcomes were derived from participants' feedback.

All coded transcriptions were analyzed twice: an initial pass-through to create a code/sub-code key; and a second review using the thematic analysis framework (Fereday & Muir-Cochrane, 2006) to find underlying patterns and themes in the transcriptions.

# 5. Results

This study and subsequent request for methods modification was approved by San José State's Institutional Review Board (Protocol # 21016) prior to being conducted.

## 5.1 Survey

A two-month open survey window (March, 2021 through May, 2021) yielded thirty-five total responses, with five responses removed due to insufficiently filled out questions, and/or participants being outside of the cohorts of interest. The final sample size was n = 25 (fourteen IWDs, eleven family members, and three care providers), not counting the care providers. Due to the small sample size and largely incomplete responses of care providers, their responses were removed from statistical analysis.

### 5.1.1 Participant Demographics

Table 1 provides the breakdown of demographic information by cohort.

### 5.1.2 Likert Questions

A series of eight five-point Likert questions (with a response-range from strongly disagree to strongly agree) were asked to participants, asking them to express their sentiments toward topics pertaining to safety and access to resources. The data in Table 2 shows a distribution across responses, thus indicating that there is no clear consensus within the population sampled. Thus, more samples can provide insight into trends regarding the aforementioned questions. The questions in the above table investigate some of the most critical aspects of the safety and affordability of vehicular modifications. An exhaustive list of questions in this category are tabulated in Appendix L.

Table 1. Breakdown of Cohort Demographics for Survey (IWD: N=14, and Family: N = 11)

| Demographic Type | Cohort | Responses | | | |
|---|---|---|---|---|---|
| | | Mean | Min | Max | Standard Deviation |
| Age (in years) | IWD | 31.16 | 18 | 64 | 15 |
| | Family | 46 | 20 | 59 | 11 |
| Number of Household Members | IWD | 3 | 2 | 8 | 2 |
| | Family | No Data | No Data | No Data | No Data |
| Income | IWD | $42,500 | $10,000 | $75,000 | |
| | Family | No Data | No Data | No Data | No Data |

| Demographic Type | Cohort | Responses (in %) | | |
|---|---|---|---|---|
| | | Female | Male | Third Gender/ Non-Binary |
| Gender Identity | IWD | 50 | 33 | 17 |
| | Family | 73 | 17 | 0 |

| Demographic Type | Cohort | Responses (in %) | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Full-time | Part-time | Retired | Home maker | Student | Not Em-ployed | Other (caregiver, seasonal work) |
| Employment | IWD | 23 | 23 | 15 | 8 | 23 | 8 | 0 |
| | Family | 36 | 7 | 0 | 21 | 14 | 0 | 22 |

| Demographic Type | Cohort | Responses (in %) | | | | | |
|---|---|---|---|---|---|---|---|
| | | Mobility | Sensory | Intellectual | Mental Health | Learning | Others |
| Disability | IWD | 52.38 | 9.52 | 0 | 28.57 | 0 | 9.53 |
| | Family | 36 | 13 | 5 | 9 | 5 | 32 |

Table 2. Excerpt of Survey Responses by Iwds and Family Members

| Question | Cohort | Response (in %) | | | | |
|---|---|---|---|---|---|---|
| | | strongly agree | somewhat agree | neither agree nor disagree | somewhat disagree | strongly disagree |
| **I feel safe with the modifications made to the vehicle.** | IWD | 29 | 14 | 57 | 0 | 0 |
| | Family | 22 | 0 | 78 | 0 | 0 |
| **I know who to contact if I need to make modifications and/or adjustments to the vehicle.** | IWD | 29 | 29 | 14 | 0 | 29 |
| | Family | 11 | 22 | 11 | 11 | 44 |
| **I/my family can afford to make modifications to the vehicle.** | IWD | 29 | 14 | 14 | 0 | 43 |
| | Family | 11 | 11 | 22 | 22 | 33 |

### 5.1.3 Sentiment Differences Between Cohorts

Using Wilcoxon signed-rank tests, a statistically significant difference was found between the two cohorts for the question "I know who to contact if I need to make modifications to the vehicle" ($W^2 = .104$). The mean rank of the Family cohort was 4.5, while the mean rank of IWDs was 1.50, indicating that family members are more aware of who to contact to adjust the vehicle. A statistically significant difference was also found between the aforementioned cohorts for "I have been in an unsafe situation while in my vehicle and feel it is due to the modifications made to the vehicle" ($W^2 = .157$). The mean rank of Family was 1.50, while for IWDs it was 0.0, indicating that family members, more so than IWDs, feel they have been in an unsafe situation due to the modifications made to the vehicle.

### 5.1.4 Socioeconomic Status and Age as Factors

The influence of age and SES on the safety level felt by the population was studied by performing linear regression analysis with responses to safety-related questions. This was conducted by mapping the responses to a five-point scale and computing an equal-weight average "safety score". The regression test returned poor linear correlation between age and the safety score with an $R^2 = 0.21$. A strong correlation for "I feel safe with the modifications made to the vehicle" was observed ($R^2 = 0.63$) when age was included as the regressor for each of the individual safety questions. This indicates that older individuals tend to feel safer with regard to the modifications made to the vehicle.

A regression test between SES and the average safety score returned a high $R^2 = 0.81$. This result confirms the expectation of SES having a positive influence on the safety level perceived both by individuals with disabilities and their family members.

### 5.1.5 Lifestyle Differences Between Cohorts

To determine differences arising from independent variables such as gender, employment status, level of development for residence (i.e., rural, city), etc., a one-way ANOVA was run independently on the responses of the two cohorts for each of the Likert questions.

*Note: For running the test, the Likert question responses were mapped to an integer scale, from -2 to +2, for "strongly disagree" to "strongly agree" respectively. Results yielded statistically significant values tied to gender and residential level of development (all statistically significant p-values are tabulated in Appendix L)*

For both cohorts, questions with statistically significant p-values were consistently tied to both residential development level and gender as independent variables. Those living in the suburbs ranked highest for feelings of safety/comfort, and access to resources such as occupational therapists and income to afford vehicles and subsequent modifications (see Fig. 4). Members of both cohorts who lived in metropolitan areas scored the lowest with the aforementioned independent variables, with those in rural areas ranking second to last (see Figs. 4, 5).

Figure 4. IWDs Who Live in Rural and Metropolitan Areas Feel Less Safe Entering and Exiting their Vehicles than Those in the Suburbs ($p$ = 0.000863).

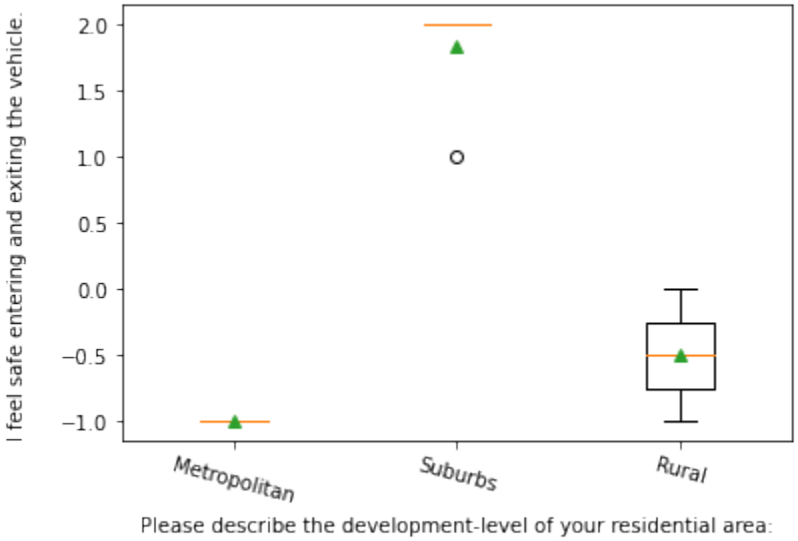
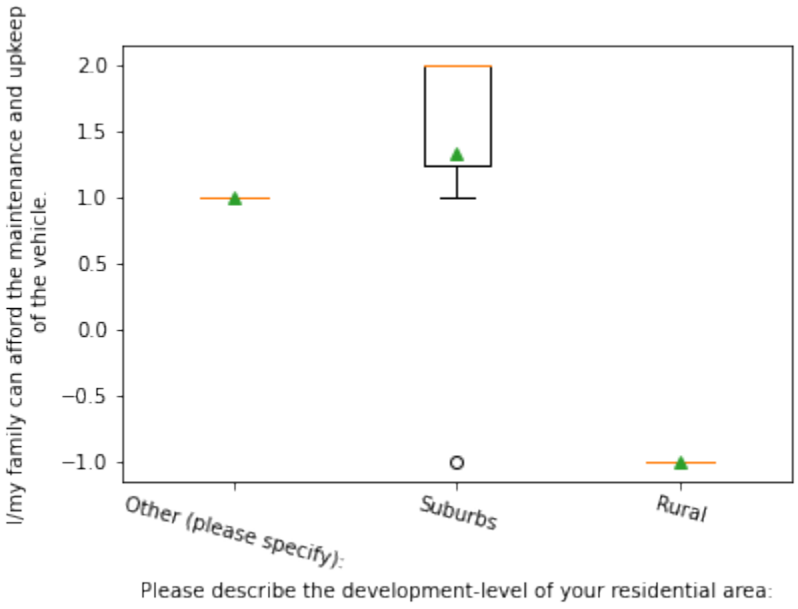


Figure 5. Family Members Living in the Suburbs Felt More Equipped to Handle the Cost of Vehicle Maintenance and Upkeep Than Those in Rural Areas. Those Who Chose "Other" did not Specify Development-Type ($p$= 0.0399).




Gender was also tied to feelings of safety/comfort, and access to resources with family members who identify as male more likely to visit an occupational therapist for the vehicle, and less likely to care for their family member with a disability while the vehicle is in motion (see Fig. 6).

Figure 6. Family Members who Identify as Male are More Likely to Receive Assistance from an Occupational Specialist for the Vehicle Versus Family Members who Identify as Female *(p* = 0.0212).

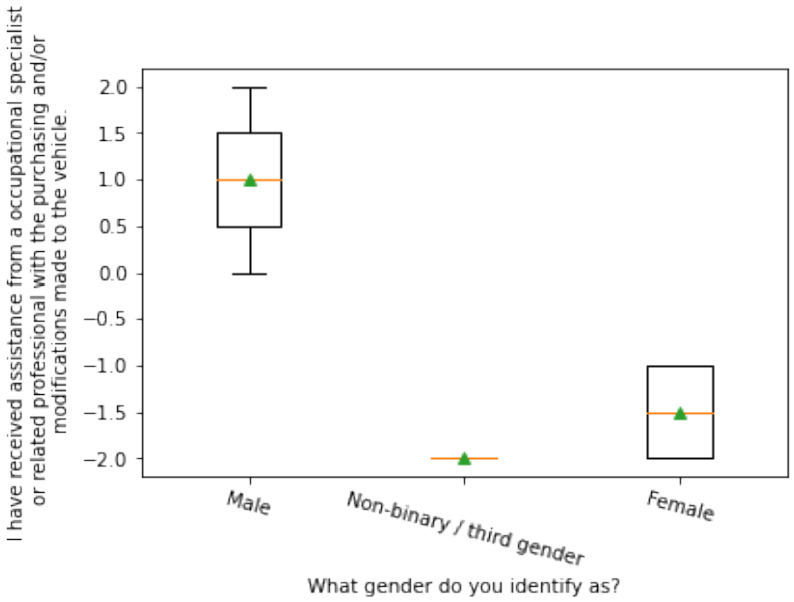
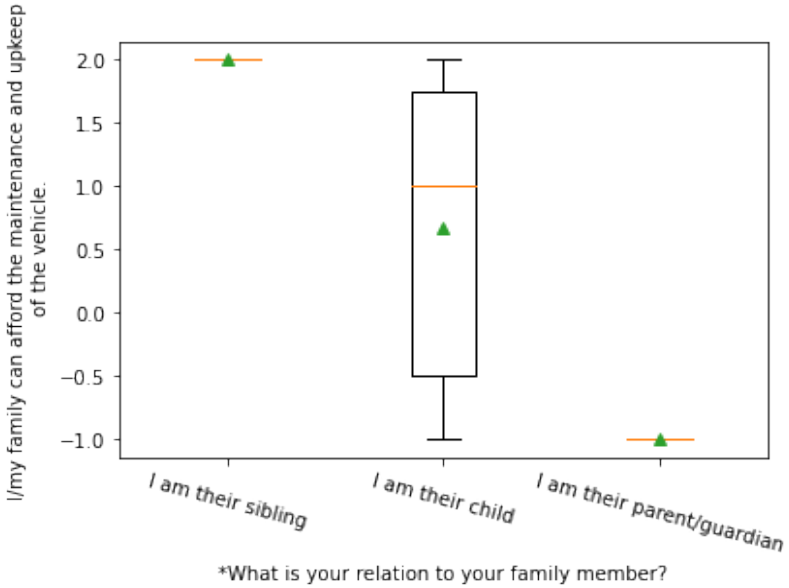
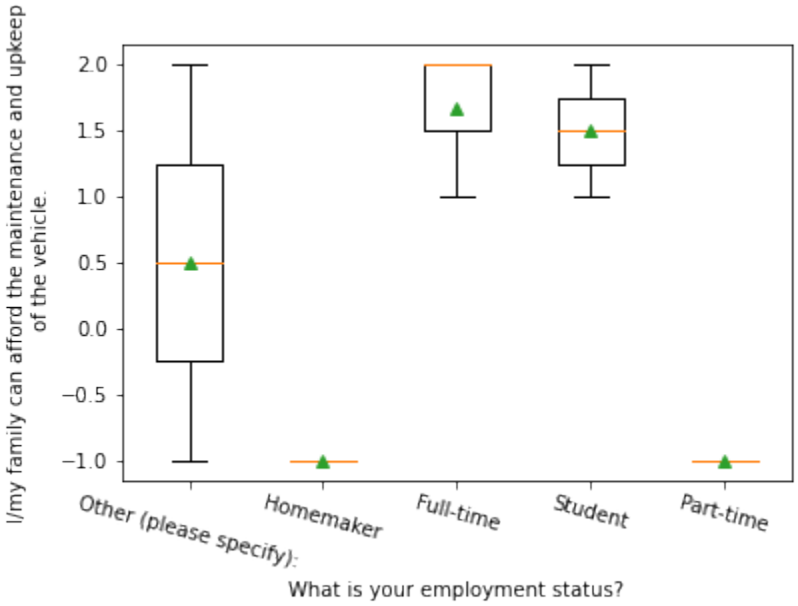



Figure 7. Siblings of IWDs Felt more Equipped to Handle Vehicle Expenses than the Children and Parents of IWDs (*p* = 0.0929).



Other observations included that siblings of IWDs felt the least safe with the vehicle modifications of all the family member subgroups, and felt most strongly that they could afford modifications to vehicles (see Fig. 7). Furthermore, those with mobility-related disabilities (e.g., multiple sclerosis) reported needing care while the vehicle is in motion. Last, and perhaps most surprising, students ranked almost as highly as full-time employees for family members who felt they could most afford modifications to vehicles (see Fig. 8).

Figure 8. Full Time Family Member Employees and Students Felt they were Able to Afford Vehicle Maintenance and Upkeep Better than those who Work Part-Time and are Homemakers ($p$ = 0.1436).




### 5.1.6 Survey Takeover by Bots

Over a span of four hours, the study's survey was inundated by 180 responses. Duplicate and gibberish responses to open-ended questions were strong indicators of a bot takeover. The survey was frozen to prevent further bot attacks, and a new survey and link was generated for further distribution. Bot survey responses were removed from Qualtrics before the cleaning and downloading stage of all data. It is suspected that because the links were made on publicly accessible sites such as Twitter and Reddit, survey bots designed to crawl social media sites located the link.

### 5.1.7 MTurk Surveys

After several iterations of the MTurk screener, the full survey created for MTurk workers was opened to qualified participants. An analysis of fifteen completed surveys yielded low-quality results. Along with attention-checks that were filled out and/or left blank, participants skipped all

questions not required to be filled out. Due to ethics stipulations, participants were able to skip numerous questions, thus rendering data that was discarded in its entirety.

## 5.2 Interviews and Open-Ended Survey Questions

### 5.2.1 Description of Participants

As of the writing of this report, a total of n = 4 participants (two IWDs, two family members) were interviewed. Participants ranged in age from twenty-five to seventy-two, with an average age for IWDs of thirty and an average age for family members of sixty-four. Both interviewed IWDs had mobility-related disabilities, and both family members had adult children with mobility-related disabilities. Participants' residences represented an even distribution of development levels, ranging from rural to metropolitan. All participants noted owning a modified van intended to transport the IWD, with one participant owning a Toyota Prius as a secondary vehicle for their family member with a disability.

### 5.2.2 Public Transit

As discussed in the literature review, public transit has been regarded as a potential mobility solution for IWDs, but transit routes and attitudinal factors remain a barrier (Jiao et al., 2013; Rosenbloom, 2007). Similar to prior research, participants in this project were wary of public transit due to being perceived as a nuisance by transit operators, along with broken or improper modifications on transit vehicles (Bezyak et al., 2017). A sense of "inconveniencing" other passengers due to potentially longer enter and exit seating times was a top reason for public transit avoidance. When asked about their use of public transit, an IWD expressed their feeling of inconvenience: "*You feel like you're inconvenienced and everybody else is because they're in a hurry trying to get somewhere and it takes the driver 30 minutes to get you on or off.*" Family members of IWDs had similar sentiments: "*It took a long time to use the tie downs in the bus. We made the bus extremely late for his next stop, and I had to apologize to everybody in the bus. I felt very embarrassed and uncomfortable.*"

### 5.2.3 Time as a Barrier

Save for one participant, most acknowledged that their vehicles could be newer and equipped with better modifications, but explained that the time it takes to purchase a vehicle and/or change modifications is a primary factor for having compromised vehicles. Two main time barriers were noted among participants: (1) the slow-moving nature of bureaucratic processes at state and federal levels; and (2) a lack of local businesses able to supply a vehicle and/or retrofit modifications.

With regard to bureaucratic processes, one family member of an IWD explained that they circumvent government funding options due to the pace of such options: "*We don't go through medical [for vehicles/modifications], we don't go through the regional centers, we don't go through any of*

*the avenues that are potentially available, because that just adds another layer of six to ten months of time.*"

The slow speed of funding approval also caused safety issues with the vehicles themselves. An IWD noted that their vehicle had been in a serious accident that severely compromised the integrity of the vehicle, but they continued riding in it for several months due to the processing time for the federal grant funds intended to help with the purchase of a vehicle. Tie downs and other equipment were aging, but the process of receiving grants was long, thus lower-quality vehicles and modifications were purchased with out-of-pocket funds that could not cover the cost of high-quality equipment.

Along with an arduous federal grant process, participants faced a local unavailability of vehicles and customized modifications. Three out of four participants noted that their vehicles came from out-of-state due to the individual needs of the disabled passenger and family members. A parent whose child was disabled noted that they desperately needed a new vehicle as it could no longer safely drive up hills, but they did not have the time to look throughout the country for a vehicle that had the needed seating position and lift.

### 5.2.4 Unsafe Vehicle Modifications

Participants expressed that lifts and tie downs were the most unsafe modifications in their vehicles. Electric lifts frequently broke down, with one parent of an IWD recalling that the electric lift on their family's vehicle stopped working while their child was being lifted into the vehicle, causing the lift to be dangerously suspended until a repairperson was called.

IWDs recalled their own instances of lifts that had low edge lips, with situations where wheelchairs were nearly driven off the edge due to miscommunications with lift operators. When asked about their feelings toward lifts, one IWD said "*I'm absolutely terrified by lifts, the hydraulic lifts that are in the back, just because they go fairly high. And they seem super sketchy, and they're always broken.*"

Tie-downs were a consistently discussed ill-fitting modification. Wheelchairs shifting while the vehicle was operating due to loosely secured and/or old tie downs were a habitual issue. Half of the participants interviewed noted situations where wedged objects such as small pieces of paper or lint prevented tie downs from securing properly. Those who drove IWDs expressed a sense of having to drive slowly and carefully due to concerns about loose and improperly secured tie downs. One family member of an IWD noted that the ill-fitting tie-downs impacted their driving: "*I always had to drive very carefully and far away from any vehicles in front of me so that I wouldn't have to slam on the brakes. I wasn't really comfortable with the tie downs and how [in]secure they were.*"

### 5.2.5 Planning Between Family Members

For all involved, the greatest challenge with regard to the vehicle work-system was communication, a social element of safety under the SEIPS model (Carayon et al., 2006, Holden et. al, 2013; Carayon et al. 2020). Both IWDs and family members explained that to take a trip in their vehicle, whether local or distant, involved a tremendous amount of planning and forethought. "*You can't just jump in and go somewhere, you have to plan it. But we can do that. And we have that's what you do. But it's not fun*", a family member of an IWD expressed.

Participants noted that taking a trip in their vehicle involved: (1) figuring out trip destination(s) and calculating the accessibility of the destination(s); (2) determining which equipment to bring (e.g., ride in manual wheelchair or electric, bring slide board for manual wheelchair) based on destination(s); and (3) communication with family members to coordinate schedules and assistance with porting equipment. A family member explained that taking their child to and from work was a "shuffle", as there was daily coordinating between their partner's and child's daily dynamic schedules. With the high level of complexity involved in the transit work-system, miscommunications between parties was frequent. An IWD recalled several instances of misunderstanding schedules and needs with family members, which left them dangerously stranded in various locations due to the inability to use largely inaccessible taxis and related transit systems.

### 5.2.6 Resource Knowledge as an Epistemological Barrier

The sole participant who was unaware of whether or not their vehicle could be better modified for their family member with a disability felt they did not know the most current technologies for vehicles and modifications, nor how to obtain government grants for improved modifications. Regarding their knowledge of current vehicle modification technology, one family member of an IWD explained that they did not feel knowledgeable on the topic: "*I didn't even know if there was any such thing as... better equipment or technologies. I just didn't even try to figure out if there was something better.*"

The aforementioned family member also described themselves as living in a rural area without access to a disability community, thus they did not know how to find information on vehicles and grants. Other participants gained the majority of their vehicle and grant knowledge by connecting with others in the community, as opposed to using websites and/or official government flyers and documents.

### 5.2.7 Well-Being

#### 5.2.7.1 Family

Family members of IWDs expressed a combination of guilt and burnout due to the difficulty of having reliable access to transportation, as well as the cognitive impact of planning daily for the transport needs of their family member with a disability. Stories of missed field trips, and concerts were abundant, along with concerns about their own health and its impact on the future of their children's access to reliable transportation. One family member noted that their vehicle broke down, making them unable to take their child to camp: "*One time I tried to take him to a special camp for disabled children . . . . [t]he van was old. And so, the van broke down. That was a very awkward and difficult situation. After that, I did not try to take him very far away.*"

#### 5.2.7.2 IWDs

Wanting to feel "normal" and integrated with others while riding in a vehicle was a common sentiment from IWDs. When asked to expand on the meaning of "normal" within the context of vehicles, IWDs expressed a desire to ride in, and enter/exit, a vehicle without being seen as a person with a disability who is "inconveniencing" others, but rather as a commonplace passenger. Upon being asked how they wish to feel when riding in a vehicle, one expressed their desire to feel more integrated: "*Being in the car [versus modified van], you have the thought that people would not recognize that you're disabled, while you're sitting in a car in a normal car seat, like leaning on the window.*"

Both personal and public vehicles often have designated seating areas away from others, such as in the back of a van, causing them to experience a sense of separation and isolation from other passengers.

# 6. Discussion and Conclusion

Through the lens of SEIPS categories (Carayon et al., 2006, Holden et. al, 2013; Carayon et al. 2020), an amalgamation of survey and interview data with regard to personal vehicles revealed factors that strongly influence the safety and sense of well-being for IWDs and their family members.

From an *organizational* perspective, participants from both cohorts within surveys and interviews noted the expense of vehicles and their subsequent modifications. Those from all income levels noted receiving/attempting to receive federal and state grants to assist with vehicle expenses. Due to confusing and slow-moving bureaucratic processes, compromised and poorly working vehicles and modifications were commonplace, with some paying out of pocket for costly equipment. Knowledge of how to navigate bureaucratic processes was largely learned through social communications. Surveys and confirmations through interviews revealed that those in rural areas who had little to no social connection to disability communities felt less knowledgeable about the process of receiving government aid for vehicles/modifications.

*Tools and technology* heavily impacted a sense of safety. Lifts (both electric and manual) and tie-downs caused the most human and equipment errors for IWDs and their family members. Although all interview participants expressed stories of being in unsafe situations due to the aforementioned modifications, survey results found family members of IWDs are more prone to feeling unsafe with modifications in place. Differences in safety insights may be due to the attention that must be paid to the road at all times by family members who are also assisting their family member with entering and exiting the vehicle, and caring for their family member while on the road. Thus, for these family members, there is more awareness of human and equipment errors.

Analysis of the interview data suggests *tasks*, *process*, *journey,* and *safety (social)* were influenced by miscommunications between IWDs and family members with regard to schedules, trip types, and additional equipment needed (e.g., slide-boards, and manual versus electric wheelchairs). Because IWDs may not be able to obtain rides from contacts or public transit due to accessibility limitations, instances of journey mishaps for IWDs and their families occur. The aforementioned insight was not confirmed with survey data due the smaller sample size for the interview portion of the study, thus the result is considered emerging until further confirmation is produced.

The *external environment* heavily influenced both the safety and well-being of IWDs and their family members, as confirmed through interviews and surveys. Statistical analysis of survey responses consistently noted that both cohorts from rural and metropolitan areas had less access to resources (affordability of vehicles/modifications, connections to occupational therapists, policy knowledge) and felt less safe in their vehicles overall than their suburban-dwelling counterparts. Interview data confirmed that those who do not have connections to others in the disability community have less access to organizational knowledge. It is suspected that safety may be

influenced by road quality in rural and metropolitan areas. Furthermore, those in the suburbs may enjoy more financial security, thus enabling them to have better access to resources.

The *outcomes* of all factors noted have profoundly influenced the well-being of both cohorts. IWDs feel limited by their vehicles and family members' schedules, while experiencing a sense of isolation due to seating positions that separate them from other passengers. Family members of IWDs expressed feelings of fatigue due to the constant planning and syncing of schedules to ensure all parties are transported.

## Limitations

Several limitations must be noted for this research. The most apparent limitation is the small sample size of this project. Also, due to the COVID-19 pandemic, participants could not be observed in their vehicles, thus violations and errors could only be understood through the perspective of participants, without the addition of researchers' critical observations. Furthermore, both the survey and interviews represent only individuals with mobility-related disabilities due to the time and resource constraints involved in recruiting individuals with intellectual disabilities, and self-selection through participants. Last, family members of IWDs for interviews only consisted of parents, as opposed to a mixture of parents, siblings, and partners.

## Recommendations for Future Study

By summarizing the data collected in this study, a list of recommendations has been created:

1) Improve federal and state outreach for IWDs and their families, and in particular those in non-suburban areas, to be better informed about vehicle/modification funding options and timelines. At this time, it is not clear to us if there is lack of awareness on the part the IWDs and family, or is it due to inadequate funding at the state of federal level, or if there is intentional neglect. A review of historical records by the funding sources of past awardees might yield insights about the geographic location and some other demographics. Furthermore, the current modality used for information dissemination could be reviewed as well. Additionally, collaborations with automotive manufacturing companies (who also provide help with purchasing adaptive equipment) may be a viable avenue to investigate.

2) Ramps and tie-downs should be designed by including feedback from IWDs (and their families/care-providers). At present, it appears that there is distrust, thus making the users hesitant to use the aforementioned hardware. This may need more human-factors-based studies to understand the usability of the interactions between the interfacing components.

3) Future vehicle designs (both private and public) that create a sense of integration with other passengers by considering the seating positions of IWDs should be pursued. At this time,

purely on the socio-economic basis of IWDs and families, it may be more prudent to investigate design interventions for public transportation vehicles.

## Future Work

Given the exploratory nature of this research, it is recommended that several factors that were broadly covered through this project be studied, including a comparative analysis of how development-levels of residences impact vehicle safety of IWDs and their family members. Furthermore, understanding how communication systems are formed and refined over time between IWDs and family members given the interdependence of both populations may provide better insights into the sociotechnical structures for healthcare settings created by families.

The attempt within this study to recruit a highly specific sub-population of IWDs within an open market of workers using MTurk leads to questions about balancing the use of accessible screeners and surveys while protecting against survey bots and false positive responses. Given that prior research has noted a sizable population of MTurk workers as having disabilities, and the proven difficulties of recruiting IWDs for research, finding more effective ways of recruiting IWDs using MTurk may be a viable future option. A larger sample size might yield more insights about the different categories of the SEIPS models that might have been salient in this exploratory study. Another design recommendation for a future study is to conduct a naturalistic study, i.e., to include ride-alongs with IWDs and their families.

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# Appendix A: Consent Form, Survey

Request for Your Participation in Research

## TITLE OF THE STUDY

Understanding the Safety and Usability of Personal Vehicles for Non-Driving Individuals with Disabilities and their Families and Care Providers

## NAME OF THE RESEARCHERS

Hannah D. Bowman, San Jose State University graduate student

Dr. Anil Kumar, Principal Investigator, Associate Professor, ISE Dept, San Jose State University

## PURPOSE

The purpose of this study is to produce an in-depth understanding of the modifications made, and role of the personal vehicle of households with non-driving individuals with disabilities. The study will comprise two groups: (1) non-driving individuals with physical disabilities; (2) individuals with family members who are non-driving and with a disability, and non-related caregivers (e.g., nurse, in-home support) with a client who is non-driving and with a disability.

## PROCEDURES

You are being asked to participate in an online survey which is anticipated to take 12 minutes or less to complete. Questions such as your demographic information and the role you play with the personal vehicle that is used to transport an individual with disabilities will be asked.

Some participants will be contacted for follow-up components of the research, which may include providing a schematic or video tour of the vehicle of interest, and a semi-structured interview. A separate consent notice will be provided for the follow-up activities.

## POTENTIAL RISKS

A risk of participation in this study is emotional discomfort, should the survey questions approach topics which you are not comfortable answering. You are free to discontinue your participation in this study at any time by not submitting your survey.

## POTENTIAL BENEFITS

There are no direct benefits to your participation in this study. However, data collected from this study may help create commercial vehicles that are more accessible for persons with disabilities.

## COMPENSATION

For those who choose to participate in the survey, you will be asked to provide your email address to enter a random lottery for one of sixteen $25 digital Visa gift cards. If you wish to be entered into the drawing and do not want to complete the survey, please follow this link: https://tinyurl.com/4v6xravs to enter the lottery (email address required). The odds of winning a digital Visa gift card for all who enter the drawing are 4 to 11. Gift card winners will be contacted after the survey has closed (anticipated May 2021).

## CONFIDENTIALITY

You will be given a pseudonym on all research that is presented to the public, such as research papers and presentations. Your email address will be collected in order for you to be entered into the Visa gift card lottery. Should you request to be part of the vehicle video tour/schematic drawing and interview, you will be asked to provide your telephone number and/or email address in the digital survey so that we may contact you.

All survey data will be uploaded to a password-secure Google Drive folder that can only be accessed by involved researchers. All identifying data will be destroyed after the study has concluded (anticipated May, 2021).

De-identified and compiled data will be shared with San Jose State University's Mineta Transportation Institute, and may be presented on the US Department of Transportation's (USDOT) website at www.transportation.gov.

## PARTICIPANT RIGHTS

Your participation in this study is completely voluntary. You can refuse to participate in the entire study or any part of the study without any negative effect on your relations with San Jose State University. You also have the right to skip any question you do not wish to answer. You may also request to withdraw or withhold any information provided during or after the survey. This consent form is not a contract, therefore is entirely voluntary. It is a written explanation of what will happen during the study if you decide to participate. You will not waive any rights if you choose not to participate, and there is no penalty for stopping your participation in the study.

## QUESTIONS OR PROBLEMS

You are encouraged to ask questions at any time during this study. For further information about the study, please contact Hannah Bowman at hannah.bowman@sjsu.edu or Dr. Anil Kumar (anil.kumar@sjsu.edu, (408) 924-7840)

ELECTRONIC CONSENT: Please select your choice below. Clicking on the "Agree" button below indicates that: 1) you have read the above information, 2) you voluntarily agree to participate.

☐ Agree

☐ Disagree

## Consent Form, Interview

## TITLE OF STUDY

Understanding the Safety and Usability of Personal Vehicles for Non-Driving Individuals with Disabilities and their Families and Care Providers

NAME OF RESEARCHERS

Hannah D. Bowman, San Jose State University Graduate Student

Timothy Le, San Jose State University Undergraduate Student

Dr. Anil Kumar, Principal Investigator, Associate Professor, ISE Dept, San Jose State University

## PURPOSE

The purpose of this study is to produce an in-depth understanding of the modifications made, and role of the personal vehicle of households with non-driving individuals with disabilities. The study will comprise two cohorts: (1) non-driving individuals with physical disabilities; (2) individuals with family members who are non-driving and disabled, and non-related care providers (e.g., nurse, in-home support) with a client who is non-driving and with a disability.

## PROCEDURES

You are being asked to provide either a video-recorded tour or schematic drawing of the vehicle of focus. Prompts to help guide the tour or drawing, such as pointing out vehicle modifications will be emailed beforehand. Prior to recording the video tour and drawing the schematic, you are asked to obtain permission from the private/business owner of the vehicle of interest. You will be required to attest to the receipt of this permission in order to upload the schematic and video to a Google form. Once the aforementioned information has been collected and reviewed, a semi-structured interview will be conducted over Zoom video conferencing software to gain a more in-depth understanding of the vehicle and persons involved. Your Zoom call will be video-recorded for analysis. You may use a pseudonym for your name when using Zoom, and can request to be interviewed with the camera off.

*Please note: COVID-19 precautions are being applied, therefore all interactions with researchers will be digital. Furthermore, to consider patient confidentiality, names and related identifiers of patients will not be collected. Lastly, in order to redeem your compensatory $50 digital Visa gift card, you will be asked to provide an email address.

## COMPENSATION

Those who choose to participate in a schematic drawing/tour and interview will be compensated with a $50 digital Visa gift card once the schematic/video tour has been submitted, and the interview has been concluded.

## CONFIDENTIALITY

You will be given a pseudonym on all research that is presented to the public such as research papers and presentations. Your actual name will appear on this consent form, and your email address will be collected in order to provide you with a gift card. Furthermore, your email address and/or telephone number (per your preference) will be collected and utilized for correspondences with researchers.

All recordings (both video and audio), notes, and related data will be uploaded to a password-secure Google Drive folder and encrypted USB drive that will only be accessed by the researchers of this study. All data obtained from your interview and schematic or filmed video tour will be destroyed three years after this study has concluded.

De-identified and compiled data will be shared with San Jose State University's Mineta Transportation Institute, and may be presented on the US Department of Transportation's (USDOT) website at www.Transportation.gov.

## YOUR RIGHTS

Your participation in this study is completely voluntary. You can refuse to participate in the entire study or any part of the study without any negative effect on your relations with San Jose State University. You also have the right to skip any question you do not wish to answer. You may also request to withdraw or withhold any information provided during or after the interview should you experience discomfort. This consent form is not a contract, therefore is entirely voluntary. It is a written explanation of what will happen during the study if you decide to participate. You will not waive any rights if you choose not to participate, and there is no penalty for stopping your participation in the study.

## CONTACT INFORMATION

If you have any questions about this study, please contact student researcher Hannah Bowman at hannah.bowman@sjsu.edu, or lead researcher Dr. Anil Kumar at anil.kumar@sjsu.edu, (408) 924-7840.

## AGREEMENT TO PARTICIPATE

Your completion of the study indicates your willingness to participate. Please keep this document for your records.

# Appendix B: Recruiting Email

Dear [name],

My name is Hannah Bowman and I am a master's student at San Jose State University currently researching vehicle accessibility for individuals with disabilities and their family/care providers. I would like to invite you to participate in a study survey designed to better understand your current transport challenges. Results from this research are intended to help inform future vehicle designs, considering the lifestyles and concerns of non-driving individuals with disabilities and family/care providers.

You are eligible to participate in this study if you are age 18 years or more, can communicate in English, and are one of the following:

- A non-driving physically individual with a disability/ies age 18-45 who is transported via a personal family vehicle
- The household family member of non-driving physically and/or intellectually individual with a disability/ies who shares a vehicle with the family member with a disability/ies
- A non-relative care provider (e.g. nurse, in-home support) who helps with the transport of a non-driving client with a physically and/or intellectual disability/ies

If interested, you may access the survey online at this URL: [insert website URL]. The survey is anticipated to take under 30 minutes to complete, and compensation is a $10 gift card [note choices of gift cards].

Please note that this survey is confidential, and no client information will be shared or collected. If you would like to learn more about this study, please contact me, Hannah Bowman, at hannah.bowman@sjsu,edu.

Thank you,

Hannah Bowman

Human Factors/Ergonomics MS Candidate, San Jose State University

# Appendix C: Survey Introduction Page

Page 1 [Presented to participants after consent form has been digitally signed vid DocuSign. This page will appear for all participants, and subsequent pages will be determined depending on the option chosen below]

This survey is intended to better understand the role of personal vehicles for households with a non-driving family member who is with a disability/ies. Please indicate your affiliation within the household (please check one option):

- I am a non-driving person between age 18-46 with a disability who takes trips in personal vehicle owned and shared within the household
- I am a family member within a household that uses a shared personal vehicle that at least part of the time is used to transport a non-driving individual with a disability
- I am the non-relative care provider of a non-driving person with a disability who takes trips in personal vehicle owned and shared within household
- None of the above scenarios apply to me

[The option chosen by the participant will determine which set of survey questions are presented. For those who choose "none of this applies to me", they will receive a message saying: Thank you for your interest in this study. Unfortunately at this time you do not qualify for this questionnaire. If you have any questions, please contact lead researcher Hannah Bowman at hannah.bowman@sjsu.edu. Thank you.]

# Appendix D: Survey for Individuals with Disabilities

**Page 2** [if the participant identifies as disabled]

1. What is your age?

[drop down, age 18-105]

[note: if participant chooses above age 45, data will be discarded]

2. How would you best describe your race (select all that apply)?

- ☐ Native American or Alaska Native
- ☐ Native Hawaiian or Pacific Islander
- ☐ Hispanic or Latinx
- ☐ Asian
- ☐ Black or African American
- ☐ White
- ☐ Other (please specify): _____

3. How many people total are in your household (including yourself)?

[drop down, 1-10]

4. Gender? _____ [prefer not to answer option]

5. What is your employment status (select all that apply)?

- ☐ Full-time
- ☐ Part-time
- ☐ Retired
- ☐ Unemployed, seeking employment
- ☐ Unemployed, not seeking employment

- ☐ Student
- ☐ Student + employed
- ☐ Homemaker
- ☐ Other: _____

6. What is your approximate annual Income?

Please write the amount in dollars: _____

7. What state are you currently living in?

[drop down]

8. Please describe the development environment where your home is located

- ☐ Rural
- ☐ Metropolitan
- ☐ Suburbs
- ☐ Other: _____

9. What Is the nature of your disability/ies

Please provide details that you are comfortable sharing with us: _____

10. For how long have you been with a disability/ies?

Please provide the number of years: _____

11. Do you actively drive a vehicle?

- ☐ Yes
- ☐ No

[If no]

- ☐ 11a. Does your family own a vehicle that you ride in?

- ☐ Yes
- ☐ No

[If yes]

- ☐ 11b. Please list the make/model and year of each vehicle that your family owns
- ☐ _____

12. How many people share the vehicle in your home (if there are multiple people with multiple drivers, please average the amount of people that drive each vehicle)?

[drop down, between 1-10]

13. Have any of the cars listed been modified to suit your accessibility needs?

- ☐ Yes
- ☐ No

[If yes]

- ☐ 13a. Please note the vehicle(s)

_____

14. [If yes on 13] To the best of your knowledge, what modifications have been made (select all that apply)? [number of times this option appears will coincide with the number of vehicles owned. Question inspired by Di Stefano et al., 2019]

[multiple select]

- ☐ Hand controls
- ☐ Steering aids
- ☐ Lowered floor/raised roof
- ☐ Ramps/hoist/wheelchair access
- ☐ Extended/additional mirrors
- ☐ Modified foot brake/accelerator

- ☐ Modified indicators/light switches
- ☐ I don't know what modifications have been made
- ☐ Other: _____

15. [If yes on 13] Who added the modifications to the vehicle(s) (select all that apply)? [Question inspired by Di Stefano et al., 2019]

[multiple select]

- ☐ Self
- ☐ Family member
- ☐ Friend
- ☐ Mechanic
- ☐ Occupational therapist
- ☐ Occupational therapy driver assessor
- ☐ Independent living center
- ☐ Local mechanic
- ☐ Driving instructor
- ☐ I don't know who added the modifications
- ☐ Other: _____

16. Who is the primary driver when you are in a vehicle?

- ☐ Family member
- ☐ Non-related caregiver
- ☐ Friend
- ☐ Taxi/Rideshare driver
- ☐ Other: _____

17. Please rate how often you rate the following modes of transportation listed below. The rating scale ranges from (1) never/rarely used, to (5) used most often.

- ☐ Personal vehicle
- ☐ Bus
- ☐ Rideshare/Taxi
- ☐ Walk
- ☐ Bicycle
- ☐ Ferry

Please note any other transportation methods: _____

18. How many times per week do you use this form of transportation? (a trip is counted as to and from a location)?

[drop down]

- ☐ Multiple times each day
- ☐ Daily
- ☐ 1 time per week
- ☐ 2 times per week
- ☐ 3 times per week
- ☐ 4 times per week
- ☐ 5 times per week
- ☐ 6 times per week
- ☐ Other: _____

19. Please rate the places you visit in your personal vehicle from most to least often, marking "does not apply" for any location that does not apply.

[multiple select]

- ☐ Work
- ☐ School
- ☐ Place of leisure (gym, park, movie theatre)
- ☐ Friend or family member's home
- ☐ Place of worship (church, temple)
- ☐ Medical appointment
- ☐ Leisure drive
- ☐ Retail store
- ☐ Other: _____

20. Thinking about the time you spend within your personal vehicle(s), please rate the following statements. If you have multiple vehicles, please choose the vehicle that you ride in most often.

The rating scale ranges from strongly disagree (1) to strongly agree (5). Please mark "does not apply" for any statement that does not apply.

- ☐ I am comfortable being driven by others
- ☐ I feel physically comfortable sitting in my vehicle
- ☐ I feel safe entering and exiting my vehicle
- ☐ I feel safe while on the road in my vehicle
- ☐ I feel safe with the modifications made to my vehicle
- ☐ I feel the modifications made to my vehicle suit my needs
- ☐ I do not need further modifications to my vehicle
- ☐ I know who to contact if I need to make modifications and/or adjustments to my vehicle
- ☐ I can afford to make modifications to my vehicle
- ☐ I can afford the maintenance and upkeep of my vehicle

- ☐ I do not need the assistance of others to enter and exit my vehicle
- ☐ Others who ride in the vehicle with me appear to feel safe and comfortable
- ☐ I feel I can travel anywhere in my vehicle
- ☐ I feel I have the support of friends, family with my transportation needs
- ☐ I feel my vehicle improves the quality of my life

21. Please select "this applies to me" for all statements that apply to you, and select "does not apply to me" for any answer that does not apply. If your family has multiple vehicles, please choose the vehicle that you ride in most often.

- ☐ I require the care from a family member and/or non-related care provider while riding in my vehicle
- ☐ There are procedures in place so that I can enter/exit and/or ride in my vehicle safely
- ☐ People have been trained on the procedures that help me enter/exit and/or ride in my vehicle safely
- ☐ I have received assistance from a occupational specialist or related professional with the purchasing and/or modifications made to my vehicle
- ☐ A friend or family member has made a modification at some point to my vehicle
- ☐ I have been in an unsafe situation while in my vehicle and feel it is due to the modifications made to my vehicle

22. If applicable, please briefly explain a scenario where the safety of you, your family member [client], or someone else was compromised while inside of your [the] vehicle

_____

23. Do you have any additional thoughts or information that you would like to share with us?

_____

In the space below, please provide your email address so that we may email you a redemption code for your $10 gift card. The access code will be sent to you within 24-48 hours. If you have any questions or comments, please contact lead researcher Hannah Bowman at hannah.bowman@sjsu.edu.

# Appendix E: Survey for Family Member/Care Provider

**Page 2** [if the participant identifies as family member/caregiver]

1. What is your age?

[enter age]

2. How would you best describe your race (select all that apply)?

- ☐ Native American or Alaska Native
- ☐ Native Hawaiian or Pacific Islander
- ☐ Hispanic or Latinx
- ☐ Asian
- ☐ Black or African American
- ☐ White
- ☐ Other (please specify): _____

3. How many people total are in your [client's] household (including yourself)? [This question will not be asked for non-family caregivers]

[drop down, 1-10]

4. Gender? _____ [prefer not to answer option]

5. What is your employment status (select all that apply)?

- ☐ Full-time
- ☐ Part-time
- ☐ Retired
- ☐ Unemployed, seeking employment
- ☐ Unemployed, not seeking employment

- ☐ Student
- ☐ Student + employed
- ☐ Homemaker
- ☐ Other: _____
- ☐ [If employed]
- ☐ Please note your occupation
- ☐ _____

6. What is your approximate annual Income? [This question will not be asked for non-family caregivers]

Please write the amount in dollars: _____

7. What state are you currently living in?

[drop down]

8. Please describe the development environment where your [client's] home is located

- ☐ Rural
- ☐ Metropolitan
- ☐ Suburbs
- ☐ Other: _____

9. What Is the nature of your family member's [client's] disability/ies

Please provide details that you are comfortable sharing with us: _____

10. For approximately how long has your family member [client] been disabled?

Please provide the number of years: _____

11. What is your relationship to the non-driving individual with a disability?

- ☐ Nurse

- ☐ In-hope support provider
- ☐ Aide
- ☐ Friend
- ☐ Household family member
- ☐ Non-household family member
- ☐ Other: _____
- ☐ [if not household family member or non-household family member]

11b. How long have you been working with the non-driving individual with a disability?

[drop down, less than 1 year-70 years]

12. Do you drive/ride along with or help your family member [client] enter/exit the vehicle?

- ☐ Yes
- ☐ No
- ☐ [If no]
- ☐ 12a. Does your family member [client] own a vehicle?
- ☐ Yes
- ☐ No

[If yes]

- ☐ 12b. Please list the make/model and year of each vehicle that your family owns
- ☐ _____

13. How many people share the vehicle in your [client's] home (if there are multiple people with multiple drivers, please average the amount of people that drive each vehicle)?

[drop down, between 1-10]

14. Have any of the cars listed been modified to suit your family member's [client's] accessibility needs?

- ☐ Yes
- ☐ No
- ☐ [If yes]
- ☐ 15a. Please note the vehicle(s)
- ☐ _____

16. [If yes on 13] To the best of your knowledge, what modifications have been made (select all that apply)? [number of times this option appears will coincide with the number of vehicles owned. Question inspired by Di Stefano et al., 2015]

- ☐ [multiple select]
- ☐ Hand controls
- ☐ Steering aids
- ☐ Lowered floor/raised roof
- ☐ Ramps/hoist/wheelchair access
- ☐ Extended/additional mirrors
- ☐ Modified foot brake/accelerator
- ☐ Modified indicators/light switches
- ☐ I don't know what modifications have been made
- ☐ Other: _____

17. [If yes on 13] Who added the modifications to the vehicle(s) (select all that apply)? [Question inspired by Di Stefano et al., 2015]

[multiple select]

- ☐ Self

- ☐ Family member [will not appear for caregiver]
- ☐ Friend
- ☐ Mechanic
- ☐ Occupational therapist
- ☐ Occupational therapy driver assessor
- ☐ Independent living center
- ☐ Local mechanic
- ☐ Driving instructor
- ☐ I don't know who added the modifications
- ☐ Other: _____

18. Who is the primary driver when you are in a vehicle?

- ☐ Self
- ☐ [Client's] Family member
- ☐ Non-related caregiver [will not appear for caregiver]
- ☐ [Client's] Friend
- ☐ Other: _____

19. [To the best of your knowledge] Please rate how often you [your client] uses the modes of transportation listed below. The rating scale ranges from (1) never/rarely used, to (5) used most often.

- ☐ Personal vehicle
- ☐ Bus
- ☐ Rideshare/Taxi
- ☐ Walk

- ☐ Bicycle
- ☐ Ferry
- ☐ [For caregiver] I do not know what other transportation methods my client uses
- ☐ Please note any other transportation methods: _____

20. [To the best of your knowledge] How many times per week do you [does your client] use this form of transportation? (a trip is counted as to and from a location)? [Will not appear if caregiver chooses "I do not know"]

[drop down]

- ☐ Multiple times each day
- ☐ Daily
- ☐ 1 time per week
- ☐ 2 times per week
- ☐ 3 times per week
- ☐ 4 times per week
- ☐ 5 times per week
- ☐ 6 times per week

Other: _____

21. Please rate the places you [your client] visit[s] in your [the] vehicle from most to least often, marking "does not apply" for any location that does not apply.

[multiple select]

- ☐ Work
- ☐ School
- ☐ Place of leisure (gym, park, movie theatre)
- ☐ Friend or family member's home

- ☐ Place of worship (church, temple)
- ☐ Medical appointment
- ☐ Leisure drive
- ☐ Retail store
- ☐ Other: _____

22. Thinking about the time you spend [assisting your client] within your [their] personal vehicle(s), please rate the following statements. If you have [your client has] multiple vehicles, please choose the vehicle that you ride in [you assist your client with] most often.

The rating scale ranges from strongly disagree (1) to strongly agree (5). Please mark "does not apply" for any statement that does not apply.

- ☐ I feel physically comfortable sitting in my [client's] vehicle
- ☐ I feel safe entering and exiting my [client's] vehicle
- ☐ I feel safe while on the road in my [client's] vehicle
- ☐ I feel safe with the modifications made to my [client's] vehicle
- ☐ I feel I can safely help my family member [client] enter/exit and travel in my [the] vehicle
- ☐ I know who to contact if I need to make modifications and/or adjustments to my [client's] vehicle
- ☐ [For family] I can afford to make modifications to my vehicle
- ☐ [For family] I can afford the maintenance and upkeep of my vehicle
- ☐ My family member [client] needs my assistance to enter and exit my [the] vehicle
- ☐ My family member [client] appears to feel safe and comfortable in my [the] vehicle
- ☐ [For family] I feel I can travel anywhere in my vehicle
- ☐ [For family] The modifications made to my vehicle do not hinder my ability to ride in/use the car
- ☐ I feel my vehicle improves the quality of my [client's] life

23. Please select "this applies to me" for all statements that apply to you, and select "does not apply to me" for any answer that does not apply. If your family [client] has multiple vehicles, please choose the vehicle that you ride in most often.

- ☐ I have trained or been trained on the procedures that help my family member [client] enter/exit and/or ride in my vehicle safely
- ☐ My family member [client] requires my care while riding in my [the] vehicle
- ☐ There are procedures in place so that I can help my family member [client] enter/exit and/or ride in my [the] vehicle safely
- ☐ [For family] I have received assistance from a occupational specialist or related professional with the purchasing and/or modifications made to my vehicle
- ☐ [For family] A friend or family member has made a modification at some point to my vehicle
- ☐ I have been in an unsafe situation while in my vehicle and feel it is due to the modifications made to my vehicle
- ☐ I have personally made modifications to my [the] vehicle

24. If applicable, please briefly explain a scenario where the safety of you, your family member [client], or someone else was compromised while inside of your [the] vehicle

_____

25. Do you have any additional thoughts or information that you would like to share with us?

_____

Would you be interested in providing more information to us about your experiences with your [the] vehicle? The follow-up will include a short tour or drawing of the vehicle, and an interview that will be between 1-1.5 hours. You will be compensated with a $40 giftbit.com gift card for your participation.

- ☐ Yes
- ☐ No

[if yes]

Please provide the best method and time of day to contact you

- ☐ Email: _____
- ☐ Phone: _____
- ☐ Time
- ☐ [Drop down]
- ☐ Morning
- ☐ Afternoon
- ☐ Evening

Thank you so much for taking our survey. The information you have provided will help create more publicly available research in the field of vehicle accessibility.

In the space below, please provide your email address so that we may email you a redemption code for your $10 gift card. The access code will be sent to you within 24-48 hours. [If yes interview] a researcher will be contacting you within 7 days to schedule a follow-up session with you. [All] If you have any questions or comments, please contact lead researcher Hannah Bowman at hannah.bowman@sjsu.edu.

# Appendix F: Video Tour Prompt

## Video Tour Prompt

Thank you for agreeing to partake in this video tour session. When available, please use a video recording device (such as your mobile phone) to show us the inside and outside of the vehicle that transports your client/family member with a disability/ies. There is no minimum or maximum time needed for the tour, please take as much time as you would like to show us around. Because we are interested in details such as the modifications made to your vehicle, please use the below points as features to touch on during the tour:

- Please briefly walk us through the overall inside and outside of the vehicle, making sure to capture doors, seats, driver area, and flooring.
- Please show modifications that have been made within the vehicle. Who made the modifications? What does each modification do? How do you feel about the modification and are there any changes that you would like to make?
- Please walk us through how the individual with a disability/ies enters and exits the vehicle. Who, if anyone, assists with getting the passenger with a disability/ies in and out of the vehicle?
- Are there modifications within the vehicle that have not, or are no longer used? If so, please show us the modifications and explain to us what happened.
- Is there a care provider/family member who must sit with the passenger during trips? If so, please show us where the care provider/family member sits

We would like to sincerely thank you for taking the time to create this video. When you have finished recording, please upload your video to the secure Google Drive page at [page address TBD]. Once we have reviewed the video, we will contact you for a follow-up interview to go a bit more in-depth about what you have discussed in this video. If you have any questions, please contact lead researcher Hannah Bowman at hannah.bowman@sjsu. Thank you.

# Appendix G: Schematic Drawing Prompt

## Vehicle Schematic Drawing Prompt

Thank you for agreeing to create a schematic of the vehicle of interest. When available, please paper or a digital drawing tool to create a schematic drawing of the outside and inside of the car used to transport the client/family member with a disability. No artistic skills are necessary--feel free to draw boxes if you feel you cannot accurately represent the outline of the vehicle. What is most important is to help us understand elements of the vehicle such as the modifications made to it. As previously noted, we are interested in the details of the vehicle, therefore have created a list of items to include in your schematic drawing:

- In as much detail, please draw the inside and outside of the vehicle, including number of seats and their location, driver dash/console, and where each passenger, including the individual with a disability/ies, generally sits while the vehicle is in motion.

- Please mark and label where modifications that have been made within the vehicle, noting who made the modifications.

- Please mark where the individual with a disability/ies enters and exits the vehicle. Who, if anyone, assists with getting the disabled passenger in and out of the vehicle?

- Please mark any modifications within the vehicle that have not, or are no longer used and write a short side-note as to why they're no longer being utilized.

We would like to sincerely thank you for taking the time to create this schematic drawing. When you have finished drawing and labeling it, please upload the schematic to the secure Google Drive page at [page address TBD]. Once we have reviewed the schematic, we will contact you for a follow-up interview to go a bit more in-depth about what you have drawn. If you have any questions, please contact lead researcher Hannah Bowman at hannah.bowman@sjsu. Thank you.

# Appendix H: Mturk Screener

Q5 We are aiming to gain a basic snapshot into the transportation situations of households in the United States. Please fill out this questionnaire to the best of your ability, and note that there are no right or wrong answers (other than the captcha question).

The survey should take approximately 2 minutes or less to complete. A sincere thank you for your time.

Q7 Please answer the following question:

What is the opposite of up?

Q1 Which of the following best describes you (select all that apply)?

- ☐ I do not currently identify as having a disability (1)
- ☐ I have a physical disability (e.g., multiple sclerosis, muscular dystrophy) (2)
- ☐ I have an intellectual disability (e.g., Fragile X syndrome, Down syndrome) (3)
- ☐ I have a sensory disability (e.g., Blind/low vision, Deaf/hard of hearing) (4)
- ☐ I have another disability not listed (please specify): (5)
- ☐ Prefer not to say (6)

Q2 Do you live in a household with someone with a disability who is non-driving?

- ☐ Yes (1)
- ☐ No (2)

Q11 What is the nature of your house-member's disability?

- ☐ A physical disability (e.g., multiple sclerosis, muscular dystrophy) (1)
- ☐ An intellectual disability (e.g., Fragile X syndrome, Down syndrome) (2)
- ☐ A sensory disability (e.g., Blind/low vision, Deaf/hard of hearing) (4)
- ☐ A psychological disability (e.g., depression, bipolar disorder) (5)

- ☐ Another disability not listed (please specify): (6)

Q14 What is the primary form of transportation for your household member with a disability?

- ☐ Someone in my household drives them (1)
- ☐ Public transportation (e.g., bus, paratransit, Uber, train) (2)
- ☐ Walk (3)
- ☐ Bicycle/skateboard/scooter (4)
- ☐ Other (5)

Q3 Are you a paid caretaker of at least one person who has a physical or intellectual disability?

- ☐ Yes (1)
- ☐ No (2)

Q4 Does at least one of your clients have someone from their household that drives them in a vehicle?

- ☐ Yes (1)
- ☐ No (2)

Q13 What is the nature of your non-driving client's disability?

- ☐ A physical disability (e.g., multiple sclerosis, muscular dystrophy) (1)
- ☐ An intellectual disability (e.g., Fragile X syndrome, Down syndrome) (2)
- ☐ A sensory disability (e.g., Blind/low vision, Deaf/hard of hearing) (3)
- ☐ A psychological disability (e.g., depression, bipolar disorder) (4)
- ☐ Another disability not listed (please specify): (5)

Q11 Do you drive?

- ☐ Yes (1)
- ☐ No (2)

Q12 What best describes your primary mode of transportation?

- ☐ Someone in my household drives me (e.g., partner, parent) (1)
- ☐ Someone I know who does not live with me (e.g., friend, caregiver) (6)
- ☐ Public transportation (e.g., bus, paratransit, Uber, train) (2)
- ☐ Walk (3)
- ☐ Bicycle/skateboard/scooter (4)
- ☐ Other (5)

Q13 Here is your ID: ${e://Field/Random%20ID}

Copy this value to paste into MTurk When you have copied this ID, please click the next button to submit the survey.

# Appendix I: Interview Questions (Family/Care Providers)

Thank you for taking the time to talk with me today. We will be going over your experiences with your [client's] vehicle, to gain an in-depth understanding of what it has been like working with the vehicle. I want to remind you that your participation is entirely voluntary, and you are free to skip over any questions that you wish to not answer, not stop this interview at any point. You may also tell me now, or later that you wish to remove your input from this research. Here is my contact information once again [type email address in Zoom chat]. I would also like to remind you that all information shared today will have the confidentiality of your family member [client] in mind, therefore names and related identifiers will be removed from this session. Do you have any questions before we begin?

## Journey/Opening Questions

1. What is your relationship to the non-driving person with a disability?

2. For how long have you known them?

3. Do you ride along with your family member [client]? Assist them with entering/exiting the vehicle?

4. [if applicable based on Q#3) Where are some of the places you go with your [client] family member regularly? Or: where are some of the places you know of that your family member [client] visits regularly

5. Who typically rides along?

## Persons

1. Who helps your family member [client] get in/out of the vehicle. What is each person's knowledge level/expertise with configuration of the vehicle?

2. How are you and/or helpers trained with assisting your family member [client] participant in vehicle/how is information passed off?

3. Do you feel equipped physically to assist your family member [client] with tasks such as entering and exiting the vehicle?

4. Did a professional assist with orienting the vehicle? Is there a continued relationship with the professional?

## Tasks

1. What is the sequence of getting your family member [client] in and out of the vehicle? [Family] Do different care providers have a differing flow?

2. Have multiple sequences been tried? Why did the current one stick? Does the sequence change, or remain the same? If so, what causes the changes?

3. How can the tasks associated with transporting your family member [client] be improved?

## Tools and technologies

1. What tools are used to get your family member [client] in/out of vehicle and to transport them? Have tools changed over time?

2. What technologies have been utilized that have failed?

3. What tools/technologies would you like to be able to use for the vehicle but do not have access to?

## Organization

1. How does the personal family vehicle fit into the lives of your [client's] household members? Who does what with the vehicle?

## Internal environment

2. How has the internal layout of the vehicle changed over time?

3. How safe does the vehicle feel? How have modifications made feelings of safety change for the individual with a disability/ies, family, caregivers?

## External environment

1. What is the environment of the vehicle like while in operation (sounds, vibrations)?

## Closing

2. Use the remaining time to point out and discuss modifications noted in the schematic/tour. Ask about each modification and its purpose. Point out any other noteworthy information provided by the participant.

3. Is there anything that you would like to add to our interview or a point or topic that I missed?

That concludes our interview. Thank you so much for taking your valuable time to speak with me today. I have learned so much about you and your family member [client]. For your time today, I will be emailing you a code to redeem the $40 gift card from giftbit.com within 48 hours. Do you have any last questions or comments before we conclude for today? Thank you.

# Appendix J: Interview Questions (Individuals with Disabilities)

**Go over consent, record video**

Thank you for taking the time to talk with me today. We will be going over your experiences with your family vehicle, to gain an in-depth understanding of your experiences. I want to remind you that your participation is entirely voluntary, and you are free to skip over any questions that you wish to not answer, not stop this interview at any point. You may also tell me now, or later that you wish to remove your input from this research. Here is my contact information once again [type email address in Zoom chat]. I would also like to remind you that all information shared today will be confidential, therefore names and related identifiers will be removed from this session. Do you have any questions before we begin?

**Journey/Opening Questions**

1) Tell me about the vehicle you use to get around

2) Who typically rides with you when you're in the vehicle?

3) I've intentionally left this question vague, because I would love to hear in your own words what having a vehicle means to you?

○ How does your vehicle fit in your life?

○ How does your vehicle fit in your family members' lives?

4. Tell me a good memory you have where your family vehicle played a key role?

5. If you wouldn't mind, please tell me a memory you have that isn't so great where your family vehicle played a key role?

**Persons**

1) Do you need assistance getting in and out of the vehicle? If so, how do they assist you?

2) How are people trained with assisting you?

3) How is that information passed off to others?

4) Do you have modifications within your vehicle?

5) [If yes] tell me about the modifications

6) Who modified the vehicle?

7) How overall would you say they did with modifying the vehicle?

**Tasks**

1) What is the sequence of getting in and out of your vehicle?

2) Have multiple sequences been tried?

3) Why did the current one stick?

4) Does the sequence change, or remain the same? If so, what causes the changes?

5) How can the tasks associated with transporting your family member [client] be improved?

**Tools and technologies**

1) Before your current family vehicle, what did your family have before?

2) What happened with the vehicle?

3) How did that vehicle compare with what you have now?

4) What is your dream vehicle to have and why?

**Organization**

1) Tell me what it's like when your whole family rides in the vehicle together

2) What are long-term trips like with the family?

3) Are there any places you avoid going in the vehicle?

**Internal environment**

1) Describe how it feels inside when the vehicle is in motion

2) If given creative freedom to design the interior of your family's car, what would the layout be like?

3) Where would you like to sit and why?

4) Tell me, safe does the vehicle feel inside?

5) How have modifications made feelings of safety change for the individual with a disability, family, care provider?

**External environment**

1) What is the environment of the vehicle like while in operation (sounds, vibrations)?

2) **Closing**

3) Use the remaining time to point out and discuss modifications noted in the schematic/tour. Point out any other noteworthy information provided by the participant.

4) Is there anything that you would like to add to our interview before we finish our conversation?

Are there any other comments related to your experiences with your family vehicle, that you would like to share?

[If no] Thank you so much for taking your valuable time to speak with me today. I have learned so much about you and your family member(s) [client]. For your time today, I will be emailing you a code to redeem the $50 Visa gift card. Do you have any last questions or comments before we conclude for today? Thank you.

# Appendix K: Code Key

Table 3. Code Key

| **Code (Deductive)** | **Description** |
|---|---|
| Technology and tools | Material objects used to do work/assist with tasks (usability, accessibility, familiarity, level of automation, portability, and functionality). |
| Outcomes (family/care provider) | Safety, satisfaction, stress, health and burnout. |
| Outcomes (IWD) | Safety [implied but not explicit: satisfaction, stress, health]. |
| Tasks | Work to be completed/undertaken. |
| Organization | Structures external to individuals that organize activities, time, space, resources. |
| Environment (external) | Macro-level societal, economic, ecological, and policy factors outside an organization. |
| Environment (internal) | Physical environment. |
| Process (other) | Series of steps to an intended outcome. |
| Process (care) | How safely care is provided. |
| Journey | Spatio-temporal interactions with multiple care settings over time. |
| Quality of Care | Desired health outcomes. |
| Safety | Harm or danger. |
| ➢ Safety (biological) | Factors related to the body. |
| ➢ Safety (physical) | Noise, environment. |
| ➢ Safety (social) | Communication. |
| Engagement | Individuals/teams can perform health-related activities both separately and collaboratively. |
| Physical Environment | Physical surroundings. |
| Configuration | A subset of possible interactions that are relevant to a process/situation. |
| Persons | An individual/team of individuals who have a collective, cohesive, similarness of knowledge (IWDs, family, care providers). |
| Adaptation | Feedback mechanism that explains how dynamic systems evolve in planned/unplanned ways. |
| Time (Process) | Time it takes to obtain a good or service through an organized system. |

| Code (Deductive) | Description |
|---|---|
| ➢ Time (process), High | Time prevents the obtaining of good/service. |
| ➢ Time (process), Medium | Time limits the limiting of obtaining a good/service. |
| ➢ Time (process), Low | Time taken does not limit the obtaining of good/service. |
| Incognito | An IWD's desires/attempts of not standing out to others for their disability. |
| "Normalness" | A IWD's desires/attempts to go about life as "normal" people partake in. |
| Planning | Process of planning to go somewhere or do something. |
| ➢ Planning (high) | Takes a lot of time/resources/energy, inconvenienced enough to never/rarely do. |
| ➢ Planning (medium) | Takes a medium amount of time/resources/energy, inconvenienced enough to sometimes not follow-through. |
| ➢ Planning (low) | Low amount of time/resources/energy, feels free to do. |
| "Good Enough" | An object/situation that is less than ideal, but must make do for life to continue on. |
| Failed Plan | When a plan (e.g., going on vacation, to work) was made but failed. |
| ➢ Failed Plan (resources) | When lack of resources (e.g., money) caused a plan to fail. |
| ➢ Failed Plan (miscommunication) | When a miscommunication resulted in a failed plan. |
| Frustration with Ableism | Expressing frustration due to lack of accessibility in the environment. |
| Frustration with Disability | Expressing frustration with one's own or other's disability. |
| Government Resources | The use of using public funding to obtain goods or services. |
| ➢ Government Resources (failed) | Unable to obtain goods/services via public funding or delay with obtaining resources. |
| ➢ Government Resources (success) | Able to obtain goods/services via public funding or delay with obtaining resources. |
| "Prove" Disability | Needing to prove to others (individuals, orgs) of disability |
| Hanging on to Equipment | Hanging on to equipment (wheelchair, vehicle etc.) for a long time per the sentiments of participants. |

# Appendix L: Statistics Tables

Table 4. Simple Linear Regression, One-Way ANOVA, Wilcoxon Rank-Sum Test

| Test | Independent Variable(s) | Dependent Variable(s) | Results | Comments |
|---|---|---|---|---|
| Simple Linear Regression | Age (rounded) | (B) I feel safe with the modifications made to the vehicle | $R^2 = 0.635$ | Strong positive correlation between age and modifications made to vehicles. |
| Simple Linear Regression | Income | (B) I feel safe with the modifications made to the vehicle | $R^2 = 0.644$ | Strong positive correlation between income and feelings of safety with vehicle modifications. |
| Simple Linear Regression | Simple Linear Regression | (C) There are procedures in place so that I can enter/exit and/or ride in the vehicle safely | $R^2 = 0.644$ | Strong positive correlation between income and feelings of safety upon entering and exiting the vehicle. |
| Simple Linear Regression | Income | Combined (A, B, C), equally weighted | $R^2 = 0.813$ | Strong positive correlation between income and general feelings of safety. |
| Wilcoxon Signed-Rank Test | IWDs/Family | I know who to contact if I need to adjust the vehicle. | $W^2 = .104$ | Mean rank of Family is 4.5, mean rank of IWDs is 1.50. Family members are more aware of who to contact to adjust the vehicle. |
| Wilcoxon Signed-Rank Test | IWDs/Family | I have been in an unsafe situation while in my vehicle and feel it is due to the modifications made to the vehicle. | $W^2 = .157$ | Mean rank of family members is 1.50, IWDs is 0.0, indicating that family members feel they have been in an unsafe situation due to the modifications made to the vehicle. |
| One-way | Employment | I/my family can | P = 0.1436 | Full time family |

| Test | Independent Variable(s) | Dependent Variable(s) | Results | Comments |
|---|---|---|---|---|
| ANOVA | Status (Family) | afford the maintenance and upkeep of the vehicle | | member employees and students felt they were able to afford vehicle maintenance and upkeep better than those who work part-time and are homemakers. |
| One-way ANOVA | Gender (Family) | I Feel safe entering/exiting the vehicle | P = 0.0119 | IWDs who identify as male feel more confident than IWDs who identify as female entering and exiting the vehicle. |
| One-way ANOVA | Development Level of Residence (IWD) | I Feel safe entering/exiting the vehicle | P = 0.0008 | IWDs who live in rural and metropolitan areas feel less safe entering and exiting their vehicles than those in the suburbs. |
| One-way ANOVA | Development Level of Residence (IWD) | I feel I can travel anywhere in the vehicle. | P = 0.1593 | IWDs who live in suburban areas feel that they can travel more in their vehicles than those in rural areas. |
| One-way ANOVA | Development Level of Residence (IWD) | I know who to contact if I need to make modifications and/or adjustments to the vehicle. | P = 0.1065 | IWDs who live in suburban areas feel more knowledgeable on who to contact to make vehicle modification adjustments than those in metropolitan and rural areas. |
| One-way ANOVA | Development Level of Residence (Family) | I/my family can afford to make modifications to the vehicle. | P = 0.0472 | Family members in suburban areas feel more equipped to afford vehicle |

| Test | Independent Variable(s) | Dependent Variable(s) | Results | Comments |
|---|---|---|---|---|
| | | | | modifications than those in rural areas. |
| One-way ANOVA | Relationship to IWD (Family) | I/my family can afford the maintenance and upkeep of the vehicle. | P = 0.0929 | Siblings of IWDs felt more equipped to handle vehicle expenses than the children and parents of IWDs. |
| One-way ANOVA | Relationship to IWD (Family) | I have been in an unsafe situation while in my vehicle and feel it is due to the modifications made to the vehicle. | P = 0.1278 | Siblings of IWDs are more apt to feel that they have been in an unsafe situation due to vehicle modifications more so than children or parents/guardians of IWDs. |
| One-way ANOVA | Type of Disability for IWD (Family) | My family member requires my care while riding in the vehicle. | P = 0.0860 | Family members who have a family member with a mobility-related disability are more apt to somewhat/strongly agree that their family member needs their care while the vehicle is in transit. |

Note: All one-way ANOVA tests have been plotted to determine means. A total of 64 tests were run for the aforementioned test, thus only values deemed to be statistically significant are listed.

Table 5. Likert-Scale Survey Question Responses

| Question | Results | |
|---|---|---|
| | IWD | Family |
| I feel safe entering and exiting the vehicle. | 62% strongly agree,<br>25% somewhat disagree<br>12% somewhat agree | 70% strongly agree,<br>10% somewhat disagree<br>20% somewhat agree |
| I feel safe with the modifications made to the vehicle. | 29% strongly agree,<br>57% neither agree nor disagree,<br>14% somewhat agree | 22% strongly agree,<br>78% neither agree nor disagree |
| I feel I can travel anywhere in the vehicle. | 50% strongly agree,<br>38% somewhat agree,<br>12% neither agree nor disagree | 50% strongly agree,<br>30% somewhat disagree,<br>20% somewhat agree |
| There are procedures in place so that I can enter/exit and/or ride in the vehicle safely. | 75% strongly agree,<br>25% neither agree nor disagree | 40% strongly agree,<br>40% somewhat agree,<br>20% neither agree nor disagree |
| I know who to contact if I need to make modifications and/or adjustments to the vehicle. | 29% strongly agree,<br>29% somewhat agree,<br>14% neither agree nor disagree,<br>29% strongly disagree | 11% strongly agree,<br>22% somewhat agree<br>11% neither agree nor disagree,<br>11% somewhat disagree<br>44% strongly disagree |
| I have been in an unsafe situation while in my vehicle and feel it is due to the modifications made to the vehicle. | 100% strongly disagree | 40% neither agree nor disagree,<br>60% strongly disagree |
| I/my family can afford to make modifications to the vehicle. | 29% strongly agree,<br>14% somewhat agree,<br>14% neither agree nor disagree,<br>43% strongly disagree | 11% strongly agree,<br>11% somewhat agree,<br>22% neither agree nor disagree,<br>22% somewhat disagree,<br>33% strongly disagree |
| I/my family can afford the maintenance and upkeep of the vehicle. | 25% strongly agree,<br>38% somewhat agree,<br>25% neither agree nor disagree,<br>12% somewhat disagree | 40% strongly agree,<br>20% somewhat agree,<br>40% somewhat disagree |
| I have been trained on the procedures that help my family member enter/exit the vehicle safely. | No responses. | 44% strongly agree,<br>22% somewhat disagree<br>33% strongly agree |

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**Hannah Bowman**

Hannah is pursuing her MSc in Human Factors/Ergonomics program at the San Jose State University at San Jose while conducting this research.

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