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Surveying people with disabilities: Insights on methods and challenges

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ABSTRACT

A fundamental challenge in researching people with disabilities lies in the difficulty collecting data representing the lived experience of people with disabilities – this is particularly true with intersectional research on the built environment, transportation, activities of daily community living (ADCLs), and well-being. There are two primary reasons for this data gap: 1) inherent challenges in surveying people with disabilities, and 2) limitations of existing public datasets, which often fail to capture the vast experiences of people with disabilities, particularly in relation to transportation, the built environment of communities, and people with disabilities' activities of daily community living. This paper provides a reflection on the challenges of gathering survey data from people with disabilities, which leads to these information gaps that are common in disability research. These insights arise from reflecting on a significant interdisciplinary research project undertaken by the authors, including data collection efforts, sampling and data collection methodology, analyzing challenges arising from current survey technologies, and partnering with individuals with disabilities in a meaningful way that acknowledged the importance of their lived experience. Key lessons learned from these data-gathering efforts include the importance of inclusive survey design, effective recruitment strategies, and robust data validation. By highlighting these lessons, this paper aims to improve future disability research and contribute to future data collection efforts that are more inclusive and effective.

Introduction

Recent research has increasingly examined how the built environment influences the disablement process. While disability is often viewed as a negative health outcome, this approach overlooks how the built environment can promote well-being and inclusion (Clarke & George, 2005). Recognizing the built environment's role in shaping disability experiences is necessary for supporting individual well-being. The design of communities—through policy and opportunity—significantly affects well-being (Ige-Elegbede et al., 2022; Turnbull, 2021), making community and transportation planners vital in fostering supportive environments for all citizens (Alidoust et al., 2024).

The design of spaces and systems directly impacts well-being by shaping mobility, accessibility, and activities of daily community living (ADCLs) (Andalib et al., 2024; Bagnall et al., 2023). ADCLs are an individual's daily activities within their community and include participation in community life in the form of work, recreation, shopping, attending school, healthcare, or socializing. The infrastructure and development patterns of the physical environment can promote the community integration of individuals through their day-to-day activities (Sutradhar et al., 2023). Access to public accommodation and services (such as recreational, educational, commercial, civic, and social activities), employment opportunities, appropriate housing, and convenient transportation access are particularly important for people with disabilities (Cox et al., 2003).

People with disabilities represent a significant yet often overlooked segment of the population in data-driven planning for the built environment (Hall et al., 2024; Koo & Hudson, 2021; Krahn et al., 2015). While existing data sources provide useful models of daily community living behavior, they fail to capture the vast experiences of people with disabilities, resulting in major gaps in understanding. Without accurate data on how this population interacts with their surroundings, planners and policymakers may struggle to understand the impact of designed environments and to design more inclusive and effective built environment systems.

Obtaining relevant data about how people with disabilities interact

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with the physical environment, and how that in turn influences their overall well-being, is not well understood (Misra et al., 2025). There is evidence that a lack of data has marginalized the needs of people with disabilities (Imrie & Kumar, 1998) and that it is disproportionately expensive socially for people with disabilities to participate in community living (Christensen, 2009). This is especially important as people with disabilities are often underrepresented in research due to accessibility issues and potential biases in data collection methods (Cerilli et al., 2024).

This study is a reflection on methodological efforts to address significant data gaps in linkages between the built environment, ADCLs, and the lived experience of people living with disabilities. The authors' motivation stems from a central question: what lessons were learned from these data-gathering efforts that can improve future research? This work examines the effectiveness of a large transportation survey design, highlights the role of advisory committees in enhancing survey development, and underscores the importance of robust recruitment strategies as part of an interdisciplinary research initiative funded by the National Institute on Disability, Independent Living, and Rehabilitation Research from 2019 to 2025 (90DPCP0004-01). The research team included disability studies, disability policy, transportation, community planning and design, qualitative research methods, computer science, geospatial and environmental modeling researchers, as well as the lived experience of disability.

The project aims to build a socio-ecological model describing the built environment factors associated with the community participation of people with disabilities, and understanding linkages between ADCLs, housing, employment, transportation, social services and systems, and community-scale policies and practices. To help construct this model, a significant data collection effort was undertaken. The focus of this paper is on the challenges of gathering survey data from people with disabilities, which leads to information gaps that are common in disability research. These insights arise from reflecting on a significant research project undertaken by the authors, including their primary data collection efforts, sampling, and data collection methodology used, the challenges arising from current survey technologies, and how the research team approached partnering with people with disabilities in a meaningful way that acknowledged the importance of their lived experience in this effort.

Challenges in surveying people with disabilities

"Nothing about us without us" is the common response of disability advocates who communicate that people with disabilities should be involved in any research efforts, decision making, or policy making that affects their lives. Despite this ethical imperative, people with disabilities continue to remain conspicuously absent from meaningful community engagement and social networks (Milner & Kelly, 2009). Many describe their experience as simply being 'in but not of' their local community. This absence extends to research on community design and accessibility (Terashima & Clark, 2021), despite the International Classification of Functioning, Disability and Health (ICF) identifying environmental factors as critical in creating and sustaining disability experiences (Gamache et al., 2017). There is also plenty of evidence of how community participation is impacted by transportation barriers, with various types and combinations of disabilities (Alimo et al., 2024; Park, Chamberlain, et al., 2022; Park, Esfahani, et al., 2022). Given that community participation is a key issue for people with disabilities, impacting the quality of life, social functioning, employment, housing, and health (Chang et al., 2013), understanding the challenges in surveying this population is essential for inclusive research.

However, capturing the lived experience of people with disabilities presents numerous obstacles, starting with definitional and classification issues. Disability is an umbrella term encompassing impairments, activity limitations, and participation restrictions, which rely heavily on interpretation and self-identification (Subedi, 2012). The absence of appropriate, common frameworks for defining disability in research leads to inconsistent language across surveys, creating significant variations in how disability is represented as an experience. These inconsistencies make it difficult to achieve standardized, comparable data that fully captures the multifaceted nature of disability, particularly when trying to distinguish between different types of disabilities and their specific impacts on daily life and community participation.

Recruitment barriers further complicate survey efforts involving people with disabilities. Despite more than one in four American adults having a disability, this population is often described as "rare" or "hard-to-reach" within survey contexts (Cerilli et al., 2024). In addition, some individuals who meet diagnostic criteria for having a disability do not consider themselves a person with a disability. Consequently, survey sampling methods must prioritize oversampling people with disabilities to achieve adequate representation. Without such oversampling, sample sizes frequently fall short of analyzing outcomes both for people with disabilities as a whole and across specific disability categories (e.g., vision, hearing, mobility) (Cerilli et al., 2024). Environmental and technological barriers, including inaccessible platforms, communication limitations, and a lack of accommodations, exclude significant numbers of people with disabilities. This is especially true for those with limited internet access or those who rely on specific assistive technologies.

Survey design considerations represent another layer of complexity when researching disability experiences. Potential barriers such as accessibility issues and cognitive load can significantly impact both the reliability and validity of collected data, making it essential to design surveys with specific accessibility needs in mind (De Cesarei & Baldaro, 2015; Wakelin et al., 2023). Similar accessibility barriers have been observed in digital transit apps, where inadequate design and lack of regulatory enforcement limit usability for travelers with disabilities (Gebresselassie & Baljko, 2025). Survey length, the instrument itself, question-wording, and visual presentation must all be carefully evaluated to accommodate various disability types. For instance, the term "accessibility" in transportation surveys often focuses on proximity to services, potentially overlooking real-world barriers such as inaccessible infrastructure or the specific needs of individuals with visual, hearing, or cognitive disabilities (Bascom & Christensen, 2017; Bezyak et al., 2020). Failure to use inclusive design approaches that maximize the accessibility of surveys biases the sample of disabled people to primarily include those who do not require alternate formats to participate (Cerilli et al., 2024). Creating inclusive survey instruments requires significant investment in specialized technical expertise and accommodations to ensure data on the experiences of people with disabilities is collected completely and accurately.

Survey fatigue and mistrust present significant barriers when working with people with disabilities. Participants' motivation to participate in research is heavily influenced by personal beliefs and past experiences (Verheggen et al., 1996). Many people with disabilities may be unfamiliar with the research process due to historically limited opportunities to participate in or make choices about research. Others may distrust research efforts based on previous experiences where they provided information but never saw tangible benefits from their participation. Additionally, this population is particularly vulnerable to exploitation, including through fraud, making them justifiably cautious about sharing personal information. A further barrier relates to compensation. While appropriate compensation is crucial for boosting motivation and addressing accessibility challenges (Mitchell et al., 2006; Yu et al., 2017), individuals receiving benefits like Supplemental Security Income (SSI) may avoid participation if compensation exceeds thresholds that could affect their eligibility. These combined barriers necessitate thoughtful approaches that build trust, demonstrate clear value to participants, and provide fair compensation without unintentionally disadvantaging participants.

These challenges are compounded by broader issues within the field of survey research. The ease, efficiency, and low cost of surveys have contributed to their widespread use—but also to frequent misuse or results that fall short of capturing the intended goals. As a result, survey research today faces mounting uncertainty. Response rates are steadily declining, while efforts to achieve robust participation increasingly demand greater financial resources. Traditional sampling frames that once provided reliable access to participants are becoming less effective, and new technologies are rapidly reshaping data collection methods in ways that are not always aligned with the needs or preferences of underrepresented populations (Groves et al., 2011).

Challenges and limitations of existing datasets

When considering large-scale data about activities, health outcomes, and demographics in the United States, there is a wide variety of resources. Some of the more popular sources include the American Community Survey, the National Household Travel Survey, and the National Health Interview Survey. The authors have summarized popular federal datasets in Table 1. Existing national surveys and methodologies have limitations that impact generalizability for people with disabilities (Cerilli et al., 2024). While these sources measure a wide variety of useful data, unfortunately, there is a lack of cohesion and consistency in capturing the relationships between how ADCLs relate to the built environment, how these relate to broader questions of social well-being and health, and how they manifest as experiences. Importantly, geographical scales and accuracy also vary across datasets.

For instance, the American Community Survey and the National Household Travel Survey include very limited data on disabilities, and their datasets tend to be aggregated. The American Time Use Survey does not contain disability identifiers and does not have a direct way to identify structural barriers (particularly use or interactions within the environment), which makes it difficult to understand experiences and community participation. The National Health Interview Survey and the Survey of Income Program Participation offer very rich datasets for people living with disabilities, but they only collect information on a limited portion of the population. Additionally, the Behavioral Risk Factor Surveillance System also includes a limited number of questions about people living with disabilities. The major challenge researchers face, then, is how to intersect this data to draw insights into how the ecosystem of social and built systems interact.

For community planning research across large areas, researchers often rely on the American Community Survey. This dataset reports disability prevalence, total workers with a disability, with specifics about types of disability (ambulatory, cognitive, etc.), and detailed occupation. The ACS provides a wide range of geographical scales for data at regular yearly intervals. ACS data can be used to understand disability-related phenomena, such as the migration of older adults (Sharma, 2012) and underserved populations and neighborhoods by social service agencies (Case & Hawthorne, 2013). However, the ACS uses relatively small sample sizes (Atkinson & Tate, 2000), making it difficult to disaggregate data for small geographic units and challenging to represent unique subgroups. This can effectively mask the experiences of marginalized groups, which can become statistically invisible. When research aims to address spatial justice for marginalized populations, it is crucial to have granular and accurate data about the spaces people inhabit (Barnes, 2009; Crampton, 2011). The ACS provides high geographic granularity and asks about six functional types of disability (hearing, vision, cognitive, ambulatory, self-care, and independent living), but it does not collect information on the duration of disabilities or subjective measures such as life satisfaction, well-being, or quality of

Table 1
Summary of key federal datasets useful for researching people with disabilities.

Dataset	Organization	Disability-Related Variables	Socio-Demographics	Geographic Resolution	Sampling	Main Strengths	Limitations
American Community Survey (ACS)	U.S. Census Bureau	6 functional types (vision, hearing, cognitive, ambulatory, self-care, independent living)	Extensive (age, income, education, race, housing, employment)	Census block groups, tracts, ZIP codes, etc.	Large (∼3.5 M households annually)	High geographic granularity; consistent annual data	Aggregate data obscures intersectional insights; limited disability detail; excludes institutionalized populations
National Household Travel Survey (NHTS)	U.S. Department of Transport. (DOT)	Mobility limitation only	Moderate (age, income, household size, employment)	State, selected metropolitan areas	Moderate (every 5–10 years)	Focus on travel behavior and mobility trends	Low representation of people with disabilities; lacks accessibility context; aggregate trip data masks barriers.
National Health Interview Survey (NHIS)	National Center for Health Statistics (NCHS)	Functional limitations, assistive devices, work limitations, chronic conditions	Strong (age, sex, race, insurance, income, education)	National only	Large (∼35 K households annually)	Rich health and disability content; consistent time series	Excludes institutionalized; small subgroups; underpowered; and self-report variability
American Time Use Survey (ATUS)	Bureau of Labor Statistics (BLS)	None in core; infer via CPS link	Moderate (via CPS: age, sex, race, employment, income)	State, selected counties	Small (∼9K/ year)	Activity and time use detail; caregiving analysis possible	No disability identifier in core; lacks activity limitation framing; no access barrier data
Behavioral Risk Factor Surveillance System (BRFSS)	Centers for Disease Control and Prevention (CDC)	Basic limitations and equipment use	Strong (age, income, employment, race, health behaviors)	State, selected counties	Very large (∼400 K + annually)	State comparisons; include optional disability modules	Telephone-based; excludes institutionalized; self-report limitations; accessibility challenges
Survey of Income and Program Participation (SIPP)	U.S. Census Bureau	Extensive: onset, severity, duration, limitations, accommodations	Very strong (income, employment, family structure, benefits)	National only	Moderate (∼30 K–40 K households per panel)	Longitudinal view of disability and policy impact	Complex survey design; underused; attrition over time
Disability and Health Data Systems (DHDS)	Center for Disease Control and Prevention (CDC), National Center of Birth Defects and Development Disabilities (NCBDD)	Sensory, cognitive, mobility, self-care, and independent living difficulties	Age, gender, race, education, income, employment status	State-level	Very large (∼ 400 k + annually)	Provides standardized data across states, and analysis of health disparities among adults with disabilities	Limited to non-institutionalized adults

life.

The National Household Travel Survey (NHTS) represents a key data source to understand the logistics of community participation by surveying mobility patterns. The survey provides basic information on household and individual-level characteristics, and activity-travel information on household members for 1 % of the population (Goulias et al., 2013). While it provides valuable insights into trip-related data, including transportation modes, trip duration, distance, and purposes, the NHTS faces similar challenges to the ACS when it comes to capturing the experiences of marginalized population groups. While travel surveys offer significant benefits by providing insights into movement patterns (e.g., mode, trip purpose, frequency), they can suffer from high non-response rates and data quality issues (Wilson, 2004). Additionally, reports have highlighted that completed diaries often omit a significant number of trips (Stopher & Greaves, 2007). Most missing trips tend to be short ones, raising concerns about the accuracy of these surveys in capturing complete travel data. Another major dilemma is that researchers have often struggled to obtain the required sample size to sufficiently represent travel behaviors (El-Assi, 2016); this can lead to underrepresentation of certain socio-demographic groups (El-Assi, 2016), including people with disabilities.

Another major challenge is geographic resolution, sampling representation, and categorizing disability in these datasets (Kamikubo et al., 2022). The National Household Interview Survey (NHIS) and the Survey of Income and Program Participation (SIPP) provide disability-related measures. For example, NHIS includes more detailed information on disability status, such as the use of assistive devices, chronic conditions, and functional limitation, but is limited to national-level analysis and lacks self-report variability or survey attrition. Also, SIPP collects data on the severity and duration of disabilities, as well as employment status and income. It also includes a large nationally representative sample of people in the noninstitutionalized population, so researchers are able to construct analysis samples of people with disabilities to test the sensitivity of their results. In addition, the data can be used to examine how changes in health affect employment and economic well-being. However, both surveys have limitations. For instance, in NHIS, some information was collected only for people with disabilities, making it impossible to compare people with and without disabilities. As an example, according to previous studies (Maag, 2006), social networks are key to employment for some people. The NHIS provides information about the social interactions of people with disabilities; however, it does not offer comparative data on individuals without disabilities. This gap could be significant for policymakers seeking to identify strategies to improve job access for people with disabilities.

SIPP also has drawbacks. For example, since the survey is a longitudinal panel, its usefulness in producing trend estimates is limited. In addition, attrition bias in SIPP is significant and therefore must be accounted for in any SIPP-based analysis. Furthermore, none of these surveys provides detailed spatial data at small geographic units such as census tracts or ZIP codes. NHIS is national level only, and SIPP contains regional data (Wittenburg & Nelson, 2006).

Despite the availability of numerous large-scale datasets that track the population-level trends, researchers continue to face challenges (Bazuin & Fraser, 2013; Cerilli et al., 2024; Spielman & Singleton, 2015) when using these surveys to study the experience and challenges of people with disabilities, particularly in relation to social life satisfaction, neighborhood and the influence of travel behavior, social capital, and surrounding environment (Chenoweth & Stehlik, 2004). Many of these datasets, such as the American Community Survey (ACS), the National Household Travel Survey (NHTS), and the American Time Use (ATU), either lack detailed disability-related variables or do not cover all variables. Furthermore, they often lack some specific socio demographics or subjective measurements that are specific to capturing the nuanced experience of people with disabilities.

Case study of the original project

This paper reflects on the authors' efforts to better understand the links between community living and the built environment, emphasizing the need to ensure that these relationships are understood as they influence people with disabilities. For this reflection, the authors conducted a reflective case study of an interdisciplinary NIDILRR project conducted between 2019 and 2025 (unexpectedly spanning COVID-19), referred to hereafter as the original project, for the purpose of developing a socio-ecologic framework describing the physical and environmental factors associated with people with disabilities and their community participation (Chamberlain et al., 2025; Park, Chamberlain, et al., 2022; Park, Esfahani, et al., 2022). This section's narrative is a description of this original project examined by the authors as a case study regarding the challenges of including people with disabilities in research/data collection efforts. This paper does not present the original project's data or outcomes but reflects on the process. The original project's framework is used to examine the effect of mainstream planning practices and policies on community participation. Although data are abundant regarding the physical environment, researchers lack a clear understanding of how individuals with disabilities interact with their surroundings and how these interactions are directly connected to their overall well-being. Specifically, there is a limited understanding of the spatial relationships between the movement to and from community amenities supporting ADCLs and how these spatial relationships, in turn, influence their social engagement within the community.

Given the challenges with existing datasets to offer these insights, the research team set out to conduct a rigorous data collection effort to fill this gap. This resulted in an effort to collect empirical, primary source data through a survey of community members with disabilities. An important characteristic of the original project was to gather integrative data across four domains: personal factors (e.g. sociodemographics, family support, disability), neighborhood characteristics (of the locations where individuals resided and performed their ADCLs), activities of daily community living (types, preference for, location, travel behaviors), and satisfaction with their social connections (social satisfaction). Three of these were gathered through survey instruments: personal factors, ADCLs/travel behavior, and social satisfaction.

In the previous sections, the authors identified the challenges of obtaining a representative survey of people with disabilities and their lived experiences. Given these challenges, the research team decided to conduct a research project in a region where the research team had prior experience and connections to disability-related support services, as well as the ability to engage with participants in person as necessary. As a result, the research team identified the Salt Lake City Metropolitan area in Utah, USA, as the original project's area for data collection. This prior knowledge offered direct access and a positive working relationship with local disability organizations (supporting recruitment), and excellent working access to data about the transportation system and the built environment.

The research team's approach evolved through three stages to adapt to the challenges of developing, distributing, and conducting a

Table 2
Three stages of survey development in the original project.

Stage	Survey Instrument	Recruitment and data collection
1	Sociodemographics + social satisfaction + travel behavior (combined instrument)	Online panel (e.g., Qualtrics) Social media pilot through disability partners
2	Sociodemographics + social satisfaction instrument | travel behavior instrument	Contact list through local organizations (e.g., independent living centers)
3	Sociodemographics + social satisfaction instrument| travel behavior instrument	Contact list through statewide travel survey

comprehensive survey on the lived experiences of people with disabilities in their communities. These stages, outlined in Table 2, reflect the adjustments necessary due to unexpected and unforeseen circumstances during the process. In the following sections, the authors elaborate on the iterative development of these surveys, highlighting specific design and implementation strategies. This includes tackling technical challenges such as ensuring data validity and preventing issues like hacking or spamming, as well as overcoming recruitment barriers such as low participation rates and achieving representative distribution. Rather than serving as a prescriptive framework, this discussion reflects the process, with lessons to be explored in Section 4.

Survey instrument design process

The original survey included three main components: 1) personal factors (sociodemographics), 2) social satisfaction, and 3) ADCLs (travel behavior, preferences, locations). A screener was developed to ensure all participants met the minimum standards as approved by the research team's University Ethics Board. The instruments used the Qualtrics platform because it works well with screen readers. The survey was originally designed as a single instrument containing all three main parts, and was eventually separated into two smaller surveys. The first included the sociodemographics and social satisfaction questions, and the second included the travel behavior and ADCLs. The first part of the survey included under 60 questions, including questions about the participants' home location, two dozen demographic variables, as well as how often, how far, and how long it takes them to get to certain amenities (e.g., grocery store, retail, recreation, etc.). The second part of the survey included travel behavior and contained 10 required questions, with up to approximately 120 questions. The range accounts solely for the number of locations (up to 10) they visited, with 11 questions for each trip (who they went with, why, where, how long, etc.).

Given the extent and complexity of the survey questions, the instruments were developed with broad application of accessibility considerations, including cognitive accessibility, to mitigate challenges that may be encountered by a range of different disabilities. Most of the questions were structured using multiple choice (including several matrix question structures) with breaks between different concepts. Demographic questions were modeled after those in the U.S. Census (U.S. Census Bureau, 2023) to ensure consistency across data, as it makes these data easier to combine for other studies related to the broader project. The development of specific questions initially started with the research team, but went through a few iterations with an Advisory Board. The Advisory Board was comprised of people with various disabilities, including intellectual and mobility disabilities, visual impairment or blindness, and others. Advisory Board members received compensation for their help in the survey design process. Their time, energy, and insights were necessary to build a survey that met the needs of participants and the data needs of the research team.

The Advisory Board also served as the first pilot group for the survey. The input received from the Advisory Board included feedback on question clarity, survey length, visual accessibility, and general design. Based on the Board's experience, several adjustments were made to ensure that the survey(s) included the appropriate accommodation for participants across the disability spectrum. For instance, the Board made a recommendation to split the instrument into two different surveys (sociodemographic/satisfaction and ADCLs/travel behavior) to minimize fatigue. All the Board's recommendations were addressed to consider different reading and cognitive needs, visual aids and screen readers, and mobility needs. The Advisory Board reviewed the questions twice, providing valuable feedback that was incorporated into subsequent revisions before finalizing the instrument.

The reading level was a challenge as a wide range of cognitive levels and requirements for data collection needed to be balanced because the travel analysis required detailed trip-level data. The research team developed the survey first to meet the requirements of these models and to maintain consistency with previous studies. The question text was reworked numerous times to ensure the essence of a standard question remained while being presented in clearer language if necessary. Questions were run through a reading level check (Long & Long, 2013) until nearly every question met the requirements of an eighth-grade reading level.

Visual accommodations had two main areas of focus: screen reader usability on the general survey, and the Google Map interface for travel-specific data. To ensure that screen reader users could access the survey, a pilot survey was conducted by a screen reader user with prior survey experience to live test the interface with the survey instrument developers. The team took notes about barriers and debriefed with the screen reader user to ensure user-friendliness. The most complex visual accommodation pertained to a custom-coded Google Map interface. Research suggests online interactive maps are difficult for screen readers (Hasan & Gjøsæter, 2021). For the implementation, the research needed individuals to identify where they traveled. The survey instrument allowed users to select a location manually on the map or enter the address or a description of the place. Implementation of this interface took several attempts with a screen reader to make sure the user first enters a place and then the system responds with the likely options to select from (this is the autofill function for searches).

Recruitment and compensation

The distribution of the survey spanned three stages. In Stage 1, the single survey instrument with all three components was deployed. Participants were recruited first via a Qualtrics Panel and then through social media. Recruitment started in June 2022 and ended in October 2022. The research team encountered significant challenges with recruitment in Stage 1, which led to a modified approach in Stage 2. The primary challenge was an almost immediate and very large number of invalid responses from bots to obtain compensation through the incentive mechanism.

At the beginning of Stage 2 in October 2022, the research team split the survey instrument into two parts, the first of which only gathered sociodemographic and social satisfaction. In April of 2023, the first revised survey was relaunched through a direct recruitment campaign to avoid wide distribution via social media. This was an effort to avoid survey bots and involved establishing a partnership with local Independent Living Centers (ILCs), which also provided support to fill out the survey. In July, the second revised survey focused on ADCLs and travel behavior, was launched, inviting participants who had previously completed the first survey instrument and who met the screening criteria for participation. Although an effective means of avoiding fraudulent participation, the process was time-consuming, and participant numbers were low. Interestingly, although the first Stage 2 survey instrument was disseminated via the client lists of the ILCs, and the second Stage 2 survey instrument could only be completed by participants who had completed the first instrument, the surveys were eventually discovered by survey bots, nonetheless. Stage 2 was completed by November 2023.

Immediately after, a third recruitment campaign started, Stage 3, using online versions of the two revised surveys. This stage solicited participants from a recent Utah Department of Transportation (UDOT) Statewide Travel Survey conducted by RSG. Through a data-sharing agreement, the research team obtained all records where individuals self-identified as having disabilities that impacted their travel abilities. These individuals were contacted and invited to participate in the first of the survey instruments through a unique link. The link allowed for the responses to be tracked to prevent subsequent fraudulent participation. In addition, the unique participation link was used to connect the data collected in the original project with that collected in the UDOT statewide travel survey. Subsequently, participants in this first invitation were asked to complete the second instrument focused on ADCLs and travel behavior. Data collection continued until February 2024.

Throughout these iterations, the research team ensured participants were compensated. Compensation was vital since it has been found to increase motivation and engagement in surveys across various populations (Göritz, 2006, 2010; Singer & Ye, 2013), including people with disabilities (Mitchell et al., 2006). The survey platform was web-based, but the team offered various ways of completing the survey (phone, in-person) to increase accessibility. Additionally, and particularly relevant to the level of compensation offered, the research team was motivated to adequately compensate people with disabilities in recognition of the value of their lived experience. During Stage 1, participants were offered compensation in the form of $100 gift cards for completing each of three planned surveys (one sociodemographic/social satisfaction survey and two ADCL/travel behavior surveys), for a total potential compensation of $300 in gift cards. The incentive amount was later reduced to $50 per survey, with a maximum total of $150. This adjustment was made to prevent the original high incentive from attracting survey bots and false participants, which led to over 3,400 invalid responses within a few days of the first batch of the survey (before the survey was closed to stop the influx of these responses).

Additionally, the relatively high incentive, intended to show appreciation for respondents' time and lived experience, may have inadvertently discouraged some people with disabilities from participating in the research because those receiving Social Security disability benefits, such as Supplemental Security Income (SSI), are required to report incentives of $20 or higher as unearned income, which can potentially result in a reduction in monthly benefits (Mitchell et al., 2006). In this situation, the temporary benefit of the research incentive may have been outweighed by the need to report additional one-time income and the impact on regularly scheduled SSI payments.

Data collection and implementation

Selecting an appropriate data collection mode is critical to achieving both inclusivity and representativeness in surveys involving people with disabilities. In the original project, the research team opted for an internet survey as the primary data collection mode due to its cost-effectiveness, accessibility features, and the ability to ensure respondents' control (e.g., comfort of their preferred location and time to complete the survey). Recognizing, however, that certain subgroups—such as older adults or individuals without reliable internet access—might face barriers to participation, the researchers offered telephone assistance as an alternative. Only a small number of participants utilized this option. The dual offering addressed the diverse needs of participants while maximizing the accessibility and representativeness of the sample, without significantly increasing costs or operational complexity.

The researchers tested several sampling frames to identify the most effective methods for recruiting people with disabilities in the project area (urban and suburban) with comprehensive internet access. This context allowed the research team to focus on general recruitment methods without implementing targeted outreach for rural populations. Each sampling frame was assessed based on its ability to comprehensively capture the target population, mitigate sampling errors, and provide high-quality, representative data (Fowler, 2013). The sampling frames included online panels, social media outreach through disability-focused organizations, contact lists from local Independent Living Centers (ILCs), and a contact list derived from a statewide travel survey. Table 3 provides an overview of the sampling frames used in the original project, highlighting their comprehensiveness, sources of sampling error, and key challenges.

Initially, the research team employed an online panel through Qualtrics due to its convenience and existing infrastructure for survey distribution. However, this approach proved challenging. The panel exhibited low comprehensiveness, as it included only individuals registered on the platform, systematically excluding those without panel awareness. Additionally, the data quality was compromised by invalid or non-genuine responses, which required extensive validation efforts. To address this, the team manually examined the thoroughness and consistency of data entries, identifying and removing suspicious or incomplete responses. Despite these efforts, this sampling frame was limited in its ability to capture a representative sample. It is useful to note that Qualtrics offers panels for medical surveys, but the cost is significantly higher and may unintentionally bias away from the general population (which was the project's target).

Table 3

Comparison of different sampling frames employed in this research.

Stage	Sample frame	Comprehensiveness	Sources of sampling error
1	Online panel (e.g., Qualtrics)	Low (only covers those registered with internet access)	Excludes those without internet access or panel awareness.
1	Social media pilot through disability partners	Low (only covers those using the social media platform and following the target agencies)	Excludes those without internet access; Subject to bot attack
2	Contact list through local organizations (e.g., independent living centers) with social media excluded	Moderate-to-high (most people with disabilities in the region, but focus on urban areas)	May exclude those not registered with ILCs; potential geographic & demographic biases; Data quality varies by the liaison's commitment & role.
3	Contact list through statewide travel survey	Moderate (32 % of Utah households invited, but only 2.8 % responded)	Excludes non-respondents from the initial survey; only covers "travel-limiting" disabilities

Social media outreach, in collaboration with organizations focused on disabilities, was another method the researchers explored. While this method allowed us to leverage existing networks, it also encountered significant challenges, including a survey bot attack that resulted in fraudulent responses. Like the online panel, this approach was restricted to individuals active on social media, excluding certain demographics such as older adults. Additional validation processes were necessary to filter out invalid responses, yet this sampling frame yielded limited success in terms of recruitment numbers and data quality.

The use of contact lists provided by local ILCs proved more effective but generated only a small, valid sample. These organizations maintain records of individuals with a range of disabilities and are trusted within their communities, making them valuable partners for recruitment. However, the more limited contact lists of the ILCs (although all relevant individuals for the original project), combined with survey response rates, resulted in a small sample. Further, the comprehensiveness of this sampling frame was limited by its focus on urban areas within the original project area, which excluded individuals not registered with ILCs or those with limited engagement in their services. The effectiveness of this approach was heavily dependent on the engagement of ILC liaisons, as their level of commitment and understanding of the original project objectives directly influenced recruitment outcomes.

The researchers also explored a recruitment strategy that built off a recent statewide travel survey, yielding a larger sample sufficient for statistical representation. This contact list included individuals who had previously completed the state travel survey and self-identified as having travel-limiting disabilities. To ensure data quality, the research team implemented additional validation steps, such as sending individualized links to the online survey instrument to respondents from the statewide travel survey. These measures not only verified the legitimacy of responses but also minimized fraudulent entries. While this method demonstrated moderate comprehensiveness, it aligned well with the case studies' research objectives by targeting individuals whose disabilities directly impacted their transportation experiences. However, it is important to note that this approach may have underrepresented people with disabilities unrelated to travel or those who did not respond to the initial survey.

Across all the sample frames employed, several common sources of nonresponse bias became apparent. Individuals who did not use email regularly or had limited internet access—such as older adults or those with lower technological literacy—were less likely to participate in the survey. Although the original project's study region benefits from widespread internet coverage, this barrier may still have excluded certain groups, particularly those with limited financial or digital resources. Similarly, full-time workers may be underrepresented, potentially due to time constraints or survey fatigue, which highlights the need to carefully consider survey length and scheduling. Furthermore, concerns about privacy and the sensitive nature of questions, particularly those related to social relationships and travel behavior, may have dissuaded potential respondents. These issues underscore the challenges of ensuring inclusivity and representativeness, even within a well-connected and urbanized project study area. To mitigate nonresponse bias, Fowler (2013) suggests various techniques, including sending advance letters, providing small incentives upfront, clearly communicating the survey's purpose and privacy protections, engaging effective interviewers for phone interviews, and ensuring a professional, accessible survey design.

Table 4 compares the demographic characteristics of the samples obtained through two of the project's primary data sources—ILCs (n = 48) and the statewide household travel survey (n = 313)—against Census data (2018–2022 ACS) for the original project's study region. While the racial composition was similar across the three data sources, with most respondents identifying as White, other demographic variables revealed notable discrepancies. The ILC sample overrepresented individuals aged 30–49, females, renters, and low-income households, reflecting the urban focus of ILCs and their client demographics. In contrast, the data from the statewide household travel survey aligned more closely with the general population but still showed some biases, including the overrepresentation of non-Hispanics, individuals with higher educational attainment, and renters. These differences likely stem from the unique characteristics of people with disabilities in the region and the sampling methods employed.

The demographic variances between the project's sample frames and the general population highlight the potential biases introduced by recruitment strategies and the inherent limitations of each sampling frame. For example, while ILCs provided access to a diverse range of disability types, their urban focus excluded rural populations. Similarly, the statewide household travel survey captured a broader geographic and demographic spread but primarily focused on individuals with travel-limiting disabilities, potentially excluding those whose disabilities do not impact transportation. These findings underscore the importance of tailoring recruitment strategies to the target population's characteristics while implementing robust quality controls to ensure data integrity and inclusivity.

Table 4
Comparison of demographic characteristics between three data sources.

	Census (2018–2022 ACS)	**Collected data ILCs (n = 48)**	**Collected data travel survey (n = 313)**
Age: 18–29	28.0 %	16.7 %	25.9 %
Age: 30–49	38.1 %	62.5 %	39.9 %
Age: 50–64	19.5 %	18.8 %	23.3 %
Age: 65 and older	14.4 %	2.1 %	10.9 %
Race: White	80.7 %	85.4 %	81.5 %
Race: Black	1.3 %	2.1 %	4.2 %
Race: Asian	2.8 %	0 %	2.9 %
Ethnicity: Hispanic	16.0 %	4.2 %	8.3 %
Gender: female	49.3 %	72.9 %	59.7 %
Education: Bachelor's degree or higher	22.5 %	20.8 %	45.0 %
Tenure: rented	30.2 %	52.1 %	48.6 %
Household income: under 35 k	14.7 %	45.8 %	32.6 %
Household income: 35 k-75 k	25.4 %	14.6 %	29.4 %
Household income: 75–150 k	36.9 %	16.7 %	22.0 %
Household income: 150 k+	23.1 %	22.9 %	16.0 %

Discussion and implications

Survey research is crucial for disability studies, providing a means to gather large-scale data directly from people with disabilities. These data help researchers from multiple disciplines understand the experiences, needs, and perspectives of people with disabilities, informing policy, programs, and advocacy efforts. This interdisciplinary experience provided ample evidence for the need to design accessible and inclusive survey instruments, as this is crucial for ensuring the validity and reliability of data collected from people with disabilities (Rios et al., 2016; Williams & Moore, 2011). However, conducting survey research with people with disabilities presents unique challenges, especially when aiming to partner with them to accurately reflect their lived experiences (Rios et al., 2016). The interdisciplinary research team's experience reflects challenges at the intersection of disability, the built environment, and travel; research on sensitive subjects or involving institutionalized or culturally diverse individuals may face other difficulties.

The project took an underrepresented approach to understanding ADCLs (including travel behavior) among people with disabilities and how the environment impacts their social satisfaction and community integration. Despite having resources and an experienced team, the researchers encountered several challenges that led to valuable lessons learned. Their experiences highlighted the need for key recommendations on two important topics for research designs focusing on ADCLs, community participation, and people with disabilities: (1) survey instrument techniques and (2) recruitment and management approaches. By sharing these insights, the authors aim to contribute to the development of more inclusive, accessible, and effective research survey practices in disability studies. The original project employed several strategies to optimize the survey design, including engaging people with disabilities in the development process, conducting pilot testing, and addressing accessibility needs across different disability types.

Survey instrument design

Survey instruments should be designed to avoid exploitative research practices by actively involving people with disabilities in shaping the data collection process (Kitchin, 2000). Engaging people with disabilities as co-researchers, conducting extensive pilot testing, and providing fair compensation are all strategies that can help ensure the research is inclusive, respectful, and beneficial to the disability community (Kitchin, 2000; McDonald & Stack, 2016). By prioritizing accessibility, inclusivity, and participatory approaches in survey design, researchers can gather more accurate and meaningful data on the experiences and needs of people with disabilities, informing policies and practices that promote their full participation in society.

An Advisory Board comprising individuals with a range of disabilities is an effective strategy to provide input and feedback throughout the survey design process. Engagement from the Board helped ensure that the survey questions were relevant, clear, and appropriately worded for the target population. The Advisory Board also served as the first pilot group, allowing the research team to identify areas for improvement in terms of question clarity, survey length, visual accessibility, and overall design. Incorporating this feedback through iterative revisions helped enhance the face validity and usability of the survey instrument. Future studies should prioritize the meaningful involvement of people with disabilities in all stages of survey development to ensure that the instrument is tailored to their unique needs and experiences (Williams & Moore, 2011). The researchers recommend implementing a disability-diverse Advisory Board during the early stages of development.

Addressing accessibility needs across different disability types was a key consideration in the survey design. The team focused on optimizing the reading level and cognitive complexity of the questions, providing visual accommodation for blind and low-vision respondents, minimizing respondent fatigue through streamlined instrument design, and leveraging assistive technologies. For example, the researchers worked with an Advisory Board to simplify the language both to reduce cognitive demands and low literacy possibility, aiming for an eighth-grade reading level. They also tested the survey with screen reader users and made necessary adjustments to ensure compatibility with assistive technologies. Future studies should continue to prioritize accessibility and usability in survey design, drawing on best practices and emerging technologies to accommodate the diverse needs of people with disabilities (Rios et al., 2016; Williams & Moore, 2011). The research team worked to adopt these practices, but also recognized the potential for the instrument to be a challenge for some individuals. Therefore, the research team developed mechanisms to conduct the survey in-person (directly or through the ILCs) and offered a dedicated phone line for support or to complete their survey on their behalf via phone.

When extensive data collection is necessary, such as in the ADCL and travel behavior survey, strategies like dividing the survey into separate or iterative modules can help manage respondent fatigue and improve data quality (Dillman et al., 2014). In the original project, the research team initially designed a comprehensive survey capturing data on personal factors (sociodemographics), social satisfaction, ADCLs (including travel behavior), and community participation. However, based on feedback from the Advisory Board, the survey was split into multiple parts to reduce participant burden while still gathering essential data. This approach aligns with evidence suggesting that shorter online surveys tend to be completed at higher response rates (Sammut et al., 2021), though there remains limited guidance for surveys requiring extended time commitments, such as transportation studies that capture complex travel behaviors. The surveys implemented in this study's original project were lengthy but were aimed at not being repetitive. To facilitate this process, maintaining confidential user IDs throughout the survey protocol and regular data observation can help ensure data quality and connection across instruments (Audette et al., 2020). As doing so is critical for longitudinal studies, and as discovered, studies may evolve to be longitudinal if there is some mechanism by which participants' responses can be linked across time and studies, maintaining confidential user IDs is highly recommended when working with people with disabilities. It should be noted that maintaining confidential user IDs can create logistical challenges regarding institutional review, privacy concerns, and data-sharing agreements.

Recruitment and management strategies

Effective recruitment and management strategies are crucial for ensuring the representativeness and quality of the data collected (Becker et al., 2004; Rios et al., 2016) across people with various types and combinations of disabilities. One important consideration is the choice of data collection mode. The original project primarily relied on an internet survey, recognizing its advantages in terms of cost-effectiveness, accessibility features, and the ability to maintain respondents' privacy (Dillman et al., 2014). To enhance inclusivity, the surveys incorporated various accessibility accommodations, such as adjustable font sizes, high-contrast modes, and screen reader compatibility, ensuring that participants with visual impairments could navigate the survey. As not all people with disabilities may be comfortable or able to participate in web-based surveys, telephone assistance or in-person options were offered for respondents requiring further support. This mixed-mode approach enabled us to reach a broader sample of people with disabilities and address potential barriers to participation (De Leeuw, 2005). The decision between different modes should be guided by the specific needs and characteristics of the target population, balancing factors such as accessibility, technological comfort, literacy, and the nature of the research questions. From the authors' experience, most participants completed the survey online, suggesting that this mode aligned well with the technological proficiency of the target population.

Another key lesson is the importance of evaluating and selecting appropriate sample frames to ensure representativeness and comprehensiveness across the diversity of people with disabilities (Fowler, 2013). The research team tested several recruitment approaches, including online panels, social media outreach through disability-focused organizations, contact lists from local organizations (e.g., ILCs), and a contact list derived from a statewide travel survey. Among these, the statewide travel survey contact list proved most effective, providing access to a substantial sample of people with disabilities who had already participated in a similar survey and self-identified as having disabilities that impacted their travel abilities. Because the travel survey primarily focused on mobility-related disabilities, contact lists from local ILCs served as a valuable supplementary source, capturing individuals with a broader range of disabilities (e.g., cognitive, sensory, and independent living). This combined approach highlights the value of leveraging existing datasets and collaborating with "gatekeepers"—organizations with established trust and connections to the target population (Becker et al., 2004). Future research should prioritize partnerships with disability organizations and the integration of multiple, complementary sample frames to enhance sample diversity and representativeness.

Compensation is another critical aspect of surveys involving people with disabilities, as it reduces exploitation and enhances motivation and engagement while recognizing the time, effort, and unique perspectives participants contribute (Mitchell et al., 2006; Murdoch et al., 2014; Stähli & Joye, 2016; Yu et al., 2017). Adequate compensation can help address participation barriers, such as accessibility challenges and survey fatigue, and is an essential strategy for reducing nonresponse bias in marginalized populations (McInroy, 2016). Recognition of the value of people with disabilities' lived experiences and history of exploitation further emphasizes the importance of adequately compensating participants. However, the original project revealed challenges with compensation, including its potential impact on disability benefits such as Supplemental Security Income —where incentives exceeding certain thresholds risked reducing eligibility—and the risk of attracting fraudulent responses (Mitchell et al., 2006). To mitigate these issues, researchers must carefully evaluate ethical and practical implications. Collaborating with disability partners and community organizations can help determine fair and appropriate compensation levels that balance inclusivity, accessibility, and unintended consequences (Mitchell et al., 2006).

The original project, upon reflection, also faced challenges related to data quality and representativeness. The longer the survey remained open, the more invalid responses were submitted, underscoring the need for time-consuming and robust data validation and quality control measures. Additionally, the demographic composition of the sample differed from the general population in several ways, including age (participants in the case study tended to be younger), ethnicity (fewer Hispanic people), income (more low-income), and housing tenure (more renters). While some differences may reflect characteristics specific to people with disabilities in the region (Lauer & Houtenville, 2018), it is critical to acknowledge and address potential biases introduced by sampling frames and data collection methods. Data quality can be affected by user-provided information, especially if responses are not provided seriously. While this did not seem to be an issue with the case study's data, strategies such as seriousness checks can help reduce poorquality inputs (Aust et al., 2013). However, there is limited research on the effectiveness of these mechanisms for people with disabilities. For example, it would be problematic to exclude data from someone with a cognitive disability based on an automated assessment that incorrectly suggests their responses are not serious.

The challenges discussed thus far have been further compounded and brought into sharper focus by the growing presence of survey bots that fraudulently complete surveys. These automated or malicious responses, often motivated by the prospect of compensation or the desire to manipulate results, undermine the integrity of the data collected and erode trust in the research process. For people with disabilities who already face barriers related to mistrust, privacy concerns, and complicated compensation structures, the added presence of fraudulent responses can reinforce skepticism about whether their participation is valued or protected. Moreover, efforts to detect and eliminate bot activity often result in more complex verification processes, which can unintentionally create new accessibility hurdles for legitimate participants. As a result, the already delicate task of engaging this population in meaningful, ethical research becomes even more challenging, underscoring the need for careful survey design, transparent communication, and inclusive technological safeguards.

Effective communication and collaboration with disability partners and local organizations is fundamental to successful recruitment and survey administration. The research team's work with ILCs highlighted the importance of building strong relationships with these organizations and ensuring that liaisons are fully engaged and informed about the study objectives. Providing clear guidelines, training, and resources to liaisons helps maintain data quality and consistency. Moreover, partnering with trusted organizations builds credibility and trust with potential participants, increasing their likelihood of involvement and reducing nonresponse bias.

When attempting large-scale data collection, particularly with transportation-focused studies requiring complex behavioral data, researchers must be prepared to address unique challenges. Transportation surveys typically require participants to share location data, travel patterns, and detailed activity logs—processes that may raise additional concerns about privacy, cognitive burden, and technological barriers for people with disabilities. Future studies should explore innovative approaches that balance research needs with participant-centered design, by incorporating real-time data collection methods that minimize retrospective recall or by developing adaptive survey technologies specifically designed for users with diverse abilities and needs.

Another important aspect of these surveys is understanding – and translating – transportation experiences that better reflect people with disabilities. Sometimes, there can be simple misunderstandings with language. For instance, when transportation is broadly referred to as "accessible transportation," it often connotes transportation that is spatially or financially accessible. However, this term "accessibility" in disability studies can mean much more than the general reference. Instead, it may overlook real-world barriers such as inaccessible infrastructure, inconsistent public transit, or the specific needs of individuals with visual, hearing, or cognitive disabilities – as well as a myriad of other functional deficiencies in the transportation system. Some of these can be captured in surveys, but may be better explored through other data collection techniques, such as qualitative methods. Therefore, future studies should consider integrating robust qualitative methods to supplement survey findings and provide richer, more nuanced data on the everyday experiences of people with disabilities. This could be done by continuing to engage with disability advocacy organizations, as well as leveraging additional community partnerships to incorporate alternative data collection strategies such as video diaries or mobile ethnography. By doing so, researchers can better bridge the gap between quantitative trends and the realities of daily life for people with disabilities, leading to more inclusive and impactful research outcomes.

Conclusion

Over the past five years, the research team has developed and continually adapted survey methodologies to overcome obstacles and address the limitations that initially hindered efforts to capture the diverse lived experiences of this underrepresented population. Research indicates that people with disabilities are often underrepresented in built environment and transportation studies. The findings show that even when inclusion is attempted, achieving adequate representation remains challenging. This highlights the need for better processes to improve participation and representation. There are several takeaways from reflecting on this case study. First, the involvement of an Advisory Board that included individuals with diverse disabilities themselves was crucial in addressing accessibility needs across different disability types and helping to hone the survey instrument development. Second, while web-based surveys proved effective, they also presented significant challenges, including the need for continuous data monitoring to mitigate issues related to automated responses and potential security breaches. Further, web-based surveys necessitated careful attention to detail to ensure they were accessible to the target population. Third, careful and intentional sample framing, including the use of multiple recruitment strategies and collaboration with local organizations, was essential in achieving a sufficiently representative sample and ensuring the inclusion of diverse participant perspectives. Fourth, compensation for participants was critical, but higher compensation ($100 – $300) necessitated rigorous data monitoring, as higher incentives can attract fraudulent responses and attempts to bypass eligibility criteria. Fifth, travel history data collection revealed both technical and conceptual limitations, as traditional transportation surveys define "accessibility" merely as proximity to services while overlooking critical barriers faced by people with disabilities, from inaccessible infrastructure to specific mobility, sensory, and cognitive needs. The authors recommend incorporating real-time data collection methods and reframing accessibility questions to capture the complex lived experiences of navigating the built environment with a disability. These lessons underscore the importance of thoughtful survey design and implementation to ensure the collection of high-quality, inclusive data that can inform policy and practice for people with disabilities.

The impetus for this research arose from the critical gaps in data related to the characterization and representation of the lived experiences of people with disabilities, particularly in the context of the built environment, activities of daily community living (ADCLs), and overall well-being. This paper was written to provide insight into the complexities and challenges inherent in survey efforts required to address these persistent gaps. The authors hope that future research efforts will prioritize rigorous survey design to enhance representativeness and accurately capture the diverse experiences of underrepresented populations.

CRediT authorship contribution statement

Keith M Christensen: Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Brent Chamberlain:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Keunhyun Park:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Motahareh Abrishami:** Writing – review & editing, Writing – original draft. **Jefferson Clark Sheen:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Teresa Larsen:** Writing – original draft, Formal analysis, Data curation.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data will be made available on request.

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