The Influence of the Built Environment on the Community Participation of Adults Aging with Long-Term Physical Disabilities: A Mixed Methods Approach

Rachel H. Desai

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The Influence of the Built Environment on the Community Participation of Adults Aging with Long-Term Physical Disabilities: A Mixed Methods Approach
by
Rachel Heeb Desai

A dissertation presented to
Washington University in St. Louis
in partial fulfillment of the requirements for the degree
of Doctor of Philosophy

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# Table of Contents

List of Figures .................................................................................................................................. v
List of Tables ..................................................................................................................................... vi
List of Abbreviations ....................................................................................................................... vii
Acknowledgments ........................................................................................................................... ix
Abstract ........................................................................................................................................... xii

Chapter 1: Introduction ....................................................................................................................... 1
  1.1 Adults Aging with Long-Term Physical Disabilities ............................................................... 2
  1.2 Community Participation for AAwPD ............................................................................... 3
  1.3 Personal and Environmental Factors Influencing Community Participation of AAwPD ........ 4
  1.4 Understanding the Role of the Built Environment ............................................................... 6
    1.4.1 Built Environments and the Community Participation of Diagnosis-Specific Populations ... 7
    1.4.2 Built Environments and the Community Participation of Adults Aging with Diverse Long-
        Term Physical Disabilities ................................................................................................. 8
  1.5 Theoretical Foundations for the Study of the Built Environment and Community
      Participation of AAwPD ......................................................................................................... 9
    1.5.1 Field Theory .................................................................................................................. 9
    1.5.2 Ecological Systems Theory ......................................................................................... 10
    1.5.3 Ecological Theory of Aging ......................................................................................... 11
    1.5.4 Conceptual Elements of Participation ......................................................................... 13
    1.5.5 County Health Rankings and Roadmaps Social Determinants of Health Model .......... 13
  1.6 Measurement of Community Participation and the Built Environment ......................... 15
    1.6.1 Subjective Measurement Techniques ........................................................................... 15
    1.6.2 Objective Measurement Techniques ........................................................................... 17
    1.6.3 Modern Measurement Techniques ............................................................................. 18
  1.7 Knowledge Gaps and Research Needs Relevant to This Dissertation .............................. 18
  1.8 Contributions of the Dissertation Specific Aims ................................................................. 20

Chapter 2: The Role of the Built Environment in the Community Participation of Adults Aging
with Long-Term Physical Disabilities: A Scoping Review ......................................................... 23
  2.1 Abstract ................................................................................................................................. 23
Chapter 3: Identifying Built Environment Factors Influencing the Community Participation of Adults Aging with Long-Term Physical Disabilities: A Qualitative Study

3.1 Abstract ..................................................................................................................... 46
3.2 Introduction ............................................................................................................... 47
3.3 Research Process .................................................................................................... 50
  3.3.1 Data Analysis .................................................................................................... 53
3.4 Results ..................................................................................................................... 54
  3.4.1 “It’s Not Safe Here”: Vigilance and Sense of Safety ........................................... 56
  3.4.2 Connection to the Community: Accessibility of and Access to Transportation ............................................................................. 57
  3.4.3 Physical Exclusion: Community Environment Accessibility .................................. 58
  3.4.4 Social Exclusion: Sense of Community ................................................................ 60
  3.4.5 Routines Disrupted: Access to Support, Spaces, and Resources During the COVID-19 Pandemic ................................................................. 61
3.5 Discussion ............................................................................................................... 63
  3.5.1 Study Limitations ............................................................................................. 66
3.6 Conclusion ............................................................................................................... 67
  3.6.1 Funding .......................................................................................................... 68
Chapter 4: Social Participation of Adults Aging with Long-Term Physical Disabilities: A Cross-Sectional Study Investigating the Role of Transportation Mode and Urban versus Rural Living

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1</td>
<td>Abstract</td>
<td>69</td>
</tr>
<tr>
<td>4.2</td>
<td>Introduction</td>
<td>70</td>
</tr>
<tr>
<td>4.3</td>
<td>Methods</td>
<td>73</td>
</tr>
<tr>
<td>4.3.1</td>
<td>Research Design</td>
<td>73</td>
</tr>
<tr>
<td>4.3.2</td>
<td>Participants</td>
<td>73</td>
</tr>
<tr>
<td>4.3.3</td>
<td>Procedures and Data Collection</td>
<td>74</td>
</tr>
<tr>
<td>4.3.4</td>
<td>Data Analysis</td>
<td>78</td>
</tr>
<tr>
<td>4.4</td>
<td>Results</td>
<td>80</td>
</tr>
<tr>
<td>4.5</td>
<td>Discussion</td>
<td>86</td>
</tr>
<tr>
<td>4.6</td>
<td>Conclusion</td>
<td>89</td>
</tr>
<tr>
<td>4.6.1</td>
<td>Funding</td>
<td>90</td>
</tr>
</tbody>
</table>

Chapter 5: Conclusion

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>Summary of Principal Findings and Contributions to Rehabilitation and Participation Science</td>
<td>91</td>
</tr>
<tr>
<td>5.1.1</td>
<td>Aim 1 Findings: The Scope of Literature on Built Environment Factors Influencing the Community Participation of AAwPD</td>
<td>92</td>
</tr>
<tr>
<td>5.1.2</td>
<td>Aim 2 Findings: Perspectives of AAwPD on the Built Environment</td>
<td>93</td>
</tr>
<tr>
<td>5.1.3</td>
<td>Aim 3 Findings: The Role of Transportation Mode and Urban versus Rural Residential Location</td>
<td>95</td>
</tr>
<tr>
<td>5.2</td>
<td>Implications for Relevant Disciplines</td>
<td>97</td>
</tr>
<tr>
<td>5.2.1</td>
<td>Community-Based Organizations and Rehabilitation Providers</td>
<td>98</td>
</tr>
<tr>
<td>5.2.2</td>
<td>Policymakers, Urban Planners, and Architects</td>
<td>99</td>
</tr>
<tr>
<td>5.3</td>
<td>Limitations</td>
<td>100</td>
</tr>
<tr>
<td>5.4</td>
<td>Future Research</td>
<td>102</td>
</tr>
<tr>
<td>5.4.1</td>
<td>Measurement Implications</td>
<td>102</td>
</tr>
<tr>
<td>5.4.2</td>
<td>Strategies for Addressing Inequities in the Built Environment</td>
<td>104</td>
</tr>
<tr>
<td>5.5</td>
<td>Summary</td>
<td>105</td>
</tr>
</tbody>
</table>

References | 107   |

Appendix | 14    |
List of Figures

Figure 1.1: An Adaptation of the Ecological Theory of Aging .........................................................12

Figure 1.2: The Flow and Relationship of the Dissertation Specific Aims .................................22

Figure 2.1: PRISMA-ScR Flow Diagram ............................................................................................30

Figure 5.1: Dissertation Summary ..................................................................................................106
## List of Tables

Table 2.1: Characteristics of Included Articles .................................................................31

Table 2.2: Summary of Articles on the Role of the Built Environment in the Community Participation of Adults Aging with Long-Term Physical Disabilities ...........................................................................35

Table 2.3: Environmental Domains Investigated within the Reviewed Articles .................40

Table 3.1: Example Interview Questions .............................................................................52

Table 3.2: Participant Demographic and Health Characteristics ............................................55

Table 4.1: Variables Measured in the Survey .......................................................................77

Table 4.2: Participant Demographic Characteristics ..............................................................80

Table 4.3: Participant Demographic Characteristics by Transportation Mode and Residential Location .........................................................................................................................81

Table 4.4: Satisfaction Responses to Three Community Participation-Related Activity Domains ...........................................................................................................................................83

Table 4.5: Hierarchical Multiple Linear Regression for Ability to Participate in Social Roles and Activities ..........................................................................................................................84

Table 4.6: Mann-Whitney U Analysis of Differences in Social Participation Ability ..........85
List of Abbreviations

AAA: Area Agencies on Aging
AAwPD: Adults Aging with Long-Term Physical Disabilities
ACLS: Americans’ Changing Lives Survey
ADA: Americans with Disabilities Act
ADI: Area Deprivation Index
CAT: Computer Adaptive Test
CBO: Community-Based Organizations
CHART: Craig Handicap Assessment and Reporting Technique
CHIEF: Craig Hospital Inventory of Environmental Factors
CIL: Centers for Independent Living
CPI: Community Participation Indicators
EFIB: Environmental Factors Item Banks
GIS: Geographic Information Systems
GPS: Global Positioning Systems
HCES: Home and Community Environment Survey
HE: Housing Enabler
IAAP: Israeli Adults Assessment of Participation
ICF: International Classification of Functioning, Disability, and Health
IPAQ: Impact on Participation and Autonomy Questionnaire
MANCOVA: Multivariate Analysis of Covariance
MAT: Mobility Assistive Technology
NIDILRR: National Institute on Disability, Independent Living, and Rehabilitation Research
PICO: Population, Intervention, Comparison, Outcome
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROMIS: Patient-Reported Outcomes Measurement Information System

PS: Participation Scale

REDCap: Research Electronic Data Capture

RUCA: Rural Urban Commuting Area

SCI: Spinal Cord Injury

SCQ: Self-Administered Comorbidity Questionnaire

SDoH: Social Determinants of Health

SWAN: Stakeholders Walkability/Wheelability Audit in Neighborhoods
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Rachel Heeb Desai

Washington University in St. Louis

May 2023
Dedicated to my family.

“Space is a place of intersecting struggles/oppression/opportunities. How we move or not move through it... shapes everything we do and big parts of who we are.”

-Makani Themba
ABSTRACT OF THE DISSERTATION

The Influence of the Built Environment on the Community Participation of Adults Aging with Long-Term Physical Disabilities: A Mixed Methods Approach

by

Rachel Heeb Desai

Doctor of Philosophy in Rehabilitation and Participation Science

Washington University in St. Louis, 2023

Professor Kerri Morgan, Chair

Adults living with a long-term physical disability experience difficulties living independently and participating in the community as they age. A combination of personal (e.g., fatigue) and environmental (e.g., transportation accessibility) factors influence these restrictions in participation. The impact of the built environment is a key aspect to consider when understanding community participation restrictions for adults aging with long-term physical disabilities (AAwPD) because these factors are often more modifiable. However, the processes by which the built environment impacts AAwPD are not well understood. Interventions targeting these factors to address the community participation needs of AAwPD are limited.

Research informing community-based organizations (CBO) that are well-positioned to serve AAwPD can help address their health and participation disparities. Previous research evaluating the influence of the built environment on the community participation of AAwPD is limited by primarily qualitative or cross-sectional data, a focus on a single diagnosis or disability group, and samples that lack racial and socioeconomic diversity. The purpose of this dissertation is to inform intervention development and service provision of CBO to improve the community participation of AAwPD by (1) characterizing the existing research knowledge of how built
environments influence the community participation of AAwPD, (2) investigating how AAwPD perceive their surrounding built environments to influence their community participation, and (3) determining the quantitative associations between built environment factors and community participation for AAwPD.

Synthesis of the current state of evidence revealed heterogeneity in measurement tools and operationalizations of community participation as an outcome. In addressing the second aim of the dissertation, I conducted semi-structured interviews with 20 AAwPD to better understand their perceptions of the impact of the built environment across a spectrum of neighborhood socioeconomic disadvantage. Our findings highlighted the importance of built environments that foster a sense of belonging and personal safety.

Statistical modeling was then used to explore the quantitative relationships between community participation and built environment factors in a sample of 331 Missouri-dwelling AAwPD. Participation in social roles and activities was found to be significantly different across transportation mode and residential location—factors identified in the first two aims. However, personal factors (e.g., pain) were significantly more predictive of restricted participation than built or social environment factors. Finally, urban-dwelling participants primarily using paratransit reported the highest ability to participate in social roles and activities.

Together, these results demonstrate the significance of the objectively measured and subjectively perceived influence of built environment factors for the community participation of AAwPD. The work presented in this dissertation provides a new understanding of how community participation for AAwPD is shaped by supportive, safe, and accessible built environments. Our findings may inform researchers, CBO, and funding agencies in future intervention development and implementation.
Chapter 1: Introduction

The environment affects all aspects of health and wellbeing, including an individual’s ability to participate in their community.\textsuperscript{1,2} Features of community environments, such as the accessibility and safety of neighborhoods, promote or inhibit an individual’s participation in meaningful social activities outside the home.\textsuperscript{3-5} These environmental features are particularly important for disability and aging populations due to the consequences of secondary health conditions and mobility device use leading them to interact with the environment differently (e.g., lack of curb cut prevents sidewalk access).\textsuperscript{6-8} Adults aging with long-term physical disabilities (AAwPD), who are at the intersection of aging and disability, experience the accumulated effects of these environmental barriers and subsequently participation disparities over a long period of time.\textsuperscript{9,10} AAwPD are a heterogeneous population representing many different diagnoses and chronic health conditions that need to be better understood so that proper intervention strategies to support participation can be identified.

Theory and research both suggest that the environment can either support or deter the community participation of AAwPD, but the processes through which environmental factors influence their participation are not well identified.\textsuperscript{11,12} There are also limited evidence-based environmental interventions to address the community participation needs of AAwPD.\textsuperscript{11,13} Community-based organizations (CBO) are poised to address modifiable environmental barriers to participation.\textsuperscript{14,15} CBO provide services and resource referrals to facilitate participation and aging in place for people with disabilities. We must ensure that our research is translatable to inform and support these organizations in providing services to diverse populations not specific to diagnosis. Thus, the purpose of this dissertation is to improve our understanding of how to
environmentally support the community participation of AAwPD to inform future interventions and improve service provision for CBO.

1.1 Adults Aging with Long-Term Physical Disabilities

The aging of the United States’ population due to advancements in medical care, public health, and technology has been accompanied by longer lifespans for people with disabilities. Over the next few decades, the United States will see a significant growth in the number of individuals who have lived with a physical disability long-term.\textsuperscript{16-17} There are currently an estimated 13 million adults in the United States who are living with a physical disability that was acquired before the age of 40.\textsuperscript{15} Individuals who age into later life with a disability acquired from birth through mid-life experience both health conditions associated with their primary disability (e.g., pressure injuries, fatigue) and aging-related symptoms (e.g., osteoarthritis).\textsuperscript{18-20} This combination leads to “accelerated aging”—or earlier and faster functional decline—for AAwPD compared to the general population.\textsuperscript{21}

The population of AAwPD includes adults living with conditions such as multiple sclerosis, spinal cord injury (SCI), or cerebral palsy over the span of multiple years. While this population has high variability regarding diagnosis, comorbid conditions, and other characteristics, they share many commonalities. First, AAwPD report high levels of pain, fatigue, and depression, which have been identified as aging-with-disability symptoms.\textsuperscript{22} Second, people with disabilities in general face social and economic barriers (e.g., lower household incomes and rates of employment) that contribute to health disparities.\textsuperscript{23,24} For AAwPD, these health inequities accumulate over the lifetime.\textsuperscript{25} Investigating the needs of AAwPD as a diverse demographic with shared experiences improves external validity, as it mirrors the populations served by CBO and will help inform their service delivery and future programming.\textsuperscript{26}
For AAwPD, the age range of 45-65 is a period during which they are especially vulnerable to early and fast functional decline and experiencing problems living independently.\textsuperscript{15,27,28} Accelerated aging begins at approximately age 45 for most AAwPD, yet eligibility for traditional aging services does not begin until age 60-65.\textsuperscript{29} Additionally, many of this population’s needs do not fit well within a traditional disability support framework. This gap often causes AAwPD to “fall through the cracks” of social services and support systems that they could otherwise benefit from.\textsuperscript{14,30} This population’s difficulties performing activities of daily living leads to restricted participation in meaningful activities in their community.\textsuperscript{31}

1.2 Community Participation for AAwPD

Participation is a complex construct with many different definitions.\textsuperscript{32,33} The World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) broadly defines participation as “involvement in life situations.”\textsuperscript{34} Community participation is a more specific form of participation that describes involvement in life situations that center around meaningful social activities in one’s community.\textsuperscript{35} We focus on community participation in this dissertation because it is key to successful aging and has become widely acknowledged as an important indicator of health and well-being.\textsuperscript{36,37} Community participation fosters a sense of belonging and connection to one’s community, facilitates physical activity, and helps to form and maintain social relationships.\textsuperscript{38-40} We define community participation in this dissertation as “active involvement in activities that are intrinsically social and either occur outside the home or are part of a nondomestic role.”\textsuperscript{35}

The importance of community participation has continued to gain recognition in the last decade. Organizations at national and global levels have called for prioritizing community participation within the larger agenda of advancing the health of people with disabilities and
older adults. In its 2018-2023 Long-Range Plan, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) reinforced the need “to enhance the ability of people with disabilities to achieve inclusion and integration into society” through the disability research agenda.\textsuperscript{41} Community living and participation remains one of NIDILRR’s three primary outcome domains. Additionally, the World Health Organization’s Active Aging Policy Framework and its Global Network for Age Friendly Cities and Communities both highlight the importance of aging adults’ active participation in society and the policies, environments, and services that can support such participation.\textsuperscript{42,43}

1.3 Personal and Environmental Factors Influencing Community Participation of AAwPD

Our previous work has demonstrated that the community participation of AAwPD is influenced by a combination of personal factors and environmental factors.\textsuperscript{26} Our team administered a comprehensive longitudinal survey to 474 AAwPD to explore their community participation over time.\textsuperscript{26} We found that aging-with-disability symptoms (i.e., pain, fatigue, and depression) were associated with lower rates of social participation, a specific dimension of community participation focusing on social roles and activities.\textsuperscript{22} Our survey also collected 215 participants’ responses to open-ended questions regarding how they experience barriers and facilitators to community participation. We analyzed these qualitative data to better understand the personal versus environmental factors at play and to establish the preliminary work needed for this dissertation. This study demonstrated that AAwPD identified both intrinsic, person-level factors and extrinsic, environment-level factors that impact their ability to participate in their communities.\textsuperscript{11} Physical effects of disability and accelerated aging (e.g., pain and fatigue) paired
with environmental factors (e.g., accessibility of neighborhood environments) were reported as influencing community participation.

Environmental factors impacting participation also include products and technology, climate and geography, social support, attitudes surrounding disability, and services, systems, and policies. Many of these environmental factors overlap significantly with social determinants of health (SDoH), defined as the conditions in which people live, work, play, and age.¹ SDoH highlight the need to address factors that are more upstream (e.g., health education, economic instability) that influence health behaviors, rather than relying on downstream medical intervention alone. SDoH underscore the significance of factors that are extrinsic to an individual. For AAwPD, these extrinsic, environmental factors contribute to health and participation disparities that must be addressed.

Examples of extrinsic factors that specifically shape the health and participation of AAwPD include access to long-term services and supports (e.g., home health aide services), the size and quality of one’s social network, employment, income, health insurance, and the accessibility of one’s home and community environments.⁶,²²,⁴⁴,⁴⁵ Because many AAwPD use mobility devices (e.g., scooters, wheelchairs) to navigate spaces in their communities, the built environment is of particular importance to their participation.⁴⁶ The built environment, which encompasses the structures and aspects of a place that were created by people, is an emerging topic of study as it relates to AAwPD and their community participation.⁴⁷,⁴⁸ For example, availability and accessibility of reliable transportation options are key to AAwPD being able to access community spaces.⁴⁹ Urban versus rural residential location, street connectivity, transportation mode, and sidewalk conditions are additional aspects of the built environment that warrant research to better facilitate the community participation of AAwPD.⁵⁰-⁵²
Targeting built environment factors in research on AAwPD is warranted for several reasons. First, the built environment is arguably more modifiable compared to person-level symptoms. Pain, fatigue, and depression are often only manageable but not curable. Second, a single intervention addressing a built environment barrier (e.g., an unsafe and inaccessible community street intersection) can positively impact a large number of people in a cost-effective way. Informing the design of built environments that are more usable and universally accessible can benefit other groups of people beyond AAwPD (e.g., children, parents using strollers, cyclists, people with low vision, etc.). Additionally, a transdisciplinary approach is beneficial for studying the impact of the built environment and how to modify it. Collaboration among rehabilitation researchers, urban planners, transportation engineers, and public health professionals can lead to more holistic and creative solutions to improve health outcomes.

Further, understanding the interactions between AAwPD and disabling built environments can help ensure their access to important opportunities and resources.

1.4 Understanding the Role of the Built Environment

Many of the organizations calling for a more holistic, participation-based approach to health have also acknowledged the built environment as a significant determinant of health and participation. NIDILRR’s Long-Range Plan outlines the priority of ensuring that transportation and other infrastructures are “accessible, useful, available, and affordable to people with disabilities” to support community living and participation. A Conceptual Framework for Action on the Social Determinants of Health, developed by the World Health Organization, identifies “material circumstances” (e.g., neighborhood quality) as working in tandem with structural determinants (e.g., an individual’s socioeconomic positioning) to create health inequities. Recently, the United States Department of Health and Human Services updated its
latest iteration of the Healthy People initiative (Healthy People 2030) by strengthening its focus on SDoH.

Neighborhood and built environments comprise one of the five pillars of the initiative’s SDoH model. Our evolving understanding of health and disability—and how they are shaped by the built environment—is reflected in these shifting priorities of organizations and public health authorities. This evolution justifies the need to assess how prior literature has explored built environment factors for AAwPD and to determine their perceived and objective relationships with community participation.

1.4.1 Built Environments and the Community Participation of Diagnosis-Specific Populations

Our knowledge of the influence of the built environment on the community participation of AAwPD has expanded over the past few decades. Foundational literature has examined both specific disability populations and AAwPD as a whole. For example, Barclay and colleagues determined through qualitative interviews with individuals aging with SCI that, among other social and environmental factors, lack of transportation served as a major barrier. Inaccessible gas stations and availability of accessible parking spaces also prevented participants from getting where they needed to go. Participants in this study also described newly built community facilities or outdoor recreational spaces in which the mobility needs of people with disabilities were clearly not considered. Similarly, a study on barriers to community participation for individuals aging with multiple sclerosis identified physical and structural barriers (e.g., transportation, community design, technology) as frequently encountered barriers to community participation. Personal assistance, social attitudes, and policies and social services were comparatively cited less by participants as barriers. Greater land use mix (i.e., integration of commercial, residential, and industrial uses of land) and a higher number of nearby community destinations were also associated with restricted community participation for individuals aging
with SCI. In further investigating the pathways of influence of the built environment, Wong et al. developed a structural equation model of relationships between environmental factors and social participation for adults aging with traumatic brain injury, stroke, and SCI. Their results illustrated that physical and social environmental barriers mediated the impact of systems, services, and policies on social participation.

1.4.2 Built Environments and the Community Participation of Adults Aging with Diverse Long-Term Physical Disabilities

Regarding research on heterogeneous samples of AAwPD, our previously described qualitative study reported on a cohort of AAwPD with a wide variety of physical disabilities. In examining factors influencing their community participation, we found a relatively even split between participants’ responses coded as environmental (50.9%) and personal (49.1%). The physical environment, which included references to transportation and accessibility of community spaces, comprised the largest sub-code within the theme of environmental factors. An additional qualitative study on individuals aging with mobility disability pinpointed inaccessible transportation and public restrooms—especially for those with bowel and bladder dysfunction—as major environmental barriers. In a mixed-methods study on adults aging with mobility disabilities, Sundar et al. also found that participants attributed their participation restrictions to a combination of poor health and neighborhood physical and social factors (i.e., proximity to activities, neighborhood social cohesion). However, using structural equation modeling in the same study, the authors did not confirm a direct causal pathway between physical neighborhood factors and community participation. Rather, neighborhood factors significantly impacted self-efficacy, suggesting an indirect effect on community participation. Finally, seminal work by Clarke and colleagues demonstrated the adverse effects of pain, fatigue, and physical function paired with poor access to community buildings on the community
participation of AAwPD. Notably, poor building access only predicted community participation restrictions for AAwPD not using mobility devices (i.e., ambulatory participants).

In this emerging body of literature, qualitative studies have generally found that participants perceive a direct influence of the built environment. However, quantitative analyses suggest that these effects are more indirect and may mediate the relationships between community participation and other variables such as self-efficacy. These inconsistencies, along with a general dearth of quantitative work on this topic, warrant further research. Additionally, the built environment barriers of transportation accessibility and availability have proven to be a common thread. This dissertation explores these inconsistencies and knowledge gaps by synthesizing existing literature and combining qualitative and quantitative methods. Our third aim also explores the role of transportation in greater depth.

1.5 Theoretical Foundations for the Study of the Built Environment and Community Participation of AAwPD

The built environment is one of the many complex variables that make participation outcomes difficult to measure. An individual’s experience of disability and their interactions with the environment are also dynamic and context dependent. Using theory to guide our inquiry of these constructs is thus imperative. Several theories and frameworks can be used to conceptually drive the study of built environment factors and community participation for AAwPD. These theories also span a continuum of abstract to concrete and are highlighted below.

1.5.1 Field Theory

Beginning with the most abstract, social psychologist Kurt Lewin developed field theory, which emphasizes an individual’s behavior as occurring in the proximal environment or “field.” Lewin famously reduced this theory into the equation B=f(P,E), describing behavior
Field theory also posits that all behaviors are goal oriented in some way. As an individual interacts with their surrounding field, their goal-directed behavior is influenced by forces and tensions within the field as well as the individual’s perceptions of them. In the scope of participation, for example, the motivation to participate in a social event in one’s community, and the execution of that goal, is influenced by the individual’s field. Whether the individual has access to transportation to the event, the perceived social climate of the event, and the accessibility of the event space all contribute to the forces and tensions of the individual’s field.

While this theory has contributed to our understanding of the importance of the environment in shaping human behavior, it lacks operational definitions and is difficult to empirically test. The deterministic and simplistic nature of this theory is also limiting, as it implies that an individual’s behavior is entirely dictated by the environment and other forces within it. The complexity of human behavior is not fully accounted for, nor are other factors considered that may be potentially relevant to behavior (e.g., health conditions, change in physical function over time). Additional theories with more defined environmental components are thus needed to support the work of this dissertation.

1.5.2 Ecological Systems Theory

Additional theoretical work that conceptualizes the environment from a systems approach is Urie Bronfenbrenner’s ecological systems theory. This theory posits that an individual sits at the center of multiple spheres of influence (i.e., microsystem, mesosystem, exosystem, macrosystem, chronosystem). The individual interacts with and is affected by these different layers. Each layer of environmental influences is a system that shapes behavior, development, and life experiences. The individual and their surrounding environmental systems are interrelated
and interdependent; it is therefore impossible to investigate the participation of an individual without also considering the environmental systems in which they are embedded.

In ecological systems theory, the microsystem and mesosystem explicitly include one’s neighborhood environment and its relationship to other important components of one’s environment such as family, work, or school. However, aspects of the influence of the built environment can be mapped onto all environmental systems. For example, within the microsystem and mesosystem, the community mobility of a wheelchair user may be negatively affected by poor street conditions and lack of curb cuts. The exosystem encompasses elements of the environment that are more distal, such as residential location and proximity to social services. Policies and federal funding that dictate how built environments are designed and maintained are classified as part of the macrosystem. The relationship between these environmental systems and community participation has yet to be adequately examined for AAwPD.

1.5.3 Ecological Theory of Aging

Powell Lawton and Lucille Nahemow’s ecological theory of aging can be used to more concretely visualize the interaction between person and environment. The ecological theory of aging describes the dynamic interplay between an individual’s competence (i.e., cognitive and physical capability) and environmental press (i.e., aspects of the environment that pose challenges). Although Lawton and Nahemow’s theory was originally developed in the context of aging, it has become widely used as a theory to generally conceptualize the interaction between person and environment. It has also served as a theoretical springboard for generating additional research hypotheses.

At the core of this theory is a graph that depicts personal competence on one axis and environmental press on another. If an individual maintains a balance of competence and
environmental press, they will live within the “adaptation level.” Just outside this adaptation level is the point at which novel behaviors and learning occur. Lawton and Nahemow also proposed two primary hypotheses: 1) the environmental proactivity hypothesis that individuals with more competence have more resources in their environment available to them, and 2) the environmental docility hypothesis that the behaviors of individuals with less competence are dictated more by their environments. According to this theory, AAwPD experience diminished personal competence due to secondary health conditions, accelerated aging, and mobility limitations, and are thus dictated more by their environment. We hypothesize that the interaction
of impaired physical function with inaccessible built environments leads to maladaptive behavior (i.e., restricted community participation) as shown in Figure 1.1. Alternatively, if AAwPD have high competence and experience too little environmental press, they may engage in maladaptive behavior due to boredom or lack of stimuli.

1.5.4 Conceptual Elements of Participation

Through qualitative focus groups with individuals with disabilities, Hammel and colleagues identified six themes that define participation: (1) meaningful engagement/being a part of; (2) personal and societal responsibilities; (3) having an impact and supporting others; (4) social connection, inclusion, and membership; (5) access and opportunity; and 6) choice and control. These themes represent what participation means to individuals with disabilities and highlight that one’s idea of full participation is multidimensional and cannot be defined by predetermined societal roles or expectations. This framework brought significant implications for the definition and measurement of participation; namely, that assessment should include items based on values and subjective meaning placed on personal, social, and societal roles. This framework also paints a clearer picture of the concept of participation that previous conceptualizations have failed to capture, such as the World Health Organization's ICF and its broad definition of participation. However, due to the nature of this study and the framework it produced, environmental factors are only broadly discussed in the context of access to resources and accommodations.

1.5.5 County Health Rankings and Roadmaps Social Determinants of Health Model

The final conceptual model relevant to this dissertation is the Social Determinants of Health Model developed by the County Health Rankings and Roadmaps Program. This model quantifies the impact of different categories of factors on health and quality of life. According to
the model, 50% of a person’s health is shaped by the physical environment and social and economic factors, while the other 50% is determined by quality and access to clinical care and a person’s individual health behaviors. Air and water quality, housing, and transit are listed as the primary physical environment factors in this model. Education, employment, income, social support, and community safety are listed as the main social and economic factors. This model illustrates the substantial role that external factors serve in determining one’s health. However, its percentages and categories of factors have yet to be validated in disability populations, including AAwPD, who interact with built environments differently. Further, built environment accessibility is not considered in this model.

Application of Theories to This Dissertation

These models, frameworks, and theories help to lay the foundation for this dissertation and shaped its development in some way. Each focuses on different aspects of the dissertation: participation, disability, aging, and environment. However, the ecological systems theory and the ecological theory of aging were the most critical to the design of our three aims. These theories acknowledge that when studying person and environment, the two are inseparable. Both theories helped shape the overarching hypothesis of the dissertation that the built environment significantly contributes to the ability of AAwPD to participate in their communities. Both theories also informed the development of the search strategy for the scoping review (Aim 1). We also used the ecological systems theory to guide the development of the interview questions for the qualitative study (Aim 2) and the interpretation of the results. The ecological theory of aging shaped the statistical analyses for the quantitative exploration (Aim 3). Additionally, Hammel et al.’s framework of participation supports our use of patient-reported outcome measures in the third aim of the dissertation, which emphasize the respondent’s perceived ability
to participate in social roles in one’s community. Finally, the County Health Rankings and Roadmaps Social Determinants of Health Model also informed the analyses for the quantitative study. Specifically, we used a hierarchical multiple linear regression to compare the magnitude of influence of variable categories (e.g., personal and health characteristics versus environmental determinants) for our study sample’s community participation against the percentages in the Social Determinants of Health Model.

1.6 Measurement of Community Participation and the Built Environment

Because there is no universal consensus on the definition of participation and not all conceptualizations follow the ICF, measurement approaches vary considerably.\(^{32,33}\) Frequency, duration, retention, satisfaction, and importance of an individual’s participation in various activities are examples of constructs often incorporated into assessment measures.\(^{73-75}\) Similarly, there are a wide variety of methodological approaches to measuring the built environment.\(^{47,52,76}\) A combination of subjective and objective measurement approaches may provide the most comprehensive understanding of an individual’s participation in context.\(^{33}\) There are also advantages and disadvantages to each approach that will be explained in more detail below.

1.6.1 Subjective Measurement Techniques

At the intersection of community participation, disability, and the built environment, researchers have often utilized subjective measures.\(^{62}\) The subjectivist approach emphasizes an individual’s perceptions, preferences, and unique life experiences in the shaping of their participation. Qualitative methods and self-report measures typically align with this approach.\(^{77}\) As previously highlighted, much of the extant literature on the role of the built environment in the community participation of AAwPD has employed qualitative methods (e.g., focus groups,
Self-report measures have been the other primary means of data collection within the literature\textsuperscript{45,78}. The Craig Hospital Inventory of Environmental Factors (CHIEF) is an example of a commonly used self-report measurement tool that captures the impact of environmental factors on participation.\textsuperscript{81} The CHIEF asks the respondent about the perceived frequency and magnitude of each environmental item’s impact on their participation.

Regarding measurement of community participation, many self-report measures assess the frequency, importance, and extent to which a respondent participates in social roles, relationships, leisure, and recreational activities. The Patient Reported Outcomes Measurement Information System (PROMIS) is a set of person-centered (i.e., self-report) assessments that measure mental, physical, and social health.\textsuperscript{82} The PROMIS measures include assessments of perceived ability and satisfaction related to participation in social roles and activities.\textsuperscript{83,84} In the third aim of this dissertation, we utilize the PROMIS social participation measures to quantitatively analyze their associations with aspects of the built environment. We also utilize components of the CHIEF to evaluate transportation availability and accessibility.

One of the key advantages to qualitative methods is that they provide insight into a person’s nuanced lived experiences that help explain rather than simply describe their behaviors.\textsuperscript{85} Because the analytical process is often exploratory and requires inductive reasoning, qualitative data can also aid in the generation of hypotheses (as opposed to quantitative research, in which hypotheses are developed apriori to be tested).\textsuperscript{86} Further, qualitative and self-report methods can unearth unexpected findings not anticipated by the original research questions. In the context of built environment-related research, a subjective measurement approach is also well-suited for eliciting the meaning and attachment people develop for different spaces.\textsuperscript{87} The subjectivist approach also aligns with many of the elements highlighted in Hammel et al.’s
framework of participation. The subjective meaning individuals develop regarding personal and societal responsibilities, having a sense of inclusion and community, and maintaining a sense of choice and control can only be measured through subjective measurement approaches. Regarding its disadvantages, quantifying the impact of the environment with qualitative methods becomes difficult, as does establishing cause-and-effect relationships. Additionally, gathering data from a large sample through interviews and focus groups is impractical.

1.6.2 Objective Measurement Techniques

An objective measurement approach assumes that there are truths that can be empirically measured. This viewpoint typically aligns with direct observational methods. Built environments have traditionally been studied using administrative data or aggregated demographic information such as zip codes. Geographic information systems (GIS) and global positioning systems (GPS) software are increasingly being used for objective analysis. GIS is a framework for gathering, managing, and analyzing geographic data, including GPS data. Other methods to objectively assess the environment include audits and environmental checklists, which can be used to systematically assess the usability and accessibility of community environments.

The objective measurement of the built environment and community participation allows for the direct testing of hypotheses, quantification of factors for future comparisons, and identification of causal relationships (assuming the study was designed appropriately). Objective measurement techniques also enable data collection and detection of patterns on a larger scale. Additionally, direct observation methods provide insight into behaviors and environments that may be impossible to study in a laboratory setting or via online survey. However, large-scale data collection via survey or administrative data can impede a researcher’s ability to assess nuanced, micro-level environmental characteristics (e.g., neighborhood sidewalk conditions).
1.6.3 Modern Measurement Techniques

Advancements in technology have led to the development of sophisticated GIS tools. Researchers can use these tools to analyze the visual composition of neighborhood environments and mark the presence of physical disorder (e.g., vandalism, litter) or green space (e.g., public parks, community gardens). Additionally, researchers have developed composite indicators of neighborhood disadvantage and socioeconomic status that provide important contextual information for addressing health and participation disparities. The Yost Index is an example of a composite indicator that incorporates multiple theoretical domains (e.g., household income, housing quality) to summarize neighborhood socioeconomic disadvantage. Indices are often based on data at the Census Block Group level, or the closest approximation to the “neighborhood” level. Researchers are increasingly using these indices as covariates in analyses to predict health outcomes, inform health policy, and improve service delivery.

The majority of the work presented in this dissertation relies on a subjective measurement approach (i.e., semi-structured interviews in our second aim, PROMIS assessments in our third aim). However, we also determined that it was necessary to evaluate aspects of the built environment using objective measurement techniques such as GIS. For example, we calculated participants’ neighborhood socioeconomic disadvantage using the Yost Index. We also geocoded participants’ addresses to dichotomize their residential location as urban or rural.

1.7 Knowledge Gaps and Research Needs Relevant to This Dissertation

The body of literature on the role of the built environment in the community participation of AAwPD continues to grow, but there has yet to be a comprehensive review synthesizing this research. There is also a clear need for evidence that includes AAwPD from racial and ethnic
minorities who are traditionally underrepresented in research. The existing literature overwhelmingly reports on samples of AAwPD that are primarily White, cisgender, and highly educated. There is inherent value in studying the community participation of racial and ethnic minorities and socioeconomically disadvantaged individuals. Their disparities in access to health and environmental resources are already well documented and likely compound with intersecting disability and aging identities. We also have a limited understanding of how the COVID-19 pandemic has impacted AAwPD, who are already prone to social isolation and difficulties accessing health care. Further, we have yet to sufficiently translate the evidence on environmental determinants of participation into meaningful implications for CBO (e.g., Centers for Independent Living, Area Agencies on Aging). CBO serve AAwPD and are well positioned to help facilitate their participation but currently focus primarily on barrier modification and removal within the home rather than out in the community. Research that is more intentionally designed for translation can help develop the capacity of CBO and long-term support services to facilitate the community participation of AAwPD. The work presented in this dissertation directly relates to these knowledge gaps and may help shape future research.

Multiple disciplines such as architecture and urban planning, rehabilitation, and policymaking also have the potential to address gaps related to built environment barriers to participation for AAwPD. In the context of urban planning and architecture, the planning processes rarely involves persons with disabilities and other potentially relevant disciplines such as occupational therapists, who are well versed in the environmental needs of AAwPD. Additionally, the Americans with Disabilities Act (ADA) guidelines are often treated as the bare minimum design standards, rather than a foundation upon which to design more inclusive spaces.
For rehabilitation providers, the ultimate goal is often to ensure the full community participation or reintegration of their patients.\textsuperscript{35} However, decreasing lengths of stay, limited insurance coverage, and a focus on acute personal factors can lead to patients being discharged with minimal to no preparation for navigating the community and living independently.\textsuperscript{110,111} Finally, regarding policymaking, there is a dearth of large-scale data on built environment barriers to inform potential policy-related changes,\textsuperscript{108} and ADA enforcement continues to be an issue today.\textsuperscript{112}

1.8 Contributions of the Dissertation Specific Aims

We must develop evidence to inform the design of built environments that better facilitate community participation, a universally recognized human right that is closely linked to health and wellbeing, for AAwPD.\textsuperscript{113,114} In this dissertation, we identify how, why, and to what extent environmental factors act as barriers for AAwPD. This knowledge can also inform the provision of community-based services and the development of systems and policies that promote healthy aging-in-place for AAwPD. The purpose of this dissertation is to explore the association between built environment factors and the community participation of AAwPD. Our overarching hypothesis is that the built environment contributes to the ability of AAwPD to participate in their communities. This dissertation is a mixed methods series of studies with the following aims:

Aim 1: Characterize the nature and scope of existing literature on the role of the built environment in the community participation of AAwPD. We conducted a scoping review of peer-reviewed literature, screened and extracted data from relevant articles, and synthesized results. The purpose of this aim was to develop a thorough synthesis of the literature, with identification of knowledge gaps and common methodologies used. Our research question was
“what is the nature and scope of the current literature on built environments and the community participation of AAwPD?”

Aim 2: Investigate how AAwPD perceive their surrounding neighborhood and built environments to influence their community participation. We conducted semi-structured interviews with AAwPD asking about their community participation and neighborhood and built environments. Our research question was “how do AAwPD perceive their surrounding built environments to influence their community participation?”

Aim 3: Explore the quantitative associations between built environment factors (e.g., transportation mode, urban versus rural living) and community participation for AAwPD. Using a sample of 331 AAwPD, we created a general linear model to explore quantitative associations between transportation mode, urban versus rural living, and participation in social roles and activities using PROMIS measures. We hypothesized that AAwPD’s reported community participation would be significantly different across transportation mode and urban versus rural residential location.

This work has resulted in a synthesis of previous literature on this topic and a new understanding of how AAwPD perceive their environments. Our results may better inform researchers, CBO, and funding agencies in intervention development and implementation. Our approach allows us to corroborate our quantitative and qualitative findings and to address a complex research question that may otherwise be challenging to measure purely quantitatively. This study is significant in that addressing current knowledge gaps will lead to the development of evidence-based interventions to address modifiable environmental factors and improve service provision from CBO for the growing population of AAwPD. Our results may also be of value to
important nonprofit funding agencies such as Smart Growth America or government agencies such as the Federal Transit Administration. Through a review of the literature, qualitative interviews, and quantitative analyses, our mixed-methods study provides a comprehensive understanding of both subjective and objective perspectives of environmental influences. The first two aims, along with our preliminary work, have informed the third quantitative aim (see Figure 1.2). The three aims serve as standalone projects not contingent on one another, but their results build upon each other and lead to more informed approaches for each subsequent aim.

Figure 1.2 The flow and relationship of the dissertation’s specific aims
Chapter 2: The Role of the Built Environment in the Community Participation of Adults Aging with Long-Term Physical Disabilities: A Scoping Review


2.1 Abstract

The purpose of this scoping review was to characterize the nature and scope of existing literature on the role of built environments in the community participation of adults aging with physical disabilities (AAwPD). A scoping review was selected to identify the volume and types of evidence available, pinpoint knowledge gaps, and clarify key concepts. Twenty-one articles were included for review, all of which were published within the last 20 years and identified components of the built environment for intervention. Results demonstrated the need for investigators to identify common indicators, use a shared lexicon, and improve dissemination of results across disciplines.

2.2 Introduction

The features of neighborhood and community environments where people live, work, and play are important social determinants of health and contribute to quality of life and well-being.\(^1,115\) The built environment, defined as the human-made and infrastructural aspects of a
place, includes community conditions such as sidewalk integrity, neighborhood traffic safety, and access to transportation. These features have particular importance for people aging with long-term physical disabilities, who often use mobility devices such as wheelchairs, walkers, or canes to navigate their communities. Built environments have historically been designed for the general population without considering the needs of diverse populations with a range of physical functioning. Physical barriers in community built environments continue to significantly impact the lives of people with disabilities despite worldwide recognition of accessibility (i.e., ensuring equal access to physical environments, transportation systems, information, communication, and technologies) as a human right for persons with disabilities.

Inaccessible built environments have major implications for adults aging with physical disabilities (AAwPD), defined as individuals who acquired physical disabilities at birth or earlier in life who are now surviving into mid and later life due to advancements in technology and health care. AAwPD experience difficulties living independently (e.g., shopping for groceries or doing laundry without assistance) and participating in their communities (e.g., visiting a coffee shop with a friend) due to a combination of personal and environmental barriers. AAwPD also experience age-related symptoms (e.g., pain, fatigue) that compound with secondary health conditions (e.g., heart disease, osteoporosis, arthritis) associated with their primary disability that contribute to earlier and more accelerated functional decline compared to the general population. Adults aging with disability contrast to those who age into disability as an older adult and have avoided disability until their 70s, 80s, or 90s, when frailty and fall-related injuries may begin to occur. Additionally, AAwPD include individuals with a variety of diagnoses, as the inherent heterogeneity represents the populations served in the “real world” by community organizations. Although factors such as sidewalk accessibility, proximity to
destinations of interest, and access to transportation have been shown to positively impact this population, the mechanisms behind how the built environment contributes to the disabling process are not well understood.63,120,121

Over the past 50 years, public health researchers have identified elements of the built environment that serve as facilitators or barriers to specific health behaviors in the general population—particularly physical activity.122-126 The past two decades have also seen a shift toward prioritizing other indicators of health such as community participation, defined as active involvement in meaningful, social activities that occur outside the home or are part of a non-domestic role.9,10,35,121 These concepts are highlighted in the United States Department of Health and Human Services Healthy People 2030 priorities that address both the neighborhood built environment and civic participation (e.g., community gardening, volunteering, participating in group activities) as significant social determinants of health.127

People with physical disabilities who face built environment barriers outside the home are more likely to restrict their participation in community activities, such as volunteering, dining out with friends, or attending church.128-131 Built environments that are inaccessible and unconducive to community participation may also lead to poorer quality of life, social isolation, and decreased physical functioning for AAwPD.25,132 For these individuals, who are already at greater risk for social isolation and decline in physical functioning, community participation remains a critical outcome to address.133 Improving our understanding of how to environmentally support this population and their quality of life is crucial, as the number of AAwPD in the United States is currently estimated at 13 million and is predicted to grow.36 As evidence has emerged over the past two decades on the relationship between built environments and community participation for AAwPD, there is a need for a comprehensive assessment of the current status of
the literature. Researchers leading this area of investigation have called for a more in-depth understanding of the diverse physical disability population and their experiences in different built environments, as well as identification of environmental features we can address or modify to maximize their participation.\textsuperscript{10,12}

While other systematic and scoping reviews have been conducted on individuals aging with certain diagnoses, supportive built environments for older adults, or physical activity behaviors in older adults with disabilities, none have examined the influence of the built environment on community participation for AAwPD.\textsuperscript{76,134-136} A systematic review of environmental features impacting the community participation of older adults found that land use diversity, street connectivity/walkability, and transportation had small to moderate effect sizes on community participation.\textsuperscript{137} However, the environmental influences for non-ambulatory individuals were not considered when examining the construct of “walkability,” for example. Bigonnesse et al. conducted a systematic literature review of the impact of the neighborhood physical environment on social participation of mobility assistive technology (MAT) users.\textsuperscript{62} Similar to Vaughan et al.’s systematic review, this review highlighted transportation barriers but also found accessibility concerns to be a major factor influencing mobility and social participation for MAT users.\textsuperscript{62} Other reviews investigating community participation for individuals with disabilities have broadly examined barriers and facilitators and have not yet surveyed the current literature with regard to adults with lifelong or long-term physical disabilities.\textsuperscript{138}

We performed a scoping review following current recommended guidelines to identify the volume of literature and types of evidence available, pinpoint knowledge gaps, and clarify key concepts being used.\textsuperscript{139,140} The purpose of this scoping review was to characterize and
synthesize the nature and scope of the existing literature on the role of built environments in the community participation of AAwPD. Results from this scoping review can inform future research questions to help us understand how built environments can better support the community participation of individuals with disabilities, including AAwPD.

2.3 Methods

2.3.1 Protocol

This scoping review followed the guidelines outlined by the PRISMA Extension for Scoping Reviews.¹⁴⁰

2.3.2 Eligibility Criteria

Studies were included in this review if they (1) were peer-reviewed; (2) involved human subjects; (3) focused on primarily adults (i.e., 18 years or older) aging with physical disabilities; (4) were published in English, regardless of country of origin; and (5) included primary outcomes or results relating to community participation and built environments. Exclusion criteria included (1) the sample involved individuals with intellectual, cognitive, or newly acquired disability, (2) the average age of participants was above 65, or (3) the study was only in the form of a conference abstract, as this did not provide enough in-depth information for data extraction. All records were exported into an EndNote library, and a medical librarian identified and removed any duplicates.

2.3.3 Information Sources

The search was run in January of 2022 with no year or language filter and an exclusion of conference abstracts in the databases of Ovid Medline 1946-, Embase 1947-, Web of Science 1900-, APA PsycInfo 1900-, and Clinicaltrials.gov. A manual search of both gray literature and
published literature was also conducted by using a “snowball” technique to identify potentially relevant sources through the reference lists of key benchmark articles.

2.3.4 Search

The published literature was searched using strategies created by a medical librarian for the influence of environmental design on AAwPD and their participation in the community. The formal question informing our “PICO” search was “what is the influence of the built environment on the community participation of adults aging with long-term physical disabilities?” The search strategies were established using a combination of standardized terms and keywords including, but not limited to, “disabled persons” AND (“adult” OR “elderly”) AND (“built environment” OR “neighborhood” OR “home environment”) AND “physically” AND (“participation” OR “instrumental activities of daily living” OR “social interaction” OR “community engagement”). Following a preliminary search, the keywords “home environment” were deemed as a necessary addition to help capture studies that investigated built environment features both within the home and community (e.g., Borade et al.’s 2021 study). A fully reproducible search strategy for an example database is provided in Appendix A.

2.3.5 Selection of Sources of Evidence

Following removal of duplicates, 1,087 articles were screened by title and abstract alone by a research team member (EH) within EndNote X9, a reference management software package (Clarivate Analytics, https://endnote.com). Any studies without outcomes or populations of interest were excluded at this stage. A customized data extraction form was then iteratively developed by two researchers (RHD and EH) in Microsoft Excel and used to chart data elements of interest from the final 158 articles (see Appendix B for full data extraction form). The form was used to collect key variables, measures, and general participant demographics such as
education level and race. AAwPD sample characteristics, including average age, disability status, and years living with disability, along with community participation indicators and measures of the built environment, were also extracted. This form was independently tested by two reviewers (RHD and EH) on three full-text articles. Minor edits such as formatting changes to improve efficiency of data collection were made prior to assessing all full texts. A field for guiding theory or conceptual framework used in the article was also added during the trialing of the form after realizing the relevance of that data point. The two reviewers (RHD and EH) then independently assessed all 158 articles using the data extraction form and met to compare, discuss, and reconcile any discrepancies in the data extracted or final eligibility decisions made.

2.3.6 Critical Appraisal of Individual Sources of Evidence

According to the PRISMA-ScR guidelines, assessing quality of the evidence is optional, as providing a broader outline of the nature and scope of the literature is the goal. In line with the recommended purpose of scoping reviews, this study therefore did not critically appraise individual articles and sought to broadly characterize the evidence.

2.3.7 Synthesis of Results

Synthesis of results occurred through descriptive statistics of basic study characteristics (e.g., geographic setting, study design, field of study) and charting of data elements of interest for each article (e.g., sample size and disability status, measurement instruments used, key findings related to the built environment). A summary table of final articles included in the review was created to understand different approaches to investigating the influence of the built environment on community participation and compare each study’s main findings. A dot plot table of the built environment domains investigated within each article was created to identify patterns and measurement gaps.
2.4 Results

2.4.1 Characteristics of Sources of Evidence

The search resulted in 1,087 unique citations, 929 of which were excluded through initial screening. Twenty-one articles were included in the final review following the assessment of 158 full-text articles for eligibility. The most common reason for exclusion of full-text articles was community participation not being studied as a primary outcome ($n = 62$). Other reasons for exclusion included the built environment not being studied as a main outcome ($n = 31$), sample
participants not fitting the aging-with-disability criteria \((n = 35)\), or the relationship between community participation and the built environment not being examined \((n = 6)\). The process for the selection of sources of evidence is pictured in the PRISMA flow diagram in Figure 2.1.

All 21 articles were published in the past two decades, with four published between 2000 and 2009 and 17 published between 2010 and 2022. Fifty-two percent of studies were conducted within the United States. A total of eight countries were represented in this review. Basic study characteristics are summarized in Table 2.1. A wide range of sample sizes \((n = 4–2,762)\) along with a variety of approaches to measuring both community participation and the built environment were reported. Forty-eight percent of studies were conducted by researchers in the field of occupational therapy, and the remaining studies \((n = 11)\) were from public health, disability studies, and physical medicine and rehabilitation disciplines.

<table>
<thead>
<tr>
<th>Table 2.1. Characteristics of included articles</th>
<th>Number ((n = 21))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Publication year, n (%))</td>
<td></td>
</tr>
<tr>
<td>2010–2022</td>
<td>17 (81)</td>
</tr>
<tr>
<td>2000–2009</td>
<td>4 (19)</td>
</tr>
<tr>
<td>Participant age, mean (range)</td>
<td>52 (34–77)</td>
</tr>
<tr>
<td>Field of study, n (%)</td>
<td></td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>10 (48)</td>
</tr>
<tr>
<td>Physical medicine and rehabilitation</td>
<td>7 (33)</td>
</tr>
<tr>
<td>Public health</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Disability</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Study design, n (%)</td>
<td></td>
</tr>
<tr>
<td>Cross-sectional</td>
<td>9 (43)</td>
</tr>
<tr>
<td>Qualitative</td>
<td>7 (33)</td>
</tr>
<tr>
<td>Mixed methods</td>
<td>4 (19)</td>
</tr>
<tr>
<td>Longitudinal cohort</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Geographic setting, n (%)</td>
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</tr>
<tr>
<td>United States</td>
<td>11 (52)</td>
</tr>
<tr>
<td>Canada</td>
<td>3 (14)</td>
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<tr>
<td>Australia</td>
<td>2 (10)</td>
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<tr>
<td>India</td>
<td>1 (5)</td>
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<tr>
<td>Sweden</td>
<td>1 (5)</td>
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<tr>
<td>United Kingdom</td>
<td>1 (5)</td>
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</tbody>
</table>

The average age of all study participants was 52 years \((34–77)\), aligning with our definition of AAwPD. Detailed information about each study is also presented in Table 2.2. Most studies \((n = 15)\) defined their samples without specific diagnoses, such as “individuals with physical disabilities,” “people with mobility limitations,” or “mobility device users.” Spinal cord injury
and multiple sclerosis were examples of specific diagnoses studied in the remaining six articles. While not all articles explicitly defined their samples as AAwPD, all studies included this demographic in their samples. Because we designed our search to capture studies that may not have focused exclusively on this demographic, we intentionally used our exclusion criteria to eliminate only those that focused solely on children, adults over 65 years of age, or newly injured individuals. When available, disability status, years with disability, and age were recorded.

Three categories of theory use emerged from the 21 studies. Eight studies clearly described a theory or framework that guided hypotheses and methodological approaches or generally grounded the work.\textsuperscript{10,61,78,101,142-145} Four articles referenced frameworks or theories briefly,\textsuperscript{12,131,146,147} and the remaining 12 articles did not reference any theory or framework. The most predominant theories or frameworks used were the International Classification of Functioning, Disability and Health (ICF) (\(n = 8\)) and ecological models of person-environment fit (\(n = 3\)) (e.g., Bronfenbrenner’s ecological systems theory, Lawton and Nahemow’s ecological theory of aging).

Community building accessibility (\(n = 8\)), street and sidewalk accessibility (\(n = 7\)), and transportation access (\(n = 7\)) were the most frequently studied domains of the built environment. Table 2.3 displays a dot plot of the most studied domains of the built environment using categories from previous research related to disability and the built environment.\textsuperscript{47,76,148} An assortment of measures was used to evaluate its role in community participation, including self-report surveys (\(n = 9\)), qualitative interviews (\(n = 8\)), global positioning system/geographic information system (GPS/GIS) data (\(n = 3\)), photographic journals (\(n = 2\)), and formal accessibility audits (\(n = 1\)). Few studies (\(n = 2\)) examined rural contexts, as most studied participants in urban or suburban contexts. The Craig Hospital Inventory of Environmental
Factors (CHIEF) \( (n = 4) \) and the Patient-Reported Outcomes Measurement Information System (PROMIS) Social Participation measure \( (n = 2) \) were the most frequently used validated assessment tools to measure built environment characteristics and community participation.

Community participation as an outcome was operationalized in a variety of ways across studies. For example, self-report surveys such as the PROMIS Social Participation measure utilizes a Likert scale to target “the perceived ability to perform one’s usual social activities.” Because qualitative interviews were used in 8 of the studies, community participation was also measured by asking participants open-ended questions, such as how various environmental factors serve as barriers or facilitators to “activities inside or outside [the] home” or “when attempting to be involved in the community.” A specific domain of the Craig Handicap Assessment and Reporting Technique (CHART) was another self-report instrument used to look at “social integration,” or “the ability to engage in the expected social relationships with family, friends, and colleagues.” Other operationalizations of community participation included “interpersonal interaction” measured by self-reported frequency of getting together with family or friends, and “formal and informal social activities; participation in political, religious and community groups; and volunteering” based on items from the Americans’ Changing Lives Survey. Three studies focused on community-based adaptive sports and exercise as a specific form of community participation. Finally, Mahmoud et al. used the Stakeholders Walkability/Wheelability Audit in Neighborhoods (SWAN) tool to document features of neighborhood built environments that allowed for opportunities to interact with others, meet friends and family, and hold public events. This study was one of 4 included in the review that incorporated both qualitative and quantitative components in capturing the concept of community participation (or opportunities for it).
All 21 studies reported influence, whether subjective or objective, of the built environment on the community participation of AAwPD. Common themes regarding the role of the built environment included 1) the perception of the built environment as a barrier to participating in meaningful community activities, 2) the built environment impacting mobility and one’s movement to travel to various activities, and 3) inaccessible built environments sending unwelcoming or negative messages that in turn lead to restricted participation. On a micro-level, factors such as smooth travel surfaces, curb cuts, sidewalks in good condition, safe street crossings, and pleasing appearance of neighborhoods were found to subjectively and objectively facilitate community participation. Within public facilities and community buildings, accessible restrooms, changing tables, door handles, and railings were found to positively shape an individual’s ability to participate in their community. On a macro-level, street connectivity, land use mix, and residential security were identified as influential for community participation. However, conflicting results were found for the variables of residential density, land use mix, and proximity. Botticello et al.\textsuperscript{52} reported that less residential density was associated with full social participation, while Schreuer et al.\textsuperscript{153} found higher residential density was associated with higher levels of participation. Additionally, Blauwet et al.\textsuperscript{150} demonstrated that closer proximity (reduced travel distance) was associated with sustained participation. Greater land use mix was associated with restricted social participation in another study.\textsuperscript{52} Although a different concept, greater land use mix theoretically reduces the travel distance to destinations of interest. Last, the psycho-emotional disablism of built environments, such as a community building’s front entrance pointing to wheelchair access around the back of the building, or a restaurant with only stairs to access a restroom, were also perceived to lead to restricted participation in the community.
<table>
<thead>
<tr>
<th>Study; setting</th>
<th>Sample characteristics*</th>
<th>Study design; focus</th>
<th>Primary environmental domains</th>
<th>Built environment measure; community participation measure</th>
<th>Key findings related to the built environment</th>
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<tbody>
<tr>
<td>Barclay et al., 2016; Australia</td>
<td>Spinal cord injury (n=17); 71% of sample aged 40-60; Avg yrs. with disability: 14</td>
<td>Qualitative semi-structured interviews; to identify facilitators and barriers to community and social participation following spinal cord injury</td>
<td>N/A</td>
<td>Self-report qualitative data (for both constructs)</td>
<td>Transportation, technology, parking, general accessibility of the built environment (e.g., gas stations, infrastructure) are often not designed with people with disabilities in mind, and this impacts participants’ ability and energy required to socially participate in their communities.</td>
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<tr>
<td>Blauwet et al., 2017; United States</td>
<td>Mobility limitation (n=134); Avg age: 41; 62% of sample with disability since birth</td>
<td>Retrospective cohort; to determine the demographic, environmental, disability-related, and functional factors associated with sustained participation in a community-based adaptive sports program</td>
<td>Proximity to program site</td>
<td>Distance calculated through Google maps; frequency of participation in community-based adaptive sports program</td>
<td>Closer proximity (i.e., reduced travel distance to program site) was independently associated with sustained participation.</td>
</tr>
<tr>
<td>Borade et al, 2021; India</td>
<td>Mobility-related disability with use of assistive device (n=25); Age range: 18-55; 72% of sample with ≥10 yrs. of assistive device use</td>
<td>Qualitative semi-structured interviews; to explore the lived experiences of adults with mobility disability using assistive devices</td>
<td>N/A</td>
<td>Self-report qualitative data (for both constructs)</td>
<td>Accessibility to buildings and public spaces (e.g., lack of disability-inclusive spatial arrangements, ramps, elevators), accessibility of outdoor mobility routes (e.g., lack of barrier-free sidewalks or footpaths and access to public transportation and toilets impact independence, life satisfaction, and social participation.</td>
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<tr>
<td>Botticello et al., 2014; United States</td>
<td>Chronic paralysis (n=508); 27% of sample ≥55 yrs.; 63% of sample with ≥2 yrs. with disability</td>
<td>Cross-sectional; to explore the associations between neighborhood and community land use and community participation</td>
<td>Residential density, land use mix, destination counts, and open space</td>
<td>Geographic Information Systems data on land use and destinations; CHART®</td>
<td>Less residential density and greater proportions of open space were associated with full occupational and social participation. Greater land use mix and higher destination counts were associated with restricted occupational and social participation.</td>
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<tr>
<td>Clarke et al., 2011; United States</td>
<td>Mobility impairment (n=1,225); Avg age: 60; Yrs. with disability: N/A</td>
<td>Cross-sectional; to investigate the role of urban built environment characteristics in the societal participation of adults with mobility impairments</td>
<td>Traffic volume, residential security, street and sidewalk accessibility, access to public transit, neighborhood social and physical disorder</td>
<td>Systematic social observation, self-report perceptions of neighborhood environment; frequency of getting together with others, using preventative health care, and voting</td>
<td>Higher residential security was associated with higher odds of engaging in regular interpersonal interaction. Poor street condition was associated with lower odds of voting.</td>
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<tr>
<td>Study; setting; setting</td>
<td>Sample characteristics*</td>
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<tr>
<td>Clarke et al., 2019; United States</td>
<td>Long-term physical disability (n=1,331); Avg age: 64; Avg yrs. with disability: 35</td>
<td>Longitudinal cohort; to examine the environmental barriers and facilitators that impact participation among adults aging with disabilities</td>
<td>Urbanicity, community building accessibility, street and sidewalk accessibility</td>
<td>EFIBb; PROMISc Ability to Participate in Social Roles and Activities</td>
<td>For individuals using mobility devices, poor community building access did not impact social participation, but other unspecified store barriers did (e.g., transportation or crowding). For individuals not using mobility devices, poor community building accessibility was associated with reduced social participation.</td>
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<tr>
<td>Heeb et al., 2022; United States</td>
<td>Long-term physical disability (n=215); Age range: 45-65; Avg yrs. with disability: 19</td>
<td>Cross-sectional; to examine individual and environmental factors influencing participation in personal and life activities among adults aging with long-term physical disabilities</td>
<td>N/A</td>
<td>Self-report qualitative data (for both constructs)</td>
<td>Physical environment (i.e., natural environment, transportation, assistive technology, and the built environment) was perceived by participants to impact their participation in community and social activities. Transportation was frequently cited as a barrier to community leisure and social activities. The components of the CHIEF related to physical and structural barriers (i.e., access to transportation, accessibility of public community and school/work buildings) were found to be the most influential barriers to participation.</td>
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<tr>
<td>Jalili et al., 2020; Iran</td>
<td>Multiple sclerosis (n=96); Age range: 25-55; Range of yrs. with disability: 2-7</td>
<td>Cross-sectional; to identify the environmental barriers affecting the participation of people with multiple sclerosis</td>
<td>Access to transportation, public community building accessibility, school or work building accessibility</td>
<td>CHIEFd (for both constructs)</td>
<td>The presence of transfer aids, large surface sizes, grab bars, storage space for wheeled mobility devices, and open space around the transfer surface acted as major facilitators to community participation. Lack of transfer accessibility at medical facilities, dressing rooms, amusement parks, and various modes of transportation limited their community participation.</td>
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<tr>
<td>Koontz et al., 2021; United States</td>
<td>Wheeled mobility device use (n=112); Avg age: 54; Avg yrs. with disability: 16</td>
<td>Cross-sectional; to identify barriers and facilitators to transfers in the community and identify intervention target areas for accessibility to improve community participation</td>
<td>Accessibility of community facilities, public toilets, transportation, and medical imaging tables</td>
<td>Self-report survey on environmental facilitators and barriers to community transferring and how transfer accessibility influences community participation (for both constructs)</td>
<td>Accessibility of transportation, sidewalks, and entrances and toilets in restaurants, stores, and other public buildings were perceived as influential to community participation.</td>
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<tr>
<td>Labbé et al., 2020; Canada</td>
<td>Power wheelchair use (n=19); Avg age: 58; Avg yrs. of wheelchair use: 9</td>
<td>Qualitative semi-structured interviews; to explore the experiences of older adults using powered wheelchairs</td>
<td>N/A</td>
<td>Self-report qualitative data (for both constructs)</td>
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<tr>
<td>Study; setting</td>
<td>Sample characteristics*</td>
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<tr>
<td>Mahmood et al., 2020; Canada</td>
<td>Mobility device use (n=24); 71% of sample &gt;50 yrs.; Yrs. with disability: N/A</td>
<td>Mixed methods; to evaluate objective and subjective features of the neighborhood environment that influence the mobility and social participation of people using mobility assistive technology</td>
<td>Street and sidewalk accessibility, safety of street features and traffic, pedestrian safety, appearance and maintenance, land use mix</td>
<td>SWAN&lt;sup&gt;e&lt;/sup&gt; and photographic documentation; self-report qualitative data from community forums</td>
<td>Functionality of street crossings and sidewalks, pedestrian and traffic safety, appearance and maintenance, and land use were aspects of the neighborhood valued by participants. The absence of multiple environmental features (e.g., curb cuts, sufficient traffic signal timing, and sidewalk condition) and a low objective score did not always translate to low subjective scores. Accessibility of sanitary facilities and restrooms, including presence/absence of ceiling track hoists, changing tables, and sufficient space surrounding toilets was reported by participants as influential to their community participation. Environmental barriers such as absence of ramps, door handles, curb cuts, accessible bathrooms, accessible parking, or smooth travel surfaces were perceived by participants to negatively influence their ability to reach community destinations of interest.</td>
</tr>
<tr>
<td>Martin et al., 2018; Australia</td>
<td>Physical disability (n=4); Avg age: 52; Yrs. with disability: N/A</td>
<td>Qualitative semi-structured interviews; to explore the lived experiences of people who use Changing Places in Australia</td>
<td>Accessibility of facilities</td>
<td>Self-report qualitative data (for both constructs)</td>
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<tr>
<td>Meyers et al., 2002; United States</td>
<td>Wheelchair use (n=25); Avg age: 47; Yrs. with disability: N/A, sample described as “chronic wheelchair users”</td>
<td>Qualitative interviews and longitudinal survey; to determine and measure environmental facilitators and barriers to reaching destinations for community participation</td>
<td>Community building accessibility, access to transportation, proximity, neighborhood safety, traffic safety, street and sidewalk accessibility</td>
<td>Self-report survey and qualitative data (for both constructs)</td>
<td>Environmental barriers such as absence of ramps, door handles, curb cuts, accessible bathrooms, accessible parking, or smooth travel surfaces were perceived by participants to negatively influence their ability to reach community destinations of interest.</td>
</tr>
<tr>
<td>Norin et al., 2017; Sweden</td>
<td>Spinal cord injury (n=123); Avg age: 63; Avg yrs. with disability: 24</td>
<td>Cross-sectional; to explore how objective housing and neighborhood accessibility are associated with aspects of participation</td>
<td>Home entrance accessibility, street and sidewalk accessibility, street lighting</td>
<td>HE&lt;sup&gt;f&lt;/sup&gt;; IPA&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Greater accessibility problems were associated with less participation and greater participation issues. Accessibility of exterior surroundings was significantly associated with autonomy indoors and family role but not with participation problems.</td>
</tr>
<tr>
<td>Richardson et al., 2017; United Kingdom</td>
<td>Physical disability (n=21); Avg age: 40; Yrs. with disability: N/A</td>
<td>Qualitative semi-structured interviews; to identify environmental barriers to gym use</td>
<td>N/A</td>
<td>Self-report qualitative data (for both constructs)</td>
<td>Forced management of structural barriers (e.g., restricted access into and within building, inaccessible equipment), in combination with psycho-emotional disableism, led participants to feel excluded within the gym environment and hindered their gym participation</td>
</tr>
</tbody>
</table>

<sup>*</sup> Sample characteristics include additional details such as sample size, age, and disabilities.

<sup>e</sup> SWAN: System for Walking and Access Nestled in Communities

<sup>f</sup> HE: Health Environment

<sup> IPA</sup>: International Participation and Disability
Table 2.2. (continued)

<table>
<thead>
<tr>
<th>Study; setting</th>
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<tbody>
<tr>
<td>Rimmer et al., 2004; United States</td>
<td>Physical disability (n=42); Avg age: 40; Yrs. with disability: N/A</td>
<td>Qualitative focus groups; to identify environmental barriers and facilitators associated with community sports participation</td>
<td>Sidewalk, path, and facility accessibility</td>
<td>Qualitative focus group data (for both constructs)</td>
<td>More adaptive equipment such as pool water chairs, Velcro straps, and upper-body equipment were identified as potential facilitators for participation. Participants identified facility accessibility (e.g., front desk height, door width, lack of ramps) as a major barrier to participation.</td>
</tr>
<tr>
<td>Schreuer et al., 2019; Israel</td>
<td>Physical disability (n=137); Avg age: 42; Avg yrs. with disability: N/A</td>
<td>Cross-sectional; to explore the relationships between daily activity participation, self-reported environmental barriers, and urban spatial measurements</td>
<td>Access to public transportation and parking, land use mix, residential density, street connectivity, street slope</td>
<td>CHIEF&lt;sup&gt;d&lt;/sup&gt;, IAASP&lt;sup&gt;h&lt;/sup&gt;</td>
<td>Higher levels of participation were significantly correlated with greater land use mix, higher residential density, and lower slope. Participants living in neighborhoods with low street connectivity perceived more neighborhood barriers to participation.</td>
</tr>
<tr>
<td>Sundar et al., 2016; United States</td>
<td>Mobility impairment (n=462); Avg age: 52; Avg yrs. with disability: N/A</td>
<td>Mixed methods sequential exploratory; to explore relationships among factors that influence community and social participation</td>
<td>Neighborhood safety, neighborhood social and physical disorder, neighborhood cleanliness</td>
<td>ACL&lt;sup&gt;j&lt;/sup&gt; and self-report qualitative data (for both constructs)</td>
<td>Participants identified neighborhood factors (e.g., access to transportation, proximity to destinations, restaurant accessibility, neighborhood safety) as potential influential factors to their community participation. Neighborhood factors demonstrated a possible indirect impact on community and social participation through self-efficacy.</td>
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<tr>
<td>Wee et al., 2009; Canada</td>
<td>Mobility impairment (n=24); Avg age: 64; 88% of sample reported chronic physical disability</td>
<td>Mixed methods; to identify personal and environmental factors that influence participation</td>
<td>N/A</td>
<td>P-scale&lt;sup&gt;j&lt;/sup&gt; and self-report qualitative data (for both constructs)</td>
<td>Accessibility of community spaces (e.g., presence of railings) and access to transportation were the factors most commonly referenced by participants as influential to their community participation.</td>
</tr>
<tr>
<td>Whiteneck et al., 2004; United States</td>
<td>Spinal cord injury (n=2,762); 46% of sample age ≥30 at time of injury; 71% of sample reported ≥5 yrs. living with disability</td>
<td>Cross-sectional; to explore environmental barriers to participation and life satisfaction and to compare their relative effects against demographic and injury characteristics</td>
<td>Access to transportation, community building accessibility, school or work building accessibility</td>
<td>CHIEF&lt;sup&gt;d&lt;/sup&gt; (for both constructs)</td>
<td>The physical and structural barrier subscales of the CHIEF accounted for 4% of the variation in participation and 10% of the variation in life satisfaction. Transportation was the most influential single built environment construct.</td>
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Table 2.2. (continued)

<table>
<thead>
<tr>
<th>Study; setting</th>
<th>Sample characteristics*</th>
<th>Study design; focus</th>
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<th>Key findings related to the built environment</th>
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<tbody>
<tr>
<td>Wong et al., 2017; United States</td>
<td>Neurological disorder (i.e., traumatic brain injury, stroke, and spinal cord injury) (n=545); Avg age: 46.8; Avg yrs. with disability: 7</td>
<td>Cross-sectional; to develop and evaluate a model of the relationship between environmental factors and participation</td>
<td>Access to transportation and parking, transportation accessibility, community building accessibility, school or work building accessibility, street and sidewalk accessibility, proximity</td>
<td>EFIBb, CHIEFd, HACEh, PROMIS Satisfaction with Participation in Social Roles and Activities, Ability to Participate in Social Roles and Activities, CPIj</td>
<td>Built and natural environments (as a combined single latent variable) mediated the indirect influence of systems, services, and policies on participation. The final model explained 63% of the variance in participation and 27% of physical environmental barriers.</td>
</tr>
</tbody>
</table>

*This column includes three study sample characteristics that were recorded to assess aging-with-disability status: diagnosis, age, and years living with disability.
N/A: data not available

Abbreviations: aCraig Handicap Assessment and Reporting Technique, bEnvironmental Factors Item Banks, cPatient-Reported Outcomes Measurement Information System, dCraig Hospital Inventory of Environmental Factors, eStakeholder Walkability/Wheelability Audit in Neighborhoods, fHousing Enabler, gImpact on Participation and Autonomy Questionnaire, hIsraeli Adults Assessment of Participation, i‘Americans’ Changing Lives Survey, jParticipation Scale, kHome and Community Environment Survey, lCommunity Participation Indicators
Table 2.3. Environmental domains investigated within the reviewed articles

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Community building accessibility</th>
<th>Land use mix</th>
<th>Neighborhood physical and social disorder</th>
<th>Neighborhood safety</th>
<th>Proximity</th>
<th>Residential density</th>
<th>Street and sidewalk accessibility</th>
<th>Traffic</th>
<th>Transportation access</th>
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<tr>
<td>Barclay, 2016</td>
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<td>Borade, 2021</td>
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</table>

Note: the following domains were investigated in one article: home entrance accessibility, street slope, street connectivity, street lighting, urbanicity, destination counts, open space, and accessibility of transportation. aNeighborhood physical and social disorder includes presence or absence of graffiti, vandalism, trash, etc. bNeighborhood safety includes pedestrian safety, residential security, and perceived physical hazards. Six articles did not study predetermined domains of the built environment.
2.5  Discussion

2.5.1  Summary of Evidence

This scoping review identified 21 articles that examined the role of the built environment in the community participation of AAwPD. Substantial heterogeneity was found within methodological approaches, conceptualizations, and findings across these studies. Of note, all 21 articles were published within the past two decades. This emergence of research may reflect how our understanding of disability has evolved from being grounded in biomedical to social to socio-ecological models; it also mirrors the evolution of general built environment and health-related research.\(^{154}\)

This review also revealed that there is emerging global recognition of the importance of studying the influence of the built environment on adults aging with disabilities and their participation in activities outside the home. However, our results illustrated a lack of consistency in defining and measuring the built environment and community participation. Community participation was defined differently across the included studies and remains an abstract and challenging construct to measure.\(^{35}\) This finding aligns with multiple previous statements coming out of rehabilitation and occupational science regarding the need for consensus and comprehensive measurement of participation.\(^{63,73,155,156}\) Studies often examined various forms of community participation, such as engagement in group sports, voting, volunteering, or socializing with friends. Furthermore, studies measured different aspects of these activities, such as frequency, satisfaction, perceived restrictions, and duration. The World Health Organization’s ICF was the most popular framework used to define community participation, with reference in eight studies.\(^{34}\) Despite continuous debate on the conceptualization of participation, the ICF
appears to be the leading framework for describing and defining community participation in the context of the built environment.

Similarly, conceptualizations of the built environment were variable across all studies. Specific aspects of the built environment, such as land use mix, street and sidewalk accessibility, and access to transportation, were examined. The dot plot shown in Table 2.3 illustrates methodological gaps. Studies selected pieces of the built environment based on research questions, convenience, or logistics. Rarely did studies measure more than two aspects of the built environment, nor did they apply their findings to real-world settings or evaluate interventions. Most studies were exploratory in their stage of research, and this is likely due to the topic’s youth. This path follows the progression of the built environment and physical activity literature that began in the late 1980s and early 1990s, with a delay between “discovery” and “delivery” stages of research. Further, our review calls attention to inconsistencies in the findings of studies investigating similar populations and outcome variables, where matching results would be expected. Discrepancies between subjective and objective assessments of the built environment’s role in community participation for AAwPD were also found. These inconsistencies warrant additional mixed methods research.

Research on the link between the built environment and health behavior has traditionally focused on physical activity and general “active living.” The Active Living Research program of the Robert Wood Johnson Foundation, formerly known as Active Living Policy and Environmental Studies, is an example of a research initiative that strengthened the knowledge base on how health is shaped by the built environment. Much of the work produced by this program included “under-studied” populations such as people with disabilities, but its mission was to address environmental contributions to physical inactivity and obesity without
consideration of broader activity participation in the community. Our review directs attention to the growing body of literature on meaningful and intrinsically social activities outside the home, which may or may not involve physical activity. Previous studies of neighborhood and environmental influences on adults with disabilities have begun to prioritize this outcome, but mobility in transit has remained the primary focus. Similar to physical activity, community participation is related to quality of life and psychosocial functioning and warrants further research as an important indicator of health and wellbeing for people with disabilities.

Finally, our results reinforce the need for built environments that do not pose barriers to participating in the community for AAwPD. The importance of inclusive built environments continues to be widely recognized, and community organizations, policymakers, and urban planners will benefit from the knowledge generated by studies such as this review that pinpoint potential areas for intervention and support. As we move toward designing and maintaining more inclusive community built environments, the end goal of universal accessibility can only be achieved if the unique needs of populations such as AAwPD are considered. While a small number of studies in this review explicitly targeted adults who had acquired physical disabilities at birth or earlier in life, most articles included alternatively defined samples that happened to overlap with our aging-with-disability criteria in terms of age, physical disability, and duration of disability (e.g., adult mobility device users, individuals with spinal cord injury, etc.).

2.5.2 Limitations

As with all reviews, one limitation is that our search strategy may not have captured all relevant articles. Our manual search that identified four additional articles was done to help combat this potential limitation. Heterogeneity among study samples, differing lexicons, and the
operationalization of the built environment and community participation may contribute to an incomplete assessment of all relevant studies. For example, this review demonstrated that community participation is defined differently across researchers and is measured using a variety of instruments.

Non-standardized reporting of participant demographics limited our ability to determine aging-with-disability characteristics for several articles. Specifically, not all authors reported participants’ duration of disability. We defined “aging with physical disability” based on previous seminal research literature,¹⁸ but we may have potentially missed important information on slightly older adults with long-term physical disabilities. Other participant characteristics such as gender and race were not always reported, posing both study limitations for generalizability and larger equity-related issues. Finally, scoping reviews do not typically utilize a risk of bias or quality assessment tool.¹⁴⁰,¹⁶⁶ Thus, we did not reach a depth of analysis that a full systematic review would have achieved.

2.5.3 Conclusions

Based on the results of this scoping review, the built environment has a clear impact, both subjectively and objectively, on AAwPD and their ability to participate in their communities. Accessible environments facilitate health and well-being for AAwPD by promoting active movement during travel to and from destinations, providing better physical access to community spaces, and sending more socially welcoming and inclusive messages. However, this review demonstrated that built-environment-related research specific to the population of AAwPD and their community participation is limited but growing. As more research on this topic emerges, a systematic review may be appropriate to identify how particular elements of the built environment influence community participation, as well as their magnitude of influence.
Heterogeneity across definitions points to the need for investigators to use shared measures and operational terms, which will aid in dissemination of implications and results across disciplines. Facilitating the use of common methods and measures may involve working with organizations sponsoring research or creating an accessible online hub or resource. More mixed methods research is needed to fully capture the influence of the built environment on the community participation of this population, specifically, to provide implications for urban planning, architecture, and public health practitioners.

2.5.4 Funding

This work was supported by a grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR grant number 90DPCP0001-01-00). NIDILRR is a center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This work does not necessarily represent the policies of NIDILRR, ACL, or HHS, and endorsement by the Federal Government should not be assumed.
Chapter 3: Identifying Built Environment Factors Influencing the Community Participation of Adults Aging with Long-Term Physical Disabilities: A Qualitative Study


3.1 Abstract

This study qualitatively explored how adults aging with long-term physical disabilities perceive the built environment to influence their community participation. A convenience sample of community-dwelling adults with long-term physical disabilities ages 45-65 participated in virtual semi-structured interviews until thematic saturation was reached (n=20). Data were analyzed using interpretive phenomenological analysis. Five themes were identified: vigilance and sense of safety, accessibility of and access to transportation, community environment accessibility, sense of community, and access to support, spaces, and resources during the COVID-19 pandemic. Multiple participants described their neighborhoods as unsafe and reported not leaving their homes in months due to inaccessible home entrances or pandemic-related concerns. These results enhance our understanding of how this population perceives environmental barriers to community participation, particularly in low-resourced neighborhoods.
during the COVID-19 pandemic. These results may inform researchers, community organizations, and funding agencies in intervention development and implementation to address built environment barriers.

### 3.2 Introduction

The built environment has consistently been documented as a barrier to participating in the community for individuals with physical disabilities.\(^{12,146,149}\) Navigating the built environment (e.g., sidewalks, transportation systems) can be especially challenging for people who use mobility devices and for those who have lived with their disability long term who subsequently may be experiencing aging symptoms.\(^{10,132,167}\) The conditions and accessibility of places where adults aging with long-term physical disabilities (AAwPD) socialize, live, and work are recognized as significant social determinants of health and well-being.\(^{1,168,169}\) AAwPD are defined as individuals between approximately 45 and 65 years who have lived with a physical disability beginning in early and/or mid-life that has continued over the life course.\(^{18,20,26}\) This population has been shown to experience accelerated functional decline due to earlier and more rapidly progressing aging-with-disability symptoms such as pain, fatigue, and depression.\(^{18,22,170}\) AAwPD experience environmental barriers that compound with aging symptoms and secondary health conditions to restrict their community participation, which is defined as engagement in meaningful activities outside the home with others.\(^{35,171}\) However, the impact of these environmental factors is complex, and the mechanisms behind them are not well understood.

The World Health Organization’s International Classification of Functioning, Disability, and Health serves as a prominent framework for understanding disability, health-in-context, and the interaction of personal and environmental factors. Yet the person-centered nature of
classification systems and frameworks such as the International Classification of Functioning, Disability, and Health fails to capture the importance of nuanced environmental factors (e.g., neighborhood safety, socioeconomic status) for outcomes beyond body functions, activities, and participation.\textsuperscript{34,169} Steps in the direction of more comprehensive environmental conceptualizations related to persons with disabilities have been made. For example, the World Health Organization’s Conceptual Framework for Action on Social Determinants of Health acknowledges the significance of the quality and safety of neighborhood, indoor housing, and working environments for health and well-being among persons with disabilities.\textsuperscript{172} The historical trajectory of our society’s approach to understanding social determinants of disability and health has shown substantial promise, yet more progress is needed.

Despite passage of the Americans with Disabilities Act (ADA)—an example of a national piece of legislation designed to prohibit discrimination against individuals with disabilities—and recognition of built environment factors as social determinants of health, many community places remain inaccessible. Lack of accessibility deprives AAwPD of full access to opportunities for community participation (e.g., attending church, seeing a movie, or dining at a restaurant with family).\textsuperscript{9,118} Under the Capabilities Approach framework developed by Martha Nussbaum, restricted community participation for AAwPD can be understood as a matter of justice and deprivation of the \textit{choice} and opportunity to participate in one’s community.\textsuperscript{173,174} The Capabilities Approach framework is increasingly being applied to research related to transportation and accessibility in attempt to bring light to inequities within the built environment and the impact of those inequities on the quality of life and participation of individuals with physical disabilities.\textsuperscript{175,176} This framework emphasizes, for example, the freedom and choice in actually accessing social opportunities, rather than simply their
existence. Additionally, this framework considers the differing capabilities and, therefore, the unique environmental and resource support needs of each individual.

Well-established quantitative evidence has demonstrated that built environment factors such as poor street and sidewalk conditions, heavy traffic, and inaccessible buildings contribute to mobility difficulties for AAwPD. However, translation of this research to evidence-based interventions that address barriers to participation for this population is limited. Further, we do not yet fully understand how perceptions of the environment and the diverse lived experiences of those at the intersection of aging and disability relate to the influence of the built environment on their community participation. Previous qualitative research with this population has investigated general facilitators and barriers to community participation, or built environment factors influencing participation in specific outcomes (e.g., physical activity, self-transfers from wheelchair to other surfaces in the community, or accessing community destinations). Other qualitative literature has studied perceptions of environmental factors influencing community participation for individuals with specific diagnoses (e.g., spinal cord injury). Diagnosis-specific approaches to understanding the impact of environmental factors are limiting and restrict the potential reach of future interventions and programming.

We must improve our understanding of the nuanced relationship between this population’s restrictions in community participation and their experience of the built environment as we work to reduce built environment inequities and ensure that AAwPD have the full opportunity to participate in society. While inclusive and universally designed environments are the end goal, the unique needs and experiences of individuals with lifelong or long-term disability must be considered to achieve this. To understand these complex constructs, we aimed to qualitatively explore the perspectives of AAwPD on the role of the built environment in their
community participation. Our secondary aim was to describe how AAwPD define community participation. Additionally, while we did not originally set out to conduct this study during the COVID-19 pandemic, the interviews that inform the results of this paper are from within the context of this pandemic. The COVID-19 pandemic amplified existing health and participation disparities for individuals with disabilities, and we thus provide in this paper the valuable perspectives of AAwPD during a time when the effects of multiple environmental factors were likely pronounced.

3.3 Research Process

Semi-structured interviews were conducted with community-dwelling adults aging with long-term physical disabilities who were enrolled in a larger pilot randomized controlled study of fall prevention in the home and daily activity performance. Participants assigned to the waitlist control group in the larger study were asked to participate in a series of interviews during the waiting period. This study examined the interview data collected on community participation and the built environment. All study activities were approved by the Washington University School of Medicine in St. Louis’s Institutional Review Board (IRB #201710186). Written informed consent was obtained from all participants prior to study enrollment.

Participants were included if they (1) had lived with a physical disability for five or more years, (2) were between the ages of 45 and 65, (3) were able to accurately respond to questions, (4) lived in St. Louis or surrounding areas, and (5) reported difficulty completing two or more daily activities according to the Older Americans Resources and Services Activities of Daily Living (OARS ADL) scale. Participants were recruited from aging and disability organizations as well as social media using convenience sampling until thematic saturation was achieved. We intentionally examined a population not specific to diagnosis to better translate our
research for community organizations. The populations that community-based organizations (CBO) serve are inherently diverse and not diagnosis specific, and there is arguably more utility in developing universal interventions that address shared environmental barriers.15,182

Interviews were conducted by an occupational therapist and lasted, on average, 30-45 minutes. The data reported in this study were collected over two separate interview sessions. Participants were given the choice of completing the interview via phone or a Zoom meeting link compliant with the Health Insurance Portability and Accountability Act (HIPAA) due to safety concerns during the COVID-19 pandemic. Interviews were conducted between December 2020 and August 2021. Prior to the interview, participants provided verbal consent for audio recording. Any accessibility requests for the interviews were accommodated. An interview guide of open-ended questions was iteratively developed and pilot tested by the research team, a community advisory board, qualitative research and disability experts, and the university’s patient advisory board. Example interview questions are provided in the Table 3.1. Questions focused on participants’ perceptions of their surrounding built environment and its role in their participation in the community. Questions were asked neutrally and without bias, providing equal opportunities for participants to discuss positive and negative aspects of the built environment. Participants were sent an email reminder two days prior to each interview reminding them of the process, date, time, and example questions that would be asked during the interview. All participants who were asked to participate in the study agreed to be part of the qualitative interviews (i.e., there were no refusals).

Demographic data including disability, years living with disability, living situation, race, age, gender, education, secondary health conditions, and mobility device use were also collected. These questions were asked separately via survey as part of the larger randomized controlled
Table 3.1. Example interview questions

<table>
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<th>Construct</th>
<th>Example questions</th>
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| Community participation     | “Please describe any opportunities that you have to do activities that are meaningful to you in your community.”  
                              | “Tell me about how you spend time with family and friends in your neighborhood or community. What makes it easy? What makes it difficult?” |
| Built environment          | “Think of a time that you felt ‘excluded’ in the community or could not get to where you needed to go because of the way your environment was set up. What about the environment was causing that?”  
                              | “What would be your ideal setup in terms of how your neighborhood or community was built or designed?” |

trial. Each participant’s self-reported primary cause of disability was categorized into the following: neurological (e.g., cerebral palsy, multiple sclerosis), musculoskeletal (e.g., amputation, hip replacement), other single cause (e.g., sensory impairment, cardiovascular), or two or more causes, based on previous literature. The Area Deprivation Index (ADI) was used to calculate a composite socioeconomic status score for participants based on home address. This index ranks neighborhoods by socioeconomic disadvantage by incorporating the theoretical domains of employment, income, housing quality, and education level. A higher score indicates greater neighborhood socioeconomic disadvantage. Finally, participant addresses were dichotomized into urban or rural residence defined by the Rural Urban Commuting Area (RUCA) classification scheme. This was done by geocoding each participant’s address using a publicly available geocoding tool through the US Census Bureau: https://geocoding.geo.census.gov/geocoder/. Incorporating multiple variables into a classification scale of 1-10, the RUCA scheme was chosen because of its consideration of commuting patterns, urbanization, and population density. The RUCA codes were then dichotomized into urban (RUCA = 1) and rural (RUCA = 2-10) based on prior research.
During the interviews, the occupational therapist took notes on emerging preliminary themes and relevant nonverbal behavior (e.g., laughing, smiling, sighing). Follow-up and probing questions were asked when appropriate to clarify and elicit additional information from participants. Each participant was provided a Visa gift card with a total of $5 following study completion and then transitioned to the treatment group for the larger randomized trial.

### 3.3.1 Data Analysis

An interpretive, phenomenological approach was taken for data analysis, which involves attempting to understand individuals’ lived experiences within context while withholding any bias or preconceived notions from the researcher’s point of view. Data analysis involved interview transcription, iterative development of a codebook, application of the codebook to all transcripts, and identification of themes aligning with the original research questions. Ongoing analysis was conducted during data collection to monitor emerging themes and assess inductive thematic saturation, in which no new codes or themes arose with additional data collection.

Audio recordings of each interview were first transcribed verbatim using Trint, an online professional transcription service, or by a member of the research team. Because the accuracy of the online transcriptions was anywhere between 60%-90%, trained graduate students then manually checked the transcripts. This process involved listening to each audio recording while reading along with the original transcript and manually correcting or adding words. Two members of the research team independently conducted initial coding of all transcripts using the qualitative data analysis software NVivo 12 (QSR International, Victoria, Australia). The research team then met to discuss and develop the final codebook that was used to code all transcripts. The two coders met weekly to discuss and reconcile any discrepancies during the
coding process. Following coding, the research team identified connections between codes to develop themes. A formal member check was conducted with five participants, which involved presenting preliminary codes to participants themselves to confirm the validity and accuracy of our interpretation of the data. The member check process followed the synthesized member check steps outlined by Birt et al., in which participants were given the option of reviewing the preliminary themes and providing feedback via email, videoconference, or mail.¹⁹⁰

3.4 Results

Twenty participants were interviewed before thematic saturation was achieved. The average participant age was 59.8. The majority of participants were women (n=14) and retired, not seeking work, or on disability leave (n=15). Eight participants identified as Black/African American. On average, participants had been living with their disability for 22 years and reported four secondary health conditions that limited their participation in daily activities. Eighteen participants lived in a neighborhood ranked above the national average in terms of socioeconomic disadvantage according to the ADI. Most participants reported their primary cause of disability to be neurological (n=10). The remaining participants reported a primary disability that was categorized as musculoskeletal (n=7) or other single cause (n=3). Eighteen participants used a mobility device. The sample was also primarily urban-dwelling, as only two out of 20 participants lived in rural areas as defined by the RUCA classification scheme. Additional demographic data are provided in Table 3.2.

Participants described meaningful social interaction and both “doing for and with others” as central to their community participation. Participants provided a variety of activities as examples of how they participated in their communities, including volunteering at food banks,
attending group exercise classes, going to the movie theater with friends and family, having dinner with friends at restaurants, and attending church. No single component of the built

<table>
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<th>Participant characteristics</th>
<th>N</th>
<th>M</th>
<th>Range</th>
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<tbody>
<tr>
<td>Age</td>
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<td>48-65</td>
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<tr>
<td>Years with disability</td>
<td>22.4</td>
<td>8-59</td>
<td></td>
</tr>
<tr>
<td>Number of SHC</td>
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<td>1-11</td>
<td></td>
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<tr>
<td>Number of SHC identified as limiting activities</td>
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<td>1-10</td>
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<tr>
<td>Area Deprivation Index (national percentile)</td>
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<td></td>
</tr>
<tr>
<td>Gender</td>
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</tr>
<tr>
<td>Man</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Woman</td>
<td>14</td>
<td></td>
<td></td>
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<tr>
<td>Race</td>
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</tr>
<tr>
<td>Black/African American</td>
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</tr>
<tr>
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<td>Primary cause of disability</td>
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<td>Neurological</td>
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<tr>
<td>Musculoskeletal</td>
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<td>Other single cause</td>
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<td></td>
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<tr>
<td>Associate degree or some college/advanced training</td>
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<td></td>
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<tr>
<td>Bachelor degree/graduate degree</td>
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<td>Employment status (missing = 3)</td>
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<tr>
<td>Retired, not seeking work, other</td>
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</tr>
<tr>
<td>Disability leave</td>
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<td>Mobility device</td>
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<td>Power wheelchair or scooter</td>
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<td></td>
</tr>
<tr>
<td>Cane/walker</td>
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<tr>
<td>Manual wheelchair</td>
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</tr>
<tr>
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<td></td>
<td></td>
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<tr>
<td>Urban vs rural residence</td>
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</tr>
<tr>
<td>Rural</td>
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Note. SHC = Secondary health conditions.

environment was identified as the most important or influential to community participation, but all participants pinpointed the effects of the built environment in some way. Safe, inclusive, convenient, aesthetically pleasing, and accessible were the overarching attributes participants
described as key to built environments that promoted community participation. Overall, community participation was highly valued by participants but often difficult due, in part, to barriers in the built environment.

Five primary themes emerged related to the perceived role of the built environment in participants’ community participation: (1) vigilance and sense of safety, (2) accessibility of and access to transportation, (3) community environment accessibility, (4) sense of community, and (5) access to support, spaces, and resources during the COVID-19 pandemic.

3.4.1 “It’s Not Safe Here”: Vigilance and Sense of Safety
How safe participants felt in their neighborhoods and larger community environments was integral to their ability to participate in meaningful activities with others outside the home. Examples of factors that contributed to feeling unsafe included poor street lighting at night, visible vandalism and trash, audible gun shots, traffic speed and driver inattention, and a fear of falling or getting stuck while in a wheelchair due to dilapidated sidewalks. One participant described having to place bright and reflective material on their wheelchair when pushing in the street due to lack of sidewalks and driver awareness:

   The streets are bad on my wheelchair as far as me getting around. Things come to gravel and, yeah, they don’t really have sidewalks for disabled people, so I have to kind of wing it sometimes. I’ve almost got hit a couple times by a couple trucks. (56 years old, musculoskeletal cause of disability, 56 years with disability)

   There were marked differences in participants’ perceived safety across levels of neighborhood socioeconomic disadvantage (as measured by both ADI and participants’ self-reported descriptions). Those who lived in disadvantaged neighborhoods discussed frequent and severe threats to safety, such as stray dogs and speeding traffic, while residents of well-resourced neighborhoods did not reference any safety concerns and focused on facilitators of safety, such as well-lit streets, benches for sitting while waiting for public transportation, or curb cuts.
In addition to physical aspects of the built environment, mistrust of other people and concerns about threatening social interactions also contributed to perceptions of safety: “I don’t feel safe being out in the community with everything going on in the world…so, it’s not because of COVID, it’s because of what goes on around our country. People don’t treat each other like people anymore” (58, neurological cause of disability, 58 years with disability). Feeling unsafe was often discussed in the context of change over time in that many participants felt that their neighborhoods and society at large had recently become more threatening. This led participants to perceive fewer opportunities for community participation and a reduced likelihood of leaving the home:

When we first came down there—I don’t want to sound like the old people—but it was a lovely neighborhood when we first got there. But just like any other parts in the city, there’s a lot of crime now. (60, neurological cause of disability, 38 years with disability)

Family members, relationships with neighbors, noise levels, aesthetically pleasing neighborhood landscaping, and street visibility through one’s windows were cited as contributing to perceived safety:

I’m very aware, very alert in my building. I have a neighbor across the street, a couple, and we share ideas, but sometimes I feel like I’m alone doing things…and I don’t like that because then I feel like my safety is in jeopardy. I’m always checking and looking—you could call it peeking or whatever. But I have to do that because I need to know what’s going on around me. (61, musculoskeletal cause of disability, 12 years with disability)

3.4.2 Connection to the Community: Accessibility of and Access to Transportation

Participants discussed the importance of transportation that was in close proximity and accessible for people with physical disabilities, as it was their physical connection to their community. There was often a desire among participants to use public transit more frequently, but safety and accessibility concerns were apparent. Distant bus stops and light rail stations and short or inconvenient service hours were described as barriers to reaching community
destinations. In reference to his town’s public bus schedule, one participant explained, “Eight to ten and then two to four. That was it! Monday through Friday. So if you left home in the morning, you couldn’t come home until two o’clock!” (64, neurological cause of disability, 12 years with disability).

Many participants routinely used the local paratransit service known as Call-A-Ride that provided an accessible, on-demand option, but barriers such as long waiting times and strict advanced scheduling requirements were still noted as inhibiting opportunities for community participation. Those who routinely drove a personal vehicle enjoyed freedom and flexibility but described struggling with transferring themselves and their mobility device into and out of the vehicle, particularly as their functional abilities declined as they aged: “I have to have a scooter to go anywhere, which—since I can’t lift it in and out of the car—where am I going? Where’s my independence?” (65, musculoskeletal cause of disability, 13 years with disability).

Participants who drove themselves in a personal vehicle also reported difficulty finding accessible parking in the community. Even if a destination had designated accessible parking, participants explained that they had encountered other vehicles that were incorrectly parked and prevented them from exiting their own vehicle or that there simply were not enough accessible spaces available.

3.4.3 Physical Exclusion: Community Environment Accessibility

Participants emphasized the general accessibility, including conditions and design, of their community as a prominent factor. The specific subthemes of sidewalk conditions and community building accessibility were embedded within this theme. Participants felt that the built environment was not designed or maintained with people with physical disabilities in mind. One participant described how using a back entrance ramp to access a restaurant made her feel:
“It bothered me a lot because you felt—because not very many people had to do it—you felt like you were inconveniencing everyone. It just wasn’t comfortable. Like everybody had to stop and get out of your way” (62, neurological cause of disability, 20 years with disability). When planning community outings, many participants explained that they would call ahead to inquire about accessibility or drive past a business or restaurant to make their own assessment of the facility’s accessibility.

**Sidewalk Conditions**

Different levels of sidewalk conditions were reported as barriers across participants. Some participants lived in neighborhoods where sidewalks were absent altogether, posing significant safety concerns if they wanted to venture out into the neighborhood. Others explained that their neighborhoods had sidewalks, but surfaces had become cracked or deteriorated due to lack of maintenance and, thus, were not usable. Finally, some participants noted smooth, flat sidewalks but an absence of curb cuts that prevented them from navigating more than a block:

“The sidewalks—they’re really crappy. So if we’re going to take a walk, we have to go out on the street. And it’s not busy busy, but it’s, you know, people can come zipping through here” (56, neurological cause of disability, 31 years with disability). Another participant noted the inconvenience that often accompanies curb cuts when present:

> The curbs are like six to eight inches high. If there’s a cut, it might be a block and a half away, you know. And they’ll comply with ADA by putting in a cut, but it might be further away from the front of the store than parking and trying to get a step, you know? At this point, I don’t understand why they don’t just pour curbs presuming it’s a cut. I mean, you don’t need that, you don’t have to have a step! (62, neurological cause of disability, 20 years with disability)

**Community building accessibility**

The accessibility of community buildings, facilities, and public spaces was central to community participation for all participants. One’s ability to move throughout a building and access all of its spaces—in addition to simply being able to enter the building—dominated
participants’ typical participation routines. For example, the presence or absence of basic requirements of the ADA (e.g., handrails, toilet and sink heights, ramps) dictated whether participants could enter and spend quality time in a facility. One participant explained how inaccessible bathrooms meant she was forced to leave the building every few hours and self-catheterize in her personal vehicle. Exploring new destinations like restaurants, shops, and parks with others was difficult for participants when they did not know the accessibility status ahead of time. Participants highlighted having to spend much of their time planning their community outings around accessibility concerns, and this, in turn, restricted their spontaneity: “I have no spontaneity. It’s very rare. It’s always call ahead. You know, can I get my chair in?” (56, neurological cause of disability, 31 years with disability). Similarly, another participant focused on the cognitive load required to participate in her community:

Anything you go to do, you have to just either pre-think about it or go drive by it. You know, does it have steps, does the steps have railings....It’s amazing how many people, buildings, and different places have no ramps and steps and no railings. (64, neurological cause of disability, 30 years with disability)

Multiple participants faced accessibility issues within their own apartment complexes or building entrances that prevented them from leaving their homes altogether. Two participants reported not leaving their homes in over a year because a ramp or assistance ascending stairs was not provided, as one described:

I can’t go outside because I can’t get back in the house if I do go outside. I kept falling every time I went outside. And we would have to call the fire department; they would have to come and hoist me up. (64, musculoskeletal cause of disability, 8 years with disability)

3.4.4 Social Exclusion: Sense of Community

Participants emphasized how the built environment contributed to their sense of community. Some who lived in self-described suburban neighborhoods felt socially isolated and less likely to seek activities outside the home, while others maintained close relationships with
their neighbors and viewed their neighborhood as a friendly and welcoming environment. Neighborhoods with a high turnover rate of people moving in and out made socializing more difficult and neighborhoods feel unstable. There were no evident differences in sense of community between urban and rural participants. As discussed in the previous theme, inaccessible built environments also sent unwelcoming messages, as it was perceived that people with disabilities were not considered in the planning of communities. This disablism eroded participants’ sense of belongingness. Participants were less motivated to be an active member of their community when they felt excluded, both physically and socially: “Accessibility does not always mean getting into the building. Having accessibility is wonderful, but if people don’t accept me as a person, that means that I won’t go back. And people do this a lot” (49, multiple causes of disability, 11 years with disability). Accessible public spaces where people could gather and interact with one another, including churches, spaces for neighborhood gatherings, and picnic gazebos, promoted a sense of community for participants: “A bunch of us will get together, and we’ll get a food truck that’ll come to the neighborhood, and everybody—there’s a common area—and everybody will come down and eat together” (58, neurological cause of disability, 58 years with disability).

3.4.5 Routines Disrupted: Access to Support, Spaces, and Resources During the COVID-19 Pandemic

The COVID-19 pandemic and associated public health response measures (e.g., social distancing requirements, shelter-in-place policies, facility shutdowns) impacted participants’ access to different forms of support, resources, and spaces. Attending church, a meaningful form of community participation for many participants, became difficult during the pandemic. Several participants stressed that they missed attending in-person services: “I can’t do much of anything ‘cause of COVID, so once it should be opening up, it should be better. Volunteering, being at
church, seeing other people…” (64, neurological cause of disability, 12 years with disability). Specifically, fear of contracting the virus in public spaces and restricted or eliminated access to transportation led to reduced community participation. One participant detailed their struggle with scheduling a ride through the local paratransit company during the pandemic:

Timing, unfortunately with COVID, that has really suffered because I think they’re down, like, 150 drivers. I have screenshots from my phone that showed I called 110 times to get one reservation....They waste so much of our time that it’s really—you don’t want to do it anymore. (59, neurological cause of disability, 20 years with disability)

Social isolation dominated the lives of many participants during the pandemic, though some expressed that nothing had changed because they already felt excluded from their communities: “You know, for me, it hasn’t been much change...I can’t get up and go anyhow” (65, musculoskeletal cause of disability, 12 years with disability). Particularly during the first year of the pandemic, many participants referenced the importance of outdoor built environments and shifted some of their community activities outside to reduce the risk of contracting the virus. However, this transition was not always successful: “I mean, Bunco has been canceled. They did have one, and it was outside, but I was like a nervous Nellie the whole time” (57, neurological cause of disability, 15 years with disability). Outdoor spaces of particular importance for participants included driveways, neighborhood parks and gazebos, and backyard patios. Many participants also tried to continue their activities virtually but missed the in-person social interactions: “It’s just not quite the same as interacting in person if you have to do it over the screen” (64, neurological cause of disability, 12 years with disability). The process of accessing an online videoconference account, logging on, and facilitating conversation was difficult for some as well. One positive change brought about by the pandemic that participants pointed to was curb-side pickup and delivery for groceries and other errands. Eliminating the need to wait for transportation, transfer in and out of a vehicle, or risk exposure to germs helped some
participants save time and effort for other, more important activities at home during the pandemic.

3.5 Discussion

The results of our study suggest that adults who have long-term experience living with a physical disability perceive the safety, accessibility, and inclusiveness of the built environment to impact their participation in meaningful activities with others outside the home. Community participation is highly valued by adults aging with long-term physical disabilities but often challenging or impossible due to barriers in the built environment. Our findings confirm extensive evidence on individuals with physical disabilities in general that not only can inaccessible built environments make traveling to community destinations difficult, but they can impede an individual’s ability to participate in community activities and lead to disenfranchisement through disablist messaging.10,12,76,146 The participants who shared their perspectives in this study have lived a large portion of their lives with a disability, and the cumulative effects of systemic social exclusion may be evident through this concept of disenfranchisement. However, many of these barriers are modifiable or fixable altogether. There are opportunities to advocate for better streets, sidewalks, and transportation options through involvement in advocacy efforts and policy decisions. For example, community-based working groups and community “walk-abouts” or “bike-abouts,” which can involve policymakers and other potentially interested parties walking or biking through neighborhoods and transit routes themselves to identify and assess features needing improvement, can lead to shared and more informed decision making.191,192 A similar process involving policymakers navigating neighborhoods and community environments using mobility devices should be considered.
This research supports current health objectives outlined by multiple national organizations to create environments that promote safety, health, and well-being. The in-depth, lived experiences and perspectives of AAwPD detailed in our study also fill a qualitative knowledge gap in research on this population, their community participation, and their perceptions of built environments. Participants’ personal stories illustrate the nuanced relationships among abstract variables that can be challenging to study quantitatively. The primary themes also demonstrate the difficulty of disentangling the physical from the social aspects of the built environment (e.g., vandalism, gun violence, and poor sidewalk conditions contributing to sense of safety). Although causation cannot be inferred through qualitative data, our results can inform future hypotheses on the relationships among latent personal and environmental factors for AAwPD.

This study also revealed the perspectives of AAwPD on the built environment during the COVID-19 pandemic. Participants’ reduced access to important resources, spaces, and support confirms prior findings on the pandemic experiences of people with physical disabilities in general. Additionally, our racially and socioeconomically diverse sample provides insight into experiences that are more representative of the general population of AAwPD. Most research on this population has reported on samples that were from well-resourced or high-income neighborhoods, and more than 90% non-Hispanic White (or included no reporting on race at all).

While both physical and social aspects of the environment have been shown to shape the community participation of AAwPD, the concepts of safety and caution have not emerged as frequently in previous qualitative research on this topic. This finding may be related to many of our participants living in low-resourced and urban environments where crime is more
prevalent or to participants’ complex intersecting identities (e.g., aging, socioeconomically disadvantaged, living with a long-term physical disability) contributing to a heightened sense of vulnerability.\textsuperscript{199,200} Further, qualitative methods are often better suited for capturing important psychological and emotional insights and may have facilitated bringing these themes to light.\textsuperscript{201}

Some aspects of the influence of the built environment that have been demonstrated using objective, population-level data (e.g., proximity, land use mix) did not emerge in this study’s results. This may be due to the subconscious human experience of certain built environment features. In other words, not all people pay conscious attention to these constructs.\textsuperscript{202}

Accessibility-related barriers to community participation for this population are supported by the ecological theory of aging in that the mismatch of one’s physical disability with challenges in the environment can lead to maladaptive behavior (i.e., restricted community participation).\textsuperscript{66} For example, as was described by a participant in her interview, a restaurant with wheelchair access around the back of the building (or with no accessible entrance altogether) may lead to an individual with a physical disability feeling unwelcomed, excluded, and less likely to dine out with friends later on. Another theoretical framework supporting our results is the ecological systems theory, which posits that a system of environmental influences shapes an individual’s behavior, development, and life experiences.\textsuperscript{65} Each of the five themes that emerged in this study can be mapped onto the various layers of environmental influence within the framework, particularly the microsystem and mesosystem, which encompass the neighborhood environment. Additionally, in alignment with the Capabilities Approach framework, our results suggest that universal design modifications that make public spaces and places accessible for all may not be enough.\textsuperscript{173,174} Certain customizations of the home environment (e.g., installing Hoyer lifts or front entrance ramps) may be needed to enhance this
population’s perceived safety and facilitate opportunities for community outings. Further, the aesthetics and maintenance of neighborhoods and community spaces may also need to be prioritized to foster feelings of safety and full community participation. Many of these themes are also relevant for individuals with disabilities in general. However, when interpreting our results in the context of the aging and disability intersection, the theme of vigilance and sense of safety may have also emerged because of a combination of prolonged social disadvantage often experienced by individuals with long-term disabilities and a loss of social capital and heightened loneliness commonly experienced as people age into older adulthood. Previous literature has noted indirect associations between loneliness, loss of social capital, and perceived neighborhood safety among older adults.

### 3.5.1 Study Limitations

One of the limitations of this study was the virtual interview setting, which may have prevented rapport building with participants. Not all body language and nonverbal communication was visible virtually, and this may have impacted our interpretation of participant responses. Additionally, all participants were from a large Midwestern city and surrounding areas, and thus, our findings may not generalize to other geographic regions due to policy, infrastructure, and other local and regional factors. Replication of our qualitative study with a rural participant sample may provide insight into how urbanicity and proximity influence community participation. Stratification by mobility device may also be warranted. Mixed methods research that combines and compares subjective and objective data is needed to better understand the nuanced transactions between AAwPD and the built environment. Quantitative analytical techniques such as structural equation and general linear modeling may enhance our understanding of the pathways between built environment variables and community participation.
for this population. Finally, while the COVID-19 pandemic coincided with our interviews and provided insight into unique experiences, it confounded most participants’ descriptions of their “typical” community participation.

3.6 Conclusion

The five themes identified in our study pinpoint areas for intervention from CBO, policymakers, and healthcare professionals. Agencies that fund and oversee maintenance of community built environments should consider examining how funding allocation and lack of maintenance may contribute to disabling built environments, such as crumbling and cracked sidewalks. CBO and healthcare professionals serving AAwPD should also consider developing processes for identifying and addressing built environment barriers restricting their community participation. Stricter enforcement of the ADA in both existing community environments and future developments, and architects and urban planners advocating for moving beyond meeting the bare minimum ADA requirements to design inclusive and welcoming spaces for all, may improve community participation for this population.

Acknowledgment of inequitable built environments and their role as significant determinants of health and well-being for AAwPD is vital to improving their community participation and contributing to broader societal change. Composite scores, audits, or Global Positioning System/Geographic Information System–based evaluations of community infrastructure and accessibility or “walkability” may help quantify these inequities, although many of these tools are not yet disability inclusive. Other user-friendly, publicly available accessibility tools that individuals can use to search restaurants, shops, or facilities ahead of time and quickly understand the destination’s level of accessibility should also be prioritized. This would allow for users to better plan their outings in their communities and anticipate potential
accessibility barriers. Future research with individuals with physical disabilities must continue to consider environmental variables to achieve a comprehensive understanding of participation.

3.6.1 Funding

This work was supported by a grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR grant number 90DPCP0001-01-00). NIDILRR is a center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This work does not necessarily represent the policies of NIDILRR, ACL, or HHS, and endorsement by the Federal Government should not be assumed.
4.1 Abstract

Background. Adults aging with long-term physical disabilities (AAwPD) experience barriers in the built environment that can hinder their ability to participate in meaningful social roles and activities. However, interventions addressing built environment barriers to participation for AAwPD are limited.

Objective. The purpose of this study was to examine how the built environment and other socioenvironmental factors influence the social participation of AAwPD to inform future interventions and service provision. We hypothesized that social participation would be significantly different between AAwPD using private versus public transportation and living in urban versus rural areas.

Methods. This cross-sectional study of 331 Missouri-dwelling AAwPD reports findings on relationships among transportation mode, urban versus rural residence, and ability to participate in social roles and activities using PROMIS measures. A multivariate analysis of covariance
(MANCOVA) explored differences in social participation across transportation mode and residential location. Linear regression examined associations among socioenvironmental factors, individual factors, and social participation.

Results. The MANCOVA demonstrated significant differences in social participation across transportation mode and urban versus rural residential location. Specifically, AAwPD using paratransit and living in urban areas reported significantly higher social participation than rural-dwelling individuals and private transportation users (p<.001). The linear regression revealed that individual factors served a larger role in predicting social participation than built or social environmental factors.

Conclusions. Our findings suggest that transportation mode plays a significant role in shaping social participation outcomes for AAwPD. However, compared to built and social environmental factors, individual factors (i.e., physical function, common “aging-with-disability” symptoms) may restrict social participation more.

4.2 Introduction
Advances in health care and technology have led to an increased lifespan of individuals with physical disabilities.36 As a result, there are an estimated 13 million adults aging with long-term physical disabilities (AAwPD) living in the United States alone.15 Throughout their life course, AAwPD experience a combination of health conditions associated with their disability (e.g., fatigue) and aging symptoms (e.g., osteoporosis).20 This combination of symptoms and health conditions leads to early and accelerated functional decline.20 AAwPD are also more likely to face long-term societal exclusion and social disadvantage than individuals without disability (e.g., lower rates of employment).25 Further, because AAwPD often use mobility
devices, their community mobility is negatively impacted by barriers in the built environment such as inaccessible transportation. These personal and environmental barriers lead AAwPD to experience difficulties living independently and participating in meaningful life activities in their communities. Both the National Institute on Disability, Independent Living, and Rehabilitation Research and the World Health Organization have called for examining the implications of aging with long-term disability for community living and participation, an important component of health for this population.

The growing research agenda on participation highlights its associations with physical and mental health and overall quality of life. Broadly, participation is defined by the World Health Organization as involvement in life situations. Social participation, a specific dimension of participation, is important to understand in the context of aging with disability because it facilitates a sense of purpose, belonging, and independence. In this study, we define social participation as the performance of an individual’s “usual social roles and activities.”

Advancing our understanding of how to support the social participation of AAwPD requires further investigation of the environmental and social factors that can act as significant barriers. Access to transportation, accessibility of community environments, and sidewalk conditions are examples of barriers—all considered part of the built environment. Compared to personal factors, however, the mechanisms behind the influence of these environmental factors are not as well understood. At the intersection of aging and disability, our previous work identified pain, fatigue, and depression as common symptoms (i.e., personal factors) that significantly impact social participation for this population. Although there are interventions that may help manage these symptoms, built environment factors that serve as barriers to social participation are more modifiable.
The body of literature on the role of the built environment in the social and community participation of AAwPD has primarily focused on the accessibility of community buildings, streets, sidewalks, and transportation.\textsuperscript{48} Urban versus rural participation differences have been comparatively under-researched, and transportation mode has not yet been investigated.\textsuperscript{48} A recent qualitative study on general transportation barriers for AAwPD found one of the largest reported barriers to be difficulty accessing various transportation modes that can accommodate mobility aids.\textsuperscript{49} The impact of this barrier on social participation is unknown. Transportation has historically been a major environmental barrier for people with disabilities in general and their participation, and despite passage of the Americans with Disabilities Act (ADA), inaccessible and unreliable transportation modes still pose barriers.\textsuperscript{49,211} Additionally, studies examining urban versus rural residential location have produced conflicting results. Botticello and colleagues\textsuperscript{212} found that individuals with spinal cord injury living in urban areas were more likely to report life dissatisfaction, while Clarke et al.\textsuperscript{9} found no significance in the ability of this variable to predict restricted social participation. Another gap that exists in this area of research is that the participant samples of most studies have inadequate representation of non-white populations. Predominantly white samples from highly educated backgrounds limit generalizability. We attempt to close these research gaps with the current study to produce generalizable findings and improve our knowledge of how built environment factors facilitate or restrict social participation for AAwPD.

The World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) helps to conceptualize the personal and environmental factors that influence the participation of persons with disabilities.\textsuperscript{34} Although the ICF does not provide a comprehensive framework of the interactions among participation and built environment factors at the
individual, community, and societal levels, it provides an approach for understanding how restrictions in social participation may arise from a mismatch between person and environment. Using this framework, we investigated how transportation mode, urban versus rural residential location, and other social and environmental factors (e.g., education, income) influence the social participation of AAwPD. Advancing the knowledge on how the built environment, in comparison to personal and social factors, influences this important outcome of health can inform policy and decision making on investments in transportation and infrastructure. This knowledge will also help organizations better cater transportation resources and design programs to overcome urban-rural barriers to service provision. The aim of this study was, therefore, to explore quantitative associations between environmental factors and social participation for AAwPD. Our hypotheses were that: (1) social participation would be significantly different between participants who reported using private versus public transportation and living in urban versus rural areas and (2) social participation would be significantly predicted by transportation mode and urban versus rural residential location.

4.3 Methods

4.3.1 Research Design

This study examined data collected in the first year of a longitudinal, participation-focused cohort study. This project was approved by the Institutional Review Board of Washington University School of Medicine in St. Louis (IRB# 201710186).

4.3.2 Participants

Much of the population of AAwPD are concentrated within the age range of 45-65, when they are particularly vulnerable to “falling through the cracks” of supports and services. Accelerated aging and functional decline for AAwPD begin at approximately 45 years, but they
are not eligible for traditional aging supports and services until 60-65. Therefore, participants were included in the study if they were aged 45-65, spoke English, and had been living with a self-reported physical disability for five or more years. We also recruited participants with a variety of diagnoses. This was done to enhance external validity and ensure that our findings are relevant to the community-based organizations (CBO) serving this population, including area agencies on aging (AAA) and centers for independent living (CIL). The exclusion criterion was inability to consent or accurately respond to survey questions. Purposive sampling was used to recruit participants from AAA, local disability organizations and CIL, and social media. The larger cohort included individuals from across the United States, but only residents from the state of Missouri—about 70% of the sample—were examined for this study. This was done to enable comparisons of individuals living in the same geographic region with similar climates, resources, and transportation systems.

4.3.3 Procedures and Data Collection
Once informed consent was obtained from each participant, a survey was either completed online by the participant or administered by the research team via telephone. Data were collected through REDCap (Research Electronic Data Capture v10), a secure, web-based platform. The survey took 45-60 minutes to complete, and participants were provided a gift card following completion. Survey development and measurement selection were done in collaboration with a community-based research network. Two social participation measures served as dependent variables, while health, environment, and sociodemographic measures served as independent variables and covariates. Data reported in this paper were collected during the first timepoint of the longitudinal study, August 2018–July 2019.
Demographic survey questions asked about age, gender, race, years living with physical
disability, residential address, and Medicaid health insurance eligibility (dichotomized as above
or below $10,008, the income ceiling for qualification in the state of Missouri in 2018). Table 4.1
outlines the remaining measures of the survey. Four measures from the Patient Reported
Outcomes Measurement Information System (PROMIS) were used to measure health and
function: (1) Pain Interference, which measures the interference of pain with an individual’s
physical, emotional, cognitive, social, and recreational life activities;\textsuperscript{214} (2) the Fatigue Profile,
which assesses symptoms of fatigue including mild tiredness to extreme exhaustion;\textsuperscript{214} (3)
Depression, which evaluates decreased engagement and positive affect, views of self, and
negative mood;\textsuperscript{215} and (4) Physical Function with Mobility Aid Short Form, which measures an
individual’s self-reported ability to stand and move with and without support.\textsuperscript{214} These four
measures generate t-scores that are compared against the general population’s mean score of 50,
and they have been validated with persons with physical disabilities.\textsuperscript{215} The Self-Administered
Comorbidity Questionnaire (SCQ) was also included in the survey and measures the impact of
12 common comorbid conditions on one’s daily life. An option for writing in three additional
conditions is also provided; scores range from 0-45, with higher scores representing more
comorbid conditions. The SCQ has demonstrated high clinical utility and strong predictive
validity.\textsuperscript{216}

To measure social participation, we used (1) the PROMIS Ability to Participate in Social
Roles and Activities Computer Adaptive Test (CAT) version and (2) the PROMIS Satisfaction
with Participation in Social Roles and Activities CAT version. The former is not time-bound and
measures one’s perceived ability to participate in usual social roles and activities.\textsuperscript{84} The latter
assesses one’s satisfaction with their participation in social roles and activities over the past
seven days. For all PROMIS instruments, a higher score indicates a greater presence of the construct being measured (e.g., higher pain score represents greater pain; higher social participation ability score represents greater ability).

Transportation mode was measured with the question, “What is your regular form of transportation?” with five response options: (1) drive self; (2) family member or friend drives me; (3) taxi, Uber, Lyft, or other private transportation services; (4) paratransit or other services for people with disabilities; or (5) public transportation such as bus, metro, or subway. When necessary for analysis, these options were dichotomized into private transportation (options 1-3) and public transportation (options 4-5). The Craig Hospital Inventory of Environmental Factors short-form (CHIEF-SF) was used to capture perceived environmental barriers to participation. The CHIEF was developed in collaboration with persons with disabilities and validated in persons with and without disabilities. This instrument examines the frequency and severity of environmental barriers to participation such as accessibility, accommodations, resource availability, and social support, with higher scores indicating greater environmental impact. Last, participants were asked a series of questions about their satisfaction with their current level of participation in nine different activity domains. If participants responded that they were unsatisfied, they indicated whether they wished to do more or less of the activity. Three of the activity domains related to social participation were used for this analysis: (1) social activities and helping others, (2) civic and religious activities, and (3) community leisure activities. The activity domain questions were developed based on extant research analyzing activity items in the Panel Study for Income Dynamics and the Midlife in the United States, as well as the Health and Retirement Study.
<table>
<thead>
<tr>
<th>Construct</th>
<th>Measurement Tool</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health and Participation Variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social participation ability</td>
<td>PROMIS Ability to Participate in Social Roles &amp; Activities</td>
<td>Item Bank v2.0 (CAT)</td>
</tr>
<tr>
<td>Social participation satisfaction</td>
<td>PROMIS Satisfaction with Participation in Social Roles &amp; Activities</td>
<td>Item Bank v2.0 (CAT)</td>
</tr>
<tr>
<td>Pain</td>
<td>PROMIS Pain Interference</td>
<td>Item Bank v1.1 (CAT)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>PROMIS Fatigue</td>
<td>Item Bank v1.0 (CAT)</td>
</tr>
<tr>
<td>Depression</td>
<td>PROMIS Depression</td>
<td>Item Bank v1.0 (CAT)</td>
</tr>
<tr>
<td>Comorbid conditions</td>
<td>Self-Administered Comorbidity Questionnaire</td>
<td>Includes two write-in options</td>
</tr>
<tr>
<td>Physical function</td>
<td>PROMIS Physical Function Mobility Aid</td>
<td>Short Form 11a</td>
</tr>
<tr>
<td>Self-rated mental health</td>
<td>Self-report</td>
<td>5-point scale (1=excellent, 5=poor)</td>
</tr>
<tr>
<td>Self-rated physical health</td>
<td>Self-report</td>
<td>5-point scale (1=excellent, 5=poor)</td>
</tr>
<tr>
<td>Satisfaction with activity levels in specific activity domains</td>
<td>Questions asking about satisfaction with current activity levels</td>
<td>Satisfied (yes/no) Activity level (more/less)</td>
</tr>
<tr>
<td><strong>Social and Environmental Variables</strong></td>
<td></td>
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</tr>
<tr>
<td>Educational attainment</td>
<td>Self-report</td>
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<tr>
<td>Living arrangement</td>
<td>Self-report</td>
<td>Alone vs with others</td>
</tr>
<tr>
<td>Social Security Disability Insurance</td>
<td>Self-report</td>
<td>Receiving vs not receiving</td>
</tr>
<tr>
<td>Health insurance</td>
<td>Self-report</td>
<td>Receiving Medicaid vs not receiving</td>
</tr>
<tr>
<td>Personal attendant services</td>
<td>Self-report</td>
<td>Receiving vs not receiving</td>
</tr>
<tr>
<td>Transportation mode</td>
<td>Self-reported primary mode of transportation</td>
<td>1) Drive self, 2) family member or friend drives me, 3) taxi/Uber/Lyft, 4) paratransit, 5) subway/bus/metro</td>
</tr>
<tr>
<td>Urban vs rural residential location</td>
<td>Rural Urban Commuting Area (RUCA) classification scheme</td>
<td>10-point scale (1=urban, 2-10=rural)</td>
</tr>
<tr>
<td>Neighborhood socioeconomic disadvantage</td>
<td>Yost Index</td>
<td>100-point scale (1=least disadvantaged, 100=most disadvantaged)</td>
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<tr>
<td>Environmental barriers to participation</td>
<td>Craig Hospital Inventory of Environmental Factors (CHIEF)</td>
<td>Short Form</td>
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CAT=Computer Adaptive Test.
Two independent variables of interest, neighborhood socioeconomic disadvantage and urban versus rural residential location, were measured using geocoding. A geocoder tool that is publicly available through the United States Census Bureau (https://geocoding.geo.census.gov/geocoder/) was used to geocode all participants’ addresses and calculate a Yost Index score. The Yost Index is used to compositely measure socioeconomic neighborhood disadvantage at the census tract level from a score of 0 (least disadvantaged) to 100 (most disadvantaged).98 The Yost Index was selected because of its transparency, reproducibility, and ability to find strengthened associations with disease and mortality.220

Geocoding was also used to calculate a Rural Urban Commuting Area (RUCA) code for each participant. The RUCA classification scheme was used to measure urban versus rural residential location for each participant. The RUCA scheme classifies census tracts using urbanization, commuting patterns, and population density. It was chosen for its consideration of transportation influences and ability to overcome issues posed by the original United States Census Bureau’s urban-rural classification scheme (e.g., omission of city or county boundaries). When necessary for analysis, we dichotomized RUCA codes (1=urban, 2-10=rural) based on previous literature.184,185

4.3.4 Data Analysis
All analyses were conducted with SPSS v28 (IBM Corp., Armonk, NY, USA), with significance set at \( p \leq .05 \). Following descriptive statistics, chi-square tests were used to examine distributional differences for urban versus rural residential location and private versus public transportation mode across demographic and socioenvironmental characteristics. A 2x2 factorial Multivariate Analysis of Covariance (MANCOVA) was then used to investigate differences in the two social participation PROMIS scores by residential location and transportation mode.
Age, neighborhood socioeconomic disadvantage, comorbid conditions, and physical function were added as covariates to the MANCOVA. To explore the influence of different categories of factors, we then conducted a hierarchical multiple linear regression predicting social participation ability. The categories of factors were divided into health and demographic characteristics (e.g., age, years living with disability, fatigue), social resources (e.g., educational attainment, health insurance), and neighborhood environmental factors (e.g., neighborhood socioeconomic disadvantage, transportation mode) based on previous relevant research. Following the MANCOVA, which included both PROMIS social participation measures, we elected to focus only on the social participation ability measure. This was decided based on the measure’s combined elements of satisfaction and meaningfulness. For example, items include, “I have trouble doing everything for my friends that I want to do,” and, “I have trouble doing all the leisure activities with others that I want do.”

We then used Mann-Whitney U and Kruskal-Wallis tests to examine differences in social participation ability and symptom (i.e., pain, fatigue, depression) severity by transportation mode and residential location. The Mann-Whitney U test was conducted to dichotomously investigate private versus public transportation mode and urban versus rural residential location. A Kruskal-Wallis test was run to identify differences in social participation ability and symptom severity among the original five transportation mode options. We also examined differences in social participation ability by neighborhood socioeconomic disadvantage and Medicaid eligibility using a Mann-Whitney U test. This allowed us to explore the role of socioeconomic status in social participation. Finally, we ran a Mann-Whitney U test to determine any differences in social participation ability between urban- and rural-dwelling participants across the five transportation modes.
4.4 Results

Participant demographics are shown in Table 4.2. A total of 331 Missouri-dwelling participants completed the Year 1 survey. Two-thirds of participants reported using private transportation (including driving themselves, relying on family or friends, and using taxis or rideshare companies). Most participants (78%) lived in an urban area. Table 4.3 shows distributional differences in sociodemographic variables by private versus public transportation mode use and urban versus rural residence.

Table 4.2. Participant demographic characteristics (n=331)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%) or M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, M (SD)</td>
<td>57.3 (5.1)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Man</td>
<td>120 (36.5)</td>
</tr>
<tr>
<td>Woman</td>
<td>209 (63.5)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>190 (57.4)</td>
</tr>
<tr>
<td>Black/African American or Other</td>
<td>141 (42.6)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Currently married/partnered</td>
<td>99 (29.9)</td>
</tr>
<tr>
<td>Single/widowed/other</td>
<td>232 (70.1)</td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
</tr>
<tr>
<td>High school diploma or less</td>
<td>122 (36.9)</td>
</tr>
<tr>
<td>Greater than high school diploma</td>
<td>209 (63.1)</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
</tr>
<tr>
<td>Paid work, full- or part-time</td>
<td>49 (14.8)</td>
</tr>
<tr>
<td>Not working</td>
<td>280 (84.6)</td>
</tr>
<tr>
<td>Transportation mode</td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>106 (32.1)</td>
</tr>
<tr>
<td>Private</td>
<td>224 (67.9)</td>
</tr>
<tr>
<td>Transportation mode</td>
<td></td>
</tr>
<tr>
<td>Bus, metro, subway</td>
<td>41 (12.5)</td>
</tr>
<tr>
<td>Paratransit or other services for people with disabilities</td>
<td>64 (19.5)</td>
</tr>
<tr>
<td>Taxi, Uber, Lyft</td>
<td>9 (2.7)</td>
</tr>
<tr>
<td>Rely on family member or friend</td>
<td>81 (24.6)</td>
</tr>
<tr>
<td>Drive self with personal vehicle</td>
<td>134 (40.7)</td>
</tr>
<tr>
<td>Residential location</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>253 (77.8)</td>
</tr>
<tr>
<td>Rural/suburban</td>
<td>72 (22.2)</td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
</tr>
<tr>
<td>Live with others</td>
<td>171 (51.7)</td>
</tr>
<tr>
<td>Characteristic</td>
<td>N (%) or M (SD)</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Live alone</td>
<td>160 (48.3)</td>
</tr>
<tr>
<td>Availability of transportation</td>
<td></td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td></td>
</tr>
<tr>
<td>Medicaid eligibility (personal annual income of ≤$10,008)</td>
<td></td>
</tr>
<tr>
<td>Medicaid eligibility (personal annual income of ≤$10,008)</td>
<td></td>
</tr>
<tr>
<td>Self-rated physical health</td>
<td></td>
</tr>
<tr>
<td>Self-rated physical health</td>
<td></td>
</tr>
<tr>
<td>Self-rated mental health</td>
<td></td>
</tr>
<tr>
<td>Self-rated mental health</td>
<td></td>
</tr>
<tr>
<td>Average neighborhood socioeconomic disadvantage, M (SD)</td>
<td>64.1 (26.0)</td>
</tr>
<tr>
<td>Problem</td>
<td>Characteristic</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----------------------------------------</td>
</tr>
<tr>
<td>Urban vs rural residential location</td>
<td>Urban</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
</tr>
<tr>
<td>Health insurance</td>
<td>Medicaid</td>
</tr>
<tr>
<td></td>
<td>Medicare, Private, Military</td>
</tr>
<tr>
<td>Medicaid eligibility (income ≤$10,008)</td>
<td>Eligible</td>
</tr>
<tr>
<td></td>
<td>Not eligible</td>
</tr>
<tr>
<td>Self-rated physical health</td>
<td>Excellent, very good, or good</td>
</tr>
<tr>
<td></td>
<td>Fair or poor</td>
</tr>
<tr>
<td>Self-rated mental health</td>
<td>Excellent, very good, or good</td>
</tr>
<tr>
<td></td>
<td>Fair or poor</td>
</tr>
<tr>
<td>Socioeconomic disadvantage†, M</td>
<td></td>
</tr>
</tbody>
</table>

*p<.05, **p<.01, ***p<.001 (two-tailed tests)
†Mann-Whitney U test conducted.

Table 4.4 displays participant responses to the three social participation–related activity domain questions. Between 40% and 51% of participants reported being unsatisfied with their current levels of activity and wanting to do more. Chi-square tests between participants living in urban versus rural areas and those using public versus private transportation showed no statistically significant differences.

Results from the MANCOVA showed statistically significant differences in the two PROMIS social participation measures across transportation mode and residential location. Using Hotelling’s Trace, public versus private transportation mode was significant at p=.025, and urban versus rural residential location was significant at p=.034. No interaction between the two independent variables was indicated (p=.756). The covariates of comorbid conditions
(p<.001) and physical function (p<.001) were statistically significant, while age (p=.124) and socioeconomic disadvantage (p=.486) were not.

Table 4.4. Satisfaction responses to three community participation–related activity domains

<table>
<thead>
<tr>
<th>Community participation category</th>
<th>Total N</th>
<th>%</th>
<th>Public Transportation</th>
<th>Private Transportation</th>
<th>X² Test Statistic</th>
<th>Urban Location</th>
<th>Rural Location</th>
<th>X² Test Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Want to do more civic/religious activities</td>
<td>148</td>
<td>45.0</td>
<td>48</td>
<td>100</td>
<td>.002</td>
<td>109</td>
<td>38</td>
<td>2.355</td>
</tr>
<tr>
<td>Want to do more social activities/help others</td>
<td>132</td>
<td>40.2</td>
<td>40</td>
<td>90</td>
<td>.178</td>
<td>95</td>
<td>33</td>
<td>2.040</td>
</tr>
<tr>
<td>Want to do more community leisure activities</td>
<td>169</td>
<td>51.2</td>
<td>51</td>
<td>117</td>
<td>.545</td>
<td>126</td>
<td>39</td>
<td>.583</td>
</tr>
</tbody>
</table>

The hierarchical multiple linear regression predicting social participation ability (shown in Table 4.5) produced a final $R^2$ of .520, with health and demographic factors accounting for approximately 43% of the model’s variance. Neighborhood environmental factors explained 6% of the variance, and social resources and factors explained 2.5%.

The Mann-Whitney U test demonstrated that public transportation users reported statistically significantly higher social participation ability than private transportation users ($U=8558.5$, p<.001). We confirmed that physical function was not acting as a confounding variable for this finding with a logistic regression predicting private versus public transportation use. Social participation ability for participants living in urban areas was statistically significantly higher than for rural residents ($U=5925$, p<.001). When examining all five transportation modes, the Kruskal-Wallis test revealed statistically significant differences ($H(4)=16.6$, p=.002). Paratransit users showed the highest mean rank in social participation ability (199.41). Participants who reported primarily relying on family or friends to drive them...
demonstrated the lowest mean rank in social participation ability (145.93). No significant
differences in symptom severity were found between public and private transportation users or
between any of the five transportation modes. However, the Mann-Whitney U test of symptom
severity by urban versus rural residential location indicated that rural participants reported
significantly higher pain (p=.005), fatigue (p=.012), and depression (p<.001).

Table 4.5. Final model of the hierarchical multiple linear regression for ability to participate in social roles
and activities

<table>
<thead>
<tr>
<th>Step 1: Health and demographic characteristics</th>
<th>R</th>
<th>R²</th>
<th>R² Change</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>.659</td>
<td>.434***</td>
<td>-2.00</td>
<td>.062</td>
<td>-2.03***</td>
<td>-3.253</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>-.122</td>
<td>.059</td>
<td>-.120*</td>
<td>-2.061</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>-.269</td>
<td>.056</td>
<td>-.296***</td>
<td>-4.744</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical function</td>
<td>.165</td>
<td>.054</td>
<td>.144**</td>
<td>3.073</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.055</td>
<td>.080</td>
<td>.030</td>
<td>.687</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>-5.180</td>
<td>.828</td>
<td>-2.72***</td>
<td>-6.257</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>-.255</td>
<td>.861</td>
<td>-.013</td>
<td>-.296</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comorbidity burden</td>
<td>.031</td>
<td>.075</td>
<td>.022</td>
<td>.411</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-rated general physical health</td>
<td>-.822</td>
<td>.560</td>
<td>-.080</td>
<td>-1.469</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-rated general mental health</td>
<td>.528</td>
<td>.492</td>
<td>.062</td>
<td>1.072</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 2: Social resources factors</th>
<th>R</th>
<th>R²</th>
<th>R² Change</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td>-.263</td>
<td>.529</td>
<td>-.027</td>
<td>-.497</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>-.326</td>
<td>.241</td>
<td>-.071</td>
<td>-1.352</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living arrangement</td>
<td>.550</td>
<td>1.017</td>
<td>.029</td>
<td>.541</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid eligibility</td>
<td>-.225</td>
<td>1.031</td>
<td>-.117*</td>
<td>-2.158</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSDI use</td>
<td>-.875</td>
<td>.952</td>
<td>-.042</td>
<td>-.920</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health insurance</td>
<td>-.314</td>
<td>1.068</td>
<td>-.017</td>
<td>-.294</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>-.405</td>
<td>.343</td>
<td>-.059</td>
<td>-1.181</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of paid or unpaid assistance services</td>
<td>.834</td>
<td>1.051</td>
<td>.041</td>
<td>.793</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 3: Neighborhood environmental factors</th>
<th>R</th>
<th>R²</th>
<th>R² Change</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation mode</td>
<td>.894</td>
<td>.317</td>
<td>.150**</td>
<td>2.825</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban vs rural residential location</td>
<td>-.122</td>
<td>.192</td>
<td>-.029</td>
<td>-.634</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Availability of transportation as a barrier</td>
<td>-.735</td>
<td>.300</td>
<td>-.118*</td>
<td>-2.450</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Terrain and climate as a barrier</td>
<td>-.516</td>
<td>.324</td>
<td>-.076</td>
<td>-1.594</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lighting, noise, and crowds as a barrier</td>
<td>-.1108</td>
<td>.305</td>
<td>-.175***</td>
<td>-3.639</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighborhood socioeconomic disadvantage</td>
<td>-.015</td>
<td>.018</td>
<td>-.040</td>
<td>-.805</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

N=331. *p<.05, **p<.01, ***p<.001.
Regarding the roles of neighborhood socioeconomic disadvantage in social participation, the Yost Index was not significant as a covariate in the MANCOVA or as a predictor variable in the hierarchical regression. However, it did show statistically significant differences in a Mann-Whitney U analysis across public versus private transportation (p<.001) but not across urban versus rural living (p=.635). Specifically, public transportation users showed the higher neighborhood socioeconomic disadvantage. The Yost Index did not significantly correlate with either PROMIS ability or satisfaction social participation measure (p=.708, p=.345).

Table 4.6 illustrates the results of Mann-Whitney U tests examining differences in social participation ability between urban and rural participants across all five transportation modes. Participants who primarily drove themselves or relied on family members or friends reported statistically significantly different social participation ability when divided by residential location. Aligning with the findings of the original Mann-Whitney U test investigating urban and rural differences, urban-dwelling participants in both transportation categories reported higher social participation ability.

### Table 4.6. Mann-Whitney U analysis of differences in social participation ability

<table>
<thead>
<tr>
<th>Transportation mode</th>
<th>Mann-Whitney U (urban vs rural)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drives self</td>
<td>1327.50</td>
<td>.004</td>
</tr>
<tr>
<td>Family member drives</td>
<td>387.50</td>
<td>.018</td>
</tr>
<tr>
<td>Taxi, Uber, Lyft*</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Bus, Metro, Subway</td>
<td>46.50</td>
<td>.643</td>
</tr>
<tr>
<td>Paratransit</td>
<td>91.00</td>
<td>.421</td>
</tr>
</tbody>
</table>

*Test not performed due to empty cell (rural).
4.5 Discussion

This study confirmed our original hypothesis that there would be differences in social participation between AAwPD using private versus public transportation and living in urban versus rural areas. Almost half of participants reported wanting to do more social participation–related activities, but a majority of the sample reported availability of transportation as a barrier. Transportation mode was a statistically significant predictor of social participation ability, while urban versus rural living was not. We also determined the impact of categories of factors predicting social participation: health and demographic factors were the strongest predictors, followed by neighborhood built environment factors, and then social resource factors. Finally, we found that participants using paratransit had the highest social participation ability. Rural-dwelling participants and those mainly relying on family members or friends for transportation showed the lowest social participation ability. However, rural participants showed higher rates of pain, fatigue, and depression, which may contribute to their restricted social participation.

Our study confirms previous findings that socioenvironmental factors significantly influence the social participation of AAwPD.9 Specifically, we found that urban versus rural residential location may not be as important as transportation mode and access. However, urban participants’ lower rates of pain, fatigue, and depression may partially explain their higher perceived social participation ability. Additional research is warranted to further explore these person-environment interactions. While more research is needed to determine why public transportation—specifically paratransit—is associated with greater social participation, this finding aligns with previous research in older adults with and without disabilities.221,222 Additionally, urban versus rural living was not found to be a significant predictor of social
participation in previous research on this population. The effects of this environmental factor are still being debated in the literature.

These findings fill a gap in our understanding of how transportation mode, urban versus rural living, and other social and environmental factors shape social participation for AAwPD, particularly in a more representative sample than has been studied in previous research. Our results highlight the magnitude of the impact of personal factors compared to socioenvironmental factors for this population. The predictive power of the social and environmental factors in our model of social participation were much lower than what has been demonstrated in previous research quantifying social determinants of health for the general population. This discrepancy is likely due to the limited span of our environmental measures, although it could also relate to participants’ experiences of aging-with-disability symptoms such as elevated pain, fatigue, and depression. Further, neighborhood- and community-level factors are more distal compared to individual factors in terms of their relationship to participation outcomes, and their influence is spread across populations.

This study showed that AAwPD living in Missouri primarily use private forms of transportation. In regions with urban sprawl such as the state of Missouri, public transportation is less likely to flourish. There are many advantages to investment in public transportation, including better traffic safety, more opportunities for physical activity, improved air quality, and cost-effectiveness. However, policymakers and urban planners must not ignore the fact that most individuals with disabilities across the United States (approximately 84%), including AAwPD, primarily use personal vehicles either as a driver or passenger. Personal vehicles, as well as paratransit services, provide more flexibility and choice in how, when, and where an individual travels. As personal vehicles become increasingly electric and autonomous, we have an
opportunity to ensure that they are accessible and equitable. In a previous study, we found that many AAwPD wanted to use public transportation more but were concerned about their personal safety. However, the location of affordable housing frequently dictates where a person lives, as well as their access to desirable neighborhood characteristics like safe and easily accessible transportation options.

This study has important implications for CBO, researchers, urban planners, and policymakers. Our results may inform CBO about what participant data could be helpful to collect and how to prioritize the needs of the individuals they serve. CBO should consider asking their clients which modes of transportation they typically use and about the accessibility and access of those modes. These data may inform service provision and improve their understanding of how to facilitate participants’ community mobility. AAwPD should be connected to transportation options that are accessible, reliable, economically feasible, and fit with their daily activity needs and social participation goals. Ensuring that individuals are aware of their community’s transportation options and resources will help them make informed decisions when planning their travel. However, based on the results of our study, CBO that work with AAwPD may need to triage clients’ needs based on physical function concerns and pain, fatigue, and depressive symptoms if social participation is the goal.

Researchers may gain valuable information by further investigating how transportation services facilitate community-based social participation. For example, exploring the preferred transportation modes of AAwPD and how they would like different transportation modes to be improved will guide our research agenda in a productive direction. Improved ADA implementation within public transportation systems may facilitate both social participation and active transportation, leading to enhanced physical and emotional health. Finally, involvement of
AAwPD and other disability populations in policymaking and urban planning processes will help ensure that equitable and appropriate decisions are made.

Limitations of this study include a cross-sectional analysis, which prevents our ability to draw longitudinal conclusions, although this was neither required for our hypotheses nor within the scope of the study. A potential confounder in our analyses was the possibility that urban areas present more opportunities for social participation. However, we attempted to combat this by examining urban versus rural differences in responses to activity domain questions asking about satisfaction with activity levels. Last, because of the state-specific sample, our findings may not generalize to AAwPD in other geographic regions due to differing transportation systems, geography, or policies.

4.6 Conclusion

Priorities for future research should include examining other built environment characteristics such as land use mix, neighborhood physical disorder, and perceived neighborhood safety. Ecological momentary assessment of social interactions during community outings may also be warranted, which would allow for comparisons of the influence of built environment factors with real-time community activities. Last, pairing objective (e.g., spatial analysis) with subjective (e.g., individuals’ satisfaction with transportation options) data may strengthen our understanding of environmental influences and the ability to inform resource provision, policy, and practice. Future efforts prioritizing transportation and other environmental factors may help improve access to community living and participation for AAwPD and individuals with physical disabilities in general.
4.6.1 Funding
This work was supported by a grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR grant number 90DPCP0001-01-00).

NIDILRR is a center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This work does not necessarily represent the policies of NIDILRR, ACL, or HHS, and endorsement by the Federal Government should not be assumed.
Chapter 5: Conclusion

5.1 Summary of Principal Findings and Contributions to Rehabilitation and Participation Science

The purpose of this dissertation was to explore the associations between characteristics of the built environment and the community participation of AAwPD, a growing population with unique needs and lived experiences. Previous literature has documented how intrinsic, personal factors are associated with a decline in function and community participation for AAwPD, but the role of environmental factors in their community participation is comparatively less understood. Thus, further examination of the environment was warranted. Environmental factors were also a primary focus of this dissertation because of their modifiability. Participation-focused interventions targeting the environment for AAwPD are currently limited; however, many of the factors investigated in this dissertation can be addressed by community-based organizations (CBO) and rehabilitation systems that facilitate independent living.

This dissertation presented three aims through which we (1) synthesized the extant literature on built environment factors influencing the community participation of AAwPD, (2) qualitatively investigated the perspectives of AAwPD on how the built environment shapes their community participation, and (3) statistically analyzed the associations between individual, social, and environmental factors and community participation for AAwPD. The purpose of this final chapter is to summarize the key research findings in relation to our research aims and discuss the value and contributions of our findings to the field of rehabilitation and participation science. This chapter will review the limitations of the three studies and propose opportunities for future research. Our findings have important implications for CBO, rehabilitation providers,
policymakers, and urban planners and architects, which will also be presented in this final chapter.

5.1.1 Aim 1 Findings: The Scope of Literature on Built Environment Factors Influencing the Community Participation of AAwPD

Heterogeneity in approaches to measuring participation and environment have long been recognized in the literature. However, a scoping review was warranted to examine current knowledge gaps and methodological approaches in research on the distinct population of AAwPD. Our scoping review summarized the landscape of literature on the unique life course of aging with a long-term physical disability and informed the subsequent aims of this project. All articles included in the review were published after the year 2000, indicating that this area of investigation was relatively nascent.

Regarding knowledge gaps, our review determined that the most commonly studied domains of the built environment were community building accessibility, street and sidewalk accessibility, and transportation access. The role of urban versus rural residential location, land use mix, neighborhood physical and social disorder, perceived neighborhood safety, and residential density were less explored. Transportation mode was not examined by any of the 21 articles included in the review. One of the primary methodological trends was the use of self-report surveys and qualitative interviews. Objective measurement approaches (e.g., GIS/GPS-based data collection and formal accessibility audits) were utilized in four articles. These results indicated a need for more quantitatively rigorous studies and contributed to the design of the third aim of this dissertation, which tested our hypotheses with statistical modeling.

Across study findings in our scoping review, we pinpointed recurring themes. First, community-based activities are often difficult to participate in for AAwPD because of
inaccessible built environments (e.g., lack of entrance ramps, elevators, handrails, paved pathways). Second, unwelcoming or disablist messaging from the built environment can lead to disillusionment and, subsequently, reduced participation in the community. This theme was particularly present in qualitative studies, through which participants had the opportunity to describe how inaccessible environments reflect societal attitudes and a lack of consideration for persons with disabilities in general. Finally, aspects of the built environment can make traveling to destinations to participate in community activities inconvenient, arduous, or even impossible. The availability, accessibility, and reliability of transportation were frequently cited environmental factors, along with the accessibility of pedestrian pathways, sidewalks, and parking spaces. This finding informed the development of the semi-structured interview questions for the second aim, which included a focus on participants’ experiences with transportation.

5.1.2 Aim 2 Findings: Perspectives of AAwPD on the Built Environment

While much of the previous literature relevant to this dissertation has utilized qualitative methods, to our knowledge, no studies have captured the perspectives of AAwPD living in socioeconomically disadvantaged neighborhoods. Moreover, much of the literature has failed to report the socioeconomic status, neighborhood disadvantage, or racial/ethnic minority status of samples. As a result, the lived experiences and perspectives of AAwPD from multiple marginalized backgrounds are underrepresented in this research. We also had yet to understand how the COVID-19 pandemic influenced the interactions of AAwPD with the built environment. The second aim of this dissertation addressed these gaps and can therefore inform more comprehensive and equitable built environment interventions.
Our qualitative investigation of AAwPD’s perceptions of built environment factors influencing their community participation presented five key themes: (1) vigilance and sense of safety, (2) accessibility of and access to transportation, (3) community environment accessibility, (4) sense of community, and (5) access to support, spaces, and resources during the COVID-19 pandemic. These findings are significant because they illustrate that AAwPD do not interact with or appraise their community environment with discrete categorization, such as through an ICF “lens.” Rather, AAwPD likely experience their environment as a system of complex and interrelated factors, as described in Bronfenbrenner’s ecological systems theory. Additionally, AAwPD living in socioeconomically disadvantaged neighborhoods may perceive different and more severe barriers to community participation due to a compromised sense of safety (e.g., speeding traffic, stray dogs, audible gunshots, loitering). This blending of participants’ experiences of social and physical aspects of their environments also confirms the importance of the mesosystem of the ecological systems theory. Bronfenbrenner describes the mesosystem as the bidirectional connections between other influential actors in an individual’s life. The mesosystem therefore encompasses other people’s behaviors and interactions with the neighborhood environment. Our qualitative findings also confirm what the ecological systems theory proposes as a whole: that an individual’s behavior (i.e., community participation) is shaped by multiple layers of environmental influences (i.e., community building accessibility, sense of safety within the neighborhood, etc). However, for many participants, the physical environmental barriers acted as the catalysts for restrictions in community participation, but feelings of disenfranchisement and lack of choice and control caused by the physical environmental barriers seem to be equally as important. This finding highlights the themes of
“access and opportunity” and “choice and control” previously outlined by Hammel et al. in the framework of participation for persons with disabilities.71

As hypothesized in our second aim, sense of safety may have also emerged as an important theme for AAwPD because aging is associated with shrinking social networks and a loss of social capital.203,204 Increasing concerns regarding safety may be compounded by the prolonged social disadvantage and discrimination that often accompanies living with a physical disability long term. Last, this qualitative project expanded the spectrum of lived experiences currently represented in the literature, aligning with calls to better reflect the effects of multiple intersecting, marginalized identities in research.227

5.1.3 Aim 3 Findings: The Role of Transportation Mode and Urban versus Rural Residential Location

Limited access to transportation and rural residential location are built environment factors that have been identified as barriers to community participation for both older adults and persons with disabilities in general.80,222,228,229 However, literature on AAwPD lacks consensus on the significance of urban versus rural residential location.9,59,230 Additionally, the influence of transportation mode on community participation has only been examined qualitatively. The purpose of the third aim of this dissertation was to explore the quantitative associations between transportation mode, urban versus rural residential location, and a specific aspect of community participation (i.e., ability to participate in social roles and activities) among AAwPD.

Our study sample included 331 AAwPD living in Missouri. Using data from the first timepoint of a larger cohort study,26 we identified that approximately half of participants were unsatisfied with their current levels of community participation. The majority of participants reported driving themselves or relying on friends or family members to drive them. We
confirmed our first hypothesis that ability to participate in social roles and activities would be significantly different between AAwPD using private versus public transportation and living in urban versus rural areas. In exploring our second hypothesis for this aim, we determined that transportation mode, along with physical function and aging-with-disability symptoms, significantly predicted ability to participate in social roles and activities. Participants living in urban areas and using public transportation—specifically those using paratransit services—reported the highest social participation ability. While urban versus rural residential location did not serve as a significant predictor of social participation ability, rural participants reported significantly greater severity of aging-with-disability symptoms (i.e., pain, fatigue, and depression).

This project is significant because it builds upon multiple foundational studies of environmental influences on this population’s community participation. First, we analyzed in depth the role of two built environment factors that limited prior research had explored (i.e., transportation mode and residential location). Second, we added an environmental “lens” to our previous work showing that more severe aging-with-disability symptoms predicted decreased social participation for AAwPD. Third, we replicated components of a previous study using a sample with greater racial and socioeconomic diversity. Furthering our knowledge of the unique personal and environmental needs of AAwPD for optimal community participation will inform how services and programming can be tailored. For example, paratransit services may be the best facilitator of community participation for AAwPD because it provides both accessible, curb-to-curb assistance as well as a safe and reliable means of transportation. While riding paratransit, AAwPD may also be able to more easily socially connect with other community members who have lived with a physical disability for a long period of time and have shared lived experiences.
The findings of the third aim also demonstrate that environmental factors do not exist in silos but rather interact with an individual’s health conditions and other personal characteristics. These interactions are consistent with a key theory grounding this work, Lawton and Nahemow’s ecological theory of aging.\(^{66}\) For example, paratransit users may face less environmental press (i.e., fewer accessibility barriers, more flexibility and choice regarding route/destination) and may be less likely to engage in maladaptive behaviors (i.e., restricted social participation). However, compared to personal factors, the influence of environmental and social factors on community participation as determined by the hierarchical multiple linear regression were much smaller than expected. Aging-with-disability symptoms were found to account for the overwhelming majority of participants’ variance in community participation. This directly conflicts with the environmental docility hypothesis of the ecological theory of aging—that individuals with lower “competence” (i.e., AAwPD) are more greatly impacted by environmental factors. Our findings are consistent with Clarke et al.’s exploration of determinants of social participation, which found no interaction between socioenvironmental factors and individual capacity.\(^{9}\) The larger magnitude of influence of personal factors compared to environmental factors also contrasts to the County Health Rankings and Roadmaps Social Determinants of Health Model, which attributes approximately 50% of an individual’s health to extrinsic social and environmental factors.\(^{72}\)

### 5.2 Implications for Relevant Disciplines

The slow and diluted translation of research to meaningful change in practice, policy, and programming is a widely acknowledged problem.\(^{231,232}\) This dissertation attempts to help bridge the research-to-practice gap by (1) reporting on a heterogeneous sample (i.e., not focusing on only a single diagnosis) that mirrors the diverse AAwPD population that CBO commonly serve,
(2) utilizing measures (e.g., the transportation mode and community activity domain satisfaction questions of the third aim) that can be easily adopted by CBO, and (3) translating our results into language that is relevant to potentially interested parties. Below, we maximize the impact of our research by outlining the implications of our work for CBO, rehabilitation providers, policymakers, urban planners, and architects.

5.2.1 Community-Based Organizations and Rehabilitation Providers

CBO such as Area Agencies on Aging (AAA) and Centers for Independent Living (CIL) help support independence and community living for people with disabilities and aging adults across the country. Including questions about clients’ transportation access, primary mode of transportation, and general perceived built environment barriers on intake forms may inform service provision. There is also a general need for more community-based programs and services that assist individuals as they transition to or stay living in the community. In the traditional rehabilitation setting, self-management skills including problem solving how to overcome built environment barriers in the community and manage one’s chronic health conditions should be a much larger focus. Rehabilitation providers should consider the community built environment in their discharge planning to ensure sustainable and independent community participation for their patients at the intersection of aging and disability.

In our third aim, AAwPD primarily using paratransit reported the highest perceived ability to participate in social roles and activities. This result may be due to the relatively low cost, curb-to-curb service, or accessible van lifts and seating that paratransit offers in the St. Louis area. However, these findings contrast with the frustrations regarding paratransit use expressed by participants in our second aim. While paratransit may be an effective option for some AAwPD, it has limitations including lack of door-to-vehicle/vehicle-to-door assistance and
scheduling difficulties. CBO should thus also consider other approaches such as chaperone assistance, an emerging alternative form of transportation support for individuals aging with disabilities. The National Aging and Disability Transportation Center has shown promising results after piloting programs that provide chaperones for hands-on, door-to-door assistance with transportation for individuals with disabilities and older adults. Chaperones currently assist with non-emergency medical transportation (e.g., to and from doctor visits and vaccination appointments), but there are opportunities for CIL and AAA to translate this program to support transportation for leisure and social purposes for AAwPD.

5.2.2 Policymakers, Urban Planners, and Architects

Despite the monumental strides in accessibility made by the Americans with Disabilities Act (ADA), our work demonstrates that these minimum standards alone are inadequate. For example, the ADA mandates that businesses maintain an accessible entrance. Although a business may have an alternative entrance with a ramp around the back of the building, participants in our qualitative project emphasized how excluded this made them feel. Urban planners and architects should move past relying on ADA standards as the bare minimum and work to design welcoming and inclusive spaces that are accessible for all. Involving AAwPD and other members of the disability community in community planning and policymaking processes is recommended to ensure that informed design decisions are made. Similarly, policymakers should incorporate accessibility safeguards (e.g., accessible intersection crosswalk press buttons, sufficient time to cross intersections) into policies such as the Complete Streets initiative, which guides the design and maintenance of streets that are safe and usable for cyclists, pedestrians, and transit riders. Improving our collection of large-scale accessibility data can also help inform policymakers of how and where infrastructure funding should be
allocated. Policymakers should be made aware of the impact poor neighborhood and community conditions can have on AAwPD and other disability and aging populations. “Walk-abouts” or “wheel-abouts” that involve policymakers experiencing built environment barriers firsthand may be a key method for raising this awareness.

5.3 Limitations

One of the limitations of this dissertation was our use of a Missouri-specific sample. While this was an intentional decision to allow for within-state comparisons, it may prevent aspects of our results from generalizing to other regions of the United States. Missouri is reliant on cars and contains substantial urban sprawl. Further, its expansion of Medicaid was delayed compared to many other states (and had not been expanded at the time our data were collected). These features reflect the state’s unique geopolitical situation and may have impacted our findings, as we cannot assume that our participants’ experiences generalize to all AAwPD.

In the third aim, the quantified influence of environmental and social factors on the community participation of our sample was much lower than we anticipated. This may have been due to our measurement tools lacking sensitivity or specificity related to the concept of community participation. The Craig Hospital Inventory of Environmental Factors (CHIEF) poses relatively broad questions that allow for subjectivity in the respondent’s answers, and it also focuses on perceived barriers to general participation. Additionally, the survey questions regarding transportation mode did not include elements of perceived accessibility of or satisfaction with the primary transportation mode. Participants’ proximity to certain resources (e.g., CIL, AAA) may have also been more important to their community participation rather than simply the population density or commuting patterns of where they live. Stronger
environmental measurement tools specific to community participation may have produced different results or performed better in the regression model.

Limitations also occurred with the introduction of the COVID-19 pandemic into the lives and daily routines of our participants. The semi-structured interviews were conducted during the COVID-19 pandemic before many participants had access to vaccines. Interviews were thus conducted remotely and may have prevented our ability to build rapport and elicit more in-depth responses. This unprecedented event also led to social isolation and severe participation restrictions that likely influenced how participants interacted with built environments.

For the third aim, we utilized a PROMIS measure of participation in social roles and activities as our primary outcome. The overarching definition of community participation used in this dissertation requires three components: (1) the individual is actively participating in the activity, (2) the activity is intrinsically social, and (3) the activity occurs outside the home or within the home as part of a nondomestic role. While the PROMIS measure’s definition deviates slightly from our original definition of community participation, it still encompasses these three foundational aspects of community participation. Of the 35 total items in the PROMIS measure’s item bank, only three items do not explicitly meet all three criteria (e.g., “I have trouble doing my regular daily work around the house”).

Finally, while a longitudinal approach was not within the scope of this dissertation, analyses examining participation trends over time would provide additional valuable insight into the role of the built environment (e.g., whether low-resourced neighborhoods are associated with a decline in community participation over time). Additionally, our sample size of 331 is
moderately large in the context of rehabilitation and participation science, but it is comparatively small for public health research on the built environment.

5.4 Future Research

Below, we outline the primary implications of this dissertation for the future study of the built environment and community participation of AAwPD. These implications are related to measurement and strategies for addressing inequities in the built environment for AAwPD.

5.4.1 Measurement Implications

Our scoping review pointed to multiple weaknesses in the literature on built environment factors and community participation of AAwPD. We identified heterogeneity in community participation definitions and measures, which contributes to inconsistencies in our understanding of its relationship to other variables. A lack of standardized and validated quantitative community participation measures hinders our ability to demonstrate causality. Additionally, future research should include more detailed questions about mobility device use. Stratification by mobility device is warranted to further explore specific barriers for specific devices, as studies in our review showed that barriers to participation do not affect all AAwPD equally.

The findings of our qualitative study call attention to the blurred boundaries between perceived built environment and social environment barriers. Participants described aspects of their neighborhood environments that undermined their sense of safety (e.g., litter, gunfire activity, poor neighbor relationships, police activity) that subsequently led them to withdraw from their communities. These features comprise the concepts of neighborhood physical and social disorder, indicators commonly studied in public health research that can signal breakdown of social control and order. The Social Cohesion Neighborhood Scale and the Ross-Mirowsky Perceived Neighborhood Disorder Scale are examples of measurement tools used to evaluate
these constructs. Subjective and objective measures assessing these constructs should be included in future investigations of barriers to community participation for AAwPD. These measures may also help identify differences in perceived barriers across a continuum of neighborhood socioeconomic disadvantage.

Targeted measurement of the satisfaction and experiences of AAwPD with various transportation modes is necessary. Cost, route flexibility, accessibility, staff assistance, staff attitudes and training, and scheduling requirements are examples of factors that may contribute to the transportation-related decisions of AAwPD. During qualitative interviews, participants cited major inconveniences and frustrations when using paratransit, yet paratransit use was associated with greater social participation in our third aim. Further examination of the transportation needs and preferences of AAwPD will advance our understanding of how to better support their community outings. Future work should consider specifically how and why paratransit use may facilitate community participation for AAwPD.

Finally, in addition to targeted qualitative and self-report methods, more objective measurement approaches examining factors beyond what is included in the CHIEF may be needed to detect stronger associations between community participation and the environment for AAwPD. For example, the Community Health Inclusion Index (CHII) is a comprehensive evaluation tool completed by a trained rater that specifically operationalizes community health inclusion for people with disabilities. The CHII’s domains include the inclusiveness and accessibility of organizational programs, policies, and staff training, as well as seventeen built environment characteristics (e.g., transportation, street intersections, parking, restrooms, and outdoor venues and routes). Transportation network analysis is an additional objective approach that may provide insight into the accessibility and usability of various transportation
systems (e.g., roads, rail lines, highways). Evaluation of these constructs may provide valuable information regarding the capacity of transportation systems to connect AAwPD to important resources, such as CIL, AAA, and destinations for meaningful community participation.

5.4.2 Strategies for Addressing Inequities in the Built Environment

The majority of the literature on environmental barriers to community participation for persons with disabilities, including AAwPD, is situated within the early stage of research (i.e., exploration and discovery). We must use this knowledge to progress the research agenda and inform the development and implementation of built environment interventions to improve the health and participation of AAwPD. For example, an emerging area of research focuses on the development of ADA implementation interventions across the United States. Many communities are proactively removing built environment barriers for people with disabilities and improving general pedestrian infrastructure using ADA Transition Plans. Valuable research opportunities exist in partnering with communities and urban planners to establish the effectiveness of these interventions for facilitating community participation for AAwPD.

Additionally, the role of the built environment as a barrier to community participation for AAwPD can be considered a wicked problem. Wicked problems are known in policy and planning fields as socially complex problems that are difficult or nearly impossible to solve because there is no definitive solution. The path to addressing built environment barriers to participation is convoluted because (1) multiple disciplines (e.g., transportation engineers, urban planners, researchers) are involved, (2) different disciplines rely on different lexicons, (3) regulatory guidelines and policies are constantly evolving, and (4) every community differs regarding infrastructure, climate, geography, culture, and resources. Progress in addressing wicked problems first requires a shared understanding of the problem itself. Collaboration
between researchers and other disciplines during community planning processes, policymaking, urban planning, and research dissemination is key to cultivating this shared understanding.

Minimizing inequities in the built environment should also be a data-driven process. New and existing data exposing built environment inequities, such as the work of this dissertation, are important for tackling this wicked problem. Researchers recently developed a community-based participatory action framework that jointly guides a researcher’s and community partner’s co-design of built environment interventions. This framework has the potential to be scaled-up or adapted to address built environment infrastructure worldwide. Finally, specific measures and data collection methods can aid in our general shift toward intervention development and implementation. For example, researchers should harness the power of crowdsourcing to identify built environment barriers on a large scale and develop composite indices to quantify an individual’s risk of encountering built environment barriers. Artificial intelligence and machine learning software also present opportunities to automate the flagging of barriers in the built environment. These data could inform the development of a publicly accessible, user-friendly, online tool that maps accessibility data across communities.

5.5 Summary

As outlined in Figure 5.1, this dissertation presents key contributions to the field of rehabilitation and participation science. Our findings strengthen the evidence base on the profound impact that barriers in the built environment have on the community participation of AAwPD. In the first aim, we identified that the existing literature on this topic is relatively nascent, although the impact of community building accessibility, street and sidewalk accessibility, and transportation access on the community participation of AAwPD is already well documented. The results of the second aim suggested that the interpretation of built
environment barriers as negative or unwelcoming may be just as impactful as the physical barrier itself for AAwPD. The third aim demonstrated that aging-with-disability symptoms may play a larger role than socioenvironmental factors in shaping community participation outcomes for AAwPD, yet significant differences in community participation were found between participants who utilized paratransit compared to those who relied on friends or family for transportation.

Individually living at the intersection of aging and disability face a unique set of circumstances. While AAwPD experience accelerated functional decline and premature aging due to a combination of aging and disability symptoms, they are also confronted with prolonged or accumulated social disadvantages due, in part, to excluding built environment barriers. The built environment merits more attention as a modifiable intervention point for rehabilitation and participation researchers, urban planners, and other relevant disciplines to facilitate the community participation and broader inclusion of AAwPD, as well as individuals with disabilities in general.

Figure 5.1 Dissertation Summary

Individuals living at the intersection of aging and disability face a unique set of circumstances. While AAwPD experience accelerated functional decline and premature aging due to a combination of aging and disability symptoms, they are also confronted with prolonged or accumulated social disadvantages due, in part, to excluding built environment barriers. The built environment merits more attention as a modifiable intervention point for rehabilitation and participation researchers, urban planners, and other relevant disciplines to facilitate the community participation and broader inclusion of AAwPD, as well as individuals with disabilities in general.
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Appendix

Appendix A

Full Search Strategy:

Ovid Medline 467 results on 03/04/21 limit to english language

Exp Disabled persons/ OR disabilit*.mp. OR disabled.mp. Or handicapped.mp. OR physically challenged.mp.

AND (Exp adult/ OR adult*.mp. OR (elderly OR elderlies OR centenarian OR nonagenarian OR octogenarian OR septuagenarian OR sexagenarian OR geriatric* OR senium*).mp. OR (senior* adj1 citizen*).mp. OR ((older OR frail*) adj2 (age* OR elder* OR patient* OR person* OR people*)).mp.)

AND (Exp social participation/ OR participat*.mp. OR instrumental activities of daily living.mp. OR social interaction.mp. OR engagement in meaningful activities.mp. OR shopping.mp. OR ((communit* OR neighborhood* OR neighbourhood*) adj3 (engagement OR interact* OR activ*)).mp. OR shopping.mp. OR (community adj1 participat*).mp.)

AND (Exp environment design/ OR Exp environment/ OR (environment* adj4 (community OR design OR physical OR built OR home OR disabilit* OR disabled)).mp. OR neighborhood*.mp. OR (healthy adj1 place*).mp. OR (design* adj1 (universal OR "human centered" OR "human centred ")).mp. OR design for all.mp. OR neighbourhood*.mp. OR (communit* adj3 (built OR design* OR physical* OR mobil*)).mp. OR (land adj2 ("use" or usage)).mp. OR community assessment.mp. OR person-environment .mp.)
Embase 414 results on 03/04/21 restricted to English

('adult'/exp OR adult*:ti,ab,kw,de OR elderly:ti,ab,kw,de OR elderlies:ti,ab,kw,de OR centenarian:ti,ab,kw,de OR nonagenarian:ti,ab,kw,de OR octogenarian:ti,ab,kw,de OR septuagenarian:ti,ab,kw,de OR sexagenarian:ti,ab,kw,de OR geriatric*:ti,ab,kw,de OR senior*:ti,ab,kw,de OR ((senior* NEAR/1 citizen*):ti,ab,kw,de) OR (((older OR frail*) NEAR/2 (age* OR elder* OR patient* OR person* OR people*)):ti,ab,kw,de)) AND ('social participation'/exp OR participat*:ti,ab,kw,de OR 'instrumental activities of daily living':ti,ab,kw,de OR ((social* NEAR/1 interaction*):ti,ab,kw,de) OR 'engagement in meaningful activities':ti,ab,kw,de OR shopping:ti,ab,kw,de OR (((community* OR neighborhood* OR neighbourhood*) NEAR/3 (engagement OR interact* OR activ*)):ti,ab,kw,de)) AND ('physically disabled person'/exp OR 'physical disability'/exp OR ((physical* NEAR/4 (challeng* OR imped* OR disab* OR function*)):ti,ab,kw,de) OR handicapped:ti,ab,kw,de) AND ('environmental planning'/exp OR 'home environment'/exp OR (environment* near/4 (community OR design OR physical OR built OR home OR disabilit* OR disabled or person)):ti,ab,kw,de OR neighborhood*:ti,ab,kw,de OR ((healthy NEAR/1 place*):ti,ab,kw,de) OR ((design* NEAR/1 (universal OR 'human centered' OR 'human centred')):ti,ab,kw,de) OR 'design for all':ti,ab,kw,de OR neighbourhood*:ti,ab,kw,de OR ((communit* NEAR/3 (built OR design* OR physical* OR mobil*)):ti,ab,kw,de) OR ((land NEAR/2 ('use' OR usage)):ti,ab,kw,de) OR 'community assessment':ti,ab,kw,de) AND ('article'/it OR 'article in
1. TS=(disabilit* OR disabled Or handicapped )

2. TS=(adult* OR elderly OR elderlies OR centenarian OR nonagenarian OR octogenarian OR septuagenarian OR sexagenarian OR geriatric* OR senium* OR (senior* near/1 citizen*) OR ((older OR frail*) near/2 (age* OR elder* OR patient* OR person* OR people*)))

3. TS=(participat* OR “instrumental activities of daily living” OR (social* NEAR/1 interaction*) OR “engagement in meaningful activities” OR shopping OR ((communit* OR neighborhood* OR neighbourhood*) NEAR/3 (engagement OR interact* OR activ*)) )

4. TS=( neighborhood* OR (healthy near/1 place*) OR “design for all” OR neighbourhood* OR (communit* near/3 (built OR design* OR physical* OR mobil*)) OR (environment* NEAR/4 (community OR design OR physical OR built OR home OR disabilit* OR disabled)) OR “community assessment” )

5. TS=( (physical* near/4 (challeng* OR imped* OR disab* OR handicapped OR function*)) OR walking OR (motor near/2 activ*) OR wheelchair* OR (wheel near/1 chair*) OR walker* OR cane OR canes )

6. #1 AND #2 AND #3 AND #4 AND #5

7. #1 AND #2 AND #3 AND #4 AND #5 Refined by: DOCUMENT TYPES: ( ARTICLE OR EDITORIAL MATERIAL OR REVIEW OR EARLY ACCESS OR LETTER ) AND
Psycinfo 122 results on 02/25/21 Narrow by Language: - english Limit to: Source Type:
Academic Journals (387) (excluding books and dissertations)

TX ( (disabilit* OR disabled Or handicapped ) ) AND TX ( (adult* OR (elderly OR elderlies OR centenarian OR nonagenarian OR octogenarian OR septuagenarian OR sexagenarian OR geriatric* OR senium*) OR (senior* N1 citizen*) OR ((older OR frail*) N2 (age* OR elder* OR patient* OR person* OR people*)) ) ) AND TX ( (participat* OR "instrumental activities of daily living" OR (social* N1 interaction*) OR "engagement in meaningful activities" OR shopping OR ((communit* OR neighborhood* OR neighbourhood*) N3 (engagement OR interact* OR activ*))) ) ) AND (DE "Built Environment" OR DE "Home Environment" OR DE "Person Environment Fit" OR TX ( (neighborhood* OR (healthy N1 place*) OR "design for all" OR neighbourhood* OR (environment* near/4 (community OR design OR physical OR built OR home OR disabilit* OR disabled)) OR (communit* N3 (built OR design* OR physical* OR mobil*)) OR "community assessment" ))) AND TX ( ( (physical* N4 (challeng* OR imped* OR disab* OR handicapped OR function*)) OR walking OR (motor N2 activ*) OR wheelchair* OR (wheel N1 chair*) OR walker* OR cane OR canes ) )

Clinicaltrials.gov 4 results on 3/4/21

built environment AND disability AND adult
### Appendix B

Data Extraction Form adapted from the Cochrane Collaboration

#### 1. General Information

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<td>2. <strong>Report title</strong></td>
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<td>(including role of funders)</td>
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<td>8. <strong>Possible conflicts of interest</strong></td>
<td>(for study authors e.g., not reported)</td>
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<td>9. <strong>Notes</strong></td>
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#### 2. Eligibility

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<td>11. <strong>Population description</strong></td>
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<td>12. <strong>Focused diseases / conditions</strong></td>
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13. **Types of outcome measures**  
   (Community participation; neighborhood built environment)

14. **Decision** (with reasons for either inclusion or exclusion)

15. **Notes:**

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**DO NOT PROCEED IF STUDY IS EXCLUDED FROM REVIEW**

### 3. Population and setting

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| 17. Source/setting of the population  
   (e.g., urban, rural, particular ethnic group) | |
| 18. Method/s of recruitment of participants | |
| 19. Notes: | |

### 4. Methods

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<tr>
<td>20. Aim of study</td>
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### 5. Participants

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<tr>
<th>Description as stated in report/paper</th>
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<tbody>
<tr>
<td>24. Total number of participants/Sample size</td>
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<tr>
<td>25. Age group</td>
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<tr>
<td>26. Disability status</td>
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<td>27. Race</td>
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<td>28. Notes:</td>
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### 6. Outcomes

<table>
<thead>
<tr>
<th>How outcomes are measured: Community Participation</th>
<th>Description as stated in report/paper</th>
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<tbody>
<tr>
<td>29. Outcomes: Community Participation</td>
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<tr>
<td>30. Self-reported or objectively reported outcomes</td>
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<tr>
<td>31. Outcome definition</td>
<td></td>
<td></td>
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<tr>
<td>32. Is outcome/tool validated? (Yes/No/Unclear/Not mentioned)</td>
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<td>33. Notes:</td>
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<table>
<thead>
<tr>
<th>How outcomes are measured: Neighborhood Built Environment</th>
<th>Description as stated in report/paper</th>
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<tbody>
<tr>
<td>34. Outcomes: Neighborhood Built Environment</td>
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<td>35. Self-reported or objectively reported outcomes</td>
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<td>36. Outcome definition</td>
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<td>37. Is outcome/tool validated? (Yes/No/Unclear/Not mentioned)</td>
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<td>38. Notes:</td>
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7. Results and findings

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<th>Other Relevant Outcomes (Note: detail here)</th>
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<tbody>
<tr>
<td>39. Outcome</td>
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<tr>
<td>40. Subgroup (if any, e.g., age-specific prevalence reporting)</td>
<td></td>
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<tr>
<td>41. Results</td>
<td></td>
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<tr>
<td>42. Response/non-response rate</td>
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<tr>
<td><strong>43.</strong> Response/non-response rate</td>
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<tr>
<td><strong>44.</strong> Any other results reported</td>
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<tr>
<td><strong>45.</strong> Unit of analysis <em>(e.g., by individuals)</em></td>
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<tr>
<td><strong>46.</strong> Statistical methods used and appropriateness of these methods <em>(e.g., proportion/%s, RR/OR)</em></td>
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<tr>
<td><strong>47.</strong> Whether results weighted? <em>(e.g., Yes/No)</em></td>
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<td><strong>48.</strong> Notes:</td>
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### 8. Limitation and mitigation strategies

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<td><strong>50.</strong> Limitation</td>
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<td><strong>51.</strong> Strategies to overcome the limitation</td>
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### 9. Conclusion

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<td><strong>53.</strong> Key conclusions of study authors</td>
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<td><strong>54.</strong> Frameworks or theories referenced</td>
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