How Far Can You Walk? Hidden Mobility Disabilities and Community Participation

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Abstract

Accessibility hinges on the interaction between an individual's functional abilities and accommodation of possible limitations in the built environment. While accommodation for persons with visible mobility disabilities (most commonly wheelchair users) is occurring, those needed for persons with hidden mobility disabilities (HMD) have been overlooked. HMD refers to the ability to walk independently but for only a short distance (35-52.5 feet) and to stand unsupported but only for a brief time (1-2 minutes).

This study compared persons self-identified as having HMD with persons reporting that they had no mobility limitations regarding various dimensions of community participation. The results indicated that there were statistically significant differences (p < .001) between the two groups, with those with HMD having significantly more problems accessing venues like open houses, standing in line to receive a service, shopping at a supermarket or mall, using public transportation, accessing a building whose parking was over 35 feet away, or accessing a check-in counter more than 35 feet from an entrance.

A recent focus on "walkable" urban environments with pedestrian-only public spaces, as well as "shared mobility" initiatives, plus an assumption that "walkable" encompasses a distance of at least two to three blocks requires some re-examination in order to ensure the possibility of social engagement and community participation of persons with HMD.

Keywords: hidden mobility disabilities, livable cities, walkability, urban design, accessible, mobility limitations, accommodation, social engagement, community participation

How Far Can You Walk? Hidden Mobility Disabilities and Community Participation

What do we want from urban life? Priorities are gradually shifting from focusing on urban centers as efficient economic generators to an equal valuing of quality of life (Lennard 2017). Movements like Making Cities Livable present a wholesome image of an urban fabric that is scaled to human interaction and enjoyment of green spaces, visually appealing, comprised of "short" distances to navigate, environmentally sustainable, and supportive of community participation and social engagement. At the heart of this vision is an unspoken assumption that affects the participation ability of millions of community members – that the foundational concept of a "walkable" distance is 10 minutes, or one-quarter of a mile, or five blocks, or 1,320 feet.

Unfortunately, this concept of "short" distance creates an unnecessary barrier for persons with hidden mobility disabilities. The need to question *distance* as an accessibility barrier has been masked by the measurements embedded in national and international surveys on disability where the minimum distance measured has ranged from two blocks (Clarke et al. 2008) to two kilometers (Rantakokko et al. 2014). If the barrier of distance can be removed, "the subsequent consequences for participation in life situations are nontrivial if adults with physical impairments are better able to engage in employment, recreation, and social interaction; to access health-care facilities; or simply to go shopping for their daily needs" (Clarke et al. 2008, 512).

What Is a Hidden Mobility Disability?

A person with a hidden mobility disability (HMD) is able to walk independently but only for a short distance and to stand unsupported but only for a brief time. The disability is "hidden" because the person looks "normal" and (unless observed over time) as though there were no mobility impediment, as compared with a "visible" mobility disability where the use of a mobility aid like a wheelchair or scooter makes it clear to the observer that mobility is compromised.

It is important to keep in mind that, from a health perspective, remaining independently mobile as long as possible has many benefits. Early adoption of a scooter or wheelchair is not an optimal solution to the barrier of distance to be walked, though many with HMD hire such aids for short-term use when faced with unavoidable long distances, such as at conference facilities or on large cruise ships.

Estimates of those with HMD in the U.S. are that of the 9.9 percent who have trouble walking, 3.6 percent do not use mobility aids – meaning that over 10.6 million Americans are likely to have HMD (Erickson, Lee, and von Schrader 2016). In Canada, it has been estimated that that 1.97 million Canadians have a mobility disability and that 19 percent of those persons, or at least 375,000 Canadians, walk without a mobility aid (Bizier, Fawcett, and Gilberts 2016).

While the need for distance accommodation for those with HMD is typically acknowledged in the issuance of disability parking decals, research on the nature and consequences of this disability was not undertaken until Fall 2016. The initial research study published by the Hidden Mobility Disabilities Alliance in March 2017 (Berkowitz and Riddle 2017a) reported the following findings of relevance to urban design:

Short distance for walking: 35 feet (with up to 70 feet walkable for 56% of respondents)
Brief time for standing: 1-2 minutes (with up to 5 minutes possible for 61%)

In addition, the research documented that 22 percent of respondents could not use antiinflammatory medication to reduce pain and that respondents had the following consequences if they walked too far:

- 77% Increased joint pain
- 52% Walk more slowly until almost not moving
- 46% Increased difficulty breathing
- 43% Have trouble walking at all the next day
- 40% Begin to stagger and lose balance

The research identified over 15 health conditions resulting in hidden mobility disabilities, of which arthritis, heart disease, and breathing difficulties were the most common. In addition, follow-up research results on persons from 15 years of age to over 85 indicated that, while some underlying health conditions worsen with age, HMD affects persons of all ages (Berkowitz and Riddle 2017b). The single significant issue by age was that persons with HMD under 55 years of age were significantly *more* likely to have difficulty as a result of walking or standing than were those with HMD who were older than 55 years. As well, younger people with HMD were more likely to be greeted by irritation or anger when they walked more slowly due to pain when compared with those over 55.

Hidden Mobility Disabilities and Urban Design

The social model of disability assumes that disability is not inherent to the person but rather is a social disadvantage that results from the interaction between functional limitations and a lack of accommodation in the environment. As stated in the 2006 UN *Convention on the Rights of Persons with Disabilities*, "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (Preamble, e). A basic tenet of community life, enshrined in that *Convention*, is that persons with hidden mobility disabilities are entitled to "full and effective participation and inclusion in society" (Article 3, 3).

The *Convention* goes on to define "accessibility" as enabling persons with disabilities "to live independently and participate fully in all aspects of life...[including] access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public" (Article 9, 1). To be accessible, a person with HMD needs to be able, without assistance, to approach, enter, pass to and from, and make use of a public area and its facilities.

Attention to removing barriers for persons with mobility limitations has focused to date primarily on access for persons with *visible* mobility disabilities, especially those using wheelchairs or scooters. Accommodations such as ramps and sidewalk cut-outs, plus changes in building codes that are focused on enhanced *maneuverability*, have gone a long way to making public spaces more accessible for those using wheelchairs or scooters.

Urban planning and the design of public spaces have, however, overlooked *distance* as a potential accessibility barrier – which is the leading barrier for those with HMD. Initiatives such as walkable cities assume that the key distance issue is identifying the point at which persons are

likely to abandon walking in favor of some type of transportation – with that point assumed to be one-quarter of a mile, or 1,320 feet (Speck 2013).

With both health and environmental goals in mind, cities have begun initiatives to encourage walking (e.g., pedestrian-only urban centers) or biking (e.g., bike lanes, rental bike racks replacing on-street parking) and to discourage driving. What if walking more than 35 feet (or one regular school bus in length), let alone 1,320 feet, engenders serious health consequences for a person?

For persons with HMD, their home environment is not generally an issue unless they live in a high-rise where parking is at a distance and/or corridors are lengthy. The primary access issues arise when the person enters or contemplates entering public/social space. An extensive literature on the physical and psychological importance of community participation and social engagement outside the home underscores the importance of that space being accessible to persons with HMD. As well, "wellbeing is enhanced through mobility as movement in physical space because the latter enables independence or subjectively experienced autonomy, as well as interdependence in the sense of relatively equal and reciprocal social relations with other people" (Ziegler and Schwanen 2011, 758).

Forsyth (2015) has provided an overview of nine themes in labelling an environment as being "walkable," of which two are of particular relevance to urban design and persons with HMD: *traversable* (or suitable for walking), and *compact* where "destinations are close enough to get to in a reasonable time on foot" (p. 10). The initial research on persons with HMD verified that, for walking to be feasible without undue pain, the surface to be walked on needed to be flat, even, and stable (Berkowitz and Riddle 2017a) – thus traversable.

It is with the notion of "compact" where the accessibility problem lies. Jeff Speck's book (2013) and TED talk on walkable cities has led communities to focus on their Walk Score and cities to develop Walkability Strategies. Correspondence between the author and Speck regarding the barrier created by assuming that 1,320 feet is "walkable" resulted in his response of "benches!" as the solution. If a person with HMD walks further than is comfortable, they typically need a minimum of five minutes sitting down to recover (Berkowitz and Riddle 2017a). Combine this finding with the fact that a minimum of 24 benches would be needed, at an average spacing of 50 feet, and the result would indicate that it would take a person with HMD approximately two hours of walking and sitting and resting to traverse the 1,320 feet distance without serious health consequences! That is not "compact" by any stretch of the imagination. A "10-minute" walking distance for a person with HMD, provided that there were a bench half way to rest on, would be no more than 100 feet.

Research Methodology and Results

Given the lack of research to identify access barriers for persons with HMD, the author began contacting a range of researchers on disability-related issues and conferring with statisticians at the World Health Organization, the UN Statistical Commission, the U.S. Census Bureau, and Statistics Canada in Fall 2016. The methodological issues encountered are summarized at www.HiddenMobilityDisabilities.com/methodological-issues/. To help address this gap in the research literature, the author designed a survey similar to those in use but focused on shorter distances, briefer times standing, and a range of potential limitations for those with hidden mobility disabilities. The author then asked the various statistical agencies to review it in order to

ensure that it was compatible with existing surveys and would produce relevant and comparable results, and made modifications as suggested.

The Survey on Hidden Mobility Disabilities was launched in January 2017 on SurveyMonkey. In order to assist respondents in gauging distance, the average length of a school bus (or 35 feet) was used. Within a year, the survey had 2,754 respondents of which 885 had identifiable hidden mobility limitations. The general findings of the Survey regarding the barriers faced by persons with HMD have been reported at www.HiddenMobilityDisabilities.com/research-report/.

For the purpose of this study, data from the 2,563 Survey respondents who had answered all questions as of 2 February 2018 were downloaded from SurveyMonkey and subdivided into two samples: those self-identified with HMD (n=671) and those reporting no mobility disabilities (n=1,742). While the Survey was targeted to those with HMD, many others had responded with comments like, "I know I don't have a mobility disability, but I found the questions so interesting that I've answered anyway."

As can be seen from the results summarized in Table 1, there are clear findings that persons with HMD face significant restrictions in community participation given the manner in which public spaces are currently designed. The inability to attend and participate in open house type activities is the number one challenge reported. Not only does this finding have implications for the design of spaces where such events take place, but it is also a warning about not relying on the popular method of "open houses" to collect public feedback on plans for public spaces.

Given the finding that the majority of persons with HMD can only stand unsupported for 1-2 minutes, it is not surprising that having to wait in line for service should be the second most difficult access barrier encountered. It would help if the norm for office or box office spaces became a design such that, as soon as one entered, one could take a number and sit down. Large retail spaces also present an immediate accessibility challenge. While a few large supermarkets provide scooters at the entrance for public use and some malls and department stores place benches strategically for resting, there is no standard yet for ensuring accessibility and importantly usually no way for a person with HMD to find out ahead of time what to expect.

Table 1: Top Three Activities That Are Problematic Because of Difficulty with Walking or Standing

Problem with:		% of	Chi-square	
	Problem?	HMD	No Mobility Issue	P-value
Attending open houses or events where	No	18.5%	61.4%	p < .001
everyone stands	Yes	81.5%	38.6%	p < .001
Standing in line for a service	No	23.8%	71.4%	p < .001
	Yes	76.2%	28.6%	p < .001
Shopping in a supermarket or at a mall	No	26.7%	76.0%	p < .001
	Yes	73.3%	24.0%	p < .001

Use of public transportation is the fourth most difficult issue for persons with HMD and a top priority for those focused on a "walkable" or "livable" city. Data in Table 2 indicate that, for

those with no mobility issue, using public transportation is generally no problem. For those with HMD, the picture is less clear, due in part to the availability in some jurisdictions of public transportation specifically for those with mobility disabilities (though informal reports and personal experience indicate that such transportation is often unreliable and time-consuming). If one examines the data further, one can see that the response is influenced by how far the person can comfortably walk. If they could walk 70 feet or more without difficulty, fewer indicated that using public transportation was a problem. If they could walk no more than 50 feet comfortably, then using public transportation became a problem for the majority of respondents.

Table 2: Results Regarding Use of Public Transportation Because of Difficulty with Walking or Standing

Sample:		% of Respondents		Chi-square
	Problem?	HMD	No Mobility Issue	P-value
Totals	No	51.4%	86.4%	m < 001
	Yes	48.6%	13.6%	p < .001
HMD: can walk no more than 52.5 feet (or	No	46.8%		
1.5 school buses)	Yes	53.2%		
HMD: can walk at least 70 feet (or 2	No	54.2%		
school buses)	Yes	45.8%		

The same pattern is apparent when persons with HMD are faced with accessing facilities with parking more than 35 feet from the entrance (see Table 3). While the general public sees no problem, those with HMD who cannot walk comfortably more than 52.5 feet do find access problematic. While they might be able to reach the entrance without undue pain or shortness of breath, they would still have a distance to walk before reaching their final destination within the building.

Some buildings provide seating just inside the entrance where one could rest, but that is not normally the case; and a person with HMD is unlikely to be able to see from the parking lot that such seating was available. In addition, municipalities are moving to consolidate parking in parking lots or garages with a zoning stipulation that parking must be available within 1-2 blocks – i.e., up to 700 feet away from the building and thereby inaccessible to a person with HMD.

Table 3: Results Regarding Use of a Facility Where Parking Is More Than 35 Feet from the Entrance Because of Difficulty with Walking or Standing

Sample:		% of	Chi-square	
	Problem?	HMD	No Mobility Issue	P-value
Totals	No	60.7%	94.7%	p < .001
	Yes	39.3%	5.3%	
HMD: can walk no more than 52.5 feet	No	40.0%		
	Yes	60.0%		
HMD: can walk at least 70 feet	No	72.9%		
	Yes	26.1%		

A similar pattern of response arises in relation to facilities where one must check in - like a hotel or hospital or fitness center or airport. Even supposing that the person with HMD starts walking just outside the facility (instead of walking from a distant parking lot), the majority of those who can walk comfortably no more than 52.5 feet report that use of the facilities would present an access problem.

Table 4: Results Regarding Use of Facilities Where the Check-In Desk is More 35 Feet from the Entrance Because of Difficulty with Walking or Standing

Sample:	_	% of Respondents		Chi-square
	Problem?	HMD	No Mobility Issue	P-value
Totals	No	61.8%	95.0%	p < .001
	Yes	38.2%	5.0%	
HMD: can walk no more than 52.5 feet	No	44.4%		
	Yes	55.6%		
HMD: can walk at least 70 feet	No	72.2%		
	Yes	27.8%		

Discussion of Findings

Research has already clarified that activity/mobility limitation in and of itself does not result in community participation restriction (Wilkie et al. 2007). We can see from the above reported results that community participation by persons with HMD is moderated instead by the amount of walking and standing required for that participation. If distance is limited to 35 feet and standing is limited to no more than two minutes or the person knows the parameters ahead of time and can strategize, there is no reason to believe that community participation would be restricted. Unfortunately those conditions are seldom the case. The good news is that the access barriers for persons with HMD are modifiable if land use planning and building codes are changed appropriately (Theis and Furner 2011).

Each of the new initiatives towards increasing the quality of life in urban living makes two critical assumptions that need to be addressed if persons with HMD are have the opportunity for barrier-free community participation:

Assumption #1: An optimum distance for daily walking is somewhere between 700 feet (Southworth and Ben-Joseph 2003) and 3,960 feet (Levasseur et al. 2015).

As the research results above have shown, even the shorter distance of 700 feet is far beyond the distance that a person with HMD can walk without negative health consequences. Sometimes this assumption is phrased as time: walk five or ten or fifteen minutes. Research on persons with HMD has shown that 56.7 percent reported not being able to walk even five minutes on a flat surface without incurring increased pain or shortness of breath (Berkowitz and Riddle 2017a).

Certainly some walking is healthy and desirable (Frank et al. 2010), and persons with HMD do get activity moving around within their home environment. But to walk for pleasure and social interaction, the environment needs to be designed for very short walks of 35 to 50 feet, with an enjoyable visual environment and a place to rest before starting back.

Assumption #2: Both health and quality of life can best be addressed by designing urban living around walking and biking and public transportation rather than the use of cars.

Most people with HMD have as much or more difficulty with biking as with walking since the most common joints causing pain (knees and hips) are the ones actively involved in biking. This particular assumption has immediate negative consequences for persons with hidden mobility disabilities regarding the quality of their community engagement, and even regarding their ability to access basic services like health care.

Initiatives to favor bikers and discourage drivers have had the consequence to date of removing on-street parking near service offices, forcing persons with HMD to choose from three less than optimal possibilities: (a) walk much further than they can, thus incurring serious health consequences; (b) park at a distance and pay for a taxi to take them to their destination; or (c) depend on friends and relatives to drive them to where they need to go. None of these support "full and effective participation and inclusion in society" (United Nations 2006, Article 3, 3).

The assumption that those needing transportation will and should turn to public transportation (Clarke and Gallagher 2013) is again problematic. While public transportation may be the answer for those who can comfortably walk at least 70 feet, those whose comfortable walking distance is more restricted indicate that relying on public transportation is problematic – both in walking to and from the transit stop, and in standing to wait for service.

A quote from a respondent with HMD expresses the challenge faced very well: "If not for my car, I would never be able to get out."

To further disadvantage persons with HMD, there is a recently-released set of *Shared Mobility Principles for Livable Cities* (Chase 2017) endorsed by a range of shared ride corporations, urban planners, and transportation organizations. Box 1 provides an excerpt with text that would disadvantage persons with HMD highlighted in bold italics. These *Principles* aim to create a public transportation environment in which people are expected to be walk several blocks to and from shared transportation options. While *Principle* #5 does reference equity in access, the overall tenor is chilling for persons with HMD. As an example, a recent release from Uber (a signatory to the *Principles*) stated that riders would be provided with "the best spot for pickup within a few blocks of your location...[and then provided with] walking directions for the last few blocks to your final destination."

Box 1: The Shared Mobility Principles for Livable Cities

- 1. **We plan our cities and their mobility together.** The way our cities are built determines mobility needs and how they can be met....
- 2. **We prioritize people over vehicles.** The mobility of people and not vehicles shall be in the center of transportation planning and decision-making. Cities shall prioritize walking, cycling, public transport and other efficient shared mobility, as well as their interconnectivity. *Cities shall discourage the use of cars....*
- 3. We support the shared and efficient use of vehicles, lanes, curbs and land. Transportation and land use planning and policies should *minimize the street and parking space used per person...*

Even if the use of cars is not actively discouraged, persons with HMD face challenges regarding how much walking will be involved once they have driven to their destination. The distance from where they can park to where they need to go can be an unpredictably long distance. Disabled parking spaces, if available, may still require considerable walking to elevators or building/mall entrances and then out to a destination office or retail facility. Paid parking may involve additional walking to reach the pay station and then return to place a ticket on the vehicle. In some cases, parking lots or garages have chosen to place disabled parking spaces in a far corner – with extra space convenient for wheelchair users – often doubling the amount of walking required.

The overriding issue for persons with HMD who are venturing to new places or new community events is a lack of ability to determine how much walking there will be. As a consequence, as one respondent put it: "I don't go if I worry that it will be too far to walk. I stay home." This realistic fear of being placed in an unavoidably unhealthy situation clearly works against community participation and social inclusion and engagement. As the example in Box 2 indicates, attempts to be accommodating may not succeed if the realities of distance are not embraced.

Box 2: An Example of Ineffective HMD Accommodation

A bank presents itself as accessible. Here is the cumulative barrier for a person with HMD who can comfortably walk 35 feet, or 14 steps = 5 feet):

A handicapped parking space is available 20 feet from the entrance, and 10 feet inside the entrance there is a sign: "If you need service sitting down, let us know." The nearest teller (who is busy with a customer) is another 15 feet away and it seems impolite to shout out. The Customer Service desk is 30 feet to the left, and a lower teller window with chairs is at the back of the bank, 40 feet away. What would be the solution that limited walking to 35 feet?

An additional issue is the matter of the variety of roles one plays in society. There are many approaches to describing roles, but they would include leader, facilitator, expert, negotiator, organizer, consensus-builder, and many more. One's ability to perform a range of such roles effectively provides a sense of potency and purpose and enhances self-esteem. However, the execution of such roles outside of the home requires that the person be able to participate meaningfully in community life. The opportunity to play active roles in one's community can disappear if one fails repeatedly to show up. Thus, creating unnecessary barriers to community participation by persons with HMD can have significant negative consequences beyond being able to engage in a particular event (Hammel, Magasi, and Heinemann 2015). The roles that one is able to play, or their limitation as mobility issues intrude, can have a profound effect on one's self-image and life satisfaction (Gignac et al. 2013).

Finally, access to community participation for persons with HMD is not only a human rights requirement but it is also a matter of the community being enriched by their contributions and they themselves retaining a critical sense of autonomy (Rantakokko et al. 2017). Being able to control one's own social engagement enhances self-esteem and self-efficacy (Sundar et al. 2016), which contributes to good health. Box 3 lists some questions for beginning to develop best practices in making full community participation accessible to persons with HMD.

Box 3: Sample HMD Design Questions for Best Practices

Here is a beginning list of questions to ask in order to determine accessibility for persons with HMD:

- 1. How far will the person have to walk from parking to the entrance to service by the usual route? If that is more than 20 feet, is there seating at the entrance so that the person can rest before walking on?
- 2. How far will the person have to walk from the building entrance to where service will actually be provided?
- 3. Will the person be required to walk from one location to another (e.g., from receiving service to a cashier), and if so, how far?
- 4. How far is a rest room from the entrance to service?
- 5. Does the person need to take an elevator? If yes, is there seating to rest while waiting for the elevator?
- 6. Is there a reception desk for the service? If yes, how far is it from the entrance? If yes, can the person be served seated at the reception desk?
- 7. If the facility is a self-service environment, how far is it from the entrance to the self-service location? Can one be seated while self-serving? How far away is assistance if that is needed?
- 8. If the person needs to wait in line, is it possible to take a number and sit down until called? If yes, how far is it from the entrance to the ticket stand? How far from the ticket stand to seating? How far from seating to where service is actually provided?

Conclusion

"The built environment can either facilitate or hinder full participation in mainstream society and is considered fundamental to integration, inclusiveness and equality for all" (Banda-Chalwe, Nitz, and de Jonge 2013). If we believe this statement to be true, then we need to re-examine land use protocols and building codes to ensure that persons with HMD are not excluded from full community participation just because they need to limit the distance they walk and the time standing unsupported in order to avoid serious health consequences.

All too often, persons with HMD are placed in positions where, if they wish to engage in society at large, they have to exchange that participation for crippling pain and increased breathing difficulties. It must be possible to update our vision of a "livable city" to support healthy community participation by those with HMD.

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