

Accessibility for Persons with Hidden Mobility Disabilities
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Background

Most of the research on people with mobility limitations has been on those with visible mobility issues – i.e., those using wheelchairs or scooters. For these people, *maneuverability* is a primary and important access issue. Clear accommodation guidelines have gradually developed in relation to the built environment, including door widths, ramp pitch, placement of automatic door openers, etc.

The accessibility needs of people who are independently mobile but who have trouble walking more than a short distance or standing unsupported for more than a brief time have been literally invisible both to the general public and within the disability community. Census questions about being able to walk a mile or stand for 60 minutes have not captured the lived experience of persons with hidden mobility disabilities (HMD). For persons with HMD, *distance* and *time standing* are primary access barriers, not maneuverability; however, there have been no guidelines that require attention to distance or to minimizing the time that people need to stand.

The lack of awareness unfortunately extends to persons with HMD themselves. All too often they allow themselves to be pressured into walking further than is healthy (“it’s just over there – not far”) or do not ask for wheelchair assistance in facilities like airports because “after all, I can walk – some.” People who “don’t want to be a bother” are usually not aware that pushing themselves to walk or stand longer than is comfortable can have specific health consequences.

In order to have informed discussions to ensure that persons with HMD are able to participate fully and effectively in society on an equal basis with others (as set out in the 2006 United Nations *Convention on the Rights of Persons with Disabilities*), it is critical to have data on these hidden mobility limitations. We need a common understanding of what constitutes a “short distance” to walk or a “brief time” to stand. The online *Survey on Hidden Mobility Disabilities* was launched in January 2017 to begin gathering such data.

This research report focuses on the responses of the first 648 qualified respondents, primarily from Canada. The results being reported are reliable within ± 4 percent at the 95 percent confidence level. A discussion of methodological issues in research on hidden mobility disabilities can be found at <http://hiddenmobilitydisabilities.com/methodological-issues/>. Subsequent research reports based on the *Survey on Hidden Mobility Disabilities* will include data from the U.S.A. and other jurisdictions.

Prevalence of Hidden Mobility Disabilities

Data from Statistics Canada’s *Canadian Survey on Disability, 2012* indicate that 7.2 percent of Canadians have a mobility disability, which in 2016 population figures equates to 2.6 million people. Of these, 18.7 percent, or 488,560 in 2016 terms, reported not using a mobility aid. So we can estimate that approximately half a million Canadians, at a minimum, have HMD.

The U.S. Census Bureau’s *Americans with Disabilities 2010* report indicated that 12.6 percent of the U.S. population have difficulty walking or climbing stairs, which would translate into 40.8 million Americans in 2016 terms. Of those, 4.5 percent, or 1.8 million people, did not use a wheelchair. In addition, the Census Bureau reported that 10.0 percent, or 4.1 million in 2016 terms, reported difficulty standing. Since neither the Census Bureau nor Statistics Canada were specifically targeting persons with

HMD and persons with HMD do not necessarily self-identify as having a disability, it is safe to conclude that these data underestimate the prevalence of hidden mobility disabilities.

While HMD can occur at any age, there is an assumption that it is most common in older people. Indeed, since osteoarthritis is a progressive disease and is also one of the most common causes of HMD, such an assumption would make sense. However, organizations focused on arthritis warn that it can occur at any age. Respondents to this survey ranged from 15 years old to over 80 years old.

Individuals with HMD usually manage effectively within their home environment, where they can arrange matters to minimize any limitations. Access issues arise from the interaction between their mobility limitations and the structure of the external environment, combined with the expectations of others regarding what constitutes a “short distance” or a “brief time.”

Of those taking the survey, 31.4 percent indicated that they walk unaided outside of their home at least once a day, thus exposing themselves to potential accessibility issues. By contrast, 30.4 percent indicated that they could not walk outside without a cane or other mobility aid, which potentially could provide a visual cue about their having a mobility limitation.

Distance as a Primary Access Barrier

For those persons with HMD, the distance to be walked is the primary and most significant access barrier. It is also the most socially challenging. When someone can walk without visible support, people usually expect that they have no mobility disability and assume that distance will pose no problem. At issue, in part, is what is perceived to be a “short distance.” Generally speaking, persons without a mobility limitation consider one block (325 feet, or 100 meters) to be “not that far.”

To help respondents estimate the distance they could comfortably walk on a flat surface without a mobility aid, the survey used a standard yellow school bus, which is 35 feet long. Survey data show that 77.1 percent of respondents could comfortably walk no more than 105 feet (32 meters, or 3 school buses) without a mobility aid, with 33.2 percent not able to comfortably walk unaided more than 35 feet (10.7 meters):

- 66.8% can walk 52.5 feet, unaided and without excessive pain
- 56.4% can walk 70 feet, unaided and without excessive pain
- 42.8% can walk 105 feet, unaided and without excessive pain

To avoid the challenge of people estimating distance accurately, Statistics Canada has adopted the approach of asking how long people can walk comfortably, with an assumption that most people with a mobility limitation would take 10 minutes to walk 100 meters. Survey results showed that 39.0 percent of respondents reported being able to walk for no more than two minutes, while 31.3 percent could walk up to 10 minutes and 13.1 percent up to 15 minutes. The data for distance compared with time are shown in Table 1 and do not demonstrate a clear relationship.

Table 1: The Relationship Between Perceived Distance and Perceived Time

Distance Walked on a Flat Surface	Length of Time Walking Unaided on a Flat Surface					Total
	2 min. or less	3 - 5 min.	6 – 10 min.	11 – 15 min.	15+ min.	
35 ft. or less	23.8%	5.8%	2.0%	0.9%	0.6%	33.1%
36 - 70 ft.	9.0%	8.6%	4.2%	1.6%	0.6%	24.0%
71 - 105 ft.	4.2%	8.2%	3.6%	3.3%	0.5%	19.8%
106 – 210 ft.	2.0%	7.2%	8.4%	3.4%	2.2%	23.2%
Total	39.0%	29.7%	18.2%	9.2%	3.9%	100.0%

Many people who are not walking purposely for exercise do not time themselves. These survey data suggest that given a visual distance cue such as a standard school bus, people with HMD actually estimate distance more accurately than time. Indeed, interview follow-ups indicated that people felt that they could quite accurately estimate distance when they thought in terms of a school bus.

While distance per se as a barrier is important, the degree of difficulty that people experience and the frequency of that experience can be even more revealing. Table 2 provides those data for difficulty in walking unaided on a flat surface for more than 35 feet (one school bus), showing that only 7.3 percent of respondents had no difficulty walking unaided for more than 35 feet without stopping to rest. By contrast, 27.8 percent indicated that they always had difficulty walking unaided for more than 35 feet without stopping to rest, while 17.0 percent reported that it was not possible for them to walk more than 35 feet unaided without stopping to rest.

Table 2: Responses for Walking Unaided for More than 35 Feet Without Stopping to Rest

Difficulty Walking Unaided More than 35 Feet Without Stopping	Frequency of Difficulty Walking Unaided More Than 35 Feet				
	Rarely	Sometimes	Often	Always	Total
No difficulty	3.6%	2.3%	0.7%	0.7%	7.3%
Some difficulty	7.8%	23.5%	10.9%	2.1%	44.3%
A lot of difficulty	3.0%	4.0%	13.9%	10.6%	31.4%
Can't do it	0.8%	0.2%	1.7%	14.4%	17.0%
Total	15.2%	29.9%	27.1%	27.8%	100.0%

Table 3 provides similar data for walking unaided on a flat surface for 15 minutes without stopping to rest, and the data show that only 3.3 percent had no difficulty with this task. In this case, 33.1 percent reported that they always had difficulty walking unaided for 15 minutes without stopping to rest, and 29.0 percent reported that this task was not possible for them.

Table 3: Responses for Walking Unaided on a Flat Surface for 15 Minutes Without Stopping to Rest

Difficulty Walking Unaided on a Flat Surface for 15 Minutes	Frequency of Difficulty Walking Unaided for 15 Minutes				
	Rarely	Sometimes	Often	Always	Total
No difficulty	2.2%	0.5%	0.5%	0.2%	3.3%
Some difficulty	6.8%	24.0%	7.5%	1.5%	39.8%
A lot of difficulty	1.8%	5.7%	12.5%	8.0%	28.0%
Can't do it	0.8%	1.0%	3.7%	23.5%	29.0%
Total	11.6%	31.1%	24.1%	33.1%	100.0%

Based on the data summarized above, 35 feet (10.7 m) could be considered a “short distance” with 70 feet (21 m) being the maximum distance that most persons with HMD can walk without serious health consequences. When considering short distances and maximum distances, one should consider whether the walking is one direction only or whether a return trip is involved, in which case a short distance would be 17.5 feet (5 m) and a maximum distance would be 35 feet (10.7 m).

The Consequences of Walking Too Far

Often in everyday life, persons with HMD are confronted with situations where they have little choice but to walk further than is comfortable (i.e., relatively pain free). What are the consequences?

In the short term, ideally a person with HMD could sit and recuperate as soon as they experienced pain or breathing problems. If that were possible, respondents indicated that they would need the following amount of time to rest before walking further:

- 28.0% 1 or 2 minutes of rest
- 41.7% at least 5 minutes of rest
- 17.6% at least 10 minutes of rest
- 12.6% more than 10 minutes of rest

However, stopping to rest is not always possible, either because of time constraints or because there is nowhere to sit down. Survey respondents indicated the following as the most likely consequences if they had to continue walking past their comfort zone:

- 76.2% Increased joint pain
- 51.7% Walk more and more slowly until almost not moving
- 45.1% Increased difficulty breathing
- 41.5% Have trouble walking at all the next day because of needing recovery time
- 38.7% Begin to stagger and lose balance
- 30.7% Become immobilized by pain or breathing difficulties
- 27.3% Increased muscle spasms

Thus, we see that a lack of accommodation can have very real negative health consequences for persons with HMD.

The Role of Impediments to Mobility

Impediments to mobility include all of the factors that would make walking more challenging for persons with HMD – such as having to navigate a slope or rough, unstable, or uneven terrain. These impediments are problematic for persons with both visible and hidden mobility disabilities; however, their effect is different for each group. For those with visible mobility disabilities, the issue is again maneuverability: How easy and safe is it to move over such terrain?

For those with HMD, the issue becomes *effort* as well as safety. Walking up a slope or over uneven ground takes more effort and muscle strain than walking on a flat surface, and the person will tire more quickly. While a person might be able to walk 50 feet on a flat stable surface, that same person may only be able to walk 20-25 feet when there are impediments.

Survey respondents were asked about the impact of three types of impediments – a slope, uneven ground, and unstable or shifting ground – and the frequency with which the respondent encountered each type of impediment. Tables 4-6 provide the results for these three types of impediments. In Table 4, the data show that only 1.3 percent had no difficulty walking unaided up a slope without stopping to rest. Rather, 38.0 percent reported that they always had difficulty walking unaided up a slope without stopping to rest, and 28.4 percent reported that this task was not possible for them. Of the respondents who could walk up a slope unaided, 31.1 percent reported that they were faced with this task often and had a lot of difficulty walking unaided up a slope without stopping for a rest.

Table 4: Responses for Walking Unaided Up a Slope Without Stopping to Rest

Difficulty Walking Unaided Up a Slope Without Stopping to Rest	Frequency of Difficulty Walking Unaided Up a Slope				
	Rarely	Sometimes	Often	Always	Total
No difficulty	0.5%	0.2%	0.2%	0.5%	1.3%
Some difficulty	3.4%	13.3%	5.1%	0.7%	22.5%
A lot of difficulty	3.0%	10.7%	22.3%	12.0%	47.9%
Can't do it	0.2%	1.0%	2.3%	24.9%	28.4%
Total	7.0%	25.1%	29.8%	38.0%	100.0%

Table 5 provides similar data for walking unaided on uneven ground without stopping to rest, and the data show that only 1.4 percent had no difficulty with this task. In this case, 36.5 percent reported that they always had difficulty walking unaided on uneven ground without stopping to rest, and 22.4 percent reported that this task was not possible for them.

Table 5: Responses for Walking Unaided on Uneven Ground Without Stopping to Rest

Difficulty Walking Unaided on Uneven Ground Without Rest	Frequency of Difficulty Walking Unaided on Uneven Ground				
	Rarely	Sometimes	Often	Always	Total
No difficulty	0.5%	0.4%	0.2%	0.4%	1.4%
Some difficulty	3.6%	13.8%	5.2%	1.4%	24.0%
A lot of difficulty	3.9%	8.8%	24.7%	14.8%	52.2%
Can't do it	0.9%	0.2%	1.4%	19.9%	22.4%
Total	8.9%	23.1%	31.5%	36.5%	100.0%

The data in Table 6 indicate that only 1.5 percent had no difficulty walking unaided on unstable or shifting ground without stopping to rest. In this case, 45.1 percent reported that they always had difficulty walking unaided on unstable or shifting ground without stopping to rest, and 36.8 percent reported that this task was not possible for them.

Table 6: Responses for Walking Unaided on Unstable/Shifting Ground Without Stopping to Rest

Difficulty Walking Unaided on Unstable Ground Without Rest	Frequency of Difficulty Walking Unaided on Unstable Ground				
	Rarely	Sometimes	Often	Always	Total
No difficulty	0.3%	0.3%	0.2%	0.7%	1.5%
Some difficulty	3.8%	7.4%	1.6%	0.5%	13.3%
A lot of difficulty	5.1%	8.4%	24.3%	10.5%	48.3%
Can't do it	0.8%	0.7%	2.0%	33.3%	36.8%
Total	10.0%	16.8%	28.1%	45.1%	100.0%

Clearly dealing with unstable or shifting ground is the most challenging impediment for those with HMD, followed by walking up or down a slope and then by walking on uneven ground.

Stairs as an Access Barrier

An often-overlooked issue for persons with HMD is how easily they can go up and down a flight of stairs – typically measured as 12 stairs. When needing to get from one level to another, the needs of those with visible mobility disabilities are usually addressed by putting in a ramp or adding an elevator. A ramp adds typically at least another 100 feet to the distance that persons with HMD have to walk, often making the next level less accessible or inaccessible rather than more accessible.

When asked about a ramp versus stairs, 45.9 percent said that they would take the stairs because of the shorter distance, even though stairs were difficult for them; while 47.6 percent said that they would take the ramp even though it was “too long” a distance because stairs posed even more of a difficulty. Only 6.6 percent indicated that stairs were preferable and not that much of a problem.

Table 7 provides data on the frequency and degree of difficulty that persons with HMD experience in climbing up and down stairs. Only 3.8 percent had no difficulty walking up and down stairs unaided without stopping to rest. In this case, 32.5 percent reported that they always had difficulty walking unaided up and down stairs without stopping to rest, and 17.8 percent reported that this task was not possible for them. Unfortunately, 26.7 percent reported that they were faced with this task often and had a lot of difficulty walking unaided up and down stairs without stopping for a rest.

Table 7: Responses for Walking Unaided Up/Down 12 Stairs Without Stopping to Rest

Difficulty Walking Unaided Up or Down 12 Stairs Without Rest	Frequency of Difficulty Walking Unaided Up/Down 12 Stairs				
	Rarely	Sometimes	Often	Always	Total
No difficulty	1.8%	1.0%	0.3%	0.7%	3.8%
Some difficulty	5.1%	18.6%	7.9%	1.2%	32.8%
A lot of difficulty	2.0%	7.3%	21.9%	14.4%	45.5%
Can't do it	0.2%	0.5%	0.8%	16.3%	17.8%
Total	9.1%	27.4%	31.0%	32.5%	100.0%

Standing as an Access Barrier

While elevators can be helpful for persons with HMD in avoiding stairs, that helpfulness may be undermined by the distance to the elevator and the amount of time standing waiting for the elevator. For many persons with HMD, the underlying cause is osteoarthritis, a degenerative joint disorder. Pain from pressure on knee and/or hip joints can result in difficulty standing for more than a brief period of time. Again, there is an issue of what a “brief time” means. The U.S. Census Bureau asks about being able to stand for one hour or longer, although it does not include limitations on standing as part of its disability definition.

Based on survey responses, 65.8 percent of persons with HMD cannot stand unaided more than five minutes. More specifically:

- 5.2% Can't stand unaided without pain at all
- 29.3% Can only stand unaided up to 2 minutes
- 31.3% Can stand unaided between 3 to 5 minutes
- 18.8% Can stand unaided between 6 to 10 minutes
- 15.3% Can stand unaided between 11 and 15 minutes

Based on these data, two minutes or less would be an appropriate definition for a “brief time.”

In daily life, persons with HMD often end up unexpectedly having to stand while they are waiting. If a person is standing in line for service and they reach their threshold of severe pain, what are they to do?

Recognizing that 15 minutes is the absolute outer limit regarding standing without severe pain for many persons with HMD, Table 8 provides data on survey respondents' experience with standing for 15 or more minutes unaided and without a pause for rest. Only 2.2 percent had no difficulty standing unaided for 15 minutes or more without sitting down to rest. With regard to standing unaided for 15+ minutes, 31.3 percent indicated that this was not possible for them, and 42.6 percent reported that this task was always difficult for them. Unfortunately, of those who could stand unaided, 33.9 percent reported that they often had to stand for 15 minutes or more unaided and had a lot of difficulty doing so.

Table 8: Responses for Standing Unaided for 15 or More Minutes Without Rest

Difficulty Standing Unaided for 15+ Minutes Without Rest	Frequency of Difficulty Standing Unaided 15+ Minutes				
	Rarely	Sometimes	Often	Always	Total
No difficulty	0.7%	0.5%	0.0%	1.0%	2.2%
Some difficulty	3.5%	13.3%	4.2%	0.5%	21.5%
A lot of difficulty	2.0%	6.7%	23.3%	13.1%	45.1%
Can't do it	1.0%	0.5%	1.8%	28.0%	31.3%
Total	7.2%	21.0%	29.3%	42.6%	100.0%

Barriers to Community Engagement

Rather than viewing disability as a deficit of the individual, the social model of disability assumes that disability is a social disadvantage that results from the interaction between functional limitations of the individual and a lack of accommodation in the environment.

Much of community life is organized in such a way that the ability to walk and stand are taken for granted. When asked about common forms of social engagement, survey respondents indicated that the following were problematic:

- 83.3% Attending open houses or receptions where everyone stands
- 77.9% Seeking service from an office where one is expected to stand in line
- 75.6% Shopping at a supermarket or mall
- 54.6% Using public transportation
- 43.2% Going to a building where parking is 35 feet or more from the entrance
- 42.0% Using a facility where the check-in counter is further than 35 feet from the entrance

In order to obtain more detail about how persons with HMD manage accessibility issues publicly, survey respondents were asked what they would do in a shopping mall if their destination were more than 300 feet away. The responses were as follows:

- 55.0% Walk as long as possible and then sit and rest
- 32.7% Sit and rest for a few minutes as soon as I have difficulty
- 12.3% Keep walking despite difficulties in order to get finished more quickly

Another aspect of community life is how one is treated by the general public when experiencing obvious difficulties. Only 29.9 percent of respondents reported that others stopped to ask if they needed help. The most common responses were:

- 45.1% Ignored and treated dismissively, as though invisible
- 20.4% Treated angrily or with irritation because of appearing to block the way
- 4.6% Given pitying looks

Thus we can see that persons with HMD face a range of access issues in communities where no accommodations have been considered.

Use of Mobility Aids

Many persons with HMD use mobility aids from time to time, particularly on “bad” days (excessive pain) or when long distances are involved. Data in Table 9 indicate that the most common mobility aid used is a cane, though 34.6 percent never use one. Wheelchairs or electric scooters are used by 22.5 percent of respondents for long distances (such as in an airport); however, 66.5 percent never use a wheelchair or scooter. The use of walkers with seats is even less common.

Table 9: Use of Mobility Aids

When Used	Mobility Aid		
	Cane	Walker with Seat	Wheelchair/Scooter
Never	34.6%	71.9%	66.5%
Rarely	14.7%	7.8%	5.4%
Often, more than unaided	14.5%	5.9%	4.4%
Only for long distances	9.5%	7.3%	22.5%
Always	26.6%	7.1%	n/a

Use of Medications

Joint pain is a symptom that is frequently present in HMD and is the most common consequence of having walked too far. Of the respondents, 37.2 percent reported using anti-inflammatory medication daily to manage pain. Another 29.6 percent reported using anti-inflammatory medication occasionally, and 11.6 percent rarely. If such medication is effective in suppressing pain, their use might extend a person's ability to walk or stand. However, 21.6 percent indicated that they could not take anti-inflammatory medications because of health reasons.

Underlying Health Condition

As has been reported elsewhere, osteoarthritis is a common cause of HMD, and 45.1 percent of the respondents identified arthritis as the primary underlying health condition. However, a number of other health conditions were mentioned by at least 1.5 percent of respondents, namely:

- Asthma
- Back, disc, vertebrae problems
- Chronic fatigue syndrome
- COPD (chronic obstructive pulmonary disease)
- Diabetes
- Ehlers-Danlos syndrome
- Fibromyalgia
- Heart disease
- Hip or knee injuries
- Multiple sclerosis
- Myasthenia gravis
- Neuropathy
- Parkinson's disease
- Stroke

Implications for Accommodation

Based on the results of the *Survey on Hidden Mobility Disabilities*, accommodation guidelines need to address four main areas of challenge that hinder full and effective participation in society. The following are examples of types of policies that could be adopted in order to accommodate persons with HMD:

1. *Distance to be walked – one way:*

As a rule of thumb, a "short distance" for a person with HMD is no more than 35 feet. What is often forgotten is that the 35 feet needs to be to a destination or seat where the person can rest and recover. Keeping in mind the negative consequences of having to walk past one's comfort zone, guidelines could be specified for issues like the following :

- A maximum distance from a main entrance to on-street parking near that entrance.
- A maximum distance from a main entrance to off-site lane or parkade parking.
- At least one universal restroom within a short distance of the main entrance.
- The positioning of handicapped parking stalls so that the driver's door is within a short distance of an elevator.
- A maximum distance from a seated waiting area to the service window in a government service office.

- A maximum distance from public parking to out-of-doors public amenities such as waterfronts, parks, viewing sites, etc.

2. *Impediments to mobility, including stairs:*

Distance is compounded by any impediment that results in extra effort being required to navigate in space. What might have been a short distance if the surface was smooth and horizontal can become lengthy when the surface is uneven, unstable, or sloped. The following are the types of guidelines that could be helpful in increasing accessibility:

- Provide a short distance alternative to having to navigate a slope such as a ramp, which puts stress on knee joints.
- Provide a smooth, stable, even surface so that walking is as effortless as possible.
- Ensure the availability of an elevator rather than stairs or a ramp, where possible.

3. *Length of time standing without an option to sit:*

Keeping in mind that over half of the survey respondents could not stand comfortably for more than five minutes and that two minutes would be a maximum “brief time,” the following types of guidelines could be helpful:

- Where access to a public service requires standing in line, provide a ticket number dispenser at the entrance with seating for people to wait their turn.
- Where individuals are expected to stand using service kiosks, provide a seated alternative.
- Where possible, provide online alternatives for accessing public services from home.
- Ensure that public consultations occur in a seated format (rather than standing in the traditional open house manner).

4. *The ability to sit and rest on benches or chairs until pain subsides:*

It is sometimes not possible to prevent walking or standing beyond one’s comfort zone. In such instances, the person with HMD needs to be able sit in order to remove pressure from painful joints or regain one’s breath. The following guidelines could be helpful regarding where to place benches or chairs:

- For individuals waiting for elevators.
- At intervals of least every 35 feet for:
 - Buildings with entrances set back from the street more than 35 feet.
 - Corridors longer than 50 feet in facilities such as hospitals, schools, public buildings.
 - Shopping malls.
 - Public viewing sites.

As a companion piece to regulatory guidelines, public education is also critical. “Sidewalk rage,” or frustration with people who walk slowly, is increasingly an issue. We need to educate not only the general public, but also health care professionals (including physiotherapists) who are often the person with HMD’s primary point of contact, planning departments, architects, and others involved in designing public space. In addition, we need to provide empower persons with HMD, letting them know that their experiences are shared by others and helping them strategize regarding when and where to obtain assistance.