

## Visitability Interview Responses

In its report, *Increasing Home Access: Designing for Visitability*, AARP published a compendium of interviews with individuals about national visitability initiatives [http://assets.aarp.org/rgcenter/il/2008\\_14\\_access.pdf](http://assets.aarp.org/rgcenter/il/2008_14_access.pdf). In that spirit, The Montana Housing Task Force (MHTF) and the Montana Disability and Health Program (MTDH) have been collecting online testimonies about individual and community level activities related to visitability.

A visitable home welcomes *all* visitors including those with physical disabilities. Design features make it easy to get into and move around the home. A visitable home has one zero-step entrance (front, side or rear), doors with 32 to 36 inches of clear passage space, and one bathroom on the main floor with maneuver space for a wheelchair.

These testimonies have been used as public comment before the Montana Board of Housing (August 2010) and in visitability presentations throughout Montana.

The survey is available at <http://www.surveygizmo.com/s/453201/visitability>

The testimonies below have been edited to add missing words and correct spelling and punctuation.

### Testimonies

#### Testimony 1

**I first heard the term “visitability” when ...** a friend shared the Summit's newsletter with me. My role in visitability is as a consumer. My daughter uses a wheelchair and now that she is getting older, we have had to install a ramp and take out the front steps in order to get her safely out the front door to the sidewalk. Now we are looking at having our doors widened and a bathroom remodeled that will work better for her. A friend of mine built a 'visitable' house for their son in a wheelchair, and the ease of getting the wheelchair around is so great! Ease of getting out of doors to the bathroom to his room, etc. is amazing.

#### Testimony 2

**I first heard the term “visitability” when ...** Darren Larson shared with me the term "visitability" while I was assisting him when he was in town at a convention. I have a 7 year old son who was born with Spina Bifida. I am a consumer for him. He is paralyzed and is in a wheelchair. We don't have visitability in Kansas, but I sure wish we did. I rent my home. It is hard to find a rental home that is designed for a disabled person that is reasonably priced. We don't go to other people's homes much because of the inconvenience of having to carry my son in and out. When I buy a home it will be visitable. I've never had the experience of giving my son the freedom of visitability. I wish I could. It would be very beneficial.

### Testimony 3

**I first heard the term “visitability”**... recently from a friend who is handicapped.

### Testimony 4

I don't remember **when I first heard the term “visitability.”** My wife and I made our home visitable when we remodeled. We had friends whose parents used scooters, and we wanted them to be able to visit. I have a good friend who uses a wheelchair, and I wanted our house to be welcoming to him when he came. And I have colleagues who can only join some parties if they can get in. The first time one of my good friends who used a wheelchair visited was a frightening event. He backed down a sloped grassy hill in his power chair and was stopped by the edge of our deck. It took four of us to extricate him from the predicament so he could join the party. Then it took six of us to get him out. Now, with the ramp and the 0 step entrance he and others can cruise in and out like anyone else. So, we've been able to have more social gatherings with a wider range of friends. It's been great.

### Testimony 5

**I first heard the term “visitability”**... around 18 years ago at an ADAPT action; I heard the term from Eleanor Smith who originated it. I am a consumer and community member. My husband uses a wheelchair. All too often in the past 20 years, we have not been able to go to parties, gatherings, political fundraisers and community events because the personal homes that were the venues were not "visitabile." If most homes were visitable, we could freely go to block parties; celebrations for birthdays, graduations, political fundraisers and other house parties without worrying if we could get in the front door, or use the bathroom. We would feel valued and included in our neighborhood and community instead of often feeling marginalized.

### Testimony 6

**I first heard the term “visitability”** ... when Summit ILC called my home a few months ago and told me about it. I am a consumer. **I am affected by a lack of visitability** ... when I could not go out with my family because the place we were to visit had stairs and no ramp or elevator. I sit home a lot because of it. If things don't change I won't be able to live a normal life.

### Testimony 7

**I first heard the term “visitability”**... in October of 2010. I was at a conference for Independent Living, and they had a session on visitability. I am a consumer. I am in a wheelchair, but I am in regular classes. Most of my friends do not have a disability so they have regular homes. Since I have gotten older, I can't go over to their houses. If my friends' homes were accessible, I could go to their houses like a normal teenager.

### Testimony 8

**I first heard the term “visitability” when I was** ... speaking with a friend who was unable to visit my home. I do not have a direct role in visitability, but I would like my friends to be able to visit me. I was unaware of visitability until I became friends with a person who uses a wheelchair

outside of his home. We enjoyed coffee and movies together, but he had to always host movie night because he could not get into my living room. It opened my eyes to how few homes are accessible to him. I would be able to have all my friends with me or host movie night if my home was built to be accessible to all.

#### Testimony 9

**I first heard the term “visitability” when ...** I went to a presentation on Visitability at the University of Montana a few years ago. A national leader in visitability spoke. I do not remember her name. I am a person with a physical disability and have been affected by homes not being visitable. I have been in a wheelchair since kindergarten. I have a neuromuscular disease called Spinal Muscular Atrophy. It is very difficult or impossible to get into some houses because many houses have stairs at the entrance. When I was younger, my friend’s house had stairs going in to the house. His parents made a ramp out of a slab of wood. It was very nice that they had the ramp so I could get into their house. It was a hassle at times.

My great aunt’s house is old and I can only get into the kitchen. Because of that I have not been to her house since I was little. We have family functions at my house or at my grandparents’ house because they are accessible. My friend’s parents and my great aunt do not know about visitability. It would be wonderful if every home owner knew about visitability. Then those of us with mobility problems can feel more included rather than isolated.

If my great aunt’s house were visitable, I could have spent more time with her and my family at her house. Since her house is not visitable, we only see each other when she comes on holidays. Maybe we would be closer now. My family and I are very good at being adaptable. For instance, we made a ramp to get into a house. If home building practices change to be visitable it would make life easier and I could go to my family and friends’ house whenever I was invited. I would not have to worry about stairs, wide doorways, or there being an accessible bathroom on the first floor.

#### Testimony 10

**I first heard the term “visitability”...** when Diann explained it to me just now. I am a Disability Advocate, Adult Protective Services Worker. Visitability does not affect me personally; however, I have a client who is languishing away in a nursing home because he cannot locate accessible housing. Visitability affects me indirectly through serving clients. I have seen doorjamb “makeshiftedly” removed to allow access.

#### Testimony 11

**I first heard the term “visitability”...** in 1990, after Concrete Change had been working for several years on this issue and calling it “Basic Home Access.” I heard it in my living room from a young Japanese architect who had come to Atlanta to see the first Habitat of Humanity homes that had basic access. I am the director of Concrete Change, a national initiative-focused on Visitability. I have used wheelchair since age 3. Thus, I have been unable to visit many friends and relatives comfortably. I lived in a house for 6 months where I had to crawl on the floor each

time I wanted to enter the bathroom. I had difficulty finding places to live. I have had to limit intake of liquids when visiting others because I knew I could not use the bathroom, etc.

#### Testimony 12

**I first heard the term “visitability”...** at the request for my participation in this survey. I am an educator. We have a student who just returned to school who has a brain injury and requires use of a wheelchair at times. He needs to access bathroom facilities, and they are not ADA compliant. We are scrambling to meet his physical needs.

Older buildings have to be brought up to compliance as quickly as possible, since any day a person who needs accommodations may need to access rooms and services.

#### Testimony 13

**I first heard the term “visitability”...** from Habitat for Humanity when I was building my home. I am someone who is getting a visitable home so that my friend with a wheelchair can visit me. My current home is not visitable so my friend is not able to visit. Now, I am more likely to talk about my good experience with building a visitable home. If my friends couldn't visit, I would feel bad, and it would be embarrassing. Since I am building a visitable home, I no longer have to worry about this.

#### Testimony 14

**I first heard the term “visitability”...** in *Living Well* class at Montana Independent Living. I am an advocate for visitability. My mother and grandmother cannot visit me at my home due to stairs being a barrier. Instead we go visit her at her home or carry her up the stairs. It became personal and made me realize that you just never know when someone won't be able to enter your home. If my home were visitable, my family could visit whenever I wanted them to. I would encourage others to be proactive in the visitability movement. I have encouraged my husband to make our home visitable so that my family can come over for holidays.

#### Testimony 15

**I first heard the term “visitability”...** at *Living Well* at Montana Independent Living. I went from being someone totally healthy to being someone with a disability. Visitability is personal to me and I am spreading the word about access. When I first came home from the hospital, I could not climb up my steps. This made me home bound and relying on my family for assistance. Visitability would have given me back my independence much faster. It helps people to help themselves. I would have regained my independence much sooner if my home had been visitable.

#### Testimony 16

**I first heard the term “visitability”...** from my friend's father who uses a wheelchair and from Habitat for Humanity. I live in a visitable home. My friend's dad can come to my home now. We don't have to carry him up the stairs. That makes me very happy that my friend's dad is able to visit any time he wants to.

## Testimony 17

**Visitability is important to me because ...** I am confined to a wheelchair. People and relationships are number one priority to me. I first heard about visitability in 2007 from Laroy Williamson. I became involved with visitability due to my own personal struggles with becoming separated from society by an injury which left me paralyzed.

**Visitability or the lack of visitability affected me ...** when I had to build and design homes I couldn't enter in 2004 at the job site. My brothers and fellow co-workers were with me during this experience. I was not able to manage my job because of physical barriers. This experience shaped my understanding because it helped me to see the reality of separation of people because of convenience.

The smallest obstacles in my life become physical barriers for everyday life. Some ramps that are put up do not allow a person in a chair to go up or down them without help. For example, some ramps are too steep. If there is not another person available the place is not accessible, and the person is at risk for severe injuries if attempted alone. The desire is lost to go out into public when the access is not readily available, which leads to unnecessary struggles and embarrassment. **If more buildings were visitable ...** it would allow me to feel a part of the community and family without the feeling of being a hassle.

## Testimony 18:

**Visitability is important to me because ...** one of my friends uses a wheelchair. I was having a party at my house. I had to tell her she would not be able to use the bathroom or may not be able to get into my house. I told her she may have to use the gas station.

**I first heard the term "visitability" ...** today at this conference. I read in the program and thought it sounded interesting. **A lack of visitability affected me by ...** having my friend not be able to get into my house in July 2009 when I was having a party with 20 of my family and friends. My friend could not come to the party. Since my friend could not come to the party, I talked to my family about why she could not come. At the time, I did not know the term visitability, but I realized my home was not accessible. This affected me because I do work for a CIL and my own home is not accessible. This has affected me because I have now planned events at other places besides my home to accommodate other friends and family who have other mobility issues like my grandma who uses a walker. **The likely effect of visitability on me is ...** I am temporarily "able" bodied. Accessible design benefits all of us.

## Testimony 19:

**Visitability is important to me because ...** I was disabled in 2007; previously in 2005, I purchased my first home. As a young man in my late 20s I did not have an issue that my home was a tri-level. Now through this disability I have been in a wheelchair and forearm crutches. I have fallen multiple times trying to navigate the stairs in my home, which led to stitches, CT scans, ER visits, and glass in my eyes. I do not have the funds to fix my home and owe the bank too much to be able to sell it and move."

**I first heard the term “visitability” when ....** a friend on Facebook sent me a link. I would love to figure out a way to help others so they don't have to struggle like I have and continue to do. **A lack of visitability affected me ...** of course in my own home. It was very embarrassing to go to local businesses and figure out that they were "handicapped accessible," but I could not access the bathroom with my wheel chair. Once I had to leave my chair outside the bathroom door, and grasp the wall, doorjamb, sink, and even the rim of the toilet to make it in. I ended up slipping on the slick vinyl floor on the way out and had to get help to get back up. Thankfully I had my pants back up before I slipped. This event occurred back in April 2007. I am not going to give the business name because it is a small family owned local business, and we need them to be around here. Nobody was with me; my wife was at work, and I was trying to get some stuff taken care of on my own. Dumb me. This experience shaped my understanding of visitability: it is very important to me. I now walk with crutches/canes, but I am sure a wheelchair will be back in my future as I get older. I am disabled; I have trouble with balance so steps, heavy doors, and slick surfaces kick my butt. I have a nerve disorder, created from an industrial accident. I have limited use of my left leg and have chronic pain, which can take over and cause me to be very weak and unstable. I was very independent prior to my disability. I worked a very hard labor taxing job 40-60 hours a week. Plus I ran as a volunteer EMT on our local ambulance and was a volunteer fire fighter. I still want to be that independent person, but it seems like the harder I try at that the more I hurt. This is even in my own home. My bedroom is downstairs, the kitchen/living room is on the main floor, and the bathroom is upstairs. Very frustrating. People are very helpful around here, holding doors, offering a hand, etc. But it still is embarrassing to me. I tend to not go out unless there is someone there I know to help if needed. I feel like I have become a hermit, but even at home I struggle.

Testimony 20:

**Visitability is important to me because ...** I was once disabled. I was hit by a car. Both of my legs were broken. I used a wheelchair, walker, crutches, and a cane. I first heard about visitability at the NeighborWorks Montana housing conference in Helena. It is a great program. This could benefit many people. My grandmother was also disabled, but permanently. Things could be very difficult for her at times. My grandmother was disabled from when I was about 10 until her death when I was in my mid-twenties. I was disabled when I was late 18 to early 19 years old. This happened in Bakersfield, California. At the time, I didn't know anything about visitability, but I definitely knew when things were not very visitable! I had to change rooms and beds. Lots of things in my life had to change! **This experience shaped my understanding of visitability ...** It is very worthwhile, and I agree with it 100%. Because of my accident my right hip was messed up, and my left foot had a drop-foot with nerve damage, which is why I had problems going down steps. My grandmother had a stroke and her entire left side was immobilized. I know firsthand (the difference visitability makes) ... I will never forget. **A lack of visitability ...** would not affect me. But I do understand the significance and importance of the visitability movement.

Testimony 21:

**Visitability is important to me because ...** about 10 years ago or so, I lived in a house that had full visitable features. I did not know what visitability was about. I had Cerebral palsy and low vision issues. My brother sustained a traumatic brain injury due to an auto accident. My mom was a senior as well. We were able to live independently until finances necessitated the sale of that home. I am a peer and an accessibility ambassador with North Central Independent living services. We attended training on visitability. **A lack of visitability affected me when ...** I had to move out of this house in 2007 because it was sold. My family and live in attendants did not know much about independent living centers and visitability so I had to move to an apartment. To me visitability means independence, but we really have to make homeownership affordable.

Testimony 22:

**Visitability is important to me because...** I do not have to worry about safety with my vision. I do not have to worry about falling, and I feel safe. I heard about visitability through Summit. We did a home builders show at the University. I wanted to get around safely, and I wanted others to as well. I have a visual disability. There were always times when it was more difficult than other times. The one thing that comes to mind is the time when I was pregnant. I was home. When you are pregnant, for those who do not know (men for the most part), you have extra weight up front. This is a blessing, however, you are a little off center. Whether or not you have a disability or not, getting around is hard. When you walk you kind of waddle. Now here I am not able to see. I look down to make sure my footing is right when going down the stairs because the last thing I want to do is fall. So I look down to see what little I can see, and I cannot see my feet. So I ask myself, where is the safety here? At that time in my life I did not have a guide dog. It may not look like it, but I have great difficulty going down stairs. Seeing things far away and even looking down is hard to see where the stairs are because of my low vision. Where does one stair start and the other end? If there was a yellow strip or something that I could see, but without this, steps blend together.

I have been visually impaired since birth. When I lived in an apartment before this one, I was very fearful of going down the stairs while trying to carry my laundry, keeping my balance on steep stairs, and using my guide dog, Madrid. I only have two hands so how do I hold the laundry, the railing, and the dog? I was so afraid of falling, and it was worse in the winter with snow and ice on the stairs. I never want to lose what independence I have right now, and I know as we get older things do change. Then we figure out what we need and adapt to then. I do not want to feel unsafe.

Testimony 23:

**Visitability is important to me because ...** I was raised in a family that didn't have it. I grew up in a three story home on a farm east of Missoula. It was very difficult for my mother to climb stairs, and she did so as rarely as possible. Because the main floor didn't have a toilet, my mother kept a pickle jar to pee in.

She had a progressive neurological disability and later in life used a wheelchair. My parents surrendered our farm to the bank and moved in Missoula after losing everything; so my mother could get a PCA and a visitable home. My father got the only home available with a zero step entrance, wide doors, and a bathroom on the main floor.

The disability eventually took her life. My father spent every cent he had bringing the home to necessary universal designs and transportation for a wheelchair. One day the cables broke in the van. My mom fell face first. My mother lost several teeth in the fall when she smashed her face on the sidewalk. You never appreciate accessibility until you need it and don't have it.

I learned about the term visitability at Summit; although I lived visitability challenged early in life. Typically it costs a builder \$100 more to make a home visitable. One family member out of four will need a visitable home sometime in their life, either through injury, illness or permanent disability. As a Peer Advocate with Summit I have learned of the need, not only in my family, but in most families. Visibility is a simple, low cost precaution, which should be taken by all families for life uncertainties. In my life the event was my mom's progressive disability. But today, I have been diagnosed with the same disability and experience the same complaints she made. Visitable design can make life exponentially easier with simple planning.

I am an average person living an average life. My story proves that visitability can benefit everyone. I have hereditary SCA-2 Ataxia. This family disability affects my balance, and proprioception, and I have had many specific abnormalities. (choking, vision, loss of speech, etc.). My disability has been passed down from my ancestors.

I am finally accepting any accommodation available. I am a law student and benefit by additional testing time. I like zero steps and smooth, paved trails. I like walking sticks and even motorized vehicles like 4-wheelers. I also like grab rails. Visibility is all about making your life easier. I can climb stairs but prefer not to. Since my disability is progressive, I am guaranteed things will continue to deteriorate. I am building a new home and will not just make it visitable, but will go for universal design. I want to stay in my home as long as possible, avoiding assisted living.

Testimony 24:

**Visitability is important to me because ...** It's important for me to be independent and freely go where I choose without assistance from others. I like to get into a home and go from room to room. I learned about visitability from my work with Summit. A couple years ago I helped with a visitability booth at a builder's tradeshow at the University of Montana. **I first got involved with visitability ...** when I was asked if I would help with the visitability booth at the tradeshow and because of my home situation, being able to access my home, but not other homes. When I lived at home with my parents they built a ramp for me to get in and out, but when I moved out, they removed the ramp. Now it's difficult for me to visit them. ... My family doesn't know the term visitability. My parents built the ramp to make it as easy as they could on me and them, but the thought of basic access for all homes wasn't there.

When I was younger I could adapt to situations. When a home had steps I could get out of my wheelchair and use my arms to bump my backside up the steps. Now that I'm older I have other disabilities and less flexibility. I see it as more of a need. The younger version of me could have managed to get up the steps at my parents' home. Now, without the ramp, I'm stuck outside. I have cerebral palsy, and I am in a wheelchair. I have always said, "Steps are hazardous to my health." I have limited mobility and range of motion.

I was born premature and have had cerebral palsy since birth. I was born in the 50's, and during that time the technology was not like it was today. I was born a premie, and there were no alarms that went off if the babies in the NIC Unit (as they call it now) stopped breathing. I was at St Patrick's Hospital, and what they would do in these cases was assign a nun to sit at the incubator. If anything happened they were to alert the nurse. Well, my lungs were under developed so I was having trouble breathing. I worked so hard to breathe I got tired and stopped breathing. Apparently, I was not the only one that was tired. My mother told me that the nun who was in charge of me was 70 or older. She fell asleep. She had no clue that I stopped breathing. My mother said that in the time this nun was in charge of me, I stopped breathing five times. After that I think that it is pretty safe to say that she was removed from the nursery. The lack of oxygen was the result of my cerebral palsy. It takes longer to get things done, and it can be frustrating.

Testimony 25:

**Visitability is important to me because ...** it allows me to visit homes. In addition, it provides access if the owner should be injured or otherwise acquires a disability. I first saw the term "visitability" when I came across the Concrete Change website online. Frustration with lack of access to new homes and homes of friends and relatives were factors that led up to my learning about visitability.

I was a painting contractor and had to quit because I couldn't access the homes I was contracting for bidding or inspection purposes. It became more difficult to perform my job after my disability progressed to needing a wheelchair about five years ago in Hamilton, MT. My painters and other subcontractors were with me at the time. They had never heard the term. The building contractor's supervisor is now aware of the concept and actively promotes it to new clients. I tried to work around my disability by using my employees as my eyes, but the results were unacceptable. This experience made me appreciate the difference between accessible and non-accessible. I still want to be an active person, but am unable to pursue my chosen trade because visitability and accessibility are the exception and not the rule. I am unable to stand and can't afford the \$35,000 wheelchair that will climb steps. Usually the climb is too high for a portable ramp to reach safely.

I have Secondary Progressive Multiple Sclerosis and have lost completely the use of my legs and about 75% of the use of my right hand. No one knows the cause of MS, and no cure has been found. 350,000 people in the US are afflicted with MS. I need help getting in or out of bed or the shower or pulling my pants up. This is a limiting factor on my versatility. It limits my ability to travel long distances, utilize motels, etc., and it makes changing my schedule of going to bed or rising for the day nearly impossible. It takes me longer to get ready in the morning than it did

when I was able-bodied. I have one of the very best power wheelchairs and an adapted van that allows me to travel short distances independently. I don't get invited to friends' homes because of the lack of visitability. At this point, I am severely limited in my ability to visit friends and family. Some commercial stores and offices are off limits to me due to steps/stairs. I would enjoy the same freedom everyone else has to be able to go where they go, to visit, to shop and to do business.

Testimony 26:

**Visitability is important to me because** ... walking is becoming progressively more difficult, and it's hard to make friends when I can't access their home. When I get invited to people's homes who I don't know very well, it's really awkward. It's weird asking someone, "Can I get my wheelchair into your home?" I know that about 99% of homes have stairs. So if I'm feeling tired and don't feel like trying to walk stairs, I stay home. It seems stupid to have to not hang out with someone because they have steps. I first heard about visitability in a class at the University of Montana taught by Tom Seekins of the Rural Institute. We talked about how a typical house goes through six or seven families, and I think 60% of all families have at least one member who acquires some sort of physical disability in their lifetime.

When I was 16 or 17 I moved out of my parent's house and was unable to be adopted by family friends specifically because their home was not visitable. They had a few steps leading into the home, and there wasn't a bathroom on the first floor. You had to go up a flight of stairs to go to the bathroom. There were no bedrooms on the first floor, and because there wasn't a designated safe floor to eat, sleep, and go to the bathroom, they couldn't adopt me. Instead the State placed me in a group home that wasn't visitable either.

The person I'd consider to be my mother cried excessively when she found out they couldn't adopt me and instead I had to live in a horrible institution.

It was very difficult living in a group home when you're young, and I almost failed high school because of it. I was the only young person with a disability living in the home.

The root of the problem is that I'm not the only person who is told they can't go home because their home isn't visitable and it's too dangerous to function. I could not live with my family because their home had stairs and had to live with strangers instead. It wasn't a positive experience at all.

I have had a disability since birth called VATER syndrome. It affects my organs, back, hips, knees, and the shapes of my feet. I can walk a little bit, but also have to use an electric wheelchair to travel long distances. Manual wheelchairs are too tiring for me to use. Usually manual wheelchairs can hop up steps or curbs, but my wheelchair can't even hop up small steps or curbs.

Even though I have more mobility than most people who use wheelchairs, I'm not going to someone's home if I can't get my wheelchair into it.

Testimony 27:

**Visitability is important to me because ...** I feel really unstable on stairs. They are my arch enemy. It is important because I like the fact that if my house was visitability friendly, I could invite my friends with physical disabilities over and not worry about their safety. I heard the term visitability when I became a peer advocate for Summit. I think that was nearly two years ago. Starting to learn about visitability made me want to learn more because the house I grew up in from the time I was diagnosed with multiple sclerosis (MS) had all stairs. What I learned was I need a home with fewer or no stairs.

My experience with visitability began in 1997 at my parents newly constructed four level home. They knew nothing about visitability. And they still do not. Being a person with a disability in the house that I grew up in made me versatile, and I grew up fast. Basically I was a 23 year old who just had an incurable disability shoved onto me, and learning about the disability, I realized the hard knocks of not having visitability in my own home. Everything was wrong. My room was on the top floor. So there were four flights of stairs I had to go up to get to my room.

I just know now that now I want a home that is visitable for everyone who may want to visit. I like to try to do things by myself first. Then I will ask for help, like maybe a hand or a lift. I like a railing when taking the stairs (which my parents do not have).

Because more homes are not visitable, I stay home and do not go out with my friends on drinking binges. But I am happy about that because I don't hold my liquor very well anymore. I am happy that I have my boyfriend because he tries to keep me in tune. The change will be a bonus for all! I am looking forward to everywhere being visitable. It will make everyone who has a disability life a little easier.

Testimony 28:

**I first heard the term "visitability" ...** Currently I've heard of visitability in Philadelphia and here (NCILS/MT). My work started when accessibility ambassadors came (Eleanor Smith) about two years ago. Visitability was not placed on NCILs agenda because lots happened with transportation, so I haven't been able to work with visitability until this year. But there has been no formal push in community up to that time. Using visitability in the context of housing, I am glad to get word out in Cascade County. This is important not just for people with disabilities but for all people. I am beginning to organize a radio promotional event for builders. I tie in visitability with other important issues like transportation and disaster recovery situations.

In Great Falls we really need to focus on visitability because there is a need in NCILs service area for housing. Both the accessibility and affordability pieces need greater attention. At NCILs we get calls from people concerning accessibility after someone has experienced a fall and cannot live in the place they had before. It would be great to have more housing built. NeighborWorks is supporting that part of the bill.

Yes, there are specific instances when a lack of visitability has affected me. They have occurred throughout my life at my parents' home. My parents have a split level home that is not accessible. Only one sibling has a visitable home; but I have to go around the back in the

winter, and it does not work with snow and ice. It took the opening campaign at the home and garden show to really educate them about the visitability of homes. I was educated on this issue first, and I have been telling them for years about visitability.

I tried to educate them as a young woman, but they were not able to do anything about it. My parents are very supportive of my work. Their house is not accessible, and it will impact me again this weekend when I go to their house and participate in family activities. As I am looking to be a homebuyer, I know it is important to have these features. I am torn about my parents' debts, but I also want to participate in their lives. With technology today, accessible and affordable housing shouldn't be the way it was 30 years ago. I hope to bring this information to the homebuyer classes. I have taken the classes, but I also need to talk about what people need to look for in homes as well. It would be a great homebuyer piece if we added visitability features.

Testimony 29:

**I first heard about visitability ...** when I started at MILP in December. At that point, Bob Maffitt wanted me to be on the housing task force. Before this I was not aware of the term or concept because I do not have a disability that keeps me from entering the house, and I was unaware of what that means to people. After I was introduced to the concept itself it made total sense.

Now that I know different people in my life who have a disability and knowing that people can become disabled at any time, I share it with people because it makes sense.

About a month ago an event occurred at the Montana Independent Living Project where a lack of visitability affected me. I have been working with a couple where the husband has MS. They bought a home with steps to their master bedroom, and it did not occur to them that this would affect their lives. Now they live in two separate areas because they were unaware of this barrier at the time they purchased their home. It magnified to me that people need to know about it and hear about it. Even though this situation was someone who was living with a disability, it didn't occur to them that stairs in their own home would keep them from living in their home. It's like, wow people need this information. We get several calls concerning people who need ramps. People do not even consider ramps or the fact that they need to retro fit.

Testimony 30:

**I first heard the term "visitability" ...** probably when I started working at Summit, which was three years ago. That's when I was first introduced.

Mainly because when I was a kid I could not get into homes of friends and family members. Because restaurants and malls and stores are accessible, why not homes? I really thought it should be a community building issue as well.

Lack of visitability has affected me my whole life in friends' and family's homes. It wasn't seen as a big deal in my family because I could be packed. Family members would have to assist me into their home. It didn't bother me because it's all I knew. But it is an inconvenience to carry me into a home and for someone to have to help me.

There are a lot of people who have spinal cord injuries and other types of disabilities where they cannot be packed. They need to understand that as well, which makes visitability all that much more important.

I had one uncle that did build a ramp into his home. That is not considered home building but rather home modification.

This experience shaped my understanding of visitability because I can understand the real need for it whereas someone who is able-bodied sees visitability as a case by case situation. For example, if you are disabled your home it needs to be accessible. But I think that able bodied people don't think about that. It is difficult to visit people who do not have basic access features. Being in a wheel chair my whole life has given me an understanding of why it is so important.

Testimony 31

**I first heard the term “visitability”...** in April 2011 at Summit Independent Living Center. My role in visitability is as a consumer. I have a disease that affects my lungs and heart. I cannot climb stairs. I have several friends whom I am unable to visit due to stairs. Since I became disabled, my world has gotten much smaller. I don't attend many social events or visit many people if there will be stairs involved.

Testimony 32

**I first heard the term “visitability”...** today, when Dianna explained it to me. My role in visitability is as a consumer. I have MS and a brain injury. My home is visitable. I have not yet had an experience where I wasn't able to visit. Visitability would make accessibility to any home or business better for me with or without a walker.

Testimony 33

**I first heard the term “visitability”...** reading this paper under this definition. I have always used the term “ADA compliant.” My role in visitability is as a consumer. A lack of visitability affected me when my wheelchair could not fit into an accessible bathroom. It would be nice if the door were wide enough to let in wheelchairs. My uncle had to redo the stall.

**Things would be better if ...** Some doors are so heavy that I have to ask for help to open them. It would be nice if they were ADA compliant.

Testimony 34

**I first heard the term “visitability”...** through Meg Traci, although I know the concept. I am a consumer. My mom has progressive MS. She has moved from several homes as it has progressed further and is now in a wheelchair full time. Having a mobility impaired family member has certainly opened my eyes. My daughter is also gross motor delayed. Although it seems she may walk independently, I don't know if that will always be the case, or that she may need a walker occasionally. Our house is not visitable or accessible. My mom can still get up the four stairs (on a really good day) but only visits a few times a year (we live a mile away). When she does visit she uses a walker and it is very difficult, sometimes impossible, to use the

only bathroom in the house. It is on the first level, but too narrow for even a walker. I do see us looking for a visitable house when we move, not only for my mom, but also for my daughter AND us!

I would love to live in a community where we didn't have to think if my mom could visit a friend, or plan her grandchildren's birthday parties out of the house so my mom can attend. I would like my kids to be able to have friends over who might be mobility impaired. And, I would love to do the same!

#### Testimony 35

**I first heard the term “visitability”...** from Meg Traci of the Rural Institute, Missoula, MT and Darren Larson of Summit Independent Living Center, Missoula, MT. I am a consumer. My 2.5-year-old son has CP, and his future mobility is unknown. Getting around our 1919 house in his walker is challenging. The main floor bathroom door is too narrow for the walker. There are a few steps leading up to both entrances to the house, so I have to take him out of the walker and carry him in and out. As Heath gets bigger, and as my parents and in-laws age, visitability will become a much bigger issue in our lives. We are not yet certain whether we will be able to remain in our house.

Visitability on a wider scale would be so wonderful for Heath and our family, not only because of the logistical ease of getting around, but because of the psychological, social, and emotional impact of being "unplanned for" in the physical community. For example, it is nice to arrive at a playground and see an adaptive swing—not only can we use and enjoy it, but we instantly receive the message that someone considered us when planning the playground. This feels great!

#### Testimony 36

**I first heard the term “visitability”...** a few days ago on my friend Jenny's blog. I am a consumer. My friend Joe broke his back over a year ago and is now a quadriplegic. Last summer, he visited Missoula. We were so excited he came to town! We wanted to get together for dinner, and a restaurant wasn't in the budget. We were going to have them over, but then realized that Joe wouldn't even be able to come in the house because both our back and front doors have steps. We ended up having to meet at a park for a picnic.

We would love to be able to entertain all of our friends, and their children, in our home. Not only that, but when my Mom broke her leg and was in a wheelchair, she would have been able to watch our children with such greater ease.

#### Testimony 37

**I first heard the term “visitability”...** while reading an article about children with disabilities trick or treating. The article was highlighting Missoula, MT. I am a consumer. After having a child go through a major medical issue at nine months without any previous problems, I now know firsthand how quickly life can dramatically change. She has airway issues, no mobility issues, but our life totally changed overnight, and we now have a child with a disability. I have

met a great group of moms in my town all with children with a disability, and they have really opened my eyes to many issues.

#### Testimony 38

**I first heard the term “visitability”**... just in the last couple of years after I met Darren Larsen of Missoula Summit ILC. I am an advocate and presenter to builders, designers, etc. I was a painting contractor when I was diagnosed with MS in 2000. Soon, I was unable to access the very homes I was painting and eventually, after about six years, quit my business completely. Visitability would allow me to visit friends and family in their homes, where I am now barred.

#### Testimony 39

**I first heard the term “visitability”**... from Mamalode writer Daria Mochan. I am a consumer. We own and rent a vacation rental behind our house that has steep stairs going up to the entrance. We realized when we had an elderly couple staying how difficult it was for them to maneuver up to the house. We are working to find landscaping solutions for this ... I want to make sure we are providing a safe and welcoming place for all our guests, and any people with disabilities or aging family that visit us. We also recognize that our own main home is not very accessible.

#### Testimony 40

**I first heard the term “visitability”**... in an email from Darren Larsen. For the last 23 years, I have worked with individuals who have survived traumatic brain injury. It is becoming nearly impossible to find "affordable" housing for an individual living on \$674 a month. Many cannot afford food after the second week of the month. Even units that are overseen by MHA run \$550+. Recently I was in an apartment in Missoula to facilitate a meeting between two individuals with disability who may become roommates. I was appalled at the slum type condition of the apartment(s). These individuals are paying >\$700 a month. I speculate that CM does not approach the property management due to lack of alternative living space for their clients who reside there. Baseboards from heaters are missing, holes in walls, light switch coverings are melted ... How do we address the conditions or tackle a property management company?

**If visitability were the norm ...** my home would then be accessible for individuals who require a wheelchair or other mobility accommodations.

#### Testimony 41

**I first heard the term “visitability”**... from my daughter as I have MS and can't walk, and my youngest granddaughter is a special needs child. I am a consumer. I have secondary progressive MS and am now in a scooter or electric wheelchair. In addition, my youngest granddaughter has a spontaneous chromosomal abnormality, which limits her mobility. My daughter and son-in-law had a difficult time finding a house for me. Then it was very expensive to turn it into something I could live in. I have great difficulty going into my daughter's home. My home also has narrow doorways and halls, and I have banged into every one of them. I do have

ramps going in and out both front and garage doors. This is due to the foresight of my daughter and son-in-law. Wider hallways and doorways would be great for me. I would like a walk-in closet with better accessibility to hang up clothes. This would be great also for my granddaughter as she grows.

I moved here to be closer to my daughters. My daughter and son-in-law had great difficulties finding a house that could be renovated so I could live in it. I have a basement that I have never seen. Stair climbers are very expensive and are not covered by insurance. Thankfully, electric wheelchairs are covered. The upper cabinets in my kitchen are not accessible to me. I read about a builder in San Francisco who builds only houses with the belief that everyone is handicapped at some point in life. So far, I can function in my house, and guests can sleep in a bedroom in the basement. This is wonderful to be able to function on my own.

Testimony 42

**I first heard the term “visitability”**... from my friend, Doug Pinto. I am a realtor; relative and friend of people with accessibility needs. My mom had to avoid going places with many stairs because of health issues. I just think all homes should work on access issues and especially in new homes – it should be required.

Testimony 43

**I first heard the term “visitability”**... from the email attached to this survey. I am a builder. My granddaughter is disabled. Visitability would make it easier to care for our granddaughter.

## **Rules and Regulations:**

**The rule or regulation I think should be changed ...** I think regulation and enforcement are the sticky areas. Sometimes things can get so regulated that there is no 'wiggle' room for improvement or in case some other scenario would work for a different group or family.

**The rule or regulation I think should be changed ...** Any home constructed with any amount of government funding or tax credits, or by organizations like Habitat for Humanity, should be visitable. There is also no reason why property developers who build subdivisions or planned communities can't also build visitability into their homes. Then, public education could hopefully persuade the remaining single family home owners/builders to build homes where everyone would be welcome and where people would be more likely to be able to age in place.

**The rule or regulation I think should be changed ...** is the ADA Act. There should be a law that makes homes somewhat wheelchair accessible. Also, there should be a tax incentive to build an accessible home because it requires more money and planning than just building a regular home. You never know what is going to happen. You may be in a terrible car crash and be paralyzed for the rest of your life.

**The rule or regulation I think should be changed ...** The building codes should all adhere to ADA and be compliant so that a person with or without a disability has the same advantage.

**The rule or regulation I think should be changed ...** I believe educating builders and home owners about making homes visitable is a good way to change policy, law, or regulations. Advocating for visitability by people with disabilities at the grassroots level would be effective. This might help HUD or a local Housing Authority advocate for us at a local and national level.

**The rule or regulation I think should be changed ...** Best scenario: national legislation mandating that every new house will have basic access.

Second best scenario: passage of the Inclusive Home Design Act, since that would affect housing at least to some degree in every state.

**The rule or regulation I think should be changed ...** ADA compliance should be enforced for all public buildings and definitely for all buildings run with public funds.

**The rule or regulation I think should be changed ...** Building codes and tax incentives are the key.

Visitability is important to all even to those without a disability, like a mother going up stairs with babies or a toddler. We need to work together as a community. Let's have homes and apartments without stairs.

**If more homes were made visitable ...** Wow, I would be way more confident and feel like I could do more on my own. The rules, laws or policies that might be changed to change the minimum standard in home design ... I don't like imposing more tax or rules just for me. But I know the frustrations felt by others like me, when trying to be independent.

**If more homes were made visitable ...** I could actually go house shopping or rent an apartment without waiting for months on housing wait lists. That was my biggest problem when I was looking for a place to live. I would ask, "Can I get a wheelchair in here?" and the answer would always be no. Also I would like the opportunity to go visit friends.

**The rule or regulation I think should be changed ...** A few people felt that the laws that are in place now (FHAA, Section 811) need to be enforced rather than create new laws. Several people felt that changing the law so that all homes would be built to visitability standards. Someone added that "...just being able to get into the house would be nice." A few people weren't sure which laws would be best to change. They would have liked more information on visitability.

**Rules and regulations could be changed ...** by advocating with realtors, contractors, and legislators. Everyone should have the same rights and same lives as much as possible.

**The rule or regulation I think should be changed ...** I think visitability should be written into law or regulation. Building codes, tax incentives, and statutes could all be used. Maybe some powerful TV ads, like the MCTN ads could help make visitability cool by using popular actors.

## Partners

Many people felt that Board of Housing, AARP, Summit, Housing and Urban Development, Montana Home Choice Coalition, Neighborhood works, Department of Commerce Housing Division, Board of Housing, The Independent Living Centers, the Rural Institute, Habitat for Humanity, local Housing Authorities, local builders, state senators, and the Montana Housing Task Force were possible partners in an effort to change building regulations. These partnerships could educate legislators, state officials, policy makers, builders and architects about the need for visitability.

**I would appoint or partner** with the Board of Housing, because of their performance record in past dealings to promote inexpensive visitable design in residential housing by promoting competition through incentives for builders who cater to the needs of disabled people.

**To both reward new homebuilders** for building visitable homes and applying retrofit visitable concepts in existing homes, a tax incentive should be offered.

**Money talks;** so if people received lower premiums from insurance companies or tax breaks from the government for building safer homes with more access, they would be more likely to build visitable homes. Also there needs to be incentives to lower administrative costs for things like home inspection. Then if these opportunities were well advertised, people would take advantage to save costs.

**The resale of a home** is much greater when you appeal to a larger market.

**Enforcing both housing** and public building codes so everyone knows about visitability from the start and making sure there is accessibly housing on the reservation is also important!

**There are other states** that have made HUD standards of building as state policy. I think that the "HUD won't make us" excuse is kind of a cop out.

## Resources

AARP: <http://www.aarp.org/family/housing/>

Accessible Housing Specialists: <http://www.accessiblehousing.net>

Center for Universal Design: <http://www.design.ncsu.edu/cud/>

Concrete Change: <http://www.concretechange.org/>

Illinois Housing Development Authority:

<http://www.ihda.org/admin//Upload/Files//e28feee7-8614-4a9a-afe1-f38c38224397.pdf>

Kansas Dept. of Revenue: <http://www.ksrevenue.org/taxcredits-disabled.html>

Maisel, J. L., Smith, E., & Steinfeld, E. (2008). Increasing Home Access: Designing for Visitability. Washington, DC: AARP Public Policy Institute.

[http://assets.aarp.org/rqcenter/il/2008\\_14\\_access.pdf](http://assets.aarp.org/rqcenter/il/2008_14_access.pdf)

Montana Disability and Health

Program: <http://mtdh.ruralinstitute.umt.edu/Publications/Visitability.htm>, <http://mtdh.ruralinstitute.umt.edu/Visitability.htm>

Montana Home Choice Coalition, Inclusive Housing – Universal Design and

Visitability: <http://www3.aware-inc.org/awareinc/montanahomechoice/MHCC.asp?Title=9>

Rehabilitation Engineering and Research Center on Universal

Design: <http://www.ap.buffalo.edu/ercud>

### **For additional information please contact: Meg Ann Traci, Ph.D.**

Research and Training Center on Disability in Rural Communities, The University of Montana Rural Institute, 52 Corbin Hall, Missoula, MT 59812-7056; 888-268-2743 or 406-243-4956; 406-243-4200 (TTY); 406-243-2349 (Fax); [matraci@ruralinstitute.umt.edu](mailto:matraci@ruralinstitute.umt.edu); [mtdh.ruralinstitute.umt.edu](http://mtdh.ruralinstitute.umt.edu).

Our research is supported by CDC grant #1U59DD000991 from the Centers for Disease Control and Prevention. Opinions expressed are the author's and do not necessarily reflect those of the funding agency.

