

**Transcript for Video from Research and Training Center on Community Living Summit, held Sept. 20, 2016 in Alexandria, VA.**



Home Usability for People with Disabilities. Presenters – Researchers: Craig Ravesloot, PhD, and Lillie Greiman, MA. Participant in the research project: Margo Waters. Scientific and Consumer Advisory Panel Member: Phil Rumrill, PhD.

**Craig Ravesloot:** So, in the RFP that we responded to, the first thing was to look at large datasets to help set up and understand the problem, which was great for housing because we didn't know a whole lot about it especially as it reflected, or impacted potentially participation.

The American Housing Survey is a sample of housing unit in the U.S. that is actually being redone, or was redone, in the process of being redone. They are redoing the sampling in the survey itself, but we worked 2011 data to come up with some of these results.

Nearly 60 percent of U.S. households with an individual that uses a wheeled mobility device are in homes that have steps at the entrance. 60 percent. Of those living in multi-story homes, nearly 20 percent do not have an entry-level bathroom and over 30 percent must climb stairs to reach a bedroom. And again, these are homes that have somebody in the home that uses a wheeled mobility device.

Of those living above the ground floor in an apartment, over 70 percent do not have a working elevator. This is data that we published in the *Journal of Community Development* last year.

We also looked at the American Time Use Survey because we wanted to understand how people use their time. And Andrew and I published a study on transportation and time use in the Community Development journal.

Then we've done some additional analysis that we're just about ready to submit now, that according to the American Time Use Survey -- and this is a survey that's done on a 24-hour diary recall, so they call people up and they say 'We are going to schedule with you next Wednesday, so Tuesday, pay attention to what you do because we want to find out what you do on that day.'

This has been done for a century in different countries. People use it for public policy around the world to see how public policy affects how people use time. Compared to 88 percent of people without mobility impairment, only 55 percent of people with mobility impairment left home on their diary day. So that's the difference in just leaving home.

As you can imagine then, they spent less time in education, social and recreational activities, caregiving and community activities. As we know, they spent less time working and more time resting.

They spent 10 percent more time in self-care, despite the fact that they were less likely to do any grooming. That is, only 65 percent of people indicated that they did any grooming during their diary day compared to 80 percent of people without mobility impairment.

They were much more likely to engage in social and recreational activity without having bathed or groomed. So 29 percent of people with mobility impairments went and did social and recreational activities anyway, despite the fact that they didn't bathe or groom, compared to 17 percent of people without mobility impairment.

So to drill down a little deeper, we started our intervention development with a survey that our partners helped us develop so we could ask some more specific questions about peoples' experiences in their homes. We collected 170 surveys from people in three different communities: Fresno, Indianapolis and Atlanta.

We found that overall, people with mobility impairment compared to other people in our survey, which were primarily all people with some kind of impairment according to the American Community Survey impairment questions, so we're comparing people with mobility impairments to other impairments.

People with mobility impairment report lower satisfaction, safety and ease across the areas of their home. They're less satisfied, it's less easy to do things and they feel less safe.

But here's where it gets interesting. Compared to people without mobility impairment, people with mobility impairment rated their exertion bathing three times higher than those without mobility impairment.

34 percent of maximal exertion, using the Borg scale, which is equivalent to what a person without a mobility impairment says they exert themselves for cleaning the house. That's how much people tell us they're exerting themselves to bathe. That's compared to 11 percent of people without mobility impairments. Again, these are all people with some kind of impairment.

Then we put that into a regression equation, and we find that a standard unit increase in bathing exertion was associated with a 61 percent decrease in the number of social and recreational activities they reported on our survey. So there's a link. It's cross-sectional. It's not causal yet, but we're beginning to build the case and the story that actually, home matters in going out, and in particular, the bathroom is a place that might really matter.

So why is this? Well, living in unusable homes may require more effort for ADLs, like bathing and other kinds of things. Literally everything. Energy spent on overcoming

these problems in the home may reduce time and energy for other kinds of activities. Making homes more usable may translate into more community participation. That's the basic story.

It's actually a simple economic story. Now I have to tell the economic story for Bryce, who's not here. Because this gives us interesting testable hypotheses and we just found out yesterday, we got an award to actually examine this story here that we're very excited about.

So people have a certain capacity for efforts. Call it stamina, as another word for this, right? There's a certain level of this. And effort is scarce. We all run out by the end of the day. Most of us are tired by the end of the day.

Every activity has an effort price. We pay to do things out of our effort store, right? Effort price is determined by personal characteristics and environmental characteristics. For example, home usability. Also accessibility in the community.

The more effort I have to put into doing something, the more it takes out of what I have available. People with mobility impairments may have less capacity for effort, may face higher effort prices for activities or both – this is the fatigue part of the pain, depression and fatigue piece that the HAIL project talked about.

As such, they spent more time resting and less time engaged in activities, particularly activities with higher effort prices. To increase activity participation among people with impairments, we need to increase capacity or lower price of activities. This can be done through increasing personal capacity or by modifying the environment.

This takes us to our intervention: usability. We elected to try and see if we can get people to get engaged with centers for independent living to modify their home environment, hoping that we can see, at some point in this, changes in participation because the effort capacity that they are using to do basic things in their homes is going down.

So Lillie is going to describe the intervention and talk about a few of the outcomes that we saw from that and Margo is going to tell us about her perspective.

**Lillie Greiman:** Margo, as we said earlier, was with us from the very beginning to help us develop all components of this intervention, along with the team that Craig mentioned. And that's the team of five CIL advocates from across the country that Craig acknowledged that helped us develop pretty much every level of this intervention.

We met once a week, for maybe two years, going over all of the different tools and forms that we've ended up using. So they collaborated on survey design, intervention procedures, a couple of which are the website that we have. And we also developed a home usability plan and then the home usability network, which I think I'll go into a little bit more later.

So three CILs across the country worked with us to implement this intervention. We have accessABILITY in Indianapolis, Indiana, who also participated in the project development from the beginning, not necessarily the same individual but the same center.

DisABILITY LINK in Georgia, and Margo participated throughout the entire project and the development and then also in implementing the intervention. And then we also worked with Resources for Independence in Central Valley in Fresno, California.

Just some acknowledgments to show all of the individuals we worked with, and this was just in implementing the intervention.

So in disABILITY LINK, we've worked with Margo, Heather, and then recently Katelyn Johnson, and then also Renee Shakira – I didn't have her on here. Then, in accessABILITY, we worked with Morgan Daly and Angie Hass. And at Resources for Independence, we've worked with Joseph Cody, Barney Morris and Lillian Yang. So we've worked with quite a few advocates across all of these centers over the course of implementing this intervention.

So just to really briefly go over the intervention procedures, what it looked like -- intervention participants were recruited from our Health and Home Survey sample.

We had folks in that sample from the general population that we recruited through kind of random postcards to get general population individuals and then we also recruited from consumers of the CILs, so we kind of had a mixed sample of folks from the general population and CIL consumers.

And then we recruited from that pool, to, for consumers to work with CIL staff to work through a home usability plan here. And then identify a home usability network. And these were concepts that we developed through the development process with our CIL staff.

The home usability plan was really based on an independent living plan. It included some similar questions to really identify home usability issues. And then prioritize issues and identify a goal that they wanted to work on. And then also helped identify personal resources that the consumer had community resources that could be useful for addressing this issue and then kind of a work plan of step by step, how we're going to make progress on our goal.

And then the HUN, was kind of organized by the center, built off of resources that the center knew in the community that they built up previously pertaining to housing, and it could include fair housing centers, it could include realtors or property managers that they knew. Even handymen from the community that might be interested that they made connections with earlier or knew from the community that might be interested in participating. Like Habitat for Humanity is an excellent example of an organization that we've worked with, or that the center worked with.

And so, but the HUN network also includes, so there's kind of a community network, but then there's also the personal network. This could include personal resources that the consumer has including family members, friends, we have a lot of people who say, 'Oh, well, my brother-in-law is a carpenter. He could probably help out. Maybe you can ask him.' Or church groups, those kinds of personal resources that you can pull into your own network.

So we're just now about to wrap up the pilot work that we've done. We have recruited, I think we are actually officially at 30 right now. We're going to add one more person to this. We recruited 30 and we're working currently with 20 consumers who have either gone through the program or are currently active in the program.

And then, just a couple of the most common issues and home usability goals that were identified; very common were bathroom goals, concerns with the bathroom, which a lot of the research that our findings that Craig discussed and these were kind of also happening simultaneously as we were exploring our results from the surveys, we were experiencing that bathrooms were identified across the board as one of the most common areas of concern for individuals.

So some of the kinds of modifications we have done were grab bars, like toilet support, commode chair-type things, shower chairs, handheld showers. We also had a participant who was interested in getting a magnifying mirror to help shave every day.

And then beyond that of course bathrooms weren't the only issues. We also identified issues around exits and entrancing. So, ramps and sidewalks, need for improved lighting, then also help with cleaning and organizing your home has definitely been an issue that's come up, and has been challenging but really interesting to discuss with some of our CIL partners -- the issue of cleaning. I would love to discuss that further as well.

So I'm just going to go through a couple of photos. We got permission from some of our participants to share some of the projects that we worked on and one participant who was really interested, and lived behind her daughter and like a mother-in-law type apartment really wanted access in and out of her front door.

As you can see, she had like a little step here and then the sidewalk was kind of narrow and crumbling, and she actually had a ramp, so this is her front door. She did have some sort of ramp in her back door that she said she could use but was very unstable and unsafe and she actually had fallen off of it while using it. So she really, for obvious reasons, didn't like using it.

She wanted access from her front door because that provided access to her daughter's apartment and to the front street. So this has allowed her to come and go much easier, as you can see here she is kind of in the process of coming out of the house. These pictures are in kind of interesting order.

She's talked about how it provided an opportunity for her to spend more time with her grandchildren, which was something she really wanted to do. We worked with Habitat for Humanity to get this project done. It was an expensive project. We got the labor done. We worked with her to figure out a payment plan through the project. We had some funds so we were able to supplement her. That has still been a challenge for her. There's definitely still some challenges for these projects.

Along with kind of simpler end – that was probably one of our largest, certainly financially largest project -- but we also had quite a few basic bathroom modifications or additions like these kind of support bars that go on the side of the toilet.

And we've done quite a few of these. These are quite affordable. What's really nice as opposed to, say a grab bar, like actually secured into the wall, is we have a lot of participants who live in rentals and having some alternative modification like this that don't necessarily require a home modification request to a property manager or something offer a lot of flexibility for individuals because that can be a barrier, though there's legal expectations around home modifications and accommodation, it can be a barrier for a lot of people to try and get ready to talk to their landlord and start working through that process.

This is also a real exciting result that we had that Margo worked on. This participant didn't identify a problem with her home but did identify a problem with accessing the community. She lived in a large housing complex, and couldn't get to the bus stop because the entrance to the housing complex is right here, but there's not a curb cut on either side, and there's a bus stop up here and a bus stop further down the road.

As you can see, this sidewalk has a clear path of travel all the way to one bus stop and then ends quite abruptly right at her apartment complex. So, Margo and other folks at disABILITY LINK worked with her to advocate to the city and within like, a shockingly short amount of time to get the city to take action, they installed a sidewalk and curb cuts on both sides of the street. So now she can come and go and get the bus.

She still has a challenge as this is a very busy street. So when she's coming back she actually has to still ride the bus so she can get off on her side of the street because it is dangerous. A person was actually hit by a car while we were discussing the danger of this street crossing. So hopefully there's been some improvement. There's a crosswalk. They added a crosswalk. We still want a light. We're getting there.

So, just a couple more slides about some discussion and implications. You know, many people as we are talking about the data and this intervention is showing, people are living in homes that are not accessible or usable – but certainly homes that don't suit their needs.

We are seeing bathrooms are particularly problematic, high levels of exertion, safety concerns. So many stories of individuals using towel racks as grab bars, which are posing, I mean, the issues in the bathroom are posing huge risks for safety and injury,

and potential hospitalization, which is something we've known, but just again it's getting reinforced.

And then, people with impairments are spending their time differently. We see that they're going out less, grooming less, spending more time watching television. That was another finding from the American Time Use survey.

And all of these things combined have major implications for community participation. Through this intervention, we've seen the bathroom is a critical location for possible intervention.

And then finally, just some impacts on policy and practice. Focusing on housing as it impacts participation, we see a lot of research looking at housing in general and looking at improving ADLs but not always taking that extra step out saying, 'How does this impact involvement in the community?' Bathroom usability interventions for all of the same kind of reasons. And then tools, really developing tools for service providers to connect with housing resources and develop housing program capacity. That was definitely a goal of this project was developing a lot of these tools that we've had.

Housing is a major issue, and it's a big and it's a scary issue, but everyone at a center for independent living experiences the need for accessible and usable and affordable, of course, housing in their communities. And so hopefully kind of developing some methods that you can, you can see that there's, about, kind of breaking up, identifying smaller goals, to maybe work towards bigger goals with consumers and identifying resources.

**Margo Waters:** Thanks to Craig and Lillie for giving me the opportunity to participate. I'm going to do some reflection on participating in the research project as CIL advocate and working with my consumers.

So, there was positive outcomes and reflections here, so, like I said, one of the positive things was being able to work closely with the research team to develop this intervention and one of the things that overall I got out was that the research team did listen to us and invite us to the table, did nothing about us without us.

I really appreciated being able to share my advocacy effort and be a part of the development of the program. So, it was the researchers; they were really engaged and worked with us and had materials that they developed that really helped streamline the project.

The importance of the concept of the home usability and the difference that really made in people lives, it was like a real enhancement to their independence. Lillie gave that report on the people -- it wasn't really about her home, but she didn't have access to the community and that was one of those projects that, you know, not it's always the home that's unusable, but she's a big advocate in the community and so being able to get out and get back home safely was very important.

And with their project that they worked on, in the end, it didn't just help her, it helped the whole community because where her and my colleague both worked on this project, they lived in housing across from each other.

So one property residence there were all people with disabilities – segregated, if you look at it that way. And a lot of them used public transportation, so once they started working on that project, it helped a lot of them be able to become more independent, get out into the community, which was what they really tried to do.

And the consumers that worked on the project really spent a lot of time, were the people who were consumers of the center who were actually advocates. I think they followed through, worked on their plan and helped develop results. And there were barriers and challenges and, so, the consumer engagement was a motivation and all of the consumers who had self-advocacy, like I said, did a lot of work and completed most of their project on their own.

So there was technological barriers, too, such as not everyone is able to get Internet service. Maybe they can't afford it, and, so a lot of them not having access to the Internet prevented them from being able to do some of the work – filling out the forms, which would require assistance and, you know, when you are working at the center, you know, you have quite a few projects that you may work on, and so, Lillie stepped in and she provided extra support to help with getting the paperwork done and that.

So, you know with these kind of notes that Lillie would send back after our meetings and everything, they really helped with the development and getting work done, projects completed and a lot of people were able to move on, spend less time sitting in the house and getting out into the community.

So I think the home usability study is something that, you know, truly can help and I hope that on down the road, we'll be able to do this project with you, Lillie and Craig, again. And hopefully we can get more results. I think that even for myself, being able to get out of the home, into the community, is an important piece in being independent and living in the community, so I appreciate everything that the home usability study brought to our center.

And the consumers that did benefit from it are extremely happy. And we have one consumer who wants to turn her shed into her fitness center where when we talk about health and wellness, that's part of her disability, is needing to exercise and work on her health. But she has a shed that is really, like how we talk about home modifications and the funding that can cost to do like rolling showers and things like this, so this is a big project. And I promised her that once we got over the hump with this, that we would go back and revisit that and maybe come up with some ideas, some resources and, you know, help her to complete that project that she so dearly wants and need. So that's what I got, all I have to add to this.

**Lillie:** Thank you, Margo.

**Phil Rumrill:** Margo, if that's all you have to say for now I'd sure rather listen to you than listen to me, I want to talk to you after. You've got a lot to say. And it's a great pleasure for me to be here with you all Glen and Martha and Val. Thank you for the opportunity to work with this project and to serve on the Scientific and Consumer Advocacy [Advisory] Panel. If it makes for a lousy acronym, SCAP, it is a great group to be part of and an honor to be involved with all of you and to have an opportunity to review this project, which is another in a long line of the authentic and street-level kinds of projects that Glen your center does and Craig and Dr. Seekins and everyone there is Montana. This is what you guys do and embodies the spirit of participatory action research, which is really, you know, how it ought to be. As I'm thinks about these findings, first of all I kind them really fascinating, Craig, to see kind of in black and white the extent of the issues around accessibility, usability, the discrepancies between people with and without disabilities in terms of these issues. But it really, I think, gives cause for some ambivalence as we think about community participation and particularly the role that housing plays there.

I think your findings really do indicate clearly some of the progress that we've made in beginning and continuing to make in terms of broadening the notion of accessibility out to this idea of usability and then extending out to community participation. It also strikes me as it often does when you look at statistics in the broad sense of how far we, the work we still have yet to do. I'm just thinking about the large proportions of people with disabilities who are still living in inaccessible and therefore, unusable homes, so we must do better than that.

In terms of the, and then is usability even enough, Margo in the example here where your consumer could get in and out of the home, but then the sidewalk doesn't work. So you are really kind of relegated to the home environment unless you can figure out some creative way to cross the street, and so how does this connect in that way? I'm also struck, Craig, in your parlance, the exertional price of activities of daily living for people with disabilities, the price that people who don't have disabilities simply don't have to pay, and how we can go about reducing that and the centrality here in your study of the bathroom in the home to those activities of grooming and hygiene and daily living and how, you know, when you are spending hours getting ready for the day that doesn't leave as much time for the other aspects of community participation that we know people with disabilities want to engage as much as anyone else and simply, for reasons of sheer energy expenditure, they just don't have the time and energy to, to engage in. So, this is a great beginning. And I look forward to where you guys take this next. I'm also struck that your three sites here are in urban or suburban settings, and, but I don't think anything about your methodology is unique to those settings. I don't need to tell you guys in Montana about the implications her for rural considerations. Is'm sure your findings would be different but the model here would apply, you know, very directly, and perhaps different issues around transportation and resource utilization and things of that nature that you all know more about than I do.

But I see this as a universally applicable model and that's very, very encouraging. Thinking about something that Dr. Seekins said earlier this morning, too, about the disability as an ecological phenomenon, and in the work that you are doing here, particularly as we look at home usability, the environmental reciprocal is certainly alive and well and that's important to see. I think it is important to think about disability and how it's changing, not just as the social and political and cultural environments that people with disabilities interact with change, but the very nature of disability itself is changing owing to the kinds of conditions that people are dealing with and these whole kind of emerging disabilities that we see that are fairly new to medical science or are emerging in great numbers in specific segments of our population. Population aging, of course, accounts for a lot of this and I'm just thinking about, as the older the more I think about aging, but we know we have 77 million members of the baby boom generation, born between 1946 and 1964, what they all have in common is none of them are getting any younger, right? The number of 65-year-olds in America is going to double between now and 2030. And with age, starting at about age 30, we see the incidents of disability increasing as a straight linear function of age. So, people with disabilities, thanks to advances in medical technology and intervention are living longer and healthier and more active lives than ever before. They are also dealing with age related conditions that aren't necessarily associated with their original disabilities.

We also see people who didn't have disabilities at other times in their lives incurring age-related conditions, orthopedic impairments, for example, diabetes, two-thirds of all people who are legally blind are over the age of 65, rheumatoid arthritis, as people get older, dementia, the number of people dealing with dementia is going to double in the next 20 years. So we start to see, you know, the kinds of conditions that people are dealing with and wanting to overcome are getting more complicated simply as our population continues to age. That's one example.

Then I'm thinking about traumatic brain injury epidemic. The increase of mild and moderate TBI, owing to sports and recreational injuries. The increased number of brain injuries associated with military combat, of course, and of violence, and then of course the secondary conditions, Craig that you alluded to and the HAIL project where we see pain, primary pain disorders too, but also conditions that are accompanied by pain, and depression and fatigue. You put those three things together and it creates a totally different take on usability, on community participation and all of those issues. So, as we look at the changing nature of the disability community how environments have to change, it just strikes me that this is an ongoing and dynamic process. We're all going to have plenty of work to do in this area for the next 40, 50 years for sure. So the more things, the more things change, the more things change. They don't stay the same and this is a really good start, I think, at looking at this issue of housing which has been understudied as a conduit to full community participation. So I commend and congratulate you for this great work and thank you all for having me here. It's great to be here.

**Amanda Reichard (off camera):** Hi. Amanda Reichard at the Institute on Disability at the University of New Hampshire. I wanted to kind of build on what Tom said, by saying that I would like to encourage us all to not just look at the dynamic interactions, but I think it's important that we start to find ways to measure the economic impact – and I'm not an economist nor pretend to be – but if we can measure the economic impact – I think in all three of the presentations we've seen today, they all have the domino effect of, if you improve this, then that improves this, and that improves this. But if we can start to think creatively about how to assign an economy to that and a cost to that, then we can use the numbers to make the arguments to policymakers about how, why they need to be investing in tools like HAIL to train people at the CILs and to hopefully, ultimately have dollars to do what you are doing so through this program so that you don't have to do it at the individual level -- there's already funding out there and you are spending time getting it to all the people instead of going door-to-door trying to look for the money. So that's just, broadly speaking, think about how in the next iteration – all of us, in the next iterations of our projects – start to think about how we can assign a cost to this and a savings to this even like you know the one example, just saving money on the drugs of that one person that you guys worked with. And just think about the domino effect of that in saving. Thank you.

**Jessica Chaiken (off camera):** I just had a quick question about – oh sorry, Jess Chaiken, with NARIC. You mentioned briefly that some of the relative costs of the solution, the intervention. And we know on average workplace accommodations are less than \$500 and many are free. Did you find similar with the home modifications?

**Lillie:** So it's kind of tricky because the range is so huge. The grab bars in the bathroom, for instance, I think those cost 50 dollars. So for those kind of standard grab bar modifications goes from \$30 to \$150. The more expensive thing we installed was a stand-assist pole that goes from the ceiling to the floor but then, to get the cement done was about \$2,000. If you are talking about walk-in or roll-in shower the costs keep going up. So, this intervention, focused on, you know accessing the resources of the individual and the community and what was available, whether or not we could take on some of those larger projects. So we've recently had a woman install lighting in her cabinet, a woman with low vision, I think that cost \$100. So, it's been really variable and it's across a huge spectrum. But some of these smaller changes that we're seeing are pretty meaningful for individuals, are really less than \$200 dollars sometimes.

**Kelly Mack (off camera):** Hi, Kelly Mack from ACL. I'm wondering, were there any interactions or feedback from property managers? I'm just testing the waters on what the reaction was on these changes.

**Lillie:** We definitely had some consumers, and I think we saw a little bit of this in Atlanta, Margo, if you want to talk...

**Margo:** It was a consumer and her bathroom wasn't accessible. And she was wanting to request a raised toilet. And so, with the project, the raised toilet could have been had

but she didn't have a network where she could get the plumber or someone to properly install it. So that was an issue there. But as Lillie said with the grab bar-type toilet seat, that was something that she could get without going to the property management to enable her to get a toilet install. And this person, I think her worry was that her way in getting on and off of that wasn't something that would be what she could use after a while, you know, she was concerned about it not being strong enough. So, it's different barriers, you know, that may have held up some progress with her getting that toilet that she needed. But, as we got on into the project, she passed away and we never got the opportunity to continue to work on that, so.

**Lillie:** Yeah, that was unfortunate.

**Craig:** I'd like to comment, too, that while in this pilot work where we're just trying to look at is this feasible idea, I don't know that we came across a lot of this, but it certainly is part of a vision of having a network, where, and the network, including people like other property managers. So if you have one group that is a stickler on this or is not particularly cooperative, we would like to have a network that includes a very cooperative property manager who can weigh in on this and say, 'Hey, this is something you all need to do or you're going to end up in big trouble.' And that's a peer relationship. So our bigger vision for this is that be that those things would be dealt with through the CILs and through the network of people who could help move some of those problems with the property managers.

**Jane Tilley (off camera):** Hi, I'm Jane Tilly with the ACL and I have a suggestion and a question. So the suggestion is that all of these pilots have some great results but they're small. And I'm assuming, maybe there there's some kind of resource center or you already are trying to look across sites to have a common evaluation plan so that you can prove the worth of these various interventions. So that's the suggestion if you are not already doing it. The reason I'm making the suggestion iss a lot of these things are things that could be funded under Medicaid or home and community-based services waiver. I do a lot of work in dementia and in that field, if you can prove cost savings at the state level, you get a lot more of an audience for making those kind of expansions under Medicaid.

**Craig:** Absolutely. Yes, we are working, thanks to our Federal partners, on expanding the home usability project starting October 1. We've got to get home, we have a lot to do. But also, when we survey people with impairments, when you look at the American Community Survey data on this, most people aren't Medicaid eligible, right? So we're trying to work toward a model that has much more applicability than Medicaid and just institutionalization under Medicaid. We'd like to have something that is useful for a much broader population. But I like your notion I think I heard in that, if you show this within Medicaid you get a bigger audience. I think that's a great idea. Thank you.

**Marcella James (back to camera):** What about apartments when people with a disability have to live in apartments, are the property owners required to help people with disabilities to like get up and down or have a ramp? Are they responsible for that?

**Craig:** Yes and no. So this is part of our project, that buildings that were built that have more than four units built after about 1990 are required to have accessible units in place. The ground floor units are supposed to be accessible. They are not always, but there are some specific mandated requirements. We found out only 10 percent of people that indicate they have an impairment are living in these homes, in the apartments that were built since 1990, because of course they are newer and they're more expensive. So 90 percent of the people currently living are not in these covered homes, or apartments, I should say.

**Pimjai Sudsawad:** Just want to comment on the question not directly answer the question but just want to bring your attention to what another network project that we fund called the ADA National Network and that network was founded specifically to answer the public's question about requirements, rights and responsibilities of those under ADA. They provide free services. They have all the materials available. You can call the 800 number and ask for technical assistance for anything that you'd be interested to learn. Or solve your own issues about understanding the rights and responsibilities under ADA. I can give you information after the end of this talk.

**David Keer:** David Keer, disinterested social observer. [Laughter] I would like to pick up on a point Amanda made as well as a comment made by the person from ACL who spoke most recently, and to issue a challenge, if I might, to ACL and NIDILRR leadership who happen to be in the room, which is to consider opportunities of funding possibilities to perhaps ramp up some of these pilot interventions, to test them in a variety of geographical areas. Also to consider the possibility of developing a center for dissemination of some of these most promising interventions that might expand beyond the network of CILS and might go to other networks or providers who might or might not be familiar even with the existence of the CILS.

**Bob Williams:** Bob Williams. First, have you given thought to what the sustainable funding stream might be to bring these efforts to scale and have you thought of ways we might try to drive the cost of these modifications down?

**Craig:** Yes and yes. We're talking about the folks who we know who use a lot of healthcare resources, so to Amanda's point, we do need to be looking at the cost and the effectiveness and the cost outcomes of these types of interventions, because they are relatively inexpensive and the potential outcome in terms of cost, just vis-à-vis increased participation. So, you know, just the woman who's able to get out easier and spend more time with her grandchildren, we don't know the potential effect of that on her psychological well-being and the effect on her, her physical well-being and if that translates into cost. Or the example from the person who helped us in designing the survey who says, "I go to the hospital less." These are all costs that are being currently

picked up through healthcare. So if we can show that, then I think that our partners like you at ACL will say now here's some data I can take to Congress to say these things need to happen within the healthcare industry. That change is happening anyway. A project that Tom is working on now is looking at rural communities support for people when they transition out of a hospital, so that if somebody comes out with some impairment they have supports starting right then. That's got to be cost-effective if we can show those kinds of things, that's going to work. In terms of driving the cost down, yeah, I've had one kind of wonky idea, to be honest, that I'd really love to try, and Gwen Gillenwater gets a little mad at me when I say this, but nationally it looks like there probably is enough accessible housing for people who use wheeled mobility devices -- it's just that it's not necessarily in the right places and it's not affordable. In rural places doesn't exist, and this is where Gwen says, 'You haven't been to rural South Carolina.' Well I have, but I think she's right - it probably doesn't exist there. But the point is, in places where there is accessible housing that was built since 1990, I think it would probably be cost-effective with regard to health care utilization if we just do some house swapping with people, right?

So somebody is on the second or third floor without an elevator and we go and say, 'Hey if you would like to move into a place that's accessible so you can go right out to the public transportation, we'll make that happen.' We can find someone in a ground floor unit and doesn't need it and they would rather be in a different school district. We can make all this happen for a couple grand. Everybody is moved and everybody is happy. I think we can track the cost on something like that, and say, 'Look, there's no modification here, we're just getting people in the right places.' Everybody is happier.

It's a wonky, crazy idea that Tom and I hatched on an airplane a couple of years ago. But that starts to drive the cost down, it's just another way of thinking about do we have the right people in the right places as time goes on and as we have more and more places that are built out, that are more fully accessible because our independent living centers are advocating and watching the builders as they build out these apartment complexes to make sure they are building the accessible apartments that they're supposed to be.

**END**