

**Semi-Structured Interviews Investigating the Need to
Adjust Current Adult Changing Table Regulations**

Telephone Survey 2019

Conducted for:

Florida Building Commission

Conducted by:

University of Florida Survey Research Center

Bureau of Economic and Business Research

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Executive Summary

Key informant interviews were conducted with members of the disabled community in order to assess the need to make changes to the Florida Building Code as it relates to installation of adult changing tables in public spaces. The interviews were conducted between May 4th, 2019 and May 29th, 2019. The questionnaire was developed by the UF Survey Research Center and approved by the Florida Building Commission on March 29th during a meeting with the Accessibility Technical Advisory Committee. 30 key informant interviews were conducted with members in the disabled community, primarily from members of The Family Café, an organization advocating for needs in the disabled community. Additional participants were recruited via a referral process at the end of the interview. Key takeaways are:

- Adult changing tables are viewed by the community as an overwhelming net-positive.
- The absence of adult changing tables currently makes it difficult for non-ambulatory people and their caretakers to participate in society and the needs of the community are not being satisfied.
- Access to adult changing tables would be safer, cleaner, more private and less stressful for people that need them compared to the current situation.

Method

The University of Florida Survey Research Center (UFSRC) was contacted by members of the Florida Building Commission to explore whether the current prevalence of adult changing tables in public places is serving the needs of members in the disabled community, and if not, to look into the nature of those problems. In consultation with members of the Florida Building Commission, it was determined that semi-structured interviews would be the best method for addressing this issue. The UFSRC received institutional review board approval under IRB #201900837 to conduct semi-structured interviews for the project. UFSRC contacted a wide number of organizations that advocate for the disabled community in an effort to gain access to member lists to contact people affected by these issues to participate in a semi-structured interview relating to how the

availability of adult changing tables public places would affect the disabled population. Though many organizations expressed an initial willingness to help, no organization would allow us direct access to their membership lists. Only one organization, The Family Café, aided our interviewing effort by e-mailing their members on the project's behalf, asking them to participate. The UFSRC created an online instrument to help facilitate the scheduling of calls at times and dates most convenient for the respondents. The Family Café sent two e-mails on the project's behalf on April 10th and May 22nd of 2019. UFSRC began conducting interviews on May 4th and continued through May 29th. Due to the challenges the project faced in recruiting qualified respondents, the UFSRC instituted a referral method to augment the respondent pool. At the end of every completed interview, we asked the participant if they knew anybody else affected by these issues. If so, the UFSRC attempted to collect their contact information and conduct the survey with them. Additionally, some participants forwarded the recruitment e-mail they received to other potentially interested persons. Calls were transcribed using www.rev.com, a reputable vendor UFSRC has used in the past for projects that involved transcriptions. The maximum number of contact attempts made per respondent was limited to six to reduce respondent burden. The average interview took around 18 minutes to conduct.

Summary of Themes

Based on our interviews, it appears individuals in the disabled community and their caretakers are largely unable to find an adult changing table when and where it would be helpful. Most participants reported having knowledge of adult changing tables: they had not only heard about adult changing tables but had first-hand experience using them. Information from disability advocacy groups such as The Family Café and word of mouth seem to be the ways most participants received information about adult changing tables with two respondents specifically mentioning going to the Universal Changing Places website (www.universalchangingplaces.com). The overall availability of the tables is currently lacking. Respondents reported that although they have encountered them while participating in typical activities, adult changing tables are few and far between. This situation was described by participants as a “huge problem” and

“incredibly difficult”. Caretakers are usually forced to perform changes on bathroom floors, backseats of cars, and/or more-or-less secluded outdoor locations. Because the expectation is that they will be unable to find an accessible table, caretakers will make sure their charge has used the bathroom prior to leaving the house so they do not have to be changed on the floor of a bathroom. Frequently, these bathrooms are too small to perform a change unless a family bathroom is available. Caretakers also cite the lack of privacy that the current situation affords the people who need adult changing tables, and believe their dependents deserve better. Because actually coming across a changing table they can use is so rare, most respondents reported that they do not choose places they can go based on the availability of an adult changing table: it is not reasonable to anticipate that one will be available. Furthermore, most establishments have not been accommodating when asked for alternatives to the bathroom floor, with many respondents citing negative experiences when such inquiries are made. Every respondent that participated in this project said they would find widespread installation of adult changing tables to be “very helpful”. An increase in accessible tables would improve quality of life for these individuals dramatically by allowing the disabled community to go to more public places without worrying about having to make the choice to perform diaper changes in public or change plans and return home. Typical reports include: being unable to go shopping with their dependents due to the lack of an accessible bathroom that would fit their needs. Other respondents reported delaying plans and/or not participating in events if there would not be a safe place to change their loved one or client. Respondents think that the handicapped and disabled community, specifically those in wheelchairs, would benefit the most from increased availability of adult changing tables, followed by the caregivers themselves. The current prevalence of adult changing tables in public places is very low and is absolutely not meeting the needs of the community according to the participants. Overall, installing more adult accessible tables would reduce stress associated with changing in public while allowing for the disabled community to have a more active and visible role in society while helping all parties maintain their basic dignity. Increasing the number of adult changing tables would be a substantial improvement in the quality of life for these individuals.

Selected Quotes

“I think it would make it easier to take her a lot more places. I have a highly intelligent child who is going to college, but we run into these problems like how to take her to the bathroom and do all those things. I'm not even sure how to I'm going to send her off to college if it isn't a few blocks from the house which is what we're doing now. Clearly it would make a huge impact for her, and getting her out in the world. Perhaps we think about that with a job for her, too. How's she going to go to the bathroom with a job, somewhere? I didn't even know how to do that.”

“We've, I think even when we were going down to South Florida and you try to go to a restroom on the way to where you're heading, you know like even a turnpike scenario, at least then you'll have a bathroom big enough to fit the wheelchair in and a couple of people to help, but it still gets really awkward and always seems to make it hard.”

“One of the things that was very frustrating was the little places and there's no separate either family or disabled bathrooms. You know, you've got the men's rooms that have one in them, and the lady's room may have one in. But you can't take your husband into a lady's room for these things. Or take the wife and the daughter into the men's room. You get very creative at times with that. You know, dive in there together and then tell people I'm sorry I have to bring my husband in to help my daughter who can't stand. If you hear a man's voice, don't panic. That's how tricky it gets trying to maneuver these things because if there were places that I could get her laid down and do the job. But, I can't hold her up as well as manipulate everything else that's supporting. So, anywhere you have to give people more options.”

“Travel is always a problem. It's just, you can't find a facility to use. You have nowhere to lay them down. It becomes a two person event. In London I was shocked that we went into what they called special needs bathrooms. They were supposed to be only special needs, they weren't for families or anything like that. And they literally had lifts in there that you could use to lift somebody onto the toilet. I was floored. I didn't know how to use them because we don't have anything like that in the US, so that intrigued me..., the London Zoo, had a trailer set up. It had a ramp going up to it. It was a big long room. It had a huge changing

table on it that we used and it had the toilet and it had a lift. It had everything. I just think that would be amazing to have in places like stadiums, and zoos, and concert halls, even if they just had one of them that you could find at some point. All of those are challenging things for us.”

“I've wished that they were available at public places, it would really be helpful. Especially government offices where I'm required to go, like the DMV and other places. You're required to go there, there's often long waiting times, and then if you have a special needs child or adult that has to accompany you that's incontinent, it's not always possible to just leave them until you get home. It's certainly not comfortable, but in my daughters case it's not possible if she soils herself to a degree that it needs immediate attention.”

“It's a real problem. We actually bought a different kind of car so that we could take care of her needs inside of our vehicle, which in Florida is really difficult because it's hot, you have to leave a running vehicle in a parking lot. We're doing whole outfit changes in our car. In our previous vehicle we didn't have privacy and so that's how we accommodate her, or she just doesn't participate out”

“Well, right now we don't have passes to Disney anymore because even though they do have tables that you can change on, and some of them are very long, they're not big enough for my child anymore.”

The only place that was accommodating was Disney where they said we could use the medical facilities to do that. But then it was problematic because the exam rooms do not have toilets or sinks, well they have a little sink in them. But they're not really set up for toileting activity. And the actual bathrooms are in another location. So, they weren't really designed to accommodate somebody who needed changing and toileting.”

“We were just at an autism even at a place that is a physical therapy office and they did not have a full sized changing facility in their facility. They had bathrooms, they did have some baby changing tables. They did have some potty accommodations and I know they mainly go with child clients. But I just thought that surprised me.”

“It makes me feel creepy. To be dressing and undressing my daughter in public places parked in a car. Our van is a camper van, so it has window shades that we

have to pull them all up and then it makes me feel like other people are wondering what we're doing. Even though it's somewhat private, it still makes me feel vulnerable and kind of weird. My daughter doesn't mind it. It also makes our van smell like a toilet. Really very smelly place. And there's no running water so we have to do all the cleanup with wet wipes and then haul that trash somewhere and dispose of it properly. So, it's minimally adequate.”

Interviewer Guide

INTRODUCTORY SCRIPT:

Hello, my name is _____. I'm calling from the University of Florida.

You received an email from The Family Café in April inviting you to tell us about how the lack of powered-height adjustable changing tables in public settings affects you or loved ones. The University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

We are calling you because you completed the online scheduling form when The Family Café e-mailed you. Your input will help inform and shape the commission's ruling

Everything you say will be confidential and will be reported with no identifying information.

There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer and you can stop the interview at any time. I want you to know this call will be recorded for quality control purposes and will be transcribed, summarized and aggregated with other participants.

This survey should take 10 to 15 minutes.

(If you have questions about the study, you can contact Perry Leibovitz at 352-392-2908. If you have questions about your rights as a participant, you can call (the University of Florida) IRB#2 at 352-392-0433.)

| Issue Area | Stem Question | Follow-up items |
|--------------------------------------|--|--|
| General Impression | 1. First, I'd like to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you | 1b. Anything else? |
| Awareness | 2. Have you heard about adult changing tables | 2a. Where have you heard about them (Word of mouth, magazines, disability advocacy groups, etc.) |
| Is Lack of Changing Tables a Problem | 3. How much of a problem is not having an adjustable adult changing table when you are participating in society? | 3a. Can you tell me about a specific example? 3b. How did this affect you/make you feel? |

| | | |
|-------------------------|--|---|
| | | |
| How Helpful | 4. How helpful would it be to you if public places had adjustable adult changing tables available to use? | 4a. What types of things would you be able to do? Places to go? 4b. Overall, please describe how your quality of life would change if universal changing tables were more prevalent? |
| Choosing what to do | 5. When choosing things to do or places to go, do you consider if certain places will have changing tables for adults? | 5a. How helpful/accommodating are these locations when you ask about adult changing tables? 5b. What things/places in particular? |
| No access | 6. What do you do if you have no access to a changing table? | 6a. Can you give me a specific example? 6b. How did this affect you/make you feel? |
| Participation in events | 7. Are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table? | 7a. Have you delayed or changed plans because there was no adult changing table? |
| Who would benefit. | 8. If more adult changing tables were installed in Florida, what types of people would benefit the most? | 8a. Why do you think that? 8b. Anything else? |
| How prevalent? | 9. When you're participating in society, how often do you encounter an adult changing table accessible to you? | [IF THEY GIVE VAGUE ANSWER LIKE "A LOT" TRY TO GET A PERCENTAGE OF TIMES. 9a. Do you think this is adequate? |
| Other | 10. Anything else that you would like to share with me? | |

Interview Transcripts

Resp 1

Participant: Hello?

Interviewer: Hello. My name is [name]. I'm calling from the University of Florida. You received an email from the Family Cafe in April inviting you to tell us about how the lack of powered height adjustable changing tables in public settings affects you or loved ones.

Participant: Yes.

Interviewer: The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Cafe emailed you. Your input will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing this [crosstalk 00:01:11]-

Participant: Yeah, I understand.

Interviewer: But your answers will help the Florida Building Commission make informed decisions.

Participant: Yes. That's awesome.

Interviewer: Okay. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any questions you do not wish to answer, and you can stop the interview at any time. I want you to know this call will be recorded for quality control purposes and will be transcribed, summarized, and aggregated with other participants. This survey should take ten to fifteen minutes.

Participant: Okay.

Interviewer: The first little bit of the survey is a powered height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of, yes or no?

Participant: Yes. Yes.

Interviewer: Okay. First I'd like to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Yes. I have an uncle who is disabled, and he is in a wheelchair. So when I take care of him he's incontinent, you have to take him off. It's hard to find any type of changing tables to put him on. They have baby ones but not adults. It's very uncomfortable and you have to go back in the car or in the seat, and it's very embarrassing for people of handicaps.

Interviewer: Understandable. Is there anything else?

Participant: Yeah, I think that they should have those, like a room by itself where family members can go in for more handicapped accessible, because there's a lack of handicapped accessible things around anywhere.

Interviewer: And is there anything else you would like to add?

Participant: Mm-mm (negative)

Interviewer: Okay, have you heard about adult changing tables?

Participant: Yes.

Interviewer: Okay, where have you heard about them, word of mouth, magazines, disability advocacy etc.? [crosstalk 00:03:47]

Participant: Word of mouth.

Interviewer: Anywhere else?

Participant: Word of mouth and The Family Café.

Interviewer: Okay. How much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: Very hard.

Interviewer: Can you tell me about a specific example?

Participant: Yes, we go out to hotels sometimes on vacation and people don't, if they're not - we go to the [inaudible 00:04:26] Family Café, everybody else is disabled so everybody understands. But when we go out as a family and they don't understand, there's people looking at us, think something's wrong with us because he has problems and we have to change him almost in broad daylight, everybody sees everything. It's a great thing to have a room with a changing table and stuff, it's convenient for privacy.

Interviewer: How does this effect you or make you feel?

Participant: It makes me feel very strong to be able to take care of my uncle better with this type of product.

Interviewer: How helpful would it be to you, if public places had adjustable adult changing tables available to use?

Participant: I think it would be very beneficial for everybody that has any type of adult that needs a changing table because lots of regards because they can't just out of nowhere, they have problems, and they can't change them in the middle of the mall or a movie theater or anything. They have to go to the bathroom and the bathrooms have nothing there. They have baby changing tables but they need adults, so they're very beneficial for everybody.

Interviewer: What types of things would you be able to do, places to go?

Participant: If you had those you could go endless places like Disney World a lot because my uncle likes to go out to see things and stuff and a lot of limitations because we always have to be mindful that we have to change a diaper it [inaudible 00:06:34] to be secretive because you don't want to show everything. So, very beneficial.

Interviewer: Overall, please describe how your quality of life would change if universal changing tables were more prevalent.

Participant: I believe it would be a lot of pressure off of our daily lives because it's a daily thing that we have to deal with. Everyday we have to take him out, we take care of him everyday, were always on the go, so if we take him with us and he has to go to the bathroom and we have to stop it takes a lot of time. It takes hours, a good half hour to get things done and it [inaudible 00:07:24] our schedule off because of stress but just having this would be so much more beneficial because you get him up there get it done put him back in the wheelchair even faster.

Interviewer: When choosing things to do or places to go do you consider if certain places will have changing tables for adults?

Participant: I never thought they would have changing tables for adults.

Interviewer: How helpful/accommodating are these locations when you ask about adult changing tables?

Participant: If they have them they're very accommodating, at the Family Café's we go to, they're very accommodating, they're very helpful and they understand our needs.

Interviewer: What do you do if you have no access to changing tables?

Participant: We usually have to go to a private spot, say in the mall we go to a restroom but we go to a family restroom. We have to get him out of the wheelchair and it's kind of really hard, we have to actually put blankets down on the floor and we have to take off his diaper and stuff like that and his pants and stuff like that because there's nothing there. Family restrooms I understand but there's baby ones they have little toilets and big toilets but they have no changing table for adults.

Interviewer: How did this effect you/make you feel?

Participant: It makes me really upset that people don't realize that there's people that have disabilities that are people like everybody else but they have more needs than others and be more compassionate and understanding that be patient sometimes and be able to have equipment that we need for our family members or friends to be able to live a good life.

Interviewer: Are there places or events that you are unable to participate in due to lack of accessibility to an adult changing table.

Participant: Many things, sometimes we can't go to outdoor adventures or anything because we'd have to go back to the car. If they have public restrooms it would be fine but everywhere we go everything never has a changing table.

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Participant: Yes, many times.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: Any families with adults that are wheelchair bound or handicapped from the bottom, they need someone to pick them up, place them on the table, it would be beneficial for a lot of people in Florida. A lot of people, families, I see so many.

Interviewer: I'm sorry I didn't mean to cut you off

Participant: No, I'm good.

Interviewer: Was there anything else?

Participant: That's it. I'm just saying it would be so awesome if we had that.

Interviewer: When you're participating in society, how often do you encounter an adult changing table accessible to you?

Participant: Not very often.

Interviewer: What percentage of the time, would you say?

Participant: Around where I am? Zero percent.

Interviewer: Do you think this is adequate?

Participant: No, it's not adequate, at all.

Interviewer: Anything else you would like to share with me?

Participant: No, I think that legally this issue should be pressed forward and put on to what ever we can do to make it go into effect because it really will help a lot of families and just a lot of stress off of people because we take care of a lot of people all these families we have stress ourselves because we have to take care of others and I think that would be very beneficial. Little things make a big thing, little small things help a big thing. I really believe in this.

Resp 3

Participant: Hello?

Interviewer: Hello. My name is [name]. I'm calling from the University of Florida.

Participant: Uh-huh.

Interviewer: You received an email from the Family Café in April inviting you to tell us about how the lack of powered, height adjustable changing tables in public settings affects you or loved ones.

Participant: Yeah. I'm raising my grandson who had a stroke in utero.

Interviewer: Okay. So, the university ...

Participant: He's now 103 pounds.

Interviewer: Oh, okay.

Participant: Almost 12 and ...

Interviewer: Okay, well the university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

Participant: Yep.

Interviewer: We are calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the commission's ruling. Everything you say will be confidential and will be recorded with no identifying information. There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes and will be transcribed, summarized, and aggregated with other participants. This survey should take 10 to 15 minutes.

So, I just have to read this part. A powered, height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations, or incontinence, they provide a safe, sanitary and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you, or someone you take care of? Yes or no.

Participant: Absolutely, yes.

Interviewer: Okay. Okay. So, first I'd like to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: I'm raising a severely disable child. I'm only 5'1. He is now almost five feet and I'm having to transfer him in and out of chairs and all the other things that go along with that. He is incontinent, in diapers probably forever. So, when we go out, to not have somewhere that I can change him can be very inconvenient and uncomfortable for him.

Interviewer: Okay. Anything else?

Participant: Not that I can think of.

Interviewer: Okay. Have you heard about adult changing tables?

Participant: Oh, I have. There's a website, I'm trying to remember the name of it, changing spaces that actually started, I think in the U.K., but there is now a U.S. version going around. An organization pushing for this same thing that's called Changing Spaces U.S.A. I follow their page and input there, as well as wherever else I can.

Interviewer: Okay. Have you heard about them from anywhere else like word of mouth, magazines, disabled advocacy groups, etc.?

Participant: Probably not magazines, but ... No, probably not. That was the first place and very few places have them.

Interviewer: How much of a problem is not having an adjustable, adult changing table when you are participating in society?

Participant: Oh, huge. Especially now. I mean, it wasn't so much before. Like I said, he's just now getting towards being 12 and when we was small, it wasn't that big of a deal. Of course, when they hit 50 pounds, they no longer fit on the changing tables in stores, like the fold down ones on the wall. So, he passed that up years ago. As soon as they don't fit on those, you're kind of very limited. Sometimes you decide not to go places because of that.

Interviewer: Okay. Can you tell me about a specific example?

Participant: Well, anytime we go ... Even doctor's offices. You know, you go out to your appointments, and you have nowhere to change them. He's much too big. I can't even find a place, you know, sit him in my van on the floor because I can't lift him back up from the position I have to put him in, in the back of the van by myself. Usually I'm by myself with him. So, trying to maneuver that, I can get him laying down, but getting him back up and into his chair by myself because he can't help, is very difficult. So you do, you just ... A lot of times, I mean, doctors appointments you can't not go to. So, usually ... A lot of them even have in their offices, not to change on their exam tables. So, it's like what do you do?

Interviewer: Okay. How did this affect you or make you feel?

Participant: It makes me feel bad for him because, I mean, first of all especially if it's a dirty diaper, it's, you know, if we're out somewhere it can be putting off other people because they're smelling his diaper that I should've changed. Then you also have the problem with he doesn't have this terribly bad problem with it, but a lot of our kids and even the adults have problems with skin breakdown. So, if you can't change a dirty diaper, they're sitting in it for who knows how long until you can get somewhere to change it. So, that's not good for the person that's needing to be changed. It just, all around, it's just hugely inconvenient.

Interviewer: How helpful would it be to you if public places had adjustable, adult changing tables available to use?

Participant: Huge. It would show that they cared because it is such a emotional, it can be a very emotional problem because you know that, that person's not comfortable sitting in that diaper. You really don't want him sitting in it and even if it's just wet. If you had someplace to change that person, like I said, it really would show that they cared about, you know, the general public. I know spacing. My Mom is disabled and she doesn't need the changing place, but over the years before ADA accessible was a thing, you know, she couldn't even get in a bathroom for a long time. Some she still can't get there if they're not, if they're grandfathered in where they don't have to change, which I know would probably be an issue still because there are places that can't adjust. There are places that would have spots if they cared to.

Interviewer: Okay. What types of things would you be able to do, or what types of places would you be able to go?

Participant: I know some airports, I don't go generally to them too much, but I do once in a while to pick people up and malls, especially. They, in most cases, would have the spacing to do that, to make the adjustment, and make a room. We do go to the Family Café. He doesn't generally go too much anymore, but I know that they always make an area as family friendly for the changing as possible while people are going to their sessions. So, it's just so helpful when people go out of their way to make those everyday things that you have to do, possible. The malls, the ... I said, the airports, the malls. Just any store where it's possible to do that.

Interviewer: Okay. So, just to elaborate, prong off that. Overall, please describe how your quality of life would change if universal changing tables were more prevalent.

Participant: Like I said, we decide not to go somewhere because I have done that many times. I would not have a place to change him, and I would think, "No, I'm just not going to do it. I'm just not going to go out because he won't get changed until we get home." So, I will just decide not to go places, and we just stay home. You know, for your mental health, staying home, I'll tell you, it can get old when you can't go places because of one issue or another with a disabled person in your home. Any little thing that can make that part easier, is huge.

Interviewer: Okay. I know you kind of already said it, just to want to ask, when choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: Absolutely. Absolutely.

Interviewer: How helpful or accommodating are these locations when you ask about adult changing tables?

Participant: I really haven't asked a lot when I've been out places. I mean I've asked for them. Even at a children's hospital that I go to in Tampa, not Tampa in Saint Pete, they do not have one. That blows my mind because they cater to, I mean their clientele is sick and disabled children. We go to their outpatient building, and they do not have one. I've had to change him on the bathroom floor. I'll tell you, nothing makes you madder than having to lay your child on a dirty bathroom floor.

Interviewer: Okay. That leads me to my next question. What do you do if you have no access to changing tables, or to a changing table?

Participant: Like I said, you have to just do what you have to do. If you can't wait until you get home, you do. You just gotta do however you can, including laying on a dirty bathroom floor.

Interviewer: How did this affect you or make you feel?

Participant: Terrible. Terrible for him because you know it's probably extremely dirty. Especially in a hospital. The germs and people walking in having walked on whatever they walked on all day long. Yeah.

Interviewer: Okay. Appreciate your thoughtful comments and sorry if I'm kind of asking something that you've covered.

Participant: Nope. That's okay. I'm sure you've got your list.

Interviewer: Are there places or events that you are unable to participate in due to lack of accessibility to an adult changing table?

Participant: Well, let's say I don't take him to stores. I don't take him for anything that's going to be an all day thing because being able to change him isn't possible. We don't go to the mall and walk around for hours. That might be different if they did have that.

Interviewer: Okay. Have you delayed or changed plans because there was no adult changing table?

Participant: I don't think I've delayed any. I mean, like I said, there's times when I definitely don't go somewhere because I know I'll change him, but I don't think I've delayed anything.

Interviewer: Okay.

Participant: I just don't go.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: Oh, all the way from children too large for the fold down changing tables once they hit the 50 pounds, all the way through adults that have caregivers that, you know, are incontinent. So, they would be a huge ... There really is no limit. I mean there's even people that haven't been disabled their whole life that have come to be in their later years needing incontinence products and have an accident out in public. Then what do you do? So, to have them in a mall, or wherever, would be just huge.

Interviewer: Again, just to clarify, why do you think that?

Participant: Because again, you wouldn't a lot of times people would not go because they know that they won't be able to take care of their needs.

Interviewer: Okay. Anything else?

Participant: Nothing I can think of, off the top of my head.

Interviewer: Okay. When you're participating in society, how often do you encounter an adult changing table accessible to you?

Participant: I have not come across an adult changing table. His therapy, not his therapy but Turbo Medical place that he goes to in Largo, Florida has like a therapy table that's low that I can lay him on. That's one of the only places that we go, besides a couple of doctor's offices, that even have one. The Shriner's, right around the corner from you, has a high, low table that I can use my foot and hit the button, and it raises the table up after I get him on it. That's huge.

Interviewer: What percent of times, then would you say?

Participant: That I have had one? Oh, probably 10%, if that.

Interviewer: Okay. Anything else you would like to share with me?

Participant: Nothing that I can think of, off the top of my head.

Interviewer: Okay. Now, this will move us into our next section. So, when traveling was there a time that the height of a bed was an accessibility problem for you or someone you take care of? Would you say yes or no?

Participant: No. I have not had that problem because I don't travel with him.

Interviewer: Okay.

Participant: We have a total bed issues. His bed is called a sleep safe bed, if you want to look it up. It's like an overgrown crib.

Interviewer: Oh. Okay.

Participant: It's sort of mobile. He has DP'd, he's in a wheelchair and all, but he can do like an army crawl and he does not understand safety. He cannot stand by himself, but if he rolls over, he would be on the floor and if you put him back in the bed, he'd be on the floor again. He just would not understand, "Oh, I better not do that again." So, his bed is ... I don't know what we'd do without it. So, it's called the sleep safe bed and it is amazing. So, I don't travel with him anymore because he also chews everything. So, if he wakes up and I'm sleeping, he would be chewing on phone cords and if I put him like on the floor on a mat or something, he would be chewing on whatever he could chew on. So, yeah, I don't travel with him like that anymore.

Interviewer: Okay. Well thank you very much for your time and help talking to me. I would like to ask you if you know anybody else that you think we should talk to that would be interested in sharing their challenges and story, specifically related to adult changing tables and/or bed heights. Would you say yes or no?

Participant: I don't know anybody off the top of my head that I would give you their information without speaking to them first because I don't know them well enough to do that.

Interviewer: Okay, would you say or no, then?

Participant: I do know people, yes. He goes to a school full of disabled children. I just don't know them well enough where I would give you ... If you wanted to email me and I could forward an email to somebody, I could do that.

Interviewer: Let me see here. If you ... What's your email?

Participant: [email address]

Interviewer: So, I've got [email address]?

Participant: Yep and if it's okay, I could even put it on that Changing Spaces site, if that would be okay.

Interviewer: I'm not sure. What I'm going to do, is I'm going to put this into the system that you would like ... If they would like, they could email you at your email address [email address] with a message that you could forward to anyone that you know. I'm just going to add that you're just apprehensive to just give away people's information. So, I just have if you would like to email her at address [email address] with a message that you could forward to anyone that she knows, and she of course being you, and that she or you are apprehensive to give info of people without speaking with them or having some sort of communication.

Participant: Yes.

Interviewer: Bear with me just a moment, okay?

Participant: Sorry, he's asleep and I am doing some stuff.

Interviewer: No, that's fine. Okay, give me a moment here. It kind of gave me an error, so let me pull your record back up. Sorry, I had a computer error, so I just had to retype it.

Participant: Sure.

Interviewer: I said you just don't want to give out anyone's info without asking first and that you asked to email, that you can email ... They can email you at [email address], which is [email address].

Participant: Correct.

Interviewer: Okay, let me see if it will go through this time. Okay. Those are all the questions that I have. Again, thank you very much for your time and help and I hope you have a wonderful rest of your day, okay?

Participant: You too. Thank you so much.

Interviewer: You're welcome. Bye-bye.

Participant: Bye-bye.

Resp 5

Participant: Hello?

Interviewer: Hello. My name is [name] and I'm calling from the University of Florida. We spoke with-

Participant: Yes, hi.

Interviewer: So, we just spoke with someone at this number about a survey that assesses and determines the need to adjust building codes, by interviewing people affected by current standards. Are you the person that we spoke with?

Participant: Yes.

Interviewer: All right. Is now a good time to continue?

Participant: Yes, that's fine.

Interviewer: All right, beautiful. So the first thing I have to ask here is a powered high adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone that you take care of? Yes or no?

Participant: Yes.

Interviewer: All right. So [inaudible 00:01:00] basically, you know what's going on. As I said, my name is [name], and I'm calling from the University of Florida. And you received an email from the [inaudible 00:01:08] in April inviting you to tell us how the lack of power height-adjustable changing tables in a public setting affects you or your loved ones. The university is conducting research for the building commission to assess and determine the need to adjust the building code, by interviewing people who are affected by current standards. We're calling you because you completed an online schedule, [inaudible 00:01:25] when the Family Café emailed you, and your input will help inform and shape the commission's ruling.

Everything you say will be confidential, and reported with no identifying information. And while there's no compensation for completing this survey, your answers will help the Florida building commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions, and you don't have to answer any question you do not wish to answer, as well as you can stop the interview at any time. I want you to know this call will be recorded for quality purposes, and will be transcribed, summarized, and aggregated with other participants, and the survey should take approximately 10 to 15 minutes.

Participant: Okay.

Interviewer: All right. So first things first. I would like to ask you to tell us a little about yourself, and why the lack of adult changing tables is an important issue for you.

Participant: Well, I have a very sick elderly grandfather, and he could benefit from something like that. And I haven't seen any of them at anywhere I have been. So that, I feel, would be a necessity for people that are getting of the age and need to be able to have that access.

Interviewer: And is there anything else you'd like to add before we move on?

Participant: No.

Interviewer: All right. So have you heard about adult changing tables?

Participant: No, not until just recently when you guys brought up the topic.

Interviewer: Okay. And how much of a problem is not having adjustable adult changing tables when you're out participating in society?

Participant: Well, where my grandfather's concerned, he has had frequent accidents before, because he has incontinence. So sometimes it would help to have that accessible when we're, say, out for dinner, or going to the movies, or anywhere that involves activities to him. Because he does use a power scooter to get around most of the time, so that would be very much a issue for him. If he could have something like that, it would benefit him.

Interviewer: Okay. All right. And you did speak about going to restaurants and things like that. If you could, could you give me a specific example?

Participant: Just like, I'd like to have them implicated in the restaurant, so if he did need to be changed, or have to access them, they would be nearby where we could get to them.

Interviewer: Okay. And you've already gone over this a little bit, but if you could maybe elaborate, how helpful would it be to you if public spaces had adjustable changing tables available for use? Such as, what kind of things would you be able to do?

Participant: It would be easier for us to get him up and down onto it. I would expect them to be I guess handicap proof, so the safety issue wouldn't be as unsafe. When we try to take him out and do it on our own, there's chances of him falling, stuff like that. Where if he had a changing table, it would be a lot easier for him to get in and out of. And it would be a smooth process for him.

Interviewer: So when choosing things to do, or places to go, do you consider if certain places will have changing tables for adults?

Participant: I would say that more restaurants should have them. I also feel that parks and recreation places should have them. Even hotels I feel should have them. Like five-star hotels, that have ... I know some of them have implicated a lot of handicapped qualities

already, I've never one's that have changing tables, so that would be something to have in a hotel, access to handicap center.

Interviewer: And we've actually come to the next point. You talked about hotels, how helpful or accommodating have hotels been if you have asked about adult changing tables?

Participant: I'd be very helpful because it would eliminate, I would say less frequent accidents, and more secure (with him being able to be changed) with his day, rather than being in by the incontinence or having issues with accidents and wetting.

Interviewer: And so what do you do if you don't have any access to a changing table?

Participant: It gets very hard you know. We usually gotta put him on the bed, prop him up on a pillow, you know. Its me and my mom and she's very short and so am I so it becomes a bit of an issue. A lot of times you could probably end up hurting yourself and its not good for him as well. You have to worry about the falling factor-

Interviewer: Mm-hmm (affirmative)

Participant: So if we had something like this, it would benefit everyone that was helping, as well as the person that needs to be changed and taken care of.

Interviewer: And so elaborate a little on that as well, how does this affect you or rather how does it make you feel?

Participant: I'm sorry, what did you say? I'm sorry.

Interviewer: I just want you to elaborate a little bit if possible, on how it makes you feel when you don't have access to a changing table.

Participant: I feel upset, I feel that we should have ways of being able to help ones that have developmental disabilities or are handicapped. I think that it would benefit everyone, that these were implicated into everyday life.

Interviewer: If more adult changing tables were installed in Florida, what types of people do you believe would benefit the most?

Participant: Definitely the handicapped, and the disabled. They would definitely benefit the most out of it.

Interviewer: And when you're participating in society, how often do you encounter an adult changing table that's accessible to you?

Participant: I'd like to have it as much as possible for our loved ones that need it. I think that they should have it everywhere you go. There's bathroom accessibility as well as handicapped stalls, I think they should implicate the changing tables in there as well.

Interviewer: All right. And lets just kinda I guess rephrase the question here, but how often have you encountered an adult changing table that's accessible?

Participant: I haven't seen any at all yet [inaudible 00:07:24].

Interviewer: Okay. And it looks like some are a little self evident, but I still would like to ask, do you think this is adequate?

Participant: It would be adequate and helpful, yes it would.

Interviewer: Okay. And is there anything else you would like to share with me?

Participant: No, that's it.

Resp 7

Participant: Hello

Interviewer: Yes, Hello, My name is [name] I am calling from the University of Florida.

Participant: Yes

Interviewer: Yes, we spoke to someone at this phone number about a survey for the [crosstalk 00:00:28]

Participant: This is me.

Interviewer: Oh. Okay. Then would you happen to have some time to began that survey.

Participant: Yes I do.

Interviewer: Oh. Okay. So just to began[inaudible 00:00:37] adult adjustable changing tables as a convenient and safe way for caretaker's to assist individuals who may be unable to fully care for themselves, for adults who manage mobility limitations or incontinence. They provide a safe, sanitary, comfortable and save for assisted changing.

Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or No?

Participant: Yes, there was one bathroom where I was at and the grab bars were so out of wack that I'm partially paralyzed on my right side and the grab bars happen to be on the right side.

Participant: So I couldn't use the so they had this at one of the restaurants, I don't remember which one, but I was like you know, hey it works.

Interviewer: Oh. Okay, so just before we began just to tell you a little bit more, you received an email from the Family Café in April inviting you to tell us about how the lack of power to height adjustable changing tables in public setting effects you or a loved one. The university is conducting research with the Florida building commissions, to asses and determine the needs to adjust the building codes, by interviewing people effected by current standards. We're calling you because you completed the online scheduling form on the Family Café emailed you and your input will help form and shape the commissions ruling. Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey but your answers will help the Florida building commission make informed decision.

Your participation is voluntary, there are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer and you can stop this interview at anytime. I want you to know that this call will be recorded for quality control purposes and will be transcribed[inaudible 00:02:24]with other participants and this survey should take 10 to 15 min.

But first I would like to ask you to tell us a little bit about yourself and why the lack of adult changing tables is an important issue for you?

Participant: I am totally blind, I am partially paralyzed on my right side, I've got CP and a spinal cord injury and when I first had my spinal cord injury, I really wasn't able to stand yet or do the slide transfers, you know what I mean?

Participant: So having that made it easier for the person helping me because for about a month and a half I had to wear protective underwear.

Participant: Because of the lack of mobility, Does that make sense?

Participant: And trying to do that without that was very, very, very difficult. I mean I've gotten to where I can stand to do most myself now but you know, when it first happen it was..I still have problems with hotels.

Participant: A lot of hotels they. [00:03:30]laughing. Have these real high beds and I'm in a chair, well how am I suppose to get over there?

Interviewer: And then, so have you heard about adult changing tables and if you have, where have you heard about them?

Participant: I've seen them in one restaurant but that is it.

Interviewer: Oh. Okay.

Participant: I haven't seen them in a lot of places, I know they have the ones for the kids but that doesn't help an adult.

Participant: I've got friends who have spina bifida and they have to use catheters and things and sometimes I have to help them in some settings which you know it doesn't phase me[inaudible 00:04:12]it's just part of what you gotta do, but when it is not really accessible it does make it difficult.

Participant: Because both of us sometimes use chairs so, sometimes getting two chairs into there can be interesting!

Interviewer: Yeah. And so how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: In terms of numbers or?

Interviewer: So it said, how much of a problem is not having an adjustable adult changing table when you are participating in society? And if you have a specific example, we would like you to share that.

Participant: Well can I say it depends on the location.

Interviewer: Yeah, that's fair, you can say whatever you would want.

Participant: Well, it depends on the location and the set up too.

Participant: Um, some of the newer updated bathrooms are far more accessible.

Participant: Um, some places have gotten in to where they have family restrooms and that tends to make it a lot easier because my assistant is a guy.

Participant: So sometimes, I mean guy going into the women's restroom, you know.
[00:05:22]Laughing. Can be interesting.

Interviewer: Yeah. And so.

Participant: We've worked around it but you know, yeah, it can be tricky.

Interviewer: Oh. Okay. And how does that affect you or make you feel?

Participant: What, in terms of, I get frustrated when we don't have what we need.

Participant: I mean, you can only improvise so much.

Interviewer: Yeah. And.

Participant: I mean the family restrooms have definitely helped, when they are offered.

Participant: Because then it's like a private restroom. Does that make sense?

Interviewer: Yeah.

Participant: Verses a stall, does that make any sense?

Interviewer: Yeah. And so How.

Participant: Then again like I said.

Interviewer: Yeah.

Participant: Hotel beds can be a problem as well cause I saw the survey was about hotels too and.

Interviewer: Yeah, that's. So that survey would be the next survey we do.

Participant: Okay.

Interviewer: After we are done with this one. And so this next question is, how helpful would it be to you if public places had adjustable adult changing tables available to you?

Participant: It would make it easier when the bathrooms are not truly accessible.

Interviewer: And so what type of things would you be able to do or different places you would be able to go?

Participant: Well, I know would have my right to, I would have privacy.

Participant: And I know then that people wouldn't be upset if it takes longer. Does that make sense?

Participant: Because one of the problems that you have is even though we have the handicapped stalls there are people that are able bodied that use those and then I can't get into it because somebody who does not need it is using it.

Participant: The only place that I know of that really makes the handicap restroom only available to the handicap is the down town public library in Orlando, Florida. They have a handicap accessible restroom on the third floor that is kept locked. When you want in there you go to community relations they open the door and that is how you get in there.

Participant: And they did that because they don't want people that don't need it not using it.

Interviewer: Yeah.

Participant: I do like that. Of course because it's newer it's more up to standard, got plenty of enough room for the chairs. I mean I don't use a big manual chair, but I have to in situations where that was all I could get and that bathroom in the library is big enough that you can get a bariatric chair in there very very easily.

Interviewer: So over all please describe how your quality of life would change if universal changing tables were more prevalent?

Participant: Well I wouldn't stress out about finding a place to go to the bathroom.

Interviewer: And when choosing things to do or places to go do you consider certain places will have changing tables for adults?

Participant: Unfortunately, I have not found that many of them around so it's difficult but if more were available, absolutely.

Interviewer: And so, how helpful or accommodating are these locations when you ask about adult changing tables?

Participant: They don't even know what they are, in most places.

Interviewer: Oh. And what do you do if you have no access to a changing table?

Participant: Well, that's when I go hunting for the family restroom or if they don't have that, then what I will do is I will have one of their employees have to stand by the women's door if my caregiver is in with me. Does that make sense?

Participant: I've done a number of that.

Interviewer: And how does this affect you or make you feel?

Participant: I get frustrated that I don't have the same privileges as like my fiancé you know? If he wants to go to the restroom he can go.

Interviewer: And so, Are there places or events that you are unable to participate in due to lack of accessibility to an adult changing table?

Participant: I haven't found any yet. I've just learned to get very creative.

Participant: Just what you learn to do when you have to.

Interviewer: And have you delayed or changed plans because there is no adult changing table?

Participant: Can you read that last question again?

Interviewer: Yeah. Have you delayed or changed plans because there was no adult changing table?

Participant: I've had to delay them to make sure I had a place to use the bathroom. One of the biggest problems that I have is I like going outdoor events. And you know how they have their portable bathrooms? They don't always have, they say they are handicap accessible. Thank God I can walk a little bit because you can't get the chair in there even though they say they are handicap accessible. They are saying because they have a grab bar that they are handicap accessible. Which, fortunately, like I said I can walk on those. But what if somebody couldn't? So a lot of times what I try to do is if I'm going to an outdoor event, I go to the bathroom before I leave my house and then I try to make sure I know where somewhere is that's close to where I am going to be so I can use a restroom. I work around that one.

Interviewer: All right, and so if more adult changing tables were installed in Florida, what types of people would benefit the most and why do you think that?

Participant: People that really couldn't get out of their wheelchairs that have the slide transfer because it's difficult to change on the floor, on the bathroom stall. That's not easy.

Interviewer: And would there be anything else you would like to add?

Participant: Well, I wish they would mandate that stores have to have at least one family restroom available. So that would make it so much easier.

Interviewer: OK, so when you are practicing sitting in society, how often do you encounter an adult changing table accessible to you?

Participant: Not very often.

Interviewer: And do you think this is adequate?

Participant: No, I feel they should be available if people need them, they should be able to use them.

Interviewer: Regarding the subject of adult changing tables, is there anything that you would like to share with me?

Participant: Well, I think we need to educate the public on the need for those. And my only other concern is are they going to keep them sanitary? You know, the places.

Resp 8

Participant: Hello.

Interviewer: Yes hello. My name is [name]. I'm calling from the University of Florida. You received an email from the Family Café in April inviting you to tell us about how the heights of bed affects your loved ones while traveling.

Participant: How what?

Interviewer: How the heights of beds affect your loved ones while traveling.

Participant: Okay.

Interviewer: Yeah, the University is conducting research with the Florida building commission to access and determine the need to adjust the building code by interviewing people affected by current standards. And so, we're calling you because you completed the online scheduling form when the Family Café emailed you and your info will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing this survey but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes and it will be transcribed to summarize and aggregated with other participants.

Participant: Okay.

Interviewer: Yeah. The survey should take about 10 to 15 minutes.

Participant: Okay go ahead.

Interviewer: All right. And so, a powered high adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence they provide a safe, sanitary, and comfortable space for assisted changing. So, was there a time that an adult changing table would have been helpful to you or to someone you take care of? Yes or no.

Participant: Yes.

Interviewer: Okay. And so, just to begin first I'd like to ask you to tell us a little bit about yourself and why the lack of adult changing tables is an important issue for you.

Participant: I have two special needs children that wear pull ups and these would be very helpful in going into department stores, grocery stores, and restaurants to be able to change them rather than in a tiny little stall.

Interviewer: And would there be anything else you'd like to add?

Participant: No.

Interviewer: Okay. And have you heard about adult changing tables?

Participant: No, not other than Family Café.

Interviewer: Okay. And so, how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: Very much so.

Interviewer: And can you tell me about a specific example?

Participant: When your child soils their pants and you've got to change her in the car.

Interviewer: And so, how did this affect you or make you feel?

Participant: Very sad. Very inconvenient.

Interviewer: And how helpful would it be to you if public places had adjustable adult changing tables available to you?

Participant: Oh my God very very much. It would be wonderful yes. It would affect me a great deal. I would probably shop in those places a lot more or try to get near those places.

Interviewer: Okay. And so, what type of things would you be able to do or places to go?

Participant: Well, you would be able to go a lot more places, restaurants, shopping centers, just regular stores like Walmart, grocery stores, gas stations. We travel a lot so to have them in convenient store gas stations would be wonderful.

Interviewer: Okay. And so, overall please describe how your quality life would change if universal changing tables were more prevalent?

Participant: It would make us older folks who are caring for special needs children a lot easier. Because even in the back seat of a car it's very very difficult when your child is 11 and you have one that's 18, it's very very difficult. So, this would really be helpful.

Interviewer: And so, when choosing things to do or places to go do you consider certain places will have changing tables for adults?

Participant: What do you mean? Will I consider? I would be more likely to go to those places.

Interviewer: And so, how helpful and accommodating are these locations when you ask about adult changing tables?

Participant: I've never asked. Like I told you these are ridiculous questions because you're duplicating.

Interviewer: Yeah so, you can answer whatever you like it's just whatever you feel comfortable answering. If you have different examples you could use those too but if they're all the same that's perfectly fine as well.

Participant: Okay.

Interviewer: Yeah. So, this next one is what do you do if you have no access to a changing table?

Participant: Use the back seat of your car, or make do in the little tiny stall, or well not necessarily a little tiny stall. You wait it for a handicap stall to become available. You have to carry extra pads to put down on the floor because usually public restrooms are not that clean.

Interviewer: And so, how does this affect you or make you feel?

Participant: Very angry.

Interviewer: So, are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Pretty much entire society makes it very very difficult for anyone that is handicapped, or has special needs children, caring for an adult, or just caring for themselves. These would be the greatest thing since white bread.

Interviewer: And so, have you delayed or changed plans because there was no adult changing table?

Participant: Yes. Very much so. We will deliberately go to a place that we feel is safe and secure rather than to go inside a place that we know is very tiny, doesn't have even a handicap stall. So, yes we've had to make lots of detours and changes in plans.

Interviewer: And so, if more adult changing tables were installed in Florida what types of people would benefit the most and why do you think that?

Participant: I don't know if it would benefit the most but I'm going to say anyone and everyone that has a special need or is handicapped.

Interviewer: Okay. And so, when you're participating in society ...

Participant: [inaudible 00:07:03]

Interviewer: Okay. And would there be anything else? Hello?

Participant: Hello.

Interviewer: Yes can you hear me?

Participant: Hello.

Interviewer: Yes can you hear me mam?

Participant: Are you there?

Interviewer: Hello?

Participant: Hello.

Interviewer: Hello mam can you hear me? Hello?

Participant: Hello.

Interviewer: Hello can you hear me mam?

Participant: Yeah I can now. I couldn't there for awhile.

Interviewer: Oh okay. So, I was just asking if there was anything else you would like to add?

Participant: Well, one of my biggest concerns is even when these are placed it may end up being similar to what babies have and that still would be dirty changing tables. If you as a parent or caregiver aren't willing to clean them chances are they're probably not going to get cleaned and that's the standard. So, I would hope that there would be some sort of incentive. For example, if you placed it in a Walmart store and they agreed to take care of it that they would really make sure it's clean and tidy and it would be put in a private location. Whereas a lot of baby changing stations are out in the open.

Interviewer: And so, when you're participating in society how often do you encounter an adult changing table accessible to you?

Participant: Never.

Interviewer: And do you think this is adequate?

Participant: No.

Interviewer: Okay. And so, is there anything else you would like to share with me mam?

Participant: I just hope that America would take to heart those that are in need of something like this because it is long overdue.

Interviewer: And so, just a follow up question. When traveling was there a time that the height of the bed was an accessibility problem for you or someone you take care of yes or no?

Participant: Yes.

Interviewer: Okay. And so, this would follow around the same format. So, again first I'd like you to tell us a little bit about yourself and why the height of the bed is an important issue for you relating to mobility.

Participant: Well, being of short stature and only being five foot when you have a bed that's right there at you at five foot you have to lift whomever you're wanting to put on that and it makes it very difficult. So, it would be wonderful if there was a step stool of some sort that came down and these beds were no higher than maybe four to four and a half feet tall. I have actually never seen one ever in any place and don't know if there is access to these anywhere in the United States.

Interviewer: And would you like to add anything else to that?

Participant: No.

Resp 9

Participant: Yo!

Interviewer: Hello! My name is [Interviewer]. I'm calling from the University of Florida.

Participant: This is [name]. We talked the other day.

Interviewer: Do you have a moment to speak with us now?

Participant: Shoot me your questions, man. What do you got? Let's make this ten minutes go quick.

Interviewer: A powered height-adjustable adult changing table is a convenient and safe way for a caretaker to assist individuals who may be unable to fully care for themselves.

Participant: Right, right, right. We are caregivers, and we take care of our daughter, and we travel every once and a while.

Interviewer: We just need to double check everything to finish this off very quickly. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no?

Participant: Absolutely.

Interviewer: Just before we begin, you received an email from The Family Café in April inviting you to tell us about how the lack of powered height-adjustable changing tables in public settings affects you or your loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

Participant: Right. We talked the other day. We went through all of that, and I said you'd just have to call me back, and we'd go through the questionnaire.

Interviewer: I understand. I'm just required to go through it again. We are calling you because you completed the online scheduling form when The Family Café emailed you and your input will help inform and shape the commissions ruling. Everything you say will be confidential and will be reported with no identifying information. There's no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. This call will be recorded for quality control purposes and will be transcribed, summarized, and aggregated with other participants. The survey should take 10 to 15 minutes.

First, I'd like to ask you to tell us a little about yourself and why the the lack of adult changing tables is an important issue for you.

Participant: I have a daughter who's been severely disabled since she was two months old. She is now 21, almost 22. She's been 100% disabled. We have to pick her up and put her in a feeding chair. We have to feed her. We have to pick her up and put her in her bed. We have to pick her up and put her into a shower chair and shower her so she's 100% care. I think that summarizes her condition. She's visually impaired. She's a cerebral palsy child. She's non-verbal. Developmental stage is somewhere around six months to a year. Six months actually. Anyway, will that paint the picture for you?

Interviewer: Yeah. It's whatever you want to say. Again, it's whatever information you want to give us.

Participant: All right. That's where we're at right now. She lives with her mother and father. We do 100% of her care. She has no caregivers outside the family home. My mother does come by and visit and watch her for special occasions but, other than that, we are the only caregivers. We would be the ones who could answer this questionnaire.

Interviewer: Since you have heard about adult changing tables, where have you heard about them?

Participant: We've utilized them in some locations that we've found. They're very few and far between. I believe we've found them in the Fort Lauderdale airport, terminal one now has a bench type seat that you're able to change your child in, in their family stall. Miami Children's has full-sized changing tables in some of their restrooms. I'm trying to remember off the top of my head where else we've seen them. Honey, can you think of any places we've actually seen them out and about? A couple of the new Disney parks, in their containment bathrooms, have large changing tables for special needs kids over the infant sized. Unfortunately, they're few and far between.

Interviewer: Mm-hmm (affirmative)

Participant: My wife and I, we just traveled to Pennsylvania, and we didn't see any changing tables outside the state that would work for us unfortunately. So, at the national level, still very lacking or non-existent.

Interviewer: How much of a problem is not having an adult changing table when you are participating in society? Can you tell me about a specific example?

Participant: The lack of a changing table for her size, and she's only 4'1", so we're not talking about a fairly large child. Obviously, the infant changing tables are everywhere you can find. She's too heavy for those, so we find ourselves in other airports literally putting a blanket down and changing her in a corner somewhere away from people, away from cameras. We find ourselves out in public finding a location that's kind of guarded, so we can change her on a bench. Unfortunately, it's rather undignified for her and it's embarrassing for us, to be quite honest with you. To have to change her, literally, sometimes on a carpet on the floor, in a restaurant on the floor, or we take her back to our car and literally have to change her in the car with the door open as people walk by. Its very uncomfortable and very sad that they think the children but don't think about

the special needs families and the special needs adults that are out there in the community at all.

Interviewer: How helpful would it be to you if public places had adjustable adult changing tables available to you?

Participant: It'd definitely reduce the embarrassment of laying her on the floor and having people walk by seeing her being changed, number one, and actually seeing things that they shouldn't see as we're changing her. Again, it's embarrassing for her. It's undignified for her. It's embarrassing for us to have to do it. I mean, we're not gonna let her sit in her own feces, being wet, and ending up having medical issues because there's a lack of them.

It would be very helpful. We wouldn't have to put off changing her or travel all the way out to the car, depending on where we are, to try to do it in a little more private setting. Again, still, you're doing in the car on the floor with the door open. It's still not private. It would be less of a burden on us for transfer from her wheel chair onto an actual changing table instead of having to transfer her to a floor or into the open doors of a vehicle to try to get her on the floor and change her and then try to transfer her back out. It would be safer for her as an individual. It would be safer for me, the caregiver, in the way of possible of injury while I'm doing it. I could go on. In a perfect world, yeah, that would be nice. Right now, they don't exist.

Interviewer: When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: I'm sorry what was the question?

Interviewer: When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: If we knew that there was going to be a changing table in one place or another and it was a comparable place, like if one Mexican restaurant had a changing table and one didn't, then we would probably pick the one that had better facilities for her. That would go for entertainment locations and so forth. I would have to say yes, it would definitely make a difference on what we would select to do and where we would select to go based on that. Obviously there's other factors that come into play when you go to look for a place to travel to or to entertain you. That would definitely make a decision one way or another when it came down to the last couple of points. Oh can we change her there? Yeah, it would. Absolutely.

Interviewer: How helpful or accommodating are these locations when you ask about adult changing tables?

Participant: How helpful are they? They're not. They just say no and they turn around and go back to doing what they were doing before you even started asking them. When you ask if they have a private location or an office or something like that they could allow you to go in

there and change her, I would say somewhere around 85-90% of people say no. About ten percent of the time you get somebody with some kind of compassion that would say "let me check," and I would say probably three percent come back and say sure we have a location you can utilize. It is very seldom that we get somebody to say "yes, my boss said you can use the back office here, when you get done if you'll remove the diaper and close the door behind you" or something like that. There's never accommodations like "oh you can use the sofa in there" or whatever. It's never that. It's usually on the floor again because she is taller than a small, baby changing table. You can't change her on two chairs.

Interviewer: So I know you mentioned this a bit before, but we have to ask, what do you do if you have no access to a changing table?

Participant: Unfortunately, we're just changing her in public. We're changing her in the car with the open door so the public can walk by and actually see. We're changing her on a bench outside in the open air. We've changed her on a small support wall that separates two areas before. Little alcoves that there's door to a building or to an area that may not be utilized at the moment when we change her. Again, we'll throw a blanket on the floor, put her on top of a blanket and change her on the blanket. It's not pretty. At times, it's not safe either. Usually it's my wife and I and somebody's holding her so she doesn't fall off while I'm changing her or whatever. There's a safety issue there too. You're doing it out of the necessity of getting her out of a wet or dirty diaper so she doesn't end up with medical issues such as sores or irritation to her skin to the point where she ends up hospitalized.

Let me just say, the last thing we need is for her to end up like Christopher Reeve with a spot on her body that ends up being infected to the point where it can affect her life, which is what happened to Christopher Reeve. When you say how important is a place to change your child, it's that important. The kids and the adults out there, that's the extent that it could go to if you don't take the time to change somebody in a timely manner. They can end up with irritation, irritation can lead to infection, infection can cause loss of life. Anyway, go ahead. Next question.

Interviewer: Are there places or events that you are unable to participate in due to lack of accessibility to an adult changing table?

Participant: Not typically. Nothing stops us and like people. Some people will not go to an event or refrain from going to an event because of the lack of a changing table. We're completely opposite. We go whether there's a changing table available or not because we believe that, whether the access is there or not, she has the right to go wherever we go. Just because she's disabled shouldn't preclude her from going anywhere. Same thing with her service dog. She has a service dog and she goes with us. When it comes to a service dog's accessibility to go to a restroom, it's just as difficult if not more difficult. We won't even go there because you're not asking those questions yet but that's a whole other issue.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most and why do you think that?

Participant: What kind of people would benefit? Well, all the caregivers would benefit in safety, cleanliness, controlled environment. The caregivers would benefit. The actual individual that's special needs or needs to be taken care of. Like my wife says, the general public is gonna be spared from the public indecency or the mental issues that might come up because of it. We've gotten to the point where we're like "oh well." Other people I'm sure are thinking... I can't even think right now. I got up at five this morning sorry. The number of things that people think when you have to change a child in public, when you have to change anybody in public. And my daughter's not functional.

For the functional child that's in a wheelchair, the teenager or even the adult that's in a wheelchair, that needs to change a diaper because of incontinence or have assistance in helping change them, they don't have to sit and wait until they get to an appropriate location and put through the rigors of people watching them and being able to smell them and go "oh, they're dirty" or whatever. The whole connotation that afflicts the special needs community because somebody's went to the bathroom in their diaper and they can smell it.

Interviewer: When you're participating in society, how often do you encounter an adult changing table accessible to you and do you think this is adequate?

Participant: No it's not. The availability is just short of nil. When we do find one, it's like a little ray of sunshine pointing at the table with hallelujah chorus playing. If we find one, a little ray of sunshine beaming on it, or a spotlight. You're like "there it is! Unbelievable! There's actually a changing table here." It is very few and far between. I would say one out of every 15 or 20 changes that we do when we're out in public, we may find a changing table that's available to her or an appropriate place that we can utilize.

Interviewer: In general, is there anything else you'd like to share?

Participant: I just think, based on the direction of our country, based on the direction of our president, and the direction of the state, in general, towards special needs kids and accessibility, it's been lacking for a long time. The turning of the head and all that, we don't believe in. We've always been inclusive with our child in whatever we do. The old adage, that you should lock them in the attic, should be lost. It still carries true to this day with the state and, like my wife said, with people that we meet, still have that mental thought that "oh well, she should be at home. She shouldn't be out. She should be put away somewhere. We shouldn't have to deal with watching you feed her or seeing her so disabled."

The whole deal with the state and the community not embracing special needs, it's time to shed that jacket and put on an acceptance coat of embracing everybody. Whether they're black or white, special needs or not special needs, gay or not gay or straight or whatever. I don't think we're getting the same breaks as everybody else. Disney's even shown their colors. If the child is autistic then they get special services versus the normal child or the special needs child. Well she's special needs but she's not autistic so she can't go to the front of the line. I think everybody needs to take a step back and take a look at where the special needs community is, really. Yeah, there's people out there that are trying to take advantage. But there's also people like us that really need and should

get the same respect that a mother with a newborn has. Newborns gotta be walking and talking and out of diapers within a couple years. My daughter is 21 going on 22, and we change six diapers a day, 365 days, for 21 years. And we won't be stopping anytime soon.

Interviewer: We just have a few more questions. When traveling, was there a time that the height of a bed was an accessibility problem for you or someone you take care of? Yes or no?

Participant: Not typically because we're caregivers. We're still fairly young. But, as we get older, that is going to become an issue. I know people that don't have caregivers are going to have issues with bed height no matter what. Based on the fact that they have to transfer, depending on the height of their chair, it's an issue. Because we're caregivers and we're still fairly young, it's not too bad. We've encountered some beds that are a little higher than others. We've encountered beds that are lower than others. Right now, like I said, it's not so much an issue. But, as we get older, those high beds will become an issue for safety for us. The possibility of injuring ourselves while we transfer her to a higher bed or as we lean down real low to get her out of a bed and transfer her to and from a wheelchair.

Like my wife said, just her rolling out of the bed, based on the fact she's a special needs child, there's no way to keep her in the bed if she's really high and she rolls out. Every time we travel we have to go through gyrations to figure out how to keep her in bed. The short answer right now, not a lot of issues in the way of height for us, but other issues like trying to keep her in bed and so forth, for us in particular.

Interviewer: I'd just like to ask if you know anybody else that you think we should talk to that would be interested in sharing their challenges and stories, specifically related to adult changing tables or bed heights. If you don't know any, that's perfectly fine as well.

Participant: My friend that has a special needs child that I went to school with but his child is actually being taken care of full-time by a home. He would be unavailable. The other gentleman I went to school with who has an autistic child but he's high functioning. My wife had some friends but they just recently lost both their special needs kids. So I would have to say no right now.

Interviewer: That's perfectly fine.

Participant: My wife has another friend who has a child that's special needs, but he doesn't travel at all with her. She stays at home. She has caregivers watching her.

Interviewer: Those are all the questions I have sir. I really appreciate your time speaking with us. I hope you have a wonderful day.

Participant: Good luck. Have fun. One of the reasons I answered all your questions is because you're a gator boy, right?

Interviewer: Yes.

Participant: Okay. Both my sisters were gator girls. A bit of fun up there, so enjoy yourself. Are you in the local area or are you up there in Gainesville?

Interviewer: No, I'm in Gainesville.

Participant: Had some fun times there just a couple days ago. I'm up in my fifties now. Enjoy. You guys have fun and good luck with your reports and stuff. This is all gonna be summarized and put together to go to the state? Is that what you're saying?

Interviewer: Yeah. We're reaching out to a bunch of people first, and then everything will be transcribed, and then everything will be summarized. That information, they'll put up with the Florida Building Commission.

Participant: Okay. We appreciate it, but unfortunately, the way this state goes, I have little faith in them. After all the years that we've been going through this, they've treated us, the special needs community in general not us individually, they've treated us poorly. Like I said, the president has shown his true colors in trying to take the money from special needs elderly people and special needs children. We've physically had money taken out of our Medicaid funding for us. To say the least, we have little to no faith. But we can appreciate your dedication and we can appreciate you guys trying to do an in run. If it works, I will applaud you.

Interviewer: Hopefully, it does. Thank you for your time sir.

Participant: No, thank you. Enjoy. Bye.

Interviewer: Bye.

Resp 11

Participant: Hello.

Interviewer: Hello. My name is [interviewer]. I'm calling from the University of Florida.

Participant: Mm-hmm (affirmative).

Interviewer: You received an email from the Family Café in April inviting you to tell us about how the lack of powered height adjustable changing tables in public settings affects you or loved ones. The University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the commission's ruling.

Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer. You can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes and will be transcribed, summarized, and aggregated with other participants. The survey should take 10 to 15 minutes.

A powered height adjustable adult changing table is a convenient and safe way for caretakers to assist in individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no.

Participant: Yes.

Interviewer: Okay. We will just start the survey. Is now a good time?

Participant: Yeah. It's time.

Interviewer: Okay. First, I'd like to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Well, I wouldn't just say adult. I have a child, but she will be an adult eventually. The lack of adult, more larger child, changing table is important because, first, as a parent, I will have to take care of someone that is non-mobile for the rest of their life. All that bending and picking up is a lot of strain on the back. I mean, I wouldn't be able to do that at some point anymore as the child gains weight. Also... What was I saying? I mean, if there is nowhere for me to change my child, I have to take them either outside to the car and change them in the trunk, or take them back to the hotel room and change

them there. If I'm in the middle of trying to listen to one of the conferences or speakers at the Family Café, I have to go all the way back upstairs, up the elevators, to the rooms to go and change her diaper. That's inconvenient because, by the time I would probably come back, it would probably be over. I can't think of anything else right now.

Interviewer: Okay. Have you heard about adult changing tables?

Participant: Yes.

Interviewer: Okay. Where have you heard about them? Word-of-mouth, magazines, disability advocacy groups, et cetera?

Participant: Disability advocacy groups. They put one in the Children's Hospital.

Interviewer: Okay. Anywhere else?

Participant: No.

Interviewer: Okay. How much of a problem is not having an adjustable adult changing table when you're participating in society?

Participant: When I what?

Interviewer: When you are participating in society.

Participant: I mean, it's very hard. I'm trying to squeeze a wheelchair into a small tight space in the bathroom. Then the doors aren't handicapped accessible so that I'm trying to hold the door open and push the chair in at the same time. Then I end up trying to use the baby changing table. There's a weight limit on the baby changing table. Then my child is hanging over the baby changing table. Due to the... I forget what it's called. Like when you have a brain, or like cerebral palsy, sometimes the balance, I guess, that you have as a child. They do some kind of test to see if you react to falling and stuff like that. Then she gets scared. She starts yelling and all that because she's hanging off and feels like she's going to fall off the table, but she's really not. I mean, it's just really inconvenient because it's uncomfortable for her. It's uncomfortable for me because it's a small space. I am trying to quickly hurry up and change here. Like I said, there's not a lot of room in the bathroom. Trying to squeeze into the bathroom with all the other people in there, and the doors not being accessible and stuff like that.

Interviewer: Okay. You've given me some specific examples. How did this affect you or make you feel?

Participant: A little frustrated.

Interviewer: How helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: You said how what? How helpful?

Interviewer: How helpful.

Participant: I mean, it would be very helpful because then my child would have privacy more, which is the most important thing. Changing her in back of my car, there's not a lot of privacy. I'm trying to quickly change her without other people seeing, or trying to find a spot where no one can see her while I'm changing her. Then I wouldn't have to be bending over and lifting and picking her up and stuff as much, bending down trying to change the diaper. It would ease strain on me physically. What else? It would make the child feel more comfortable and secure.

Interviewer: Okay. When choosing things to do or places to go, do you consider certain places will have changing tables for adults?

Participant: I think I don't really take her many places that much because things are not accessible and they don't have those kind of items available, or I have to make sure that I change her diaper before I go to that place, or I can't stay long because she probably will have to use the bathroom and I need to change her. It's pretty inconvenient.

Interviewer: How helpful or accommodating are places when you ask about adult changing tables?

Participant: I have actually never asked about that. I think I've asked more about having a handicapped accessible entrance or doorways more than I've asked about the adult changing tables. I think because I'm so used to just changing her at home or after we leave from wherever we are.

Interviewer: Okay. Going off of that question, when choosing things to do or places to go, do you consider certain places will have changing tables for adults, what things or places in particular?

Participant: Restaurants.

Interviewer: Okay.

Participant: Retail stores. I mean, really, restaurants and retail stores.

Interviewer: Okay. What do you do if you have no... I know you may have in due discourse answered some of these questions. I'm sorry if I'm reiterating anything or asking you to repeat yourself. Just following along with the questions, what do you do if you have no access to a changing table? Can you be specific?

Participant: I have to go back to my car and change her or leave the place.

Interviewer: Again, how does this affect you or make you feel?

Participant: Inconvenienced. I feel that's why I have to just have somebody available to care for her at home because I know it's not going to be very easy for me to get her in and out of places or give her the additional care that she needs to change her diaper and feed her and stuff like that.

Interviewer: Are there places or events that you were unable to participate in due to the lack of accessibility to an adult changing table?

Participant: I can't really think of any one off the top of my head.

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Speaker 3: Mommy. [inaudible 00:10:29].

Participant: No. [inaudible 00:10:32].

Speaker 3: [inaudible 00:10:34].

Participant: Outside. I'm sorry. What was the question?

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Participant: Not that I can think of.

Interviewer: Okay. If more adult changing tables were installed in Florida, what types of people would benefit the most, and why do you think that?

Participant: It would benefit the pediatric community with children who have disabilities and their parents. Florida has a big population of children with disabilities. I think that they focus more on the senior citizens. I feel there's a lot of [inaudible 00:11:37] for parents of children with special needs. That's a big concern for them. It would help them be able to take their children more places and get more things done without worrying about how they're going to change them or when they need to change them and what have you.

Interviewer: Anything else?

Participant: No.

Interviewer: When you're participating in society, how often do you encounter an adult changing table accessible to you?

Participant: Never.

Interviewer: Okay. I understand your response. I've just got to clarify what percentage of times would you say?

Participant: What percentage of what?

Interviewer: What percentage of times would you say?

Participant: Would I say what?

Interviewer: When you're participating in society, how often do you encounter an adult changing table accessible to you? What percent would you say?

Participant: Oh, a hundred percent of time there's never one available.

Interviewer: Okay. Okay. Do you think this is adequate?

Participant: Meaning do I think it's fair or am I sure about the answer I gave you?

Interviewer: Do you think that percentage or not having adult changing tables accessible to you, do you think this is adequate?

Participant: I mean, I think that my statement is true, and that it's not adequate. They should have more changing tables. Like I said, there's a large population of people with medical needs.

Interviewer: Okay. Anything else you would like to share with me?

Participant: No.

Resp 12

Participant: Hello.

Interviewer: Hello. My name is [interviewer]. I'm calling from the University of Florida. You received an email from the Family Café in April inviting you to tell us how the lack of powered height adjustable changing tables in public settings affects you or loved ones.

Participant: Yes.

Interviewer: The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

Participant: Okay.

Interviewer: We're calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information. There's no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions.

Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to know this call will be recorded for quality control purposes and will be transcribed, summarized and aggregated with the other participants. This survey should take 10 to 15 minutes.

Participant: Okay.

Interviewer: Okay, so a powered height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. I may refer to it as an adjustable adult changing table or universal changing table throughout the phone call. Was there a time that an adult changing table would have been helpful to you or someone you take care of, yes or no?

Participant: Yes.

Interviewer: Okay. First, I'd like to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Okay. I have a son who was born with cerebral palsy and several other disabilities. He is incontinent, so he does require someone to assist him changing. With all of his daily activities, period. He requires care 24 hours a day. I am a disabled veteran, so lifting him is very difficult. Having to change him on the floor of a bathroom is not only disgusting, I

would not want to be changed on the bathroom floor to be looking up at toilet bowls, but it's also... I'll have to lift him from a floor position. My son is currently 16 years old, 105 pounds, 5'10" as of December. He grew from 5'2", 88 pounds in August. I do not have an updated height and weight as of December, so I'm pretty sure he's a lot bigger now. I'm only 5'4".

Interviewer: Okay. Was there anything else?

Participant: Not that I can think of just yet.

Interviewer: Okay. Have you heard about adult changing tables?

Participant: Yes.

Interviewer: Where have you heard about them, word of mouth, magazines, disabled advocacy groups, et cetera?

Participant: I heard about the Universal Changing Spaces campaign that took place in the U.K., and then got to Milwaukee, Wisconsin. Then I found out that Orlando was trying to... well, mothers, parents, I should say, in Orlando were trying to be the second state in the nation to implement this. The first place I was told, and I haven't been able to witness it, that has the adult changing tables is Orlando International Airport, but we don't fly very often, so I haven't been able to witness it. I've learned of it from online parent support groups that I'm a part of.

Interviewer: Okay. Anywhere else?

Participant: No.

Interviewer: Okay. How much of a problem is not having an adjustable adult changing table when you're participating in society?

Participant: It's a huge problem. I have to make sure that he is already changed before we leave the house and hope that he hasn't gone to the bathroom too much when we're out and about. I try to have him involved in as many social activities as I can, so he plays baseball. When we go to baseball fields, there are no handicapped bathrooms, so I have to take him to my car and change him in the trunk of my car. That's just one example. I could give you several other ones.

There are no changing tables in museums. There are no changing tables at theme parks. In past visits to theme parks here in Central Florida, I have to take him to the first aid station. So, God forbid if we have too many heat strokes or heat exhaustion patients taking up the bed, I don't have a bed to change him on.

Interviewer: How does or did this affect you or make you feel?

Participant: Well, makes me feel angry, frustrated. I feel singled out. I'm sure my son feels grossed out because he constantly has to be changed on the floor, staring at dirty toilets or in the trunk of the car, and that can't feel good. Since he doesn't talk, I can't ask him how it makes him feel, but I know he knows he's different because he can't go to the bathroom like the rest of us.

Interviewer: Okay. How helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: It would be like a 150% much better... I don't even know how to put it into words. Life would just be so much easier because I feel like our disabled community can't enjoy the things in life that the rest of us can because they're limited to the things that they have to have at home. I don't want my son to live his entire life at home, that's not a good life. I'd like for him to be outside, I'd like him for him to interact with other people, and his disability shouldn't stop him from being able to do that. The fact that we don't have bathrooms that could accommodate him, it stops him from being able to have a colorful life.

Interviewer: What types of things would you be able to do?

Participant: Well, for one, I could take him to a museum. When we go to the movies, they don't have diaper changing tables in there either. And he loves the movies. So whenever we go for a new movie, I have to make sure he's changed prior to and I have to put extra, like, chuck pads on his wheelchair seat in case he leaks through. For example, Endgame is a three-hour and two-minute movie, that's without the preview in the beginning, and that's without staying afterwards, after the credits, to catch whatever they're going to show you. So you're looking at almost four hours where he has to sit in his own filth because I have no place to change him.

Interviewer: Okay. I know you may have... you kind of have elaborated on a little, just to clarify, though, overall, please describe how your quality of life will change if universal changing tables were more prevalent?

Participant: I feel that if we had... If more people knew about what the disabled community were going through, everybody would fight for this because everyone should be able to use the bathroom accordingly. That shouldn't even be a question. That's life. We all go to the bathroom, and no one would want to be changed on the floor. Nobody would want to be sitting in their own filth for hours. This would be a huge, a huge impact on the life of a disabled person.

Interviewer: Okay. When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: Yes, I decide whether or not he can go.

Interviewer: How helpful or accommodating are places when you ask about adult changing tables?

Participant: They look at me weird.

Interviewer: Okay. What things or places in particular?

Participant: We went to the Orlando Science Center, and they told me that I could try to use the changing table that they had in there. I advised them that the changing table in the bathrooms are for infants and that the weight capacity is 60 pounds, which he has surpassed a long time ago. They just give me a blank stare. So I can't take him there. Believe it or not, hospitals do not have a changing table. So when I had an asthma attack, and I was transported with my son, he had to sit in that until my husband could get to us because there is no place for him to be changed. In a hospital.

When we go to Disney, we have to go to the first aid station. All the first aid stations, for the most part, at SeaWorld and at Universal, they're all at the front of the park. So if we're in the back of the park, enjoying a ride, and there's an accident, anything, I have to rush him to the front of the park to change him. And that's if they have a bed available.

Interviewer: Okay. Again, I know you've kind of touched on this already, but what do you do if you have no access to a changing table?

Participant: We leave.

Interviewer: Can you give me a specific example?

Participant: We leave, and it's less money spent at the establishment.

Interviewer: Okay. Can you give me a specific example?

Participant: Like the science center, you mean? Or maybe the movie theater.

Interviewer: Yeah, either.

Participant: We've gone to movies before where I've had to be comped back my tickets because my son made a mess, and I couldn't... We carry extra clothes for him, it's just that it was... there's no place to be able to change him, so I had to drive all the way home, and bathe him, and change him. Whereas if they had a changing station, I already had the things I need to change him, I could just change him and clean him up at the sink, and all would be well.

Happened at the science center. It's happened at the movie theaters. It happens at rest stops. If we're driving down to Tampa, rest stops do not have changing tables either, and that's a nightmare. We retired from the military and moved back to Florida in 2015. On the drive from Washington state here, there wasn't a single stop that had a place where I could change my son. We changed him in the car.

Interviewer: How did this affect you or make you feel?

Participant: Extremely angry, extremely frustrated. I know this isn't true, but I always feel like we are the only parents on the planet that have a disabled child. I feel like we're the only ones that experience what we're going through. And it doesn't matter how much I tell people, "We need to change this, we need to change that," I feel like I'm the only voice. That's what it makes me feel like.

Interviewer: Are there places or events that you were unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yeah, we can't go to the festivals. They had a Puerto Rican Day Parade on the 27th of April. I can't take my son to that. Armed Forces Day at any of the military installations. We can't go because they have porta potties. Definitely can't take him in a porta potty, so we can't ever go to those events. So, basically, if there are any events that don't have a changing space for my son, my son can't go, which a lot of times means I won't go because if he can't participate, I refuse to participate. They don't want my money if my son can't participate.

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Participant: Yeah, I've canceled plans completely.

Interviewer: Okay. If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: Anybody who's wearing a diaper. Anybody that has a colostomy bag. Anybody that's required to carry oxygen with them. It gives them more room for their oxygen, for them to be able to sit on a toilet or sit on a changing table and handle what they need to handle.

Interviewer: Okay. When you're participating in society, how often do you encounter an adult changing table accessible to you? Like what percentage of the time?

Participant: Maybe 1%.

Interviewer: Okay. Do you think this is adequate?

Participant: Yeah, because, in all honesty, when we take him... The places we take him, are the places that I mentioned. The theme parks, I have to take him to the first aid. They don't have diaper changing tables. The movie theaters, they don't have changing tables, so have to change him in the car. When we go to the playground, the bathrooms at the playground are only for able-bodied individuals. I mean even wheelchairs don't fit in playground bathrooms.

Interviewer: Okay. Anything else you would like to share with me?

Participant: No, I think these are pretty awesome questions, though, and I hope you're interviewing more parents like me.

Interviewer: Okay. Yeah, we definitely understand and trying to help out the best we can [crosstalk 00:13:53]-

Participant: I appreciate that. I really do.

Resp 14

Participant: Hello?

Zach: Hello. My name is [Interviewer], I'm calling from the University of Florida. You received an email from the Family Café in April inviting you to tell us about how the lack of powered height adjustable changing tables in public settings affects you or loved ones.

Participant: Yes.

Zach: The university is conducting research with the Board of Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey, but your answers will help the Board of Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes, excuse me, and will be transcribed, summarized, and aggregated with other participants.

Participant: Not a problem.

Zach: This survey should take 10 to 15 minutes.

Participant: Okay.

Zach: A powered height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. I may refer to it as an adjustable adult changing table or universal changing table throughout the phone call. Was there a time that an adult changing table-

Participant: Hello?

Zach: Yes, can you hear me? Hello? Hello? Hello, can you hear me?

Participant: Hello?

Zach: Hello. Yes, can you hear me?

Participant: Yes, I can hear you.

Zach: Okay. I may refer to it as an adjustable adult changing table or universal changing table throughout the call. Was there a time that an adult changing would have been helpful to you or someone you take care of? Yes or no.

Participant: Yes.

Zach: Okay. First I'd like to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: My name is [name]. I have my doctorate in physical therapy. Assisting with handicapped individuals is part of my profession. My wife contracted early onset aggressive dementia five years ago, and there are many locations that don't have family bathrooms, so I end up taking her into the men's room and going to the handicap stall and locking that, and assisting her going to the bathroom on the men's side. It's uncomfortable for most women when I go into that side.

Participant: Several restaurants though have allowed me to do that with an attendant standing at the door saying, "Hey, there's a man in there helping his wife in the bathroom." But family room or adult changing tables I'm assuming, I would hope would then go into a family restroom because taking a female into the male restroom, even though it's an adult changing table, my wife has soiled herself on multiple times, but I can't just go into the men's room and change my wife. Same with in the women's room. I can't go in and use a women's adult changing table having to spend that length of time in the women's restroom.

Participant: Just in my situation, some rest areas have the family restroom. A lot of times I've been there, they've locked, so I've taken her into the men's room anyway. I try to travel late at night with her so that way I don't have the interference of other people. But pretty much her access is male/female without a family separate stall, or separate unit.

Participant: My son has autism, but he's high-functioning, so he can go into the restroom, and go by himself, and come back out. So I don't need a changing table with him, but there are some issues with door locks in the public stalls that give him difficulty.

Zach: Anything else?

Participant: I think that pretty much summarizes what I've been through and what I've done with my wife and my son.

Zach: Okay. Have you heard about adult changing tables?

Participant: Well, not really, other than if it's a changing table, I'm hoping it's low enough to the ground they could sit on like a bench and... All I'm thinking of is baby tables, and now adults, because I did put diapers on my wife today.

Zach: How much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: 80% while in society.

Zach: Okay. Can you tell me about a specific example?

Participant: Well, my wife soiling herself because we can't get to an appropriate restroom in time. Again, with her dementia, when she tells me she has to go, if I can't get right to a spot right then and there, she'll soil herself. And probably in the last three months, let's say once a week. These last two weeks she hasn't been out in public, it's been at home.

Zach: Okay. How did this affect you or make you feel?

Participant: Well I have to stop whatever I'm doing and take her home. Basically it interrupts the social interactions we have through life, and in our community. Some of our close friends know that she has dementia, so they understand, but not everybody does.

Zach: How helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: It would help me a lot, but again, what I had stated earlier was if there's an adult adjustable changing table in the men's restroom, and I have my wife with me, that's only a 10% effective tool. If there's also a family restroom at whatever public areas there so that parents could take children in, or an adult husband can take an adult wife in, that adult changing table would enable me to take my wife out and be more sociable, at least 90%.

Participant: We have dogs, and so we take our dogs down to one local, not restaurant, but bar that's dog friendly, and she goes down to that, and I manually take her into the restrooms, and go with her, take her with me. As long as I stay on top and every two to three hours take her to the restroom whether she says she has to go or not, I can keep her from soiling herself. But if I get occupied for something, and come back and four hours later, she might be sitting in her own urine. Even though I put a diaper on her, she'll completely fill the diaper, and keep going. Then if it's out in public, I have to take her all the way home because there's no place that I can actually sit her down, change her, and get her out of the stuff like that. Whereas if I had those options then I would carry the adult diaper bag with me, so to speak.

Zach: What other types of things would you be able to do?

Participant: Well I guess the best comparison, although is not accurate, I just think of a family that has a young child, a baby in diapers. Wherever they go, if the baby soils the diapers, soils themselves, they change the diaper and continue their daily social activity. When it comes to an adult that's got dementia that needs to be in these type of diapers, you can't just typically change their diaper and continue the day because there's no place around to do that. You actually have to go all the way back... no where close to being at home, I usually end up taking a towel, folding it in the chair, and letting her sit in her own soil until we get home.

Zach: When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: Not at this time because I haven't had the benefit of access or use of them. So it hasn't limited my choice of going to those facilities. However, if I was aware of facilities that had this type of thing, I would frequent them more.

Zach: Are there places or events that you're unable to participate in due to the lack of the accessibility to an adult changing table?

Participant: Let me think on that one. The Street Fest, the Scottish Festival we go to, I can usually access into the handicap plop johns, so that's usually okay. When we go to events like that, I'm particularly on top on her. Every two hours I'm trying to put her into the plop john, and have her go to the bathroom so she doesn't soil herself. So really when I have an event like that, I'm in a pre-attack mode knowing that there's going to be limited access, so every two hours I'm taking her in. I haven't had a need at a event for an adult changing table that I can remember.

Zach: Have you delayed or changed plans because there was no adult changing table?

Participant: Yes. Well because she's soiled herself, or because the access was not... not based on just the tables alone, but just the distance, the toilet access, and the terrain that she would have to traverse.

Zach: Okay. If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: Caregivers, adult caregivers that are basically assisting the handicapped individual. Now, basically as a physical therapist, there are many physical attributes that could be used to assist a caregiver in terms of caring for male or a female with an adult changing table. My background in physical therapy, I could talk quite a bit about that, but for the specific instances of my wife, it's just her ability to stay in a social event or a community event and not necessarily soil herself.

Zach: Okay. When you're participating in society, how often do you encounter an adult changing table accessible to you? Like what percentage of the time would you say?

Participant: Less than one percent of the time.

Zach: Okay. Do you think this is adequate?

Participant: No. It's not.

Zach: Anything else you would like to share with me?

Participant: Pretty much as a physical therapist that assists individuals handicaps and disabilities, the state of Florida, we're not very good in some of the services and situations we offer for

these people of these sorts. I pretty much have been practicing for the last 34 years, well 31 years here in Florida, with patients in wheelchairs all the way through spinal cord injuries with families, and orthopedic injuries, car accidents, things like that. We really could benefit from more, I guess, public assistance for caregivers assisting people with handicaps, both mental and physical. We're getting to be more and more, I mean, if you look at Go Fund Me now is the third leading insurance, people that need healthcare, they got to Go Fund Me, that's the third leading funding for healthcare. That means a lot of people are doing the healthcare on their own. I said I'm a provider for my wife for her healthcare, and my son in autistic. I was recently laid off from my job, so now I'm doing this currently without being employed. I'm planning on getting a job in the next couple of weeks, but people that don't have this quick access to that kind of work don't have those resources available.

Participant: For me, with my son especially with autism, there's very, very limited resources in the state to assist people overall, whether it's tables, whether it's increased family restrooms in addition to a men's room, women's room, and a family room, that kind of... I know it requires legislation, and of course builders don't want to do that, but those would be a bigger help. The family-oriented rooms, and access for caregivers and healthcare providers to assist disabled people, both mental and physical.

Participant: I think that pretty much covers it. Sorry. Long diatribe.

Resp 15

Participant: Hello?

Interviewer: Hello.

My name is [Interviewer], I'm calling from the University of Florida.

Participant: Yes?

Interviewer: You received an email from the Family Café in April inviting you to tell us about how the lack of power height adjustable changing tables in public settings affects your loved ones.

Participant: Yes.

Interviewer: The University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

We are calling you because you completed the online scheduling form-

Participant: Right.

Interviewer: -when the Family Café emailed you.

Participant: Yes.

Interviewer: Your input will help inform and shape the Commission's ruling. Everything you say will be confidential, and will be reported with no identifying information.

Participant: Okay.

Interviewer: There's no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions.

Participant: Okay.

Interviewer: Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time.

Participant: Uh-huh.

Interviewer: I want you to know that this call will be recorded for quality control purposes, and will be transcribed, summarized, and aggregated with other participants.

Participant: Okay.

Interviewer: This survey should take 10 to 15 minutes.

Participant: No problem.

Interviewer: Okay.

A powered, height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. I may refer to it as an adjustable adult changing table, or universal changing table throughout the phone call.

Participant: Okay.

Interviewer: Was there a time that an adult changing table would have been helpful to you, or someone you take care of, yes or no?

Participant: Yes.

Interviewer: Okay. So, first I would like to ask you to tell us a little about yourself, and why the lack of adult changing tables is an important issue for us.

Participant: Okay, so I'm a parent of a child with [autism spectrum disorder 00:02:11]. She is not potty trained. He's 12 years old. Going out with her is an experience because, you know, she doesn't let us know if she has to go to the bathroom out there. [inaudible 00:02:35]

Interviewer: I'm sorry. You're breaking up really bad. I'm only-

Participant: I just ... One moment.

Interviewer: Okay.

Participant: Okay. Can you hear me now?

Interviewer: Yes, ma'am. That's better.

Participant: Okay, okay.

Participant: Like I was saying, my daughter's 12, she's not potty trained and non verbal. When we're out with her, we very often have to change her diaper. Without a changing table, it's very, very difficult.

Interviewer: Okay.

Anything else?

Participant: No. I think that's enough, I guess.

Interviewer: Okay.

Have you heard about adult changing tables?

Participant: Yes.

Interviewer: Where have you heard about them? Word of mouth, magazines, disability advocacy groups, et cetera?

Participant: At [inaudible 00:03:23] Family Café, so disability advocacy group.

Interviewer: Okay.

How much of a problem is not having an adjustable adult changing table when you're participating in society?

Participant: It's incredibly difficult. Incredibly difficult.

We have to do what we can. Sometimes floors are dirty. My daughter cannot do anything to assist. My husband, also, is handicapped and it makes it much more difficult for him, as well.

Interviewer: Okay.

Can you tell me about a specific example?

Participant: Yes.

We went to an event. It was a special event for children with special needs. They had porta potties. The didn't have the regular bathroom. We could use it, but there was no changing table, so we had to go ... The porta potties clearly, we couldn't do it in there. There wasn't enough room for me to maneuver and be able to change her diaper, so we had to do it outside, on the grass.

It's not that the bathrooms were locked, the bathroom, we could use it, but they also had porta potties, but there was no changing table in the bathroom.

Interviewer: Okay.

How did this affect you, or make you feel?

Participant: Well, it was a little embarrassing. You know, she's 12, so I didn't want anybody watching us, that's uncomfortable. It was outside, in front of everybody, there was no privacy.

Interviewer: How helpful would it be if public places had adjustable adult changing tables available to use?

Participant: I guess, on a scale of one to 10, I would say a 10 of being much less stressful, and allowing us to be able to go out and do things in the world, and in society as you say, with one less thing to worry about.

Interviewer: What types of things would you be able-

Participant: Well, bathrooms are often very dirty, you know? To change her diaper in a bathroom where there's no changing table, you have to take her pants off, her shoes off. The floor is dirty, there could be urine, different kinds of things. I have to bend down, and hurt my back, bend over.

In a stall, there's not enough room in the stall, so we have to go to the handicapped stall, if it's big enough. It's really a problem.

Interviewer: What types of things would you be able to do?

Participant: Well, I'd be much more comfortable going to the store. I could take her food shopping and not have to stress. I could take her to outdoor activities, if I knew that there was going to be some kind of ability to change her comfortable. I could just do a lot more things.

I would go to the movies with her. The movies, shopping, theater, to eat.

Interviewer: Okay.

Overall-

Participant: The only part-

Interviewer: Okay.

Participant: Go ahead.

Interviewer: Overall, please describe how your quality of life would change if universal changing tables were more prevalent?

Participant: Number one, we would feel more confident going out on activities. We would get out of the house more.

Having a child with special needs is incredibly stressful. Any stressor that can be removed or mitigated is very helpful. This would really ...

Two things. One, it would allow us to feel more confident and comfortable going out. Number two, it would eliminate or greatly decrease the stressor of how will we change her when she has to be changed.

Interviewer: Okay.

When-

Participant: Also, the stigma. There's a stigma, also. If there's an adult changing table, it's obvious that it's for an adult and there would be less of a stigma about why I'm changing my child in the bathroom on the floor.

Interviewer: Okay.

When choosing things to do, or places to go, do you consider if certain places will have changing tables for adults?

Participant: No, it never occurs to me that any place will because I've never seen one that has.

Interviewer: Okay.

What do you do if you have no access ... I know you ... I'm very sorry if I'm repeating, or asking questions and making you repeat yourself.

Participant: That's okay. It's totally fine. Yeah, it's fine.

Interviewer: What do you do if you have no access to a changing table?

Participant: I have to change her ... I have to figure it out. I'll put something down on the floor so that I can change her using the floor. I have to be bending down and in uncomfortable positions. I don't want to put my diaper bag, or my purse, I don't want to put that on the floor in the bathroom, so I try to hold them while I'm changing her, which is virtually impossible.

It requires a lot of creativity, which is why, sometimes, I won't take her with me if it's a problem.

Interviewer: Are there places or events that you're unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Going to the pool, sometimes, we're limited, taking her to the pool. Going to the beach sometimes is limiting because those ... The bathrooms they use at the beach, they can be really dirty and hard to maneuver in.

I don't like taking her to the grocery store with me, or shopping at the mall, because if I'm out for an extended period of time, she's going to, at least, have a bowel movement. It's really had to do that. It limits us in that way.

Interviewer: Have you delayed-

Participant: Concerts-

Interviewer: Oh, I'm sorry, didn't mean to cut you off.

Participant: No, that's okay. Go ahead.

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Participant: Well, we've never ... It's never been a concern that we've had, so the answer is yes. Yes. Yes, definitely. We would wait until she ... Sometimes we'll wait, and hopefully she'll have a bowel movement at home. We'll wait until she has a bowel movement. If she doesn't, we may just forgo the event altogether.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: I think anybody who has a special need, has a family member with a special need, or a friend with a special need would benefit. Anybody who has incontinence and has to wear any kind of adult diapers would benefit, and anybody with a child who's no longer a toddler, who is not potty trained for whatever reason. Physical, mental, emotional disorders, would benefit.

Interviewer: When you're participating in society, how often do you encounter an adult changing table accessible to you? What percent of the time, would you say?

Participant: Zero. I've never seen one.

Interviewer: Do you think this is adequate?

Participant: No.

Interviewer: Anything else you would like to share with me?

Participant: No. Thank you for taking the time to do this. It's appreciated.

Interviewer: No problem.

Then, the next question is, when traveling, was there at time that the height of a bed was an accessibility problem for you or someone you take care of, yes or no?

Participant: No.

Interviewer: Okay.

Well, thank you very much for your time and help talking to me. I would like to ask you if you know anybody else that you think we should talk to that would be interested in sharing their challenges and stories specifically related to adult changing tables and or bed heights, yes or no?

Participant: I mean, i can't really think of ... I know a lot of people in the ... Not really at the moment, I guess.

Interviewer: Okay.

Well, again, those are all the questions that I have. Again, thank you so much for your time and helping explain your situation, stories. We really appreciate it.

Participant: Thank you. I appreciate you, as well. Have a nice evening.

Interviewer: Thank you, you as well. Bye bye.

Participant: Thank you. Bye bye.

Resp 16

Participant: Hello.

Interviewer: Hello. My name is [Interviewer]. I'm calling from the University of Florida. You received an email from the Family Café in April inviting you tell us about how the lack of power tied to adjustable changing tables in public settings affects you or loved ones?

Participant: Uh huh (affirmative).

Interviewer: The University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the Commission's ruling.

Participant: Okay.

Interviewer: Everything you say will be confidential and will be reported with no identifying information. There's no compensation for completing the survey, but you're answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to know this call will be recorded for quality control purposes and will be transcribed, summarized and aggregated with other participants. This survey should take 10 to 15 minutes.

Participant: Okay.

Interviewer: The Powered Height Adjustable Adult Changing Table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no.

Participant: Yes.

Interviewer: Okay. First I'd like you tell us a little bit, a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Well, after my daughter was born at Kosair, well we were born in Eastern Kentucky. After three days I watched her. She, as a new mother, I came out of the hospital and it was so traumatic. I watched her suffocate to brain damage and cerebral palsy. It was my only child. And we ended up at Kosair Children's Hospital and I remember so well, they wanted me to have her go to The Home of the Innocents for children. Most people didn't want those kids that were handicapped and they'd give them away practically for

the state to take care of. But, I called my mother and she said, "We don't throw our children away, Jamie," and I said, "Okay."

So I spent the next two months at Kosair with [name], come to find out she had four major heart defects when she was born. Tricuspid atresia, transposition of the great [inaudible 00:02:55] upper lower section with defects, and a coarctation of the aorta. And I think just two of them, most kids die from. So here she had four. And she received brain damage. By the time we got to Huntington, West Virginia with her first, the doctors cut off three little locks of her hair and gave them to me for my mother and Ron's mother. And told me, said, "You can have other children, this child is severely damaged. And we don't believe in heart transplants."

So from there we went to Louisville, Kentucky at Kosair, and we spent the next two months there. I never will forget it, Doctor [name] coming in there, and I had a C-section and I was bleeding all over the hospital floor. This lady, I couldn't help it! We had left so quick, I didn't have any clothes or no money, nothing. He come and pick me up, he was like an angel. I never will forget that. Anyway! I ended up at the Ronald McDonald House, and we went through trauma after surgery. I'd spent hours trying to get her to eat, and she'd reject it. She was starving to death. And then her heart, she needed fluids, so.

I know that it's all real traumatic but it's real true! (laughs) So, after that, anyway, I learned how to do nursing skills, and I learned care taking skills from the very bottom up, and the hard way to learn things. And I tried to hold down a full-time job, but being so strong I got in a fight with the Circuit Judge in our county and he had me fired off my job. (laughs) I mean, it's been a [inaudible 00:04:40] buddy! He threatened my mother because she wasn't political and liked to say things, and he took his position too far, and I called his hand, and blah, blah, blah.

But anyway, I would travel with [name] a lot. Every chance I'd get, we'd go to Tennessee, to Gatlinburg, or we'd go to Myrtle Beach, or we'd come to Daytona, or we'd come to Saint Pete. What I'm saying is, we traveled a whole lot with her. And I noticed, the bathrooms in these interstates do not accommodate an aging population that needs sometimes, you know, you can't feed somebody in a car sometimes because they have a G-tube. Or, you know, and they need to have a real rest place, where people of older age could go down, a little separate area, just quiet. And feel their selves, or stay in there two or three hours if they need to, to have a bowel movement or catheterization.

What I'm saying is, it ought to be a mandatory thing for travelers, for us older people and people that have disabilities throughout the United States to have this. And it ought to be air conditioned (laughs). And it ought to be real open. And another thing that'd be nice to have is some kind of wet wipes available for everybody after this for hygiene. And see, that would save your water, but it would also increase your sanitary thing. So, (laughs) I'm a talker! You tell me when to stop and I'll stop, okay? Because I've been through so many things with [name] that I could talk on so many different levels! So, (laughs) I'm talking to help other people, maybe? Maybe!

Interviewer: Okay. And your participation definitely will. So, just to clarify, is there anything else you'd like to add?

Participant: (laughs) Well yeah, I would like to say something to this community, and to the Chairman and to the State Legislature of Florida -- you got to do something about these children. This shooting thing that's going on in these schools, is the most horrific thing that could happen to the United States. We are making a fearful bunch of nuts, children scared to death to go to school at an early age. So, it's going to take something really, really pronounced. And you know what, I know this sounds bad, but we're getting back to those days with all the shootings, and people don't care! If you go into one of these schools, I think laws ought to be passed, if you go in there with the intent to harm and kill and maim, okay? We're going to set up in downtown Pinellas Park down here at the court house, we're going to set us up a nice, big, old-fashioned hanging ramp. And we're not going to spend the next ten years deciding whether you're smart or can figure this out. You were smart enough to do it, you're eligible for a hanging. Old-fashioned, public.

All those little children, that got horrifically disarmed with all of this in their lives, will see this. And they'll know that there is a Lord. And that there is justice in the United States. And it's quick when it comes to this. We draw the line. I'm fed up with it. Something's got to be done. There needs to be a strict disciplinarian on this. If Trump would pick this up and make it public, I'll bet you ninety-nine percent of the mothers will back me on this. Because if it was your child, or grandchild, and you put all your energy and everything into that child, and then to have some drugged nut walk in there and do that? Well, you've got to draw the line somewhere. And so we're going to draw it right now. We're going to have public hangings! I don't want you or your family to be the first one, but if they violate the law, in thirty days it's automatic. This is the first time the United States has done this since the Old West, but boy, it worked back then too! And it's cheap. It don't cost much to buy a rope and break your neck and just let you hang there until the flies start blowing you.

I'm sorry. These little blessed children need somebody to stand up for them, because law enforcement's not doing it. I want somebody to be a man out there somewhere! There's got to be men that's fed up, and what they're doing ain't working. So let's change it and go back to our old ways of laws in the West. I bet you they had hangings in Florida at some point in time, when the sugar mills and all those things were here. I bet you. You stole, you really...oh well. I'm going to shut up. (laughs) I'm really opinionated! (laughs) I apologize to you. If you don't like what I've got to say, that's the reason I kind of got off politics. I stand up for what I believe and I stand for children. I really do, and having a handicapped child that I have kept alive, and then to have it go to school and somebody blow it's head off? (exhales) And no justice for it? And I'm stuck with all this inside of me. And the children are. And it's just going to mount and mount.

Well, enough disruptions. That guy on t.v. tonight wouldn't raise his head up. There with his hair, (exhales and laughs). Okay, enough said. That's all I've got to say right now.

Interviewer: So have you heard about Adult Changing Tables?

Participant: Oh, sure! We've used them before. I've seen them.

Interviewer: Where have you heard about them? Word of mouth, magazines, disability [crosstalk 00:10:37], et cetera?

Participant: I think in bathrooms. I've been some place, I can't remember exactly where, maybe it's around Myrtle Beach? I was making an assessment one time, (laughs) I started doing assessments on all these bathrooms, because it's important to me. Because we have so many people out on the roads, traveling. And remember, we are an aging population. People my age are 63 and older, but yet we still got this travel bug, you know? We like to go run around and go to different places, and it just needs to be upgraded. Looks like Disney would do some kind of a collaboration with their bathrooms, because that's the first port of entry into this State. They should be fabulous! The bathrooms the state of Florida builds. Where they give the orange juice when you're first coming in? That is so neat. I like that, great idea. Give away something free. But, orange juice in Florida is sky high! (laughs) You go to Walmart, it's outrageous! Even the local grown stuff. So, anyway. That's all I'm saying.

And I've got one more thing I want to say -- this is not about adult changing tables -- but it's about your future. This red tide? There needs to be something done about that. I mean, seriously, something done about it. Not just a bunch of suits and ties running around trying to figure out what's going on. Somebody, somewhere knows what's going on or what happened. It just needs to be enough investigation on it, you know? I don't know.

Interviewer: Okay...so how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: Oh my goodness! If you go into one, and say, like [name], she's very fortunate that I didn't have to pick her up, she could function. When she lost the oxygen, it cut her body in half. On her left side is very tired, and on her right side, it's perfect. So, the Lord blessed her there, he gave her a leg so she could go and travel and do things. What I'm saying is, we've been in places like the Hyatt Regency, oh my God! Those beds. They're up to my waist, and I'm five foot ten! I tried to get [name] up on the bed, and it's, oh my God! They're not built for children. More for conventions, I think (laughs). But, having a height and not being able to move it lower could make for a terrible fall for somebody.

Interviewer: How helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: Well, sometimes, now listen. You've got to be reasonable. I mean, you've really got to be reasonable. [inaudible 00:13:40] downtown, they had a lot of mom and pop businesses down here, and they were [inaudible 00:13:46] in Gulfport and other places. The buildings aren't built for six foot changing tables. Probably, the floor joints, if they weren't made out of concrete, probably wouldn't hold it. This is going to be a battleground for business owners versus handicapped. And you don't want that! That's not good politics. So, when the law is written it needs to be with an understanding. Go in gently and ask the business owners if they could do this. And if they can accommodate, that's wonderful! And the big high-price places like Hyatt Regency and fancy restaurants and all that, they've got the money, they can do it. But nine times out

of ten, your mom and pop people won't support it because it costs their income going out, and they don't have that many handicapped people coming at night to get drunk and ride their Harleys off, you know what I'm saying? It just ain't going to happen. So that's my opinion on that. Just be understanding of the mom and pop businesses.

Interviewer: Okay, but how helpful would it be to YOU if public places had adjustable adult changing tables available to use? Like what types of things would you be able to do?

Participant: Well, if [name] has an accident, which she does, and I don't know if all of you people that's taking this information down, if you guys would take a diaper and fill it up with water and sit in it while you're doing it, for about eight hours, then you kind of get a greater compassion for the need for a change (laughs). Having those tables, you know, if you can't stand on your own, that's the only way you've got to change, is you've got to lay down. Now you're going to have to look at how many people are going to be in this position. Of course Florida has such a diverse age. You know, you have to look. There's a lot of people from up North coming down here, though. And all down that 75 Corridor, and 95, that all needs to be prepped for people aged, that would have these in there, up and down the 75 Corridor. (laughs) It would be very helpful.

Interviewer: When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: Well, yeah. When I'm traveling, when I'm going to Myrtle Beach or coming to Daytona or whatever, when I stop at the Florida state line, I'm ready to be loved on (laughs). You know? I'm ready for somebody to say, "Welcome to Florida! We've got wet wipes here for you, and aspirin if you need them! (laughs) I don't know, just having some kind of a little vending machine in the bathrooms, with personal care items. Instead of having to get into your luggage to try to get style. It'd be a big help.

Interviewer: What do you do if you have no access to a changing table?

Participant: Oh, what do I do? I would take the diaper off. One time we went down to Gatlinburg, and I don't know why, but I didn't take but one diaper with me. I had no butt wipes, what I call butt wipes, a mat or table or whatever for her to lay down on the ground and change. Of course, she was younger, but this time that we were there, she was around eleven years old. She was getting up to about three foot tall. And she had an accident on herself. And here we were, a hot day like it is today in Florida. Ninety degrees in the Cherokee Mountains, and there is absolutely nothing around but a car wash. (laughs) Nothing! Having a changing table would be like having a Cadillac (laughs).

So, what I did, I went over to the car wash, and lucky for me I found a towel. I wrapped the towel, and then I took some of the strings and stuff and wrapped the towel to where it made, like, a big, to where it would stop the water from hitting her skin so hard. And make it soft to where I could use it, to where I could help get the stuff off of her (laughs). And we went into a car wash, and the lift on her van it's kind of wiry, and I laid the towel down there and put her down, and then I took the water hose off the car wash and put it through the towel. And it really worked well! I mean, it didn't hurt her

skin, she got the feces off of her, I got everything blown off and clean up, so it worked! But I don't recommend that for just everybody. If you've got the privacy there at the car wash (laughs). But we ended up getting her clothes cleaned up, and she had a fresh diaper, and I got back in the van and washed my hands. I said, "Thank you, Lord," and went on! (laughs) That's the things we've done before.

Interviewer: How did this affect or make you feel?

Participant: Well, you know, given the Cherokee people, if they knew the situation down there, they would probably fund some kind of a better facility, coming into the great Cherokee, out of the Smoky Mountains. They don't realize how many people are handicapped and have special needs, but we want to come and see their culture too, so. (laughs) Yeah we do, we've been down there before, lots of times. I've been to a motorcycle meet down there one time. I've been to the Cherokee a lot.

That's where you were born, [name] (laughs).

Interviewer: Are there places or events that you were unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Well yeah, there's lots of things like that. But normally, if we know that we're going to go somewhere, like we went to Tropicana Field and listened to Tim McGraw one night, and [name] did her business and everything before we'd leave. Because we know that places like that usually don't have handicapped bathrooms. And that's fine. Normally, now, if [name] has an accident and we're not traveling like we were, I will go ahead and just come home. It's easier to take a bath. Showering, that's very, very important. Especially if it's really bad (laughs).

Interviewer: Have you delayed or changed plans because there was no adult changing tables?

Participant: Oh yeah! There's been times that's happened.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: I'm trying to think exactly what. The assisted living people would. Women, all their lives prior to becoming aged, have been very careful of their hygiene, and then to come to some place where they need help. You know, this is the time to do it. Their bladders start giving out, and they have to go to a bathroom every fifteen to twenty minutes. They need to change their personal care things they have on. So, there's lots of reason for things like that.

Interviewer: When you're participating in society, how often do you encounter an adult changing table accessible to you? What percentage of the time, would you say?

Participant: (laughs) I'd say less than one percent!

Interviewer: Do you think this is adequate?

Participant: Well no, because most of them, I was looking the other night at McDonald's, they have their changing table inside of their handicapped. And I thought, "Well, that's really nice." And it had a little sign there, if you need wet wipes or whatever, you can ask at the front desk. So I thought, "Well, that's nice!" You know? But it's not adult. If McDonald's has to put in adult changing tables, they've got the money to do it. But it'd be a matter of looking, I would start with their new bills. You know? I don't know! Disney World, I don't know how they do it. I haven't been over there in so long. We haven't been there since 2000. So, I don't know if they do stuff like that or not. I know [name] got lost over there, and thank God they helped me find her (laughs). Oh well. That's another story.

Interviewer: Anything else you would like to share with me?

Participant: I think I've talked your leg off, I mean, I really have! I ran for Congress in Kentucky, and I want to tell you something I did, because nobody else cares. But I'm going to tell you this! In 1998, I went and ran for Congress in Kentucky's 6th congressional district. I took five hundred dollars of our grocery money, went to Frankfort with my two signatures from my poll, and I applied and I run for Congress, because I wanted to start a children's hospital in Eastern Kentucky. Stupid is as stupid is! I didn't plan on doing anything big. So me and Bill got out on our motorcycle, we rode everywhere, we got twenty-some thousand votes. I got a lot of publicity out of it! But we didn't get no children. But I went to Bill and Melinda Gates' Foundation, one of their things is children's healthcare.

I ran again in 2000, and I talked to Bill Gates again about our children's hospital, about [name] and all the stuff that's happened to us. Then, in 2002 I ran again, I got eighty-six thousand votes the third time, I spent no money. Absolutely none! I didn't have to file any of the old paperwork, or do anything, because I didn't reach the five thousand dollar threshold for contributions. I asked nobody. It was all free. But what I'm getting at? I got a phone call about six weeks ago from a friend of mine, Bill Gates and Melinda Gates, put I think three million dollars into [inaudible 00:24:29] Medical Center for a children's hospital. And that's where I'm from. So, I just want to tell you, don't be afraid to run for office (laughs). Just get out there and try, and wonderful things will happen. And what you're doing right now, I'm glad you're doing this for the University, because it's part of your training and growth and development. Just don't be afraid to try, is what I'm saying. I just thank the Lord that he's blessed the children there. There'll be no more moms, and their kids suffocate, because a doctor doesn't recognize congestive heart failure in a baby.

So, I've said enough! Thank you (laughs).

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Participant: Hello?

Interviewer: Yes, hello. My name is [name]. I'm calling from the University of Florida.

Participant: Yes.

Interviewer: Okay. So, just before we begin, a powered height-adjustable adult changing tables is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary and comfortable space for assisted changing. So was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no?

Participant: Absolutely.

Interviewer: Okay, and so just before we begin you received an email from the Family Café in April inviting you to tell us about how the lack of powered height adjustable changing tables in public settings affects you or loved ones. The University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form from the Family Café emailed you. Your input will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information.

There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answer to these questions. You do not have to answer any question you do not wish to answer. And you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes and will be transcribed, summarized, and aggregated with other participants. And this survey should take 10 to 15 minutes.

So first I'd like to ask you to tell us a little bit about yourself and why the lack of adult changing tables is an important issue for you.

Participant: I am a mother of three children who are affected by cerebral palsy and have limitations on their physical abilities. Two of the children are completely quadriplegics and must depend on others to change them and keep them hygiene-wise and comfortable and so forth.

Interviewer: Mm-hmm (affirmative).

Participant: The other child is able to ... He walks with forearm crutches and he is capable of using a restroom himself, although there are some issues with that as well, my main focus is on the two that my husband and I must care take and provide all those needs for them.

Interviewer: Mm-hmm (affirmative).

Participant: Why I'm interested in the survey is I feel this has been needed for a long time. I'm so excited that it's actually one of my issues that I've told my kids I feel like if my life ever was not as busy, it would be something I would actually of picked as a campaign and then poof the next year this survey came out asking that somebody must have started it as well.

When you visit any facility, if you're going to a doctor's appointment, if you're going to get x-rays, if you're going to go to an amusement park, if you're going to go to a restaurant, if you're going to go any place you have to call the school up or wherever they are, or you yourself have to be aware and say, I may need to put extra pads in because I'm not gonna have a place to lift 96 and 100 pound people because there is no place safe except on the floor to change these children.

Interviewer: Mm-hmm (affirmative).

Participant: I also feel like it would benefit if there was a person having even a seizure. Because if a person is in a seizure, they don't have a safe place to go down to. If family's new that there was a restroom that had a ability to put them on a surface that was at least above ground that you're not breaking your back trying to give this person ... the family member, loved one, in a safe situation but that I feel like it would be also a medical accommodation for people that have seizures that they don't have to go all the way to the floor, that they would actually have a place that somebody would be able to help them and work with them.

So I'm actually double full because we do have seizures in our house as well, so it is something that's been a reality that we know we'd have to go. When you lift a child that heavy off from the ground, not midway, the strain it puts on your back and the worry and fear that you have that you're going to hurt them or drop them trying to go from the floor, all the way to the floor up to back into their chair, is not safe as well. Whereas if you had that little bit of leeway where you're midway so that you could ... It's still not great for our backs but at least it gives an option to be able to do it.

I'm going to end here. I think I've given enough and now I'll listen to any other questions, but there's just multiple, multiple reasons when we go on a trip if a child has a BM, you don't want that poor child to have to sit in the soiled because you have no where to put them and no where to make them feel our common rights. All of us have that feeling of, well we should have food, drink, and an ability to go to the restroom. A handicapped person doesn't have those same accommodations, really, because we're only considering a person in a wheelchair. Which, trust me I want them to have that benefit as well, I just feel like there needs to be ... there's so many caretakers now with the elderly coming into the population too that it's just dignity.

Interviewer: Mm-hmm (affirmative). And would there be anything else you'd like to add to that statement ma'am?

Participant: I would love to hear that statement back and see if there is anything I've left out. I'm teasing, but no, I feel like I've got the gist there.

Interviewer: Oh okay, and so we just do have some other things we want to go over. So you have heard about adult changing tables, so where have you heard about them?

Participant: Well in limited businesses that deal directly with handicapped such as our Custom Mobility is a business that deals with serving the population and getting them durable equipment, wheelchair molding, vans, that types of stuff, they have a restroom that has a setup where there is that available to us. And then also when they would visit Shriners, there is one location in Shriners that people could go there to use that area to be able to change a person, an adult-sized person instead of a children. But other than that, we've always made our own where if we go like to Busch Gardens or any amusement type park and we know that the whole day they would have to go, we actually go the First Aid places and ask to use the rooms that people get to go if they're having some kind of situation.

So only those two businesses have we had the actual changing appropriate room available.

Interviewer: Mm-hmm (affirmative). And so how much of a problem is not having an adjustable adult changing table when you are participating in a society? And can you tell me about a specific example?

Participant: Extremely. Gosh, repeat that first part that you said? How much of a?

Interviewer: So it was, how much of a problem is not having an adjustable adult changing table when you are participating in society? And if you can [crosstalk 00:09:39] could you tell me about a specific example?

Participant: Yes. So if I just say extremely difficult, that's extremely difficult, that works. So one situation was we were trying to enjoy an amusement park and we went into the restroom because we could smell that there was a situation that someone needed a changing. My daughter was probably ... This starts early so, but this particular, I'll just go like this, this time she was ... This probably happened at 16.

We tried to use the counter, they have like a ... They actually did have a counter space that was equipped for children and they had made it as part of a counter, so it looked like it would support her weight, whereas you know they can't go on those little ones. But her length, because she was 16 and she was a tall girl, she wasn't a small infant, her length was too long. So just trying to ... Going in there and trying to get her out of her outfit and her not falling off was a concern to the point where I actually had to have my husband come into the women's bathroom because I did not want her ... We had a way to be able to change her that she was able to lay on this particular counter set up that they had, but it was so small that I was afraid she would fall of. So he had to keep monitoring to turn her because there was such limited space in order to pivot and clean

her up that we just had to apologize to the other patrons and ask them to give us a moment so we could take care of her.

So it's humiliating, because to be honest it's ... You do get comments in that situations where population doesn't understand what you're trying to accomplish. Another time we went to go change my son who has ... This was probably just last year. We went to go, he also needed a change, he was going through some different medical situations and so he ... but he was urinating a lot more and so he [inaudible 00:12:19]. We basically were in a public place and I had to have my other children, who I have three other children and they had some friends along as well, and had to make a human wall around us so that my child could be laid on the floor, no type of padding, no type of cleanness for him, so that we could change him so that we knew that he would not then be irritated. His skin would break down because we weren't able to change him. So we basically made a human wall around to protect him from public eye, because we had no where to go into a stall. And then we had to go from the floor to lift him back up, and so again as I said, when you're requiring caretakers to go from a floor atmosphere up to a wheelchair, the strain that is caused on their back, the strain that's caused on the fear of them falling, is just real and it's not a safe situation.

But I'd also like to add at this time, so there's two examples just with my children, but this has happened quite often in our life, but those are two specific examples, but many times individuals who are the caretakers have to just decide, or they'll come home from an event and basically have a child or their person that they're caring for in a sopping, that has leaked over on to their clothes, that has leaked on to their chair, that we have to then take the whole entire cover on the chairs and we have to wash the sheets that are underneath the person, because we haven't had an opportunity to be able to change them. So you know that you're basically ... This human being, who should be treated with far more dignity has to go with the sopping wet clothes or the sopping wet wheelchair because there is not a place to actually change them.

So I just think it's important to really have that emphasis and that understanding that ... it's really a hard decision. And I can't imagine, because at least our family all does hang out together. I can't imagine if you're a single person trying to take care of a single individual. We're lucky enough that we have the ability to one person take the top, one person take the bottom and pick them up.

Interviewer: Mm-hmm (affirmative).

Participant: If you're a single individual you wouldn't be able to even get the person out of the chair when you do need to get the person out of the chair.

Interviewer: And so this next question is, how helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: It would be 100% helpful. I would allow us to keep [inaudible 00:16:01]. You wouldn't have to leave an event that your family can, and it takes an effort to even get to a special event such as Disney or Busch Gardens, or some family place to enjoy. Even if

they're grocery shopping. Our trips are not short and so it does take time, so we may have to visit multiple places to do shopping, or we may need to go to doctor's appointments that the specialists are actually an hour away and an hour back. And then the appointment isn't quick, a long distance period of time.

If that person has to go, if this was made available, if the adult changing tables were located in areas that we could change them, it would be one less worry on somebody's mind that they're making sure that that individual that is handicapped is being treated with dignity, that they themselves are part of society, that they actually get to have that need met so that they don't have to leave the park early because there's a possibility of a mess or not being able to change them or causing a breakdown on their skin because it's not taken care of. It would be a huge relief to know that you get to give that dignity to that individual. And then have their family be able to continue on with the day of this enjoyment.

Interviewer: Mm-hmm (affirmative). And you have mentioned this before, but when choosing things to do or places to go, do you consider certain places will have changing tables for adults

Participant: We plan things out where we have gotten to the point now where yes, we do. And we've gotten to the point where we think ahead of where ... So like if we're going to maybe go to the park like I said, we will find out where the first aid areas are at the parks. If we're going to go to a fancy restaurant or to the beach, we consider getting ... We don't go to the beach unless we get a hotel room so that we have a way to go back to the hotel room and have the bed to be able to change the individual. So there's no like trip to the beach like other families will get to do. You have to add that expense of having a hotel room so that you're family member who is coming with you who will need access to be changed has that room available.

So needless to say, we don't get the experiences of going to the beach as often as another family does, but it actually does limit even your ability to visit places because you are tied to will you be able to change someone and make them comfortable?

Interviewer: And so how helpful or accommodating are these places when you ask about adult changing tables?

Participant: Repeat that again.

Interviewer: So I was asking how helpful or accommodating are these locations when you ask about adult changing tables?

Participant: How helpful are the people who work there? Or how helpful ...

Interviewer: Yes, just in general if you've ever asked about adult changing tables at these locations, like the parks or the hotels or any public place.

Participant: If they don't have actual adult changing tables, what they have is like where somebody else, a non handicapped person visits the park and may be diabetic or may have eaten

something or because they've made themselves nauseous on the ride or they banged their head as they've coming off the ride, but these are actually like the cots that they use to accommodate the other patrons of that park or that situation. And so we ask to use those rooms, and a lot of times even that there's a screen to divide ... And fortunately often there's not anyone in the rooms, at least we've just been fortunate. One time there was another, in one of the four cots that were available there was another individual who was there with their family.

And there was some embarrassment that you had to apologize that you were going to be changing, but there was a screen to be able to surround the cot. But there was some embarrassment that you were having to change in a bed right next to the person who was also there for another reason. But it all worked and they were accommodating.

Interviewer: And as you've mentioned this, but I just have to ask, what do you do if you have no access to a changing table?

Participant: If we have no access to a changing table, we have come up with creative ways of taking the children to the floor, all the way to the floor and then having somebody stand in front, having other individuals go in front to make a human coverage with their own bodies to allow us to have the privacy. We've done where we had like beach towels with us so we've made again like a little tent type area to provide coverage. Again at this point I'd love to mention the fact that seizures as well, like not just changing tables in a sense of the very traditional where you're trying to keep up with somebody's hygiene.

We have had situations where a child has gone into a seizure at like we went to Orlando Ice, the ice process and we've had to take a child that is seizing, because you want to get the on their side and keep them from seizing. If there were restrooms with that availability where somebody would be able to administer the oral or the anal Diastat to stop seizure, that would be beneficial because we've had to unfortunately go to a floor [inaudible 00:24:45] on the floor and not have privacy and just tried to make a little area where we kind of can section off from the public view and then do our best with covering to take care of a situation.

We've had a situation with one of the two children who has a feeding tube where the feeding tube completely came out, and so again we had to lower the child all the way to the floor. You're going on a public dirty place. Now there you don't have to cover them for decency because the tube is located on their belly, so it's acceptable. But you are, you do feel conscious and where your concern should be with the individual who you need to get the feeding tube back in, you don't have a situation that is sanitary for the person. You're basically laying them on the public walk path, but over to the side. And then it's made it very difficult to go from a flat ground back up into their chair. It's not safe.

Interviewer: And so are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Many.

There are parks that don't have that access or have such a limited access that you actually avoid going to those businesses because you're not going to be able to ... There's not a first aid type setting where it's not with the cots. It limits us to travel. We don't feel like we can go further than two hours out to visit. So if we want to go visit some place, you have to put all of that into your traveling as to how will you provide changes? How will you provide if something were to go astray? So it keeps you close to your local community and prevents you from traveling distances unless you're going to be getting a hotel room, unless you're going to take a trip which that involves a lot of extra income to constantly have to have to, or constantly have to pay for rooms in order just to do your local zoos. You have to stay within a radius is what I feel our family has chosen to handle it.

So we try to stick within a certain radius of our home instead of being able to visit places, a state park or ... It's supposed to be accessible. It's supposed to be opened and able to accommodate everyone in society.

Interviewer: Mm-hmm (affirmative).

And so if more adult changing tables were installed in Florida what types of people would benefit the most and why do you think that?

Participant: First would be the actual quadriplegic, handicapped. So first I think it would be the individual who needs to be changed that they are then given an opportunity to participate in going to see Florida and get to their doctors appointments and have a place to be changed. Second it would, way up there, would benefit of course the caregiver because the caregiver wouldn't have to choose not to change the child or to go to the floor. So I really feel ... And then third it would benefit others as well because it would allow them to see a population that should be part of their experience. You know like we're supposed to be an inclusive society that everyone is able to interact. And I know that handicapped people, because even though I'm not a handicapped person I have to make the decisions for the two handicapped.

We're not able to access community events. We're not able to be out in the public areas because there's not this available. It is limiting and this would open an make the community actually available. I mean I completely forgot about that too is that we have to even go to fireworks because you have to consider traffic, you have to consider ... I mean just things that people take and feel that, "Oh, I'm going to go do the fireworks down at Channelside," I know it's not close to you so you may not know what I'm talking about. But anything you're wanting to take in, if you want to go to a baseball game, you're having to think of all those limitations of because there's not that available. But if that was open to people I really think you would see more ... Our veterans, our ... Everyone has to make that consideration of if they can take care of their necessities.

Having these adult-sized changing tables would just open the access to the community.

Interviewer: And so when you're participating in society, how often do you encounter an adult changing table accessible to you?

Participant: Only at two businesses.

Interviewer: Mm-hmm (affirmative). And do-

Participant: It's the only time I've had that and, sorry, go ahead.

Interviewer: Oh you can go ahead.

Participant: So only at two businesses. Both which clientele are handicapped therefore they're more aware. But in the regular setting, I've never encountered an adult changing table.

Interviewer: Mm-hmm (affirmative). And do you think this is adequate?

Participant: No.

Interviewer: And so regarding the adult changing table topic, would there be anything else that you would like to share with me?

Participant: Adult quadriplegic individuals want to be a part of their community. My own two 19 year olds who come out to dinner with us, who do go to family recreation areas such as the beach, Disney World, Busch Gardens, participate at getting to see fireworks. Their faces light up and their curiosity and their exploration and wanting to have that feeling of being a part of humanity is important and they should not be limited and deprived from having the same experiences. There should be accessible adult changing tables so that effort can be made for them to continue to be part of their communities.

Resp 19

Participant: Hello.

Interviewer: Hello. Can you hear me?

Participant: Yes, sir.

Interviewer: Okay. So, my name is [interviewer]. I'm calling from the University of Florida and so just before we begin, just to start off, a powered height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility at limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no.

Participant: Yes, sir.

Interviewer: Okay. So, just before we begin, you received an email from The Family Café in April inviting you to tell us about how the lack of powered, height adjustable changing tables in public settings affects your loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when The Family Café emailed you. Your info will help inform and shape the commission's ruling. Everything you say will be confidential, and will be reported with no identifying information. There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to note that this call will be recorded for quality control purposes, and will be transcribed, summarized, and aggregated with other participants, and this survey should take 10 to 15 minutes.

So, to begin, first I'd like to ask you to tell us a little bit about yourself, and why the lack of adult changing tables is an important issue for you.

Participant: Well, my name is [name], and I take care of my mom. She's 84 years old. She lives with me, and sometimes when we go either out to public places or we stay in a hotel, it's a little hard for [inaudible 00:02:12] because she's 84. I usually have to go with her any place she goes because of [inaudible 00:02:19].

Interviewer: So, have you heard about adult changing tables?

Participant: No, sir. I haven't.

Interviewer: Okay. So, how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: Well, sometimes when you go to the public places, there's a lot of people, not in the hotel, but usually in the bathroom. There's a lot of people, and they don't have no space either for the wheelchair to go in. You have to say excuse me, excuse me, and then sometimes, when we are ready getting to the place, it's already too late, and things like that. I see that any place that has something that can help the elder person, not only my mom, but anybody that has or is elderly, that would be very helpful.

Interviewer: So, how did this affect you or make you feel?

Participant: I'm sorry. Say that again.

Interviewer: How did this effect you or make you feel?

Participant: Well, it doesn't affect me, but sometimes it's a little hard for me.

Interviewer: All right, and so how helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: I'm sorry. Could you repeat that?

Interviewer: Yeah, so I said how helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: Well, it would be very helpful. It will be good with time, stuff like-

Interviewer: Would you mind repeating that? The phone seemed to cut off.

Participant: [inaudible 00:04:20] in the public places because it help me with my mom and all the older people, that are old.

Interviewer: So, what types of things would you be able to do, or places to go?

Participant: I'm sorry. Say that again.

Interviewer: What types of things would you be able to do, or what types of places would you be able to go if public places did have adjustable adult changing tables?

Participant: Well, it would be more easier for me to help my mom.

Interviewer: So, when choosing things to do or places to go, do you consider certain places will have changing tables for adults?

Participant: Well, I think they should have them in hotels. If you have them in public places, like them that they have for the babies, they should have a little space for the elderly person too.

Interviewer: Okay, and how helpful or accommodating are locations when you ask about adult changing tables, if you do ask?

Participant: No, I don't ask because if I don't see one, I don't ask if they have it or not.

Interviewer: Okay. So, what do you do if you have no access to a changing table?

Participant: Well, I just help my mom because it's hard for her to do it by herself, but sometimes it's a little hard for me too because the bathroom, well you know, the inside of the bathroom, there's not enough space for me and her, so sometimes it's hard. I try to manage. I take a little longer, but I try to manage.

Interviewer: Okay. So, are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Well, the hotels.

Interviewer: So have you delayed or changed plans because there was no adult changing table?

Participant: I'm sorry. Could you repeat that?

Interviewer: Yep. So I said have you delayed or changed plans because there was no adult changing table?

Participant: No. No.

Interviewer: So if more adult changing tables were installed in Florida, what types of people would benefit the most, and why do you think that?

Participant: Well, I think the elderly person would be more helpful for them, and for the family like me. I take care of my mom, so we have to go to a public place. I have to go with her because it's hard for her to any kind of thing for herself, so I have to be with her any place I go with her. I think it will help the person, the elderly person, and the family member too.

Interviewer: Okay. So, when you're participating in society, how often do you encounter an adult changing table accessible to you?

Participant: You say how many times?

Interviewer: I just said when you're participating in society, how often do you encounter an adult changing table accessible to you?

Participant: I don't understand that question. So, I'm sorry.

Interviewer: That's fine. So, you can give a percentage of how many times you've encountered a changing table that's accessible to you.

Participant: Okay, what you mean by that is how many times have I used one?

Interviewer: No. How many times you've encountered one?

Participant: For elderly person, none. Never.

Interviewer: Okay. Do you think that this is adequate?

Participant: Not having one?

Interviewer: Yeah, so you said that you never encountered one. Do you think that this is adequate?

Participant: No, it's not.

Interviewer: Okay, and so regarding the adult changing tables, is there anything else that you would like to share with me about that?

Participant: No, I think, yes I think that it would help [inaudible 00:08:53] elderly person and the family that take care of them because it's hard for them, but then sometimes we forget no space for that changing thing in the bathroom. You have to either wait for someone to move out because there's not a lot of space, so that would help a lot of the elderly persons and their family too.

Resp 20

Participant: This is [name]. How can I help you?

Interviewer: Yes, hello. My name is [name]. I'm calling from the university. I'm calling on behalf of the Family Café because they invited you to do a survey about changing building codes.

Participant: Yes.

Interviewer: Would you happen to have some time now?

Participant: Yeah, this is a good time.

Interviewer: Okay. So, just before we begin, para-tight adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitation or incontinence, they provide a safe, sanitary, and comfortable space for assistive changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no.

Participant: Yes.

Interviewer: Okay. Again, you received an email from the Family Café in April inviting you to tell us about how the lack of para-tight adjustable changing tables in public settings effects your loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need, such as the building code, by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Cafe emailed you. Your input will help inform and shape the commission's ruling.

Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer. And you can stop the interview at any time.

I want you to note that this call will be recorded for quality control purposes, and will be transcribed, summarized and aggregated with other participants. And this survey should take 10 to 15 minutes. So, to begin, first I'd like to ask you to tell us a little bit yourself, and why the lack of adult changing tables is an important issue for you.

Participant: Well, I have an adult daughter with very medically complex Cerebral Palsy. So, she uses a wheelchair, and is incontinent in both bowel and bladder. So, you know, overtime the getting her onto changing tables and having the availability of changing tables in public places is not common at all. It's just simply a matter of it restricts her ability to attend functions in the community, and fully participate in life really.

Interviewer: Mm-hmm (affirmative).

Participant: Do you need more information than that?

Interviewer: I don't know, it's whatever you want to share. Would there be anything else you'd want to add to that?

Participant: Well, I think in terms of this particular issue, I think that addresses why our family needs something like that more commonly available.

Interviewer: Okay. So, have you heard about adult changing tables, and if so, where have you heard about them?

Participant: I have heard about them, but I haven't ever actually seen one. I would like to learn more about them, and think it would be extremely useful when trying to travel about the state.

Interviewer: Okay. Where specifically have you heard about them?

Participant: Well, I'm networked with a group of moms, and other advocates who includes one of the supporters of this notion. So, I've heard about it from that circle of peers that have just been informed about it because they're... they know someone who is especially supportive of this idea.

Interviewer: Okay. So, how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: Ask the question again. How difficult is it? How...

Interviewer: I said, how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: Oh, well it's a big problem of course because...

Interviewer: Would you be able to tell me about a specific example?

Participant: Well, sure. My most recent example is that my daughter is about to turn 21 in a few weeks. So, I'm in the process of trying to help her with devising some sort of

a micro enterprise plan. And, so as a consequence of that we travel to Pensacola over Spring Break in March, and as sort of in parenthesis, I travel quite regularly to doctor's appointments in Gainesville and Jacksonville also. But on this trip to Pensacola she happened to have a bowel movement as we were just starting on our way back, which is a several hour trip.

So, I stopped in the rest stop that said it was accessible, it had a family restroom and all of that. But the... there was a very nice ranger there, very willing to be helpful, but the only thing she could really offer was trying to put her on the floor. She's to a point now where it's just not safe to try to do a transfer like that.

I can't get her up and down from... I don't want to put her on the floor, of course. No matter how clean somebody thinks it is. And, it's not safe to try to do a deadlift from the floor. I can't get her up and down like that anymore. So, there's a little, like a seat, that I... I don't even really know how that would be helpful to anybody. But it would require somebody to stand, I guess, and pull a brief down standing up. Then, you know, they could sit if they needed to sit.

But it's not... my daughter uses a ventilator. So, it's not possible to do any kind of toileting on a tiny little seat. It's about two by... you know, maybe 18 inches by 24 inches, something like that. It was pretty small.

Interviewer: Mm-hmm (affirmative).

Participant: And I'm totally across the room from a toilet. So, I really didn't even see how it helped anybody, but it certainly wasn't appropriate to be helpful in our situation at all. So, I think that there has been efforts made to address it, but it's not adequate for people that use wheelchairs. I don't think even a person with more mobility than my daughter... I'm not really seeing... maybe, I suppose, some people could transfer out of a chair onto that little bench thing but, I still don't really see how that would help.

Get the brief changed, just sitting down, I don't really know how you can change a brief sitting down. I just don't get it.

Interviewer: Thank you. So, how helpful would it be to you if public places had adjustable adult changing tables available to you?

Participant: Oh, we'd be able to go out a lot more. I mean, it's not... you know, of course, we went down in flames on that attempt, and she ended up having to sit in a poopy diaper for several hours until we could get to the house because there just wasn't an alternative. So, that's... you know, there's a whole host of reasons why that's not really a very acceptable alternative. Including skin breakdown

issues, and hygiene issues, and discomfort issues. I mean, it just really is not reasonable.

So, not everybody that needs a changing table is an infant. So, having those infant changing tables in restrooms is... doesn't address the actual underlying need. So, we'd be able to travel more freely. I've gone to fairly considerable personal lengths to get the vehicle that's accessible, and you know, done what I could do to make her interacting in the community more seamless. But you know, this is an area that until she became so old that I could really do those kinds of transfers anymore, I could occasional find... like there's a few ladies' rooms that have sofas and things like that, where I could sort of make due from time to time.

But there's... I don't think there's anything in men's rooms. So, I don't know what in the world men are supposed to do. I think they're in an even worse situation than ladies are, because they have a little bit more attempts at fancying up some ladies' rooms. But in terms of restrooms in public places, there's nothing. Stadiums, rest areas, parks, all that. There's nothing. There's just nothing.

So, nobody else goes all day without any ability to use the restroom. So, how in the world can you expect people with disabilities to be able to do that. It's just not reasonable.

Interviewer: So, overall, please describe how your quality of life would change if universal changing tables were more prevalent.

Participant: Oh, the... hold a minute. There's a word I'm looking for. What is it? The best practices and, I think, the goal of... parenting somebody with a disability as... well, any disability really, is to provide people with a typical life as possible. So, there's nothing typical about not being able to use the restroom in a public place.

So, it would allow access to functions that were not really able to attend. We'd be able to travel more. We'd be able to just participate in a more enriching way in the community. And, the adjustable feature of that notion of an adjustable changing table is the protecting the back, and ability to continue to provide care for the caregiver as well.

Inevitably, one or both parties would get hurt if it was a fixed changing table that you know, didn't accommodate the person with the disability or the caregiver trying to go through all the shenanigans needed to actually address the business end of making that work. So, that's kind of how I see it.

Interviewer: Thank you. So, when choosing things to do or places to go, do you consider certain places will have changing tables for adults?

Participant: Well, I don't really expect it anywhere. So, I guess the answer to that is no. I certainly would take that into consideration if I thought it was more widely available. I don't know where they've been installed, and where they haven't been installed. So, I just hope that it doesn't become a huge issue.

Interviewer: So, what do you do... I know you kind of touched on this before, but what do you do if you have no access to a changing table?

Participant: I either have to leave early. You know, I'm pretty resourceful, so generally I can... I don't know. I don't know. I don't even really know what to say. I just either try to... for medical appointments there's usually some place in the... oh shit. I just spilled coffee everywhere. Crap.

Interviewer: What do-

Participant: Yeah, just a second.

Interviewer: Okay.

Participant: Are we almost done?

Interviewer: So, there are just around four, maybe a little bit more questions for the adult changing table. Then, we also have another follow up one for bed heights, but you don't have to participate in that one if you don't want to. But we are almost done with the-

Participant: Yeah, of course I want to. I want to give you all the information that you think the Building Commission needs.

Interviewer: Oh okay.

Participant: I can take care of the other thing-

Interviewer: Oh okay.

Participant: ... in a minute.

Interviewer: Yeah. Would you like to move on, or do you still need a moment?

Participant: I don't remember exactly what that question was. So, help me out with the question again.

Interviewer: Yeah. So, I was asking what do you do if you have no access to a changing table? [crosstalk 00:17:55] you were mentioning about doctor's offices.

Participant: What I started to say was, right. Not really doctor's offices. Most of the appointments that she has out of town are... at hospitals or clinics where there's exam tables and things like that, that we can use to make a change. If it happens to be medical related, but if it's not medical related then, there's really nothing.

So, restaurants, community events, civic centers, things like that, that don't have any... I tried to go to a baseball game in Saint Petersburg a few years ago, and the seating area for people that use wheelchairs was very unaccommodating to being with another party. You could not sit with your party that you arrived with. And, the bathrooms weren't really accessible either.

So, you know, how do you do... I just want to go to a baseball game with our friends. But they had to not go with their group of friends, because they could either sit with them or sit with us. But we couldn't sit with everybody. So, how is that ADA accessible? Or compliant. So, those kind of things.

Interviewer: Okay. So, are there any other places or events that you're unable to participate in due to the lack of accessibility to an adult changing table?

Participant: I'm sure there are. I'm sure there are. I don't go to concerts. I don't go to amusement parks. I don't go to... what's another good example? I mean, really just museums, not usually. Things like that.

Interviewer: Mm-hmm (affirmative).

Participant: Like I said, most people will routinely go to without even thinking about it. Shopping is a big issue, anything like that. Malls, just regular places that people go in their daily lives. You know, she and I are trying to start this business that I mentioned earlier, and so, how is she supposed to be at work every day and not be able to toilet at work? What kind of crap is that?

So, you know, it just is... it affects day to day activities that people take for granted. They don't have the mobility issues that people like my daughter have.

Interviewer: And just to follow up with that question. Have you delayed or changed plans because there was no adult changing table?

Participant: Delayed or made, is that what you said? Delayed or made plans?

Interviewer: Oh, so I said, have you delayed or changed plans because there was no adult changing table?

Participant: Well, I would say probably not. I think I try to just do... I suppose. I mean, like I said, I don't even attempt things sometimes depending on... especially the things that are really more for entertainment, you know? More what I do is kind of prioritize what I think is worth taking that risk of her being able to either have access to some sort of facility, changing facility, or how likely I think it's going to be that she'll actually need to be changed.

So, I'm not sure if that answers the question but that's more what I do. Not that I'm really changing plans, it's just how important is it that we do this. I'd like to take her to some like Calaway Garden and, you know some entertaining kind of... that would be pretty much for entertainment or fun trips. You know, and if they're many hours away I don't generally even consider doing it, or trying to figure out a way to do it. You know, especially if it's...

So, in my particular situation, taking her out to spend the night somewhere is geometrically more complicated than taking a day trip. So, taking a day trip is complicated by one thing, you know, not wanting to have her sit in pee and/or poop all day. So, that's kind of the calculus of it, is figuring out how many hours a way we can travel.

I thought we'd be able to do that trip to Pensacola pretty much round trip, but she had a big seizure in the car and that was the end of that. Then, we were stuck. I had heard that there were a few of these changing tables in rest stops. Well I stopped at the rest stop but, the one that I happened to stop at didn't have that. So, I just made a run for getting home as quick as I could get home. So, that's probably not the safest thing in the world, being distracted by that. But, you know, that's kind of how I see the option.

Interviewer: Okay. And so, if more adult changing tables were installed in Florida, what types of people would benefit the most, and why do you think that?

Participant: I think everybody benefits because everybody benefits from being able to interact with all different kinds of people. So, if you know, I think Florida takes a lot of pride in considering their selves tourist friendly, but people like my kid aren't able to travel here. It's pretty hard to travel when you use a wheelchair because there's not really a good way to travel in a plane with a wheelchair. People driving in also are going to have problems. And, the people that... the more people see, people like my kid, out in the community, out and about doing fun things, the more accepting they'll be of that in the future. And the more likely they are to, you know, have positive experiences while traveling in our state.

I mean, it's... these are laws that were passed in the 80s, '88, was in the 80s. That stadium in Saint Petersburg was built in the 90s. So, I don't think they

made a really good faith effort to accommodate people with disabilities when they designed that. That's what I would like to see, is people making more of a good faith effort. I don't think that that has really gone on. People don't see the need for it, and they don't understand the impact that it has on peoples' lives. And the more someone like my kid, who's out in the public's eye, the more people will understand why that's important.

You know, there's a lot more universal design being used. I think a lot of that has been more to accommodate baby strollers than wheelchairs. So, yay for the baby strollers. It's been a benefit to my child too, but I don't think it's the reason it was built in that way. Like ramps in public places and things like that. So, that's the way I feel about it. It makes everything infinitely more complicated trying to plan for that.

I took my daughter to the beach for a week, and I had just her stuff was eight bins of equipment and formula, and clothing and incontinent supplies, and oxygen supplies. And that doesn't include her wheelchair, her oxygen or the actual beach stuff, floaties and all the stuff that goes with the actual beach stuff. So, just packing that and getting... and we rented a hospital bed. So, what everybody else can do for a weekend, takes literally months and years of planning and, you know, just making the community more willing to support someone like her is... would just make things a lot less complicated.

Interviewer: So, when you're participating in society, how often do you encounter an adult changing table accessible to you?

Participant: Never seen one.

Interviewer: And do you think that this is adequate?

Participant: Of course not.

Interviewer: So, regarding adult changing tables is there anything else that you would like to share?

Participant: Well, I hope that they'll consider some changes in implementing some of the proposals. I didn't remember receiving that email. So... what else was I trying to say? So, no. I'm in hopes that the building code takes it seriously, and I'm not sure exactly what they have jurisdiction over and what they don't have jurisdiction over, but I think if public places started... you know, that would become the standard. So, trying to find an alternative to you know, the adjustability piece of it is essential because it just... you know, that's why hospital beds are adjustable. Different for every person.

So, putting in a cement slab that's all the same height doesn't reach the same standards for really provide the accommodation that some people might think it's providing. It's just really not the same. I'm in hopes that they will take the adjustable aspect of it seriously because it's not a luxury. It's an essential piece of making it workable in the world.

Interviewer: I thank you so much for your time ma'am. I hope you have a wonderful day.

Participant: All right. Well if you have any followup I'm happy to help any way I can. I'm all for it.

Interviewer: All right, thank you so much.

Participant: All righty, thank you.

Interviewer: Bye.

Participant: Bye.

Resp 21

Participant: Hello?

Interviewer: Yes, hello. My name is [name]. I'm calling from the University of Florida.

Participant: Yes?

Interviewer: I'm calling on behalf of the Family Café, with some questions pertaining to adjusting Florida's building code. Would you have a moment to speak with us?

Participant: I do.

Interviewer: Okay. To begin, a powered height-adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you, or someone you take care of?

Participant: Yes.

Interviewer: Okay. And so, just to tell you a little bit more, before we begin the actual survey. You received an email from the Family Café in April, inviting you to tell us about how the lack of powered height-adjustable changing tables in public settings affects your loved ones. The University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code, by interviewing people affected by current standards.

We are calling you because you completed the online scheduling form when the Family Café emailed you. Your info will help inform and shape the commission's ruling. Everything you say will be confidential, and will be reported with no identifying information. There is no compensation for completing the survey. Their answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answer to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time.

I want you to know that this call will be recorded for quality control purposes, and will be transcribed, summarized and aggregated with other participants. And this survey should take 10 to 15 minutes.

So, first, I'd like to ask you to tell us a little bit about yourself, and why the lack of adult changing tables is an important issue for you.

Participant: I'm the caretaker, legal guardian of a 16-year old, with MPS1. He has mobility issues, and requires incontinence care. And we have to travel frequently for out-of-town, to Gainesville, Jacksonville, Tallahassee, to receive medical treatment. And there's no place to change him when he needs to go to the bathroom, or has an accident, or is

incontinent. We don't have a way of taking care of that, other than in a vehicle, and he's, you know, a 16-year old.

Interviewer: Okay, thank you. And so have you heard about adult changing tables, and if so, where have you heard about them?

Participant: I have. I have seen them, I think, online, and possibly on a news show, or something, on TV, or maybe the internet somewhere. I've never seen one personally.

Interviewer: Okay. So, how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: You want me to rate it, or give it a severity... I'm not sure how you want me to answer the question. I could tell you out of zero to 10, it's a 10. So, it's a big problem. It's a huge problem. And it's not just a matter of convenience. It's something that's needed for this population of citizens, because just for their general health, and welfare, and hygiene, you know, when they're out and about, for whatever reason, they need to be able to take care of their personal hygiene like anyone else, and go to the bathroom, or however that has to happen for them.

It's critical. It limits your ability to participate in activities in the community, or with their family, with... It limits how far they can go to seek medical care sometimes. You're very strapped into a circle of how far you can get away, that you can be able to take care of things that you need to do.

Interviewer: Okay. And how helpful would it be to you if public places had adjustable adult changing tables available to you?

Participant: Oh, how helpful. Very, very, very, very, very.

Interviewer: And what types of things would you be able to do? Or what kind of places would you be able to go?

Participant: Well, it would... First of all, for my child, for my situation, it would make traveling to medical appointments easier. It would give him back his dignity and self-esteem. It would also give him opportunities to participate in community outings, sporting events, activities that every other person who is able to use a public restroom does, and that would give them the ability to do that also.

Interviewer: And overall, please describe how your quality of life would change if universal changing tables were more prevailing.

Participant: Our quality of life would change. It would have a great impact in the improvement of quality of life for him and our family, to be able to have access to these tables.

Interviewer: Thank you. And when choosing things to do or places to go, do you consider certain places will have changing tables for adults?

Participant: In choosing places, do I consider if they will have one?

Interviewer: Mm-hmm (affirmative).

Participant: I do think about it. Well, at this moment, I don't think about if they're going to have a changing table, because I've never been anywhere that did have one. What I think about, is where are we going to be able to change him, if needed, and I make preparations that way. I would love to be able to know that there were certain locations that had these facilities available so that I could plan our activities around those locations. Does that make sense?

Interviewer: Yeah. And how helpful or accommodating are locations when you ask about adult changing tables, if you ask?

Participant: Have I ever asked about do they have one?

Interviewer: Mm-hmm (affirmative).

Participant: I've never asked.

Interviewer: Okay. And so, you touched on this a little earlier, but what do you do if you have no access to a changing table?

Participant: He has to lay down in the backseat of the vehicle. And we have to change him in the car.

Interviewer: Okay. And how does this affect you, or make you feel?

Participant: Well, it's dehumanizing. It makes him feel like he's exposed to anybody and everybody's privacy is non-existent. It's just very... It's just very lack of... I'm trying to pull my word up. It's just dehumanizing. It's just difficult. It's just very, very difficult. It's very sad. It's very hard physically to do, to manage. And then you have hygiene issues. You throw odor and disposal problems in with all that, it's a major ordeal in someone's life.

Interviewer: Are there places or events that you are unable to participate in, due to the lack of accessibility to an adult changing table?

Participant: Yes.

Interviewer: And have you delayed or changed plans because there was no adult changing table.

Participant: Yes.

Interviewer: Thank you. And so if more adult changing tables were installed in Florida, what types of people would benefit the most, and why do you think that?

Participant: As far as types of people, I would think that the users of those facilities would be disabled adults and their caretakers. Why would they benefit? Is that what you asked me?

Interviewer: Yeah, I was asking why do you think that.

Participant: Why do I think that they would benefit? Because currently, there's nowhere for them to have their diaper changed, for lack of a better word. This is an adult who may be impaired physically, but may have 100 percent mental capacity, and be a functioning, tax-paying citizen, and he has nowhere to take care of his personal hygiene, where he can be assisted in doing that. A person without those limitations, they're readily available everywhere.

Interviewer: And so when you're participating in society, how often do you encounter an adult changing table accessible to you, and do you think that that is adequate?

Participant: I've never encountered one, and no I do not think it is adequate.

Interviewer: And so regarding the topic of adult changing tables, is there anything else that you would like to share?

Participant: Yes. I would like to make sure that they need to be installed in those either female and male bathrooms, so that male and female caretakers can have access to them.

Interviewer: And anything else?

Participant: No.

Resp 22

- Participant: Hello?
- Interviewer: Hello, my name is [name]. I'm calling from the University of Florida.
- Participant: Oh yes, hi.
- Interviewer: Yes, you received an email from The Family Café in April, inviting you to tell us about how the lack of power height adjustable changing tables in public settings affects you or your loved ones.
- Participant: Yes. Yeah, actually I got that last night or yesterday I read it.
- Interviewer: Okay.
- Participant: That's why I responded immediately.
- Interviewer: Okay, the University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling because you completed the online scheduling form when The Family Café emailed you. Your input will help inform and shape the Commission's ruling. Everything you say will be confidential, and will be reported with no identifying information. There's no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and I want you to know ... I'm sorry, you can stop the interview at any time.
- Participant: Okay.
- Interviewer: I want you to know that this call will be recorded for quality control purposes, and will be transcribed, summarized and aggregated with other participants. The survey should take ten to fifteen minutes. Okay, so a powered, height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of, yes or no?
- Participant: Yes, numerous times.
- Interviewer: Okay, so first, I'd like to ask you to tell us a little about yourself, and why the lack of adult changing tables is an important issue for you.

Participant: I have a 21 year old, very profound child in a wheelchair, who is incontinent, and we can't go anywhere alone because I cannot change his diaper in public alone, because there's no place to do it. It takes two adults to do it if you're not home.

Interviewer: Okay, was there anything else you'd like to add?

Participant: Yeah, it's been a problem for years and I've been at different things talking to people about it all the time, so yeah I'm ... Is there anything you want to add? Yeah, it just makes it very hard for them to have a life.

Interviewer: Okay, have you heard about adult changing tables?

Participant: I've seen things in pictures from Sweden and stuff, where they have special needs bathrooms out in public. No, I've never seen anything like that in the United States, and I've never seen pictures of it either, so they're interesting.

Interviewer: Okay. How much of a problem is not having an adjustable, adult changing table when you are participating in society?

Participant: An immense problem, again we don't go out as often as we used to because he is now 21, and I can't do it.

Interviewer: Okay. Can you tell me about a specific example?

Participant: Well, we used to go to the movies at least once a month. We haven't gone in probably two years.

Interviewer: Okay.

Participant: They even have a family restroom in the Mall, but again, by yourself you can't stand somebody up who can't stand unassisted, and take the diaper off and put the pants on by yourself with what's available now, so yeah, his life has changed because he's growing up.

Interviewer: How does this effect you or make you feel?

Participant: Horrible, I mean in reality the poor kid doesn't have a life anymore, or adult, he's 21. He's my kid, he doesn't get to do anything fun. If he wets, you got to run some place and try and find somebody to help you. I've had to do him in a parking lot, having him sit on the edge of the car trying to do it out in public even, which I risk getting arrested for.

Interviewer: How helpful would it be to you if public places had adjustable adult changing tables available to use.

Participant: That would be great. It would be phenomenal.

Interviewer: Okay, what types of things would you be able to do, places you would go?

Participant: Well, we would start going back to the movies again, of course. We don't even take him out to dinner very often, but I can't expect every restaurant to do it, but I mean a Mall and things like that should, in his lifetime, be able to handle something, putting things like that in. He's be able to participate more in society again.

Interviewer: Okay. Overall, please describe how your quality of life would change if universal changing tables were more prevalent.

Participant: That would be great. We haven't even been to Disney World in years. I don't know if they changed and got them, but they didn't used to have anything. As he's grown, I can't handle him. They don't, I guess they do have family changing rooms. If my husband and I go, we can do it, but you have to find a room where we can both go in.

Interviewer: Okay. When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: I would consider it, but I mean right now, I don't think they exist. I don't even think about it because I don't think there is such a thing. Is there?

Interviewer: I can't, unfortunately ...

Participant: Answer my question.

Interviewer: Yeah, more than what's provided, I'm sorry. What do you do if you have no access to a changing table?

Participant: Go home.

Interviewer: Okay.

Participant: What do I do? Suffer trying to, like I've said, I've done it. I've changed him in public, in the back of my car, in the back of my van, or in the seat of his ... He has a valet seat that comes out. I've had to use that, risking arrest, or risk him ... It depends on what his capability is at the time, because he has seizures. If he's [inaudible 00:07:07] from a seizure, he has to sit in it. If he's able to assist, he can somewhat stand up, so I sometimes, I've been able to change him, but it's a big deal. I risk both of us getting hurt.

Interviewer: Okay. Are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yep.

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Participant: I just don't make the plans anymore, basically.

Interviewer: Okay.

Participant: I don't know of any adult changing tables out there.

Interviewer: Okay. If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: What types of people? Incontinent people, and families, I mean to me it would be the whole family would benefit the most.

Interviewer: Okay. Just to clarify, why do you think that?

Participant: Say that again.

Interviewer: Just a follow up question we have to ask is why do you think that?

Participant: Because it effects the whole family that we can't go anywhere, or as a family unit, we can't do things because there's no place to change him. As a whole family unit ...

Interviewer: Okay. When you're participating in society, how often do you encounter an adult changing table accessible to you, like what percentage of the time would you say?

Participant: I've never seen one, zero.

Interviewer: Okay.

Participant: I have never seen one.

Interviewer: Okay, is there anything else you would like to share with me?

Participant: No, if they started making it at least in ... If they made it happen in places that, like a Mall or the Disney World, parks, or places where there's events are held, that would be phenomenal. Life could change for him.

Interviewer: Okay. Thank you so much for your time and thoughtful answers, and comments.

Participant: Okay, question for you, is there a website or anything that tells you where they're ... I mean do they exist?

Interviewer: I honestly, we're just conducting the survey, so I don't know specifically, like any specific locations or where in Florida. The only thing I could say is to ... Let me check one thing and see if we have any information on it.

Participant: If they do exist in some places, at least that would be beneficial to know. I've never encountered one anywhere.

Interviewer: Yeah, I'm ... Let me see here. Yeah, I'm not sure where, like if there's a place. The only thing I can say is maybe online there would be some place.

Participant: Yeah, well I'm going to The Family Café next couple weeks, so maybe they'll have some information there too.

Interviewer: Okay, so ...

Participant: All right.

Interviewer: Okay, and now when traveling ... There's a second one, so when traveling was there a time that the height of a bed was an accessibility problem for you or someone you take care of?

Participant: If I'm traveling with him, I have other adults with me, so not really.

Interviewer: Would you say yes or no then?

Participant: No.

Interviewer: Okay.

Participant: The fact that there's not sides or bed rails available, even when you ask concierges, they think you're crazy.

Interviewer: Okay, well again, thank you very much for your time and helping talk to me. I would like to ask you if you know anybody else that you think we should talk to, that would be interested in sharing their challenges and stories specifically related to adult changing tables and/or bed heights, yes or no?

Participant: I'm sure there's a bunch of people, but off ... I don't know. I mean I'm not going to give numbers out, so ... What I would suggest is that you guys have a booth set up at Family Café, that would be my main suggestion because you could get ... I mean a million parents would stop by and talk to you.

Interviewer: Okay, well those are all the questions that I have.

Participant: Okay.

Interviewer: Again, thank you very much for your time and help.

Participant: This would be great if something transpired from this during his lifetime. All right, thank you.

Interviewer: Your opinion will definitely help us, so again we appreciate you providing us your input, okay?

Participant: Thank you very much.

Interviewer: You're welcome. Have a good one.

Participant: All right, you too. Bye.

Resp 23

Participant: Hello?

Interviewer: Hello. My name is [name]. I'm calling from the University of Florida. You received an email from the Family Café in April, inviting you to tell us about how the lack of powered height adjustable changing tables in public settings affects you or loved ones?

Participant: Yes. I did.

Interviewer: Okay. The University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

Participant: Hold on one second. I got to go in my house, because I can't hear you. Hold on one second, because I have fans out here, and that's all I can hear. Hold on one second.

Interviewer: Uh-huh.

Participant: I'm sorry. I had fans going in my ear, and I couldn't hear you. Go ahead.

Interviewer: Okay.

Participant: With what you were saying again.

Interviewer: It's okay. The University is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to know this call will be recorded for quality control purposes, and will be transcribed, summarized, and aggregated with other participants.

This survey should take 10 to 15 minutes, okay?

Participant: That's fine.

Interviewer: A powered, height-adjustable table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves, for adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time when an adult changing table would have been helpful to you or someone you take care of? Yes or no?

Participant: Yes.

Interviewer: Okay. First, I'd like you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: My son is 35 with the brain function of a two year old. He has a kidney disease. Every time we go out in public, we have to find a first aid station so that we can lay him down so that we can change him.

Interviewer: Okay. Anything else?

Participant: He's in diapers. It's mainly public places. I've never had to change him in a store or anything like that. But theme parks, even doctor's offices, because he's in a wheelchair. Or we have to lay him in our car, leave the facility, go into our car, change him, and then put him back in his wheelchair and take him back into the facility wherever he is visiting. Yeah. It's a very bad inconvenience to a lot of people. My background is, right now I'm currently one of the chairs of the Family Care Council, and I deal with this with children like this for the last 35 years of my son's life.

Interviewer: Okay. Have you-

Participant: It is very inconvenient.

Interviewer: Okay. Have you heard about adult changing tables?

Participant: I have not. This is the first.

Interviewer: Okay. How much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: How much of a problem is it? 100%. I lay my son on the floor on a blanket to change him.

Interviewer: Okay. How does this affect you?

Participant: In a bathroom.

Interviewer: Or make you feel?

Participant: Because it takes two people to take him out of the wheelchair, put him on the floor, and then I have to have someone that is a stranger help me pick him back up. If I had a changing table that was at the height of his wheelchair, I could pick him up. I only weigh 125 pounds. He weighs 132 pounds. You're talking, he can pivot and would be able to ... I would be able to put him on the changing table, and I would be able to change him on my own. But right now, the way it is, if we're traveling or going anywhere, usually my husband is with me and we try to find a first aid station at a place, or if we're traveling, we change him in our van, or we have to go into a family

bathroom where my husband and I can both go in. We take a blanket, we lay him on the floor, and we change him that way. Yes, it's a very bad inconvenience to society for these kids.

Interviewer: Okay. How does this make you feel?

Participant: Horrible. It's not inconvenience to me, it's an inconvenience to him, to the child, or to the adult that really needs this. I also have a niece that has to cath herself. That would be the perfect thing for her to be able to ... Her mom to get her out of her chair. Instead of cathing her in her chair, would be to put her on one of these changing tables and cath her in privacy, and then put her back in her chair. It's an inconvenience. It's horrible. It's disgusting. I don't know. It's wrong. Society needs to start accepting that children and adults are not all considered ... What do you consider normal? These people could be normal and we're the outsiders, you know what I mean?

Interviewer: Okay.

Participant: Do you understand what I'm saying? It's 100% inconvenience.

Interviewer: Understandable. I'm sorry if some of these questions overlap what you've explained.

Participant: No, no, no. It's fine.

Interviewer: Okay. Just to clarify. How helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: It would be very nice, because if you check, they have the baby ones. Once they reach, I think, it's 50 pounds, you couldn't put anybody over 50 pounds on it. A lot of people just use them for putting their purses and their packages on, where it's really for someone to change a baby. Also, they need to put a little bit more privacy, too. When you go into a rest area on I-4, it's right there by the door.

Interviewer: Okay.

Participant: It's a metal ... I don't even know. A metal shelving that you put your child on where there's no privacy.

Interviewer: Okay.

Participant: Yes. I think they should have a private room with a private changing table that could hold up, at least 300 pounds, at least.

Interviewer: Okay. What types of things would you be able to do and places you'd be able to go?

Participant: Well, in my son's case, my son will not pee in his chair. He never has and he never will. He holds it in until we find a first aid station, normally, if we go to a theme park. We haven't gone to a theme park in a while for several reasons. Because when we

went to Universal, we did go into a first aid station, and the guy was sitting there at his desk, watching us change our son. We had to put ... My husband and I stood between him and him watching my son being changed. That's another disgusting issue that has occurred in the past. But I'm sorry. I got off on the wrong ... Go ahead and read that question again.

Interviewer: No, no.

Participant: I'm sorry.

Interviewer: No, it's okay.

Participant: You're hitting a sore spot for me, because I have dealt with this all my life and it's horrible. I don't know how many times I have tried to push this issue and not got anywhere.

Interviewer: Understandable. We appreciate your opinion and your experience. But just to clarify, what types of things would you be able to do or places to go? Specifically, what places would you be able to go?

Participant: You could go to airports and have them in the airports before you get on a plane, because I'm not ... It's one thing, you could get up and go the bathroom on a plane, but you have to actually drain somebody before they get on the plane, because if they hit an air pocket or a pressure point, they are going to yell and scream and freak out. I've had my son do that before. I know my niece travels on a plane and she has to drain herself before and after she gets off the plane. Her mom travels with her. She has to be drained, and that would be nice to have something where they could actually lay down, be comfortable, and drain themselves, because it's very hard to put a catheter in when you're in a sitting position. With my son, it would be that I wouldn't have to put him on a dirty floor. I wouldn't have to worry about carrying a blanket with me, which is excess baggage.

There's not always a first aid station around to lay them on, on one of their beds, or if their beds are being used, you have to wait. Well, like I said, my son will wait. He'll hold it all day if he can't lay down. He has to lay down, and then he starts peeing. There's a lot of places you could go. You could go to parks. You could go to an outside park for picnics. You'd be able to drain them. You wouldn't have to put them in the car to change their diapers or whatever. You would have them in the some of the local parks, could have them there. It would be nice. But they would have to be ... People would have to take care of them. People would have to clean them after they use them. There's also bad things about it, too, because sanitary wise, somebody could use in and then just walk out and not clean it, or you got punks that go into a park or a bathroom and break them. There's good and bad with it.

Interviewer: Okay. When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: No. I've never thought of it that way. My son goes wherever we go. To the most elegant places, to the most common places. I don't pick out of it because of that.

Interviewer: Okay. Just to clarify, what do you do if you have no access to a changing table?

Participant: I take a blanket, or I have disposable wetting pads that we carry on his chair, and we lay them all across the floor and then I lay him on the floor in one of the handicap stalls. Or, if there's not a handicap stall available, which normally there should be, I would just lay him on the regular floor and change him right there. I would try to be as discreet as possible, because other people bring their little kids in there. A grown woman, I don't care. A grown woman ... What is she going not say? But a child could be standing there watching me trying to change him, and I'm like, "Could you please take your child over there, because I'm trying to have a little bit of dignity for my son while I'm changing him. But there's no place to change him. I'm sorry." I've waited till the bathroom was empty and hoped that nobody else came in.

But like I said, on I-4 when we're traveling up to New Jersey or on 95, we try to find places where we have a little bit of privacy, even if we have to go into a hotel and say, "Look. We need to borrow your bathroom because I need to change my son." I've done that before. Even though we're not saying in that hotel, we're still traveling. I've gone into a hotel and just said, "Could we use your bathroom for a little bit more privacy?" Or, I've changed him in my car. I lay him on the floor. We have a van, and we take him out of his chair and lay him, squeeze him between the chair and the lift and we lay him there and we change him. That's murder, trying to change him. Let me tell you, because there's no room.

Interviewer: Okay. How does this affect you or make you feel?

Participant: I'm over it now. But when my son was a little bit younger, it used to really upset me, the same way a ... I don't know if you know it or not, but in the military ... I was in the military. In the military, I had to buy diapers, \$6000 a year in diapers. It's not a necessity for you and I, but it is a necessity for my son. Society accepts it as, "Well, if we don't have 10000 people that need it, then we're not going to accept one person that needs diapers. We're not going to provide for you." Same with these changing tables. If there's not a need for it constantly, and people don't know about it or don't use it if they do have them, even for a trials, when you do pilot programs. If you can't prove that there's a need for it, then that need goes away. Even though there might be 10 people that need that changing table out of 100, they're going to say, "Well, that was only 10%. That's a waste of money. No, I don't think we should do it." Understand what I'm saying?

Interviewer: Understandable. Yeah.

Participant: Okay.

Interviewer: If adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: Special needs.

Interviewer: Okay. Just to clarify-

Participant: Any kind of special needs. Disabled people, anybody that's got a disability, not only incontinent. There might be somebody who can't change themselves. They don't have to be incontinent. They could just be that they can go on their own. If somebody helped them into a bathroom, they could use the bathroom themselves. But there's people that are sitting in their chair all day because their caretaker didn't take them to the bathroom saying, "Well ..." I've known group homes to do that, where they have the kids out in the park all day long, and the one person will say, "I have to go to the bathroom." And they will say, "Yeah, yeah. Okay. Wait. We'll get you there. We'll get you there." And six hours later, that poor little child has been sitting in a wet, poopy diaper for six hours because they can't leave the rest of the kids to take them to a bathroom. Okay? It's an inconvenience for them, but it's not an inconvenience for the person that really needs it.

My thing would be that I would say anybody in the special needs community that has incontinent problems, or even a parent with a baby could still use it. It would help them where they're not breaking their back trying to lean over in a carriage to change a baby. It's a lot easier to change a baby in a carriage than it is a grown up. But it still would be ... I think everybody would use it that needs to change a person. I'm going to say special needs more. I would say 90% would be special needs, and that other 10% would be parents.

I'm talking about in a male bathroom, too. I'm not just talking a female bathroom, because my husband used to take my son in and stand him in front of a sink to take his diaper off and put his diaper back on, because he could stand at one time. He can't stand anymore. He can't hold his weight even though it's only 120 pounds. He can't hold his weight because of his ankles. When he was younger, we could hold him in front of a sink and he would hold on to a sink and put his feet a little bit apart, we would take the diaper, off, clean him up, and put another diaper back on it and it was easy. But for people that ... Say it was my mother doing it. My mother was 88 years old and she was still changing my son's diapers. It just depends.

I think that everybody could use it, really, to save their backs, to help the individual that has to have it or need it. Especially in hotels, hotel rooms. If you're not staying in the hotel. Like the convention, the Family Café. One of the reasons we're not going to this year is because there were no rooms available. If I have to change my son, where am I going to change him if our hotel is 10 miles down the road? Am I going to put him in a car and take him all the way back to our hotel room? Or am I going to be nice and ask one of my friends who do have a room in the hotel, "Can I use your room? My son needs to get changed?" They would do that because they're my councilwoman, they're my friend.

But what happens if it wasn't a convention and we were just staying in a hotel, or we were just visiting someone and we just stopped at that hotel to have lunch or something, one of their cafes, or whatever, and my son had to be changed? I go in the

lady's room and I have to lay him on the floor. With a nice changing table, it would be more respectful to my son's dignity, and yes, it would help my back because my son is very heavy, and to put him on the floor and try to pick him back up. He has a gait belt. But to pick him back up off the floor by myself, because nobody else is in there, I can't do it. I am physically not able to do it.

Interviewer: Okay.

Participant: My husband would have to say ... I would have to ask my husband to go in and do it, and I would stand by the doorway, as long as no other women are in the bathroom. I would have to ask my husband to go in and pick him up off the floor, as I stood in the doorway and said, "Could you please wait a minute? My husband's in there picking my son off the floor." Sometimes people would say, "Oh, yeah. No problem." And some people would say, "I'm not going to wait. I don't care."

Interviewer: Okay.

Participant: Society has not accepted special needs people like they should. They accept all the other kinds of religions. They accept all the other kinds of groups, but they don't accept special needs, including when you have to buy things. Special needs ... As soon as they hear the words "special needs", the price goes right up. My son needs a ... We need a battery operated wheelchair. It's going to cost us almost 25 grand. At first, they refused to make it because my son is legally blind, so he can't work the control, so we asked for a control assist, which is for the caretaker who would be pushing the wheelchair, and the wheelchair weighs about 300 pounds because we have a defibrillator, because my son used to have grand mal seizures and has coded three times where I had to do CPR.

That's another thing. Trying to change your son in a wheelchair when you have all the baggage on the back. You have to take all that baggage off, and then try to tilt the chair back. What happens if you don't have a tilted chair? Not every wheelchair is capable of being tilted back. Yes. Those tables would be a fantastic idea in our society, in our communities. Would other people abuse them? Probably. Hopefully, we would hope that they wouldn't. But you can't guarantee that anywhere.

Interviewer: Okay. When you're participating-

Participant: I think it's a really good idea.

Interviewer: Okay. When you're participating in society, how often do you encounter an adult changing tables accessible to you? What percentage would you say?

Participant: An adult one? Never. I've never seen one. Didn't even know they existed.

Interviewer: Okay.

Participant: And I'm 64, and my son is 35, and I've been taking care of my son from day one. The closest I've ever seen was one that would fit him maybe ... Because my son is tiny,

also. He doesn't weigh the normal weight a 35 year old would weigh. I don't know if men's room have these or not. I don't know. But the women's room, as soon as you walk in the door, and the door closes, there's a little cubby hole where they put this aluminum shelf, with just a little lip so they can't fall off, and that's the changing table. But if your child is over, I'm going to say, more than three feet, your child's not going to fit there anyhow, because it's made for babies. It's not made for children over the age, I would say, over the age of ... Because they figure most kids don't wear diapers after age three. I'm going to say anywhere from age five on up, could not use those tables, that shelf. And it's not foldable. It's just a shelf. And then, you go ... Okay. My doctor's office has one, but it's a plastic thing that you pull down, and it only holds up to, I think, 50 pounds. My son's 125. There's no way I could put him on there. I don't even put my purse on there because I'm afraid my purse would break it, break the hinges.

Interviewer: Okay.

Participant: They definitely need them.

Interviewer: Okay.

Participant: Absolutely.

Interviewer: Is there anything else you'd like to share with me?

Participant: If you know anybody who's doing any kind of survey on the parking, the handicap parking, you can tell them that the people who designed the parking spaces don't give you enough room to open the lift and not scratch the car next to you. And then, some of your shopping centers will put the lines on the driver's side, knowing well that the driver isn't the handicap person. The lines need to be on the right side of the vehicle, not the left side. If you know anybody that's doing that type of survey, that's another problem we have in our communities. I have gone to many mayors, county meetings and say, "Look. The spaces aren't wide enough for a handicap van, first of all. Then, it makes it even worse because you have a lift that comes down, which is another four feet. And you just don't have enough room to open that lift without ... And then, taking the wheelchair off, you need another two feet because the wheelchair is two feet in width, in length. To take that off, that's another six feet that you need in the parking spaces, and they should also find people that don't ... People that ..."

I'm sorry. I'm a disabled vet, but I don't part in disabled parking space, that says "for van usage", because I don't believe that my car should be sitting in a handicap space that could be used by someone in a van when I can park two or three cars down in a regular parking space where I can get out of my car, I can go to the back of my car, I can take my walker out and close my trunk and go in and do what I have to do. But when I'm with my son and I try to open the lift, I sit there and I pray while my husband is taking my son off the side of the lift, because there's no room to bring him off straight ahead. You have to actually turn the chair to the side and bring him off the side of the lift so that you don't scratch somebody's car and damage their car, which is ... If I ever did that, I'd have to leave a note on the car because I'm an honest person

and I would have to say, "Look. I'm sorry, I scratched your car. Please contact me if there's a problem, or whatever." You know what I mean?

The people that are designing the handicap items are not handicapped. They are people who are trying to make a quick buck. When they design something for handicap, they need to either have somebody who's handicapped checking the design out before they actually put it into place in the state, or the county needs to listen when you say, "Look. The space isn't big enough. Look at my lift. I can't get my son off the lift." You know what I'm told? "Oh, well. Can't help you. We don't own the parking lot. This is owned by private property." That's the excuse they give you. What do we do? We park on the lines.

I know a girl who is actually in my council that her parents got a ticket because they were parked on the line, because they couldn't open their lift to get their daughter out of their van with the wheelchair lift. Security came and they gave them a parking ticket, and they went to court and the judge laughed in their faces and said, "Are you kidding me? Are you seriously giving this person in a wheelchair a parking ticket because she parked on the line because she couldn't get out of her car otherwise?" They threw the ticket out. But these are the things that our community people are being challenged with, every day of their lives, and nobody wants to hear about it. I'm glad you're doing this survey. Any survey that I hear about, I get involved with.

Interviewer: We definitely appreciate your time and thoughtful comments.

Participant: If you know somebody that's actually doing that part, that is another, in itself, that would be something else that whoever ... I'm not sure what type of class that you're doing this for. But that would be something that somebody else should take on is the handicap parking.

But I also don't believe in that guy that goes around in Florida and all he does is go after businesses because they don't have a ramp or they don't have the right handicap stuff. He just goes around with his lawyer friend and tries to sue this business and that business. He makes it bad for all of us. That's another thing that our community is up against, because you do have people ... This guy is in a wheelchair, but he also has a friend who's a really good lawyer, well known in the state of Florida, and he goes around to every county suing people like crazy. "Well, your ADA law is not up to date." Okay. You're supposed to have so much time once it's identified to be able to fix it. But this guy doesn't give them that time. He takes them to court and the judge says, "Yeah, you're right. They're in violation, \$5000 fine a day if you don't fix it." But what do you do when you've got a mom and pop that doesn't have \$5000 a day and it might take three months to get it fixed? It's not right there, either.

Indirectly, that's why I said it goes both ways. You have people who take advantage of, because they hear "disabled" and they jack the prices up, and then you've got people who are disabled who think that the world owes it to them, and they don't. It goes both ways.

Interviewer: Thank you.

Participant: But I'm glad you guys are doing this survey, because they really do need those tables and they would be a great advantage to our community, and hopefully we'll see at least one or two, like in government buildings. If we had to go to a meeting in Tampa or we go to a meeting in the legislature's building and whatever. I always said, and you can mark my words on this. I've always said, "Take all our legislatures, divide them up into groups, and put some of them in wheelchairs and tie their legs in their wheelchairs so they cannot get out, and they have to get around the building that way. Put a bandana across their eyes, another group. Let them walk around the building with an escort so they don't get hurt, but don't jump in unless you see they're going to get hurt, and let them walk around and see what it's like to be totally blind. Let them see what it's like to be totally in a wheelchair and you can't move. Let them see that maybe put their arm in a sling and they have to pretend that they don't have that arm and they can only use their other arm to do anything. Let them know what it's like to be disabled."

I think if they started in second, third grade, we wouldn't have the community as bad as we do right now, because parents are, "Oh, I don't want you playing with that child. That child's disabled." Or, you get the bullies in school. But then, when those bullies meet you when you're 20 or 30 years old, they're like, "Oh, my God. I used to bully you all the time, and you're a Congressman. Wow. You really came up in the world." You know what I mean? They grew up finally. But maybe if they started growing up and parents stopped telling them it's okay that they can bully these kids, or they can ignore them or they don't have to play with them or they don't have to associate with them, maybe if they were required to do some kind of community service, this world would be in a better place for special needs kids.

Interviewer: Okay.

Participant: They wouldn't be ruled out and they wouldn't be made fun of, and they wouldn't be staring at them every time they get a chance to.

Interviewer: Okay.

Participant: Now I've said my piece. I've had my say.

Interviewer: When traveling-

Participant: Hope that helps you.

Resp 24

Participant: Hello.

Interviewer: Yes, hello. My name is [name]. I'm calling from the University of Florida.

Participant: Yes, sir.

Interviewer: And I'm reaching out on behalf of the Family Cafe to get your experiences with adult changing tables or bed heights.

Participant: Yes, sir.

Interviewer: Yeah, would you happen to have some time now?

Participant: Yeah, mm-hmm (affirmative).

Interviewer: Okay, so a part, adjustable adult changing table as a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves, for adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes, or no.

Participant: Yes. Every day.

Interviewer: Okay. And so just before we begin, have you received an email from the Family Café in April inviting you to tell us about how the lack of ambulatory adjustable changing tables in public settings affects your loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Café emailed you. And your input will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey. Your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes, and will be transcribed, summarized, and [inaudible 00:01:59] with other participants. This survey should take 10 to 15 minutes.

First, I'd like to ask you to tell us a little bit about yourself, and why the lack of adult changing tables is an important issue for you.

Participant: Well, I have a son with special needs. He's not ambulatory, and he has outgrown the baby changing tables years ago. So anytime we're out, it is always a challenge. Because if he has an accident and we need to change, the only alternative is to either leave a venue, or if you lay him on the dirty bathroom floor, because he cannot use an

accessible toilet. An adult changing table would give us a safe, clean place to change him, and enable us to go out and enjoy our day better.

Interviewer: Thank you. And would there be anything else you'd like to add to that opening statement?

Participant: No.

Interviewer: Okay. Have you heard about adult changing tables? And if so, where have you heard about them?

Participant: Yes, I've heard about it through Universal Changing Places.

Interviewer: All right. Thank you.

Participant: On Facebook, and on the internet.

Interviewer: Okay. How much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: It's a major problem. It keeps us from being able to go out and go to certain venues. You can't really go to a concert, or plan that type of activity when you have somebody that is incontinent because that is always going to be an issue. And if something happens and you have to leave, or god forbid, lay them on the floor. Which with my son, would be very difficult to get him back up. You know? It limits our activities. And so, my hope is that someday they'll be more common place, and in more venues so that we have the same accessibility as everyone else.

Interviewer: All right. Thank you. Can you tell me about a specific example?

Participant: A specific example? Well, just trying to go to like Target or Walmart. I've actually had to go and leave full baskets of groceries, because we had to go back to our van to change his seat cover. And a lot of times, by the time you get back out to your vehicle, you just decide to go home, because it's just ... you're having to unload them, and do everything like that. It becomes just an unnecessary challenge.

Interviewer: And how does this affect or make you feel?

Participant: Me personally, it hurts me for my son, and for others, because the ADA is all about inclusion. And I feel like his lack of these facilities keeps people from not being included. We get them into venues, but they can't stay. They can't enjoy their outings like the rest of us. And it's also a question of dignity. I just don't think that anybody should ever be lain on a bathroom floor. I personally don't like walking on bathroom floors most of the time. But the thought of having to lay your loved one on that. I've talked to numerous families that have the same issue. And they said, "It's just awful."

I just feel like it's something that we should do something about. And make a difference so that people can use and offer these types of accommodations.

Interviewer: Thank you.

Participant: How would you feel if you had to be lain on bathroom floor to be changed. Or you had to stay in a wet brief all day. Nobody would want to do that.

Interviewer: Thank you. How helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: Very. Very. It would enable us to do a lot more outings, and stay out at venues longer. And enjoy those outings because we would know there is a safe place to be changed. Would be one less thing that you'd have to worry about during the day.

Interviewer: And so when choosing things to do or places to go, do you consider certain places will have changing tables for adults?

Participant: Well, I would love to say yes, but I know they're not in existence. There are very few places that have them. I was in Tallahassee and they do have three here, but that's at our FSU and two at our civic center. But that's it. Adult changing tables are very rare right now. If I knew that there was one, yes, I would definitely go to a venue, drive further if I had to.

Interviewer: Okay. How helpful or accommodating or locations when you ask about adult changing tables, if you ask?

Participant: What do you mean accommodating? Most, like I said, they're nonexistent right now. Most people don't even know that the tables exist. It's a new concept that we're trying to bring to America. Most people just ... They think you're talking about a baby changing table when you ask about a changing table because they're just not common yet. That's why what you're doing is important. Talking to people about this.

Interviewer: Okay. I know you touched a little bit about this in the beginning, but what do you do when you have no access to a changing table?

Participant: Like I said, most of the time I leave the venue. I refuse to lay my son on the bathroom floor. I will leave the venue and we go back to our car and do the best we can in our vehicle. If we can't get home, if it's super far off and we can't get home very quickly.

Interviewer: Okay. You spoke about this in the beginning as well, but are there places or events that you're unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yes. A lot of the ... Well just traveling. The rest areas, it makes it difficult. Airports, you don't want to fly somewhere knowing that you're going to be stuck in that ... He might be stuck in something for a long period of time. The fact that most of your amusement parks and all those places don't have any type of accessibility. Even our schools don't have these types of facilities for the students. So it limits where we go, or how long we stay out.

Interviewer: And just a follow up to that question then, have you delayed or changed plans because there is no adult changing table?

Participant: Yes. There's a lot of things we don't do. We don't plan to go like Disney World or any place like that because there's not a facility. We don't plan on going to movie theaters and stuff like that because there's not. It limits how long I stay out with him because there aren't adult changing facilities.

Interviewer: Thank you. If more adult changing tables were installed in Florida what types of people would benefit the most, and why do you think that?

Participant: I think there ... like the name universal changing places, they're a universal fit for a lot of people, not just like my son who he's nonambulatory and is wheel chair bound. But there is a lot of people that have incontinence issues. There's a lot of people with colostomys and catheters that need this type of table. Plus, I think that when ... He outgrew the baby changing table a long time ago, an adult changing table would still allow him as a toddler. I think parents of toddlers would really appreciate these types of facilities too. You know? Because kids are wearing, I call them seat covers, but they're wearing them a lot longer. The facilities, they're faced with the same issue that I am. Where do you change them? I think they would benefit a lot of people.

Interviewer: Okay. When you're participating in society, how often do you encounter an adult changing table accessible to you? And do you think this is adequate?

Participant: Like I said, I live in Tallahassee, we have three. I don't think that's adequate. You know? I think that we need more facilities with them. Our malls need to have them, Targets, Walmarts need to have them. Our libraries, our museums need to have them. There's so many places I could go with my son if there was a facility. Yeah, it limits. We don't get to do a lot of activities.

Interviewer: Okay. Regarding the topic of changing tables, is there anything else that you'd like to share?

Participant: No. I understand your questions, but I think, I don't know how the responses you've been getting, but this is just a new concept. There's not many of them in the state. I could probably count on my hand how many places actually have them. For people to say ... They could tell you that, yes, an adult changing table would make life easier, but I just wonder if you're getting adequate responses because people don't really understand the whole concept. You know?

Interviewer: And would there be anything else that you'd like to add?

Participant: No. That was it.

Resp 25

Participant: Hello.

Interviewer: Hello.

Participant: Hey.

Interviewer: My name is [interviewer], I'm calling from the University of Florida.

Participant: Yes sir.

Interviewer: Okay. So we spoke with someone at this phone number about a survey that assesses and determines the need to adjust the building code by interviewing people affected by current standards. Just to clarify, could I please speak to that person?

Participant: That would be me. I'm [name].

Interviewer: Okay, Crystal. You received an email from the Family Café in April inviting you to tell us about how the lack of powered height-adjustable changing tables in public settings affects you or loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

Participant: Okay.

Interviewer: We are calling you because you completed the online scheduling form when the Family Café emailed you, your input will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information. There's no compensation for completing the survey but your answers will help the Florida building commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes and will be transcribed, summarized and aggregated with other participants.

The survey should take ten to fifteen minutes.

A powered height-adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary and comfortable space for changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no.

Participant: Yes.

Interviewer: Okay. To start out first I'd like to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Okay. I have a daughter and do you want me to disclose names or just information?

Interviewer: You can just provide us information. Your thoughts.

Participant: Okay. All right, I just wanted to make sure. I have a daughter and she has a severe disabling disorder called CDKL5. And it is mainly a seizure disorder but it is accompanied with developmental delays, critical vision impairment, and pretty much she's dependent on us for everything. She will likely never be potty trained. She's only two and a half now, and she's already outgrowing the infant-sized changing tables, not to mention they're usually in the middle of the bathroom where people walk by. And as you get older you want more privacy and so they definitely lack the privacy, and the length to hold her.

Interviewer: Okay. Anything else you'd like to add?

Participant: I think that is probably the main thing. She's only 25 lbs., but she already makes the tables seem kind of flimsy.

Interviewer: Okay.

Participant: And I have many, many friends that have similar or the same diagnosis and while it is rare there are so many people out there that do need this. And they shouldn't have to change their diapers on the bathroom floor, that's disgusting because nobody even wants to touch them.

Interviewer: Okay. Have you heard about adult changing tables?

Participant: I actually have. Our civic center locally has one. And the only reason I know anything about them is mostly my friends, but then I actually went to a concert with a friend of mine and noticed the changing table sign on the accessible bathroom. And I was quite impressed that they had one at all there.

Interviewer: Okay. Was there anywhere else that you heard about them? Like word of mouth, magazines, disability advocacy groups, etc? Anything anywhere else?

Participant: No. But I'm not really plugged into social media and all that.

Interviewer: How much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: I would say on a scale of 1-10, 10 being the worst, it would be an 11. It's a horrible feeling to worry about having to figure out what to do if your child does go to the bathroom, people do and my daughter's not able to sit up. To not

know, most of the time we change her in our trunk, but some people aren't able to have a large vehicle like we are and I am afraid to ever have to change her on the floor.

Interviewer: Can you tell me about a specific example?

Participant: Yeah. We go out and about all the time. We go to grocery store, we go to restaurants. We have four kids total and to go to any sporting event with our children, two of them play sports, and to go to any of those events, there's nowhere to change our daughter. So we have to either change her in her wheelchair or change her on our trunk floor which is usually dirty because baseball stuff. And then we go to schools, we go to therapies, we go to restaurants and actually some restaurants don't even have a changing table at all. And I think that the need for it is becoming more and more common.

Interviewer: Okay. How does this affect you or make you feel?

Participant: I'm sorry?

Interviewer: How does this affect you or make you feel?

Participant: I think it's frustrating. I think that we focus a little too much on some of the wrong things sometimes. People can let transgender use each bathroom and raise hell about that but no one can realize that we have real issues.

Interviewer: How helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: I think it would make outings less stressful in an already stressful life. I think it would make certain things more accessible. We would go do more things because we wouldn't have to worry about that. I know as she gets older, we're going to be more and more anti-go out and anti-restaurant and anti-do things, because we can't.

Interviewer: What types of things or places would you be able to go or do?

Participant: Grocery shopping. Restaurants. Movies. Anything to make her feel as normal as possible. I mean normal, I hate that word but it is what it is. Anything that she can still participate as a typical child would.

Interviewer: Okay. When choosing things to do or places to go, do you consider if certain places would have changing table for adults?

Participant: I don't really, we live in a small town and I know that most places don't. Like I said, I was quite shocked that the venue that I had gone to for a concert had one, and I was quite impressed. And that made me really excited that I could take her to do things if we wanted to. But I'm not too shocked that there is nothing around her because it is a small town.

Interviewer: Okay. And what do you do if you have no access to a changing table?

Participant: We primarily use our trunk. We are blessed to be able to drive a truck, an SUV, so we use the trunk of that. But if we didn't have that I can honestly can tell you that I don't know what we would do.

Interviewer: Okay. And I know you may have touched on some of this, but just to clarify, are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yes. We can't even take her to the movies here. We can't go and go to the park. We can't go, restaurants probably are the main thing that we like to do but we don't. Anything, pretty much we can't do, unless we plan it accordingly.

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Participant: Yes. We have gone to events and left early because of it. Or had to just not go because we were concerned about the day and how it would be an all day thing and not be able to get her clean. So we just decided not to go.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: I think obviously the person that needs the help changing and has the diaper as an adult or as a large child, but I think also the families of those children and people. Because the families suffer greatly with the challenges of every day life with a disabled person anyway, and then you throw in that we can't go anywhere and that just makes life even harder.

Interviewer: Okay. When participating in society how often do you encounter an adult changing table accessible to you? Like what percentage of the time would you say?

Participant: Oh I would not even say 1%. I've literally come across one ever.

Interviewer: Okay. Is there anything else that you would like to share with me?

Participant: No, I think that that's sufficient. I would like to say, consider it as if it was your child or whoever's been near this child or mom, dad, brother, sister, you know, these are people. They don't deserve to be laying on the floor where people spit and pee and you know, disgusting stuff.

Resp 27

Participant: (Dial Tone) Hello this is [name].

Interviewer: Yes hello. My name is [interviewer] I am calling from the University of Florida and I am calling on behalf of a Family Café with some questions pertaining to such as things as Florida's building code. Is now a good time to talk sir?

Participant: I'm sorry say that again.

Interviewer: Yeah so I'm calling about a survey to see your experiences with either adult changing tables and or bed heights. It's a survey that we're doing with the Family Café. Would you happen to have some time now to do that?

Participant: Yes go ahead.

Interviewer: Okay. So a part of adult changing table is a convenient and safe way for caretakers to assist individuals who maybe unable to fully care for themselves and for adults who manage[inaudible 00:01:06] limitations or incontinence they provide a safe sanitary and comfortable space for assisted changing. So was there a time that an adult changing table would've been helpful to you or someone you take care of? Yes or no.

Participant: Yes.

Interviewer: Okay. So just before we begin, you received an email from the Family Café inviting you to tell us about how the lack of power height adjustable changing tables and public setting affects your loved ones. The University is conducting research with the Florida Building Commission to assess and determine the needs such as the building code by interviewing people affected by current standards and we are calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the commission ruling. Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey. For your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes and will be transcribed, summarized, and aggregated with other participants and so this survey should take 10 to 15 minutes.

So first I would like to ask you to tell us a little bit about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Yeah my wife and I adopted our son who is totally disabled and he just turned 14 so he's getting bigger. I'm in my 70s and my wife late 60s so as we're aging it becomes harder and harder to care for him so and we often travel with him if we're going on vacation or if we're going to hospital visits we go up to Shands quite often and this it is difficult to find some way of changing a diaper with him. We probably run into both

the changing table and as we age having it at an appropriate height where it's easy to lift from his chair to it. So having a lift with these changing tables would also be really helpful.

Interviewer: Okay. And was there anything else that you would like to add to that opening statement?

Participant: No I don't think so.

Interviewer: Okay. And so have you heard about adult changing tables and if so where have you heard about them?

Participant: Through the Family Café.

Interviewer: Okay. And so how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: Well one it makes it difficult to go out for any length of time so that obviously and particularly it is hard to know our son can't tell us he can't tell us when he needs to be changed or anything like that so it's makes it really difficult. Yeah.

Interviewer: Okay. And can you tell about a specific example?

Participant: Yeah certainly. We had a I'm just trying to think of we had a doctors' appointment yesterday and we were out and then we went to visit someone in the hospital and or the nursing home and we had so we were gone for several hours and we had no place change his diaper.

Interviewer: And-

Participant: Even in the doctors' office they really don't have any.

Interviewer: Okay. And how does the affect you or make you feel?

Participant: There's no other feelings other than frustrated that there's not more thought given and more accessibility.

Interviewer: Okay. Thank you. And so how helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: I think it would be extremely helpful yeah yeah. My wife just said we bought a van with a lift at quite an expense so that we could take our son with us and travel more easily and so obviously it would make a big difference if they were readily available.

Interviewer: And overall please describe how your quality of life would change if universal changing tables were more prevailing.

Participant: I think we would feel like our sons quality of life would change in the sense that it would be more convenient for us to take him with us and change him more often so he would be much more comfortable.

Interviewer: Okay. And so when choosing things to do or places to go, do you consider certain places will have changing tables for adults?

Participant: At this point we don't expect them to have it so it really is what we keep thinking about is part of the reason we bought the van we did is it's bigger and it has a seat that reclines into a bed with our thought that we could transfer him from his wheelchair to that bed but it's not easy it's a pretty tight space and as he grows it's going to be even more difficult so at this point it doesn't affect our plan because we they're so rare that we never expect one to be any place and so we try to plan as if there's not going to be one.

Interviewer: Okay. Thank you. And so you mentioned this a little bit before but what do you do if you have no access to a changing table?

Participant: Sometimes it means we go longer than should for a diaper change. Sometimes it means that we struggle to figure out how we can change his diaper with the conditions that we have and try to lift him or sometimes exposing him a very kind of public way trying to be discreet and changing him in the van or something.

Interviewer: And how does the affect you or make you feel?

Participant: How does it make us feel? Yeah. Yeah it makes us feel like we like someone should be more accommodating. It makes it hard for us to yeah. I would say Shriners is the only place we know of that has anything like that even at the University of Florida when we're up there at Shands and at the clinics. There's not really a space a reserved changing tables space. Yeah.

Interviewer: Thank you. And so are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yeah I would say yes. I would say that what it is meant often is instead of the whole family going one of us will go and one of us will stay behind with my son.

Interviewer: Mm-hmm (affirmative)

And so have you ever delayed or changed plans because there was no adult changing table?

Participant: Yes.

Interviewer: And so as more adult changing tables were installed in Florida, what types of people would benefit the most and why do you think that?

Participant: Well I think everyone would benefit in the sense that certainly the families that care for these individuals would benefit by having more flexibility as individuals themselves by having better care given to them and the culture would benefit because the more diverse that we are the more that people see other people with disabilities functioning and out in the public, I think that the better is for all of us.

Interviewer: Thank you. And so when you're participating in society, who often do you encounter an adult changing table accessible to you and do you think that is adequate?

Participant: I don't think we've ever encountered one. Can you remember an adult changing table? The only one is at Shands and it's really just an exam table that is accessible in bathroom that's large enough for two people to be in there to lift him onto the table and lift him off. So the kind of table that's really necessary like you say an adjustable height changing table that yeah.

Interviewer: Okay. Thank you. And so regarding the topic of adult changing table is there anything else that you would like to share?

Participant: Yeah my wife was just saying and I think it's one of those things that people make adjustments and compromises and it just reminded me of one time we were at Sea World with him and we had to change him on the bathroom floor so it's how degrading is that and unsanitary and challenging and so forth so and yet to have the decision to say "Well otherwise you don't go." I think yes a change needs to be made.

Resp 28

Participant: Hello.

Interviewer: Yes, hello. My name is [interviewer]. I'm calling from the University of Florida regarding a survey that the Family Café emailed you about that pertains to adjusting Florida's building code. Would you happen to have some time now?

Participant: Sure, absolutely.

Interviewer: Okay. A powered height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of, yes or no?

Participant: Absolutely. Yes.

Interviewer: Okay, and so just before we begin, you received an email from the Family Café in April inviting you to tell us about how the lack of powered height adjustable changing tables in public settings affects you or loved ones. The university is conducting

research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We're calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the commission's ruling.

Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answer to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes, and it will be transcribed, summarized, and aggregated with other participants. This survey should take 10 to 15 minutes.

So, first I'd like to ask you to tell us a little bit about yourself and why the lack of adult changing tables is an important issue for you.

Participant: I have a son with cerebral palsy.

Interviewer: Thank you, and would there be anything else you'd like to add?

Participant: I don't know if anything would be helpful besides that. I'm not sure.

Interviewer: Okay, that's perfectly fine. So have you heard about adult changing tables, and if so, where have you heard about them?

Participant: Social media is where I heard about it.

Interviewer: Okay. Thank you. So how much of a problem is not having an adjustment adult changing table when you are participating in society?

Participant: It's very difficult without one. We won't even go out in the community anymore.

Interviewer: Okay. Would you mind telling me about a specific example?

Participant: Oh, sure. We tried to take a family trip, and on the way we had... My son, he's in a wheelchair, and he had a bowel movement, and the only way that we could change him was to take him into a restaurant. Well, into a restaurant, into their bathroom, and they had stalls. It was too long. You couldn't put him in a stall to try to change him, so we had to lay him out. I believe we had a towel or something that we put down. But, also, he was a male in a female bathroom. It was just really awkward.

Interviewer: So how helpful would it be to you if public places had adjustable adult changing tables available to you?

Participant: Incredibly helpful.

Interviewer: What types of things would you be able to do?

Participant: We'd be able to go out in the community, for sure. A lot of times, we won't... We would only go out in the community as long as it was a very quick trip in that it was very close to home. If it wasn't within those parameters, we just don't do it anymore.

Interviewer: Overall, please describe how your quality of life would change if universal changing tables were more prevalent?

Participant: Well, obviously, it would benefit my son to be able to participate in the community. It also would be helpful if we, as a family, could participate in things as a family instead of always having to leave our special needs child at home.

Interviewer: Thank you. So when choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: Well, I'm unaware of any that we have in the community, so I don't even consider it. We don't even go anywhere unless it's a really quick trip.

Interviewer: Okay, and so how helpful or accommodating are places when you ask about adult changing tables if you ask?

Participant: I'm never asked because I don't know... I don't even think they exist.

Interviewer: Okay. I know you touched on this before, but what do you do if you have no access to a changing table?

Participant: Well, we definitely don't want to do that again. I mean, as you know, we have to go into a public restroom and lay him out on the floor, outside of a stall, within public view.

Interviewer: How does this affect you or make you feel?

Participant: Horrible.

Interviewer: Thank you. So are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yeah. I don't know of any place that we can go that have that kind of accessibility.

Interviewer: So have you delayed or changed plans because there is no adult changing table?

Participant: Yes, we just don't do it anymore. We don't try.

Interviewer: So if more adult changing tables were installed in Florida, what types of people would benefit the most, and why do you think that?

Participant: Those that are disabled that need a caregiver.

Interviewer: Thank you. So when you're participating in society, how often do you encounter an adult changing table accessible to you, and do you think that this is adequate?

Participant: Oh, no, I haven't seen one.

Interviewer: Okay, and so regarding the topic of adult changing table, is there anything else that you'd like to add?

Participant: I can't think of anything.

Interviewer: All right. On another topic, when traveling, was there a time that the height of a bed was an accessibility problem for you or someone you take care of, yes or no?

Participant: Only in our home.

Interviewer: Okay. So this will be in regards to traveling. Would you want to go with a yes or no?

Participant: Yeah, I mean, it definitely would be a problem now with his weight. If we couldn't transfer him from a wheelchair to a bed. If it wasn't the same height, that would be a problem.

Interviewer: Okay. So just to clarify and make sure I'll repeat the question. It said, when traveling, was there a time that the height of a bed was an accessibility problem for you or someone you take care of? Would you say yes or no?

Participant: Oh, no, no. We haven't encountered that problem, no.

Interviewer: Okay. Then, just before we end, I'll just like to ask if you know anybody else that you think we should talk to that would be interested in sharing their challenges and stories specifically related to adult changing tables and or bed heights?

Participant: No, I shared it on Facebook, so, hopefully, maybe, that generated some sort of response.

Interviewer: Okay, thank you so much. So those are all the questions I have, then. Thank you so much for taking the time to speak with us. We really appreciate it. I hope you have a wonderful day.

Participant: Thank you.

Interviewer: Thank you.

Participant: I appreciate it. Okay, bye-bye.

Resp 29

- Participant: Hello?
- Interviewer: Yes, hello. My name is [interviewer]. I'm calling from the University of Florida in regards to a survey that The Family Café emailed you about pertaining to addressing Florida's building code.
- Participant: Yes.
- Interviewer: Yes, would you happen to have some time to participate now?
- Participant: I sure do.
- Interviewer: Okay, perfect. A powered, height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves, for adults who manage mobility limitations or incontinence. They provide a safe, sanitary, and comfortable space for assisted changing. Was there a time when an adult changing table would have been helpful to you or someone you take care of, yes or no?
- Participant: Yes.
- Interviewer: Okay. Just before we begin, you received an email from The Family Café in April, inviting you to tell us about how the lack of powered, height adjustable adult changing tables in public settings effects your loved ones. The University is conducting research with the Florida Building Commission to access and determine the need to adjust the building code by interviewing people effected by current standards. We are calling because you had completed the online scheduling form that The Family Café emailed you. Your input will help inform and shape the Commission's ruling. Everything you say will be confidential, and will be reported with no identifying information. There's no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes, and will be transcribed, summarized and allocated with other participants. The survey should take ten to fifteen minutes.
- First, I'd like to ask you to tell us a little bit about yourself, and why the lack of adult changing tables is an important issue for you.
- Participant: Okay. I'm the primary caregiver to a child who is too large to sit on the standard changing table, and so we have huge issues about going out in public, because there is nowhere for us to change him. We do have a van that would accommodate changing him in the back, but because we have a wheelchair also, we don't have any room to do so.

Interviewer: Would there be anything else you'd like to add to that opening statement?

Participant: I don't think so.

Interviewer: Okay. Have you heard about adult changing tables, and if so, where have you heard about them?

Participant: Yes, we've heard about them on a lot of forums that I'm a member of, and with other special needs moms. I've heard about the changing tables. I've seen pictures of them, and I've even researched the cost to see if it would be something feasible that could be done in a lot of our frequented settings.

Interviewer: Okay, thank you. How much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: It has a large effect. We have to think about that. We have to carefully plan our trips and if anything comes up, if there's any emergencies, we are stuck.

Interviewer: Would you mind telling me about a specific example?

Participant: Well recently we were in Gainesville for a doctor's appointment for my child, and we went to the doctor's appointment and we changed him there, which was fine because of course there were exam rooms, so we left there and were headed to a store, and he had an accident before we got to the store, and we were two hours away from our home while we were there. We actually ended up changing him on the floor in a public restroom. I then had to bring beach towels into the public store, and had to get down on my hands and knees, as well as laying him out on the floor to change him. Then trying to get him back up off the floor, and into his wheelchair. I don't think it's very respectful to him, but I also think it's a huge sanitary issue, as well as a lot of caregivers aren't able to do that physically.

Interviewer: All right, thank you. How helpful would it be to you if public places had adjustable adult changing tables available to you?

Participant: Extremely helpful, I feel like it would take away a lot of the isolation that we feel about staying home, because we just can't go anywhere. There are not options for our child. We have to think about those things before we can go anywhere, and ultimately we usually just decide to stay home because there's nowhere for us to change him.

Interviewer: I know you ... I just touched on this, but when choosing things to do, or places to go, do you consider if certain places will have changing tables for adults?

Participant: Yes, absolutely.

Interviewer: How helpful or accommodating are these places, when you ask about adult changing tables, if you do ask?

Participant: Usually not very accommodating, but it's not because they don't want to help, it's just simply because they don't have a place that would accommodate that.

Interviewer: Okay. You touched on this a little bit previously, but what do you do if you have no access to a changing table?

Participant: We usually put down the beach towels in a public restroom, or I'll try to unload his wheelchair and then carry him to the back of my van, put up some sort of shade, lay out beach towels and they try to change him in the back of the van.

Interviewer: How does this effect you or make you feel?

Participant: Horrible, I think it's degrading to him and I think that it's also a huge burden on the caretaker.

Interviewer: Thank you, so are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yes.

Interviewer: Have you ever delayed or changed plans because there was no adult changing table?

Participant: Yes, multiple times.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most, and why do you think that?

Participant: I think that everyone would benefit from that. I think larger kids would benefit. I think the caregivers would benefit. I think obviously adults would benefit. I think that the benefits are endless because the same changing table that's used for a baby could be used for an adult if you only had one space to put something, but unfortunately it doesn't work the other way around. If you choose to use your space for just a baby changing table, it's only benefiting a limited amount of people.

Interviewer: Thank you, so when you're participating in society, how often do you encounter an adult changing table accessible to you, and do you think this is adequate?

Participant: I've encountered one over the course of my son's life, and I certainly don't feel like it's adequate. I think we should be able to go to the grocery store without worrying about having to leave our grocery cart and come home because there's not adequate facilities. We don't even have access to basic needs because of this.

Interviewer: Thank you. Regarding the topic of adult changing tables, is there anything else that you would like to share?

Participant: I think that's it. I think I've covered it

Resp 30

Participant: Hello?

Interviewer: Yes, hello. My name is [interviewer]. I'm calling from the University of Florida in regards to a survey about the Family Café emailed you about pertaining to adjusting Florida's building code. Would you happen to have a moment to do that survey with us now?

Hello?

Participant: Sorry. Are you there?

Interviewer: Yes.

Participant: Okay. Sure that's fine.

Interviewer: Oh, okay.

A Powered Height Adjustable Adult Changing Table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves, for adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take of? Yes or no?

Participant: Yes.

Interviewer: Okay.

Just before you begin, you received an email from the Family Café in April inviting you to tell us about how the lack of Powered Height Adjustable Adult Changing Tables in public settings affects you or loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Café emailed you to input, help, inform, and shape the commissions ruling.

Every thing you say will be confidential and will be reported no identifying information. There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer. You can stop the interview at anytime.

I want you to know that this will be recorded for quality control purposes, and will be transcribed, summarized and aggregated with other participants. This survey should take 10 to 15 minutes.

First I'd like to ask you to tell us a little about yourself, and why the lack of adult changing tables is an important issue for you?

Participant: I have a child that was... she had a stroke at last year at [inaudible 00:02:28]. I have a hard time when we are in public changing her because she's unable to do anything for herself. Of course, you don't feel comfortable going out in the car, trying to change your child in the parking lot.

Interviewer: Is there anything else you'd like to add to that opening statement?

Participant: No.

Interviewer: Okay.

Have you heard about adult changing tables, and if so, where have you heard about them?

Participant: I have. A friend of mine has a child that's in his 20s, she has a hard time too, changing him and she was telling me about it.

Interviewer: Okay. Thank you.

How much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: It's a huge problem.

Interviewer: Would you mind telling me about a specific example?

Participant: Well for instance, we were shopping and of course she wet herself, and I would go in the bathroom, they have the kids ones, or the little baby ones of course, but she's too big to get up there: she's too long. Therefore, it took longer to get her outside to the vehicle, in the vehicle, then you have to lay the seats down and all this, where it takes an hour to change her, where she has to sit in urine for that length of time to actually get somewhere to change her. It makes it a lot harder.

Interviewer: How does this affect you or make you feel?

Participant: Very upset.

Interviewer: Okay.

Participant: And I can only imagine how she feels.

Interviewer: Thank you.

So how helpful would it be to you if public places had an adjustable adult changing table available to use?

Participant: I mean it would be very helpful because I would be able to spend more time with her shopping and doing things that she enjoys doing, other than spending all that time trying to get to the car, to get her situated, to get her changed, and back in the chair, and back to shopping. Saves a lot time and I'm able to spend more time with her, if there were things like that.

Interviewer: Overall, please describe how your quality of life would change if universal changing tables were more prevalent?

Participant: Well mine would change because I would be able to spend more time with my child, doing the things that we enjoy. But hers would definitely improve because she would be able to do things she enjoys instead of having to spend all this extra time doing things that are unnecessary, when something as simple as having these could change her life tremendously, and a lot of people's lives.

Interviewer: Thank you.

When choosing things to do, or places to go, do you consider certain places will have changing tables for adults?

Participant: I'm sorry I didn't hear you.

Interviewer: It said, when choosing things to do, or places to go, do you consider certain places will have changing tables for adults?

Participant: Will I consider? I mean, wish they did. It would help so much more, and yeah, we would be able to do a lot more things if there was. Because there are places we can't go because they don't have anything like that.

Interviewer: How helpful or accommodating are locations when you ask about adult changing tables, if you ask?

Participant: Well, where I'm from... we're from a small town, so there's not nowhere around here, and a lot of people have never even heard of it. I didn't either until a friend of mine was telling me, and I was thinking how neat that would be and how a good idea that would be to actually have something like that.

Interviewer: What do you do if you have no access to a changing table?

Participant: I have an SUV, so we have to go to the car. And that's if there's not a lot of people or vehicles around to try to change her. If not, then we just have to go home.

Interviewer: Would you mind giving me a specific example?

Participant: We were at the mall, and she had an accident, but of course it was during the middle of the day, so there was a lot of people out walking past the car; she's just fussing around, so I don't feel comfortable changing her in the car like that with others walking by, and can see in the car. It's just inappropriate. Nobody should really have to go through that. We ended up having to come home.

Interviewer: Okay.

Are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yes. If we're at a little concert or something, that they have around here where we live, we couldn't go because there's nowhere to change her if she needed to be. It's just easier not to go, because you don't want to take them and them get excited and have to leave because they have an accident and there's nowhere to change them.

Interviewer: Okay.

Have you delayed or changed plans because there was no adult changing table?

Participant: Yes.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most, and why do you think that?

Participant: People with special needs children, or parents with that need stuff like that. Those would be the people, and then of course the caregivers, of course, because it's hard on us too. But it's hard on both of them.

Interviewer: When you're participating in society how often do you encounter an adult changing table accessible to you, and do think that this is adequate?

Participant: I've never had one available.

Interviewer: Regarding the topic of adult changing tables, is there anything else that you would like to share?

Participant: Just that they should be everywhere. Every town should have them because there's people like that everywhere. Not just certain places. That would be helpful. They were made to have them in shopping malls, and Walmart, and stuff like that. It would be just so much more convenient.

Interviewer: Okay. Thank you.

Resp 31

Participant: Hello.

Interviewer: Hi, my name is [interviewer] and I'm calling from the University of Florida. You received an email from the Family Café in April, inviting you to tell us about how the [inaudible 00:00:35] that affect your loved ones while traveling. And the university's conducting research with the Florida Building Commission to assess new [inaudible 00:00:42] by interviewing people affected by the current standards. Is now a good time?

Participant: I missed a little bit of what you were saying. It's about a survey?

Interviewer: Yes, ma'am.

Participant: [crosstalk 00:00:54] survey?

Interviewer: Yes ma'am. So let me just jump back a little bit. The Family Café, in April they sent out an email [crosstalk 00:01:00]

Participant: That's what I thought you said, okay. Hang on. I'm going to get to a place I can hear you better. Okay. Yes, it's a good time.

Interviewer: All right. A power height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no?

Participant: Yes.

Interviewer: Alright.

As I said, you received an email from the Family Café in April inviting you to tell us how the lack of power height adjustable changing tables in public settings has affected your loved ones. The University is conducting research with The Florida Building Commission to assess new [inaudible 00:01:52] needs to adjust the building code by interviewing people who are affected by current standards. We're calling you because you completed an online scheduling form when The Family Café emailed you, and your input will inform and shape the commission's ruling. Everything you say will be confidential, and we'll report it with no identifying information. And while there's no compensation for completing the survey, your answers will help The Florida Building Commission make informed decisions. Your participation's voluntary, there is no right or wrong answers to the questions. And you don't have to answer any question you do not wish to answer. You can stop the interview at any time. I also

want you to know that this call will be recorded for quality control purposes and will be transcribed, summarized and aggregated with our other participants. The survey should take approximately 10 to 15 minutes. Okay?

Participant: Okay.

Interviewer: All right, so first I have to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Well, I'm a mom of a child with special needs who is incontinent. And she's currently 48" tall and weighs over 50 pounds. So while she can transfer to a toilet, things like that, if she has an accident, and has soiled her clothing, changing her upright is very challenging for her. She doesn't have the core strength to hold herself upright while being washed. Things like that, trying to do that someplace without her laying down is really difficult. And I have, I'm 50 and I have a bad back and knees so squatting in restrooms and things like that is really challenging.

So, you know, any kind of table that would allow me to have her more at an ergonomically appropriate height for cleaning up and redressing would really be important. I've many times had to lay her down on a restroom floor and, you know, that's very unsanitary, it's upsetting to her. She can see under the booth, there's no privacy anymore. You know, there's just quite a few things that are problematic and sometimes there's not even space to do it, you know? Restrooms aren't even sized big enough for somebody to be laid down, and she's just a child. So as I foresee this going on, my back and my knees aren't going to get better and she's not going to get shorter. So you know, having this accommodation would really allow me to take her more places. And there's some places where we just can't really go because of that issue.

Interviewer: Alright, how have you heard about adult changing tables?

Participant: What's that?

How did I hear about them? I heard about them at Family Café when my daughter was much younger and it wasn't actually a problem for us yet. But I was foreseeing, you know, it being a problem because she was getting too big for standard baby changing tables. But we would usually find something, a counter or a bench or something that she was small enough, backseat of the car. But yeah, they actually showed us one and we used it at a Family Café and I was like, "Wow, this will be wonderful."

And I've wished that they were available at public places, it would really be helpful. Especially government offices where I'm required to go, like the DMV and you know, other places. You're required to go there, there's often long waiting times, and then if you have a special needs child that's in, or adult that has to accompany you that's incontinent, you know, it's not always possible to just leave them until you get home, you know? It's certainly not comfortable and, but in my daughter's case it's not possible. If she soils herself to a degree that it needs immediate attention.

Interviewer: Okay.

And you've already touched on this and I was wondering if you could expound a little bit, but how much of a problem is it not having adjustable adult changing table when you're out participating in society?

Participant: Oh yeah, it's a real problem. We actually bought a different kind of car so that we could take care of her needs inside of our vehicle, which in Florida is really difficult because it's hot, you have to leave a running vehicle in a parking lot or something, we're doing whole outfit changes in our car. But in our previous vehicle we didn't have privacy and so that's how we accommodate her, or she just doesn't participate out. And we were fortunate to be able to do that but I know many people, you know, that's not an option for them. And at some point she'll outgrow this option even in our family. And then quite honestly we don't know what options there will be. So I would love to see change on that.

I think even people with small children would find it helpful. I mean I don't think it's something that, you know, and people who [inaudible 00:07:30] I think it would be useful for a large portion of the disability community.

Interviewer: And you've actually touched on this one a little bit as well, actually quite a bit. But how helpful would it be to you if public places had adjustable adult changing tables available to use? And to go off of that one as well, what types of things would you be able to do and places you could go?

Participant: Well, right now we don't have passes to Disney anymore because even though they do have tables that you can change on, and some of them are very long, they're not big enough for my child anymore. And so, you know, they usually stop at about three feet and even with her knees bent it's, and then I have to help her up there. And so having something that I could lay her on and lift her up... Even in their medical area where their first aid is, they have hospital beds, but they're not adjustable, they're fixed high bed. So again they're either too low for me, or they're too high to lift her up onto without potentially injuring myself.

So that feature for them being able to be, hold an adult and be adjustable basically is what, even if it was just in one location at a theme park, would allow us to go again. Right now we don't feel like it's accessible anymore. And with a long wait time and things like that, the chances of her soiling herself and needing a complete change of clothing and things like that is really high. So you add those environments to that, you know? We're pretty restricted and having things like that and knowing that something like that might be available from where, in the public like at parks and stuff, would make that, like in a family bathroom or at the Target or you know, other places like that, that would make going to those places accessible for her.

Today they're not, we can't bring her.

Interviewer: Okay.

When choosing things to do or places to go do you consider if a certain place will have changing tables for adults?

Participant: Absolutely. It is like, I wish there was like a website that showed you like what kind of changing table was available, like pictures. My million dollar idea.

Interviewer: And if you have asked, how helpful or accommodating have these locations been when you've asked about adult changing tables?

Participant: You know, the only place that was accommodating was Disney where they said we could use the medical facilities to do that. But then it was problematic because the exam rooms do not have toilets or sinks, well they have a little sink in them. But they're not really set up for toileting activity. And the bathrooms, the actual bathrooms are in another location. So, you know, they didn't really, they weren't really designed to accommodate somebody who needed changing and toileting.

And, you know, also as my daughter grows up and she might be able to use a bathroom, but then would have to have assistance to go into another room to, you know. it's just, it's like really, they haven't really thought it out to make it accessible, they're just kind of making accommodations. And I appreciate the accommodations but you know, usually it's a closed room where there's a floor I can lay her down in. Or it's, [inaudible 00:11:22] theme parks, At Sea World they have a mothers nursing room, which has no water but it does have a table that's five feet long so you could potentially lay a large child on it. But there's nothing for an adult that I've ever seen other than the hospital beds at theme parks.

And we were just at an autism even at a place that is a physical therapy office in Lermontov, the Exemplar. And they did not have a full sized changing facility in their facility, you know? They had bathrooms, they did have some baby changing tables. They did have some potty accommodations and I know they mainly go with child clients. But I just thought that surprised me.

And then the public restrooms in that building were also completely inappropriate. Even the handicapped accessible one wasn't big enough for an adult even to be laid down on the floor, which is disgusting. But while I was in there there was another mother actually laying her child down in a regular stall on the floor, you know. And I just thought this is so needed. So when I saw the survey I was like yeah we need to start talking about this.

Interviewer: And another one that you've definitely touched on quite a bit, so what do you do when you don't have access to a changing table?

Participant: What we currently do is, we have purchased a late model, like a 2000, conversion van that has seats that fold down into a bed in the back and we use a hospital waterproof disposable pad to lay down, and we change our daughter in the car.

Interviewer: Okay.

Participant: it's a van [crosstalk 00:13:21] basically it's big enough for an adult to lay down in it.

Interviewer: Okay.

And how does this affect you, or how does it make you feel when you have to do this?

Participant: It makes me feel creepy, you know? To be dressing and undressing my daughter public places parked in a car. Our van has, you know it's a camper van, so it has window shades that we have to pull them all up and then it makes me feel like other people are wondering what we're doing, you know? It's not really, even though it's somewhat private it still makes me feel vulnerable and kind of weird, you know? And my daughter doesn't mind it. But it also makes our van smell like a toilet, you know? Really very smelly place. And there's no running water so we have to do all the cleanup with wet wipes and then haul that trash somewhere and dispose of it properly. So, you know, it's, you know, minimally adequate.

Interviewer: And you talked about this with going to Disney, but are there other places or events that you're unable to participate in too? Or participate in due to the lack of accessibility to a changing table?

Participant: Yeah, [inaudible 00:14:52], Target, Walmart, pretty much every single public outdoor park, swimming locations, public pools, they're all inaccessible because of that. In the YMCA they had benches that you could lay down on, but they're in the open, there was no private rooms with a table or a bench that you could lay down. And like I said, my daughter is only four feet tall, so, you know, right now. But she will be a very tall person. Her sisters are quite a bit tall. Her oldest sister is over six feet tall. So, you know, let's see. Yeah I mean pretty much everywhere is pretty inaccessible for her.

Churches sometimes, they're more accommodating. They're willing to find someplace that's private [inaudible 00:15:55] you know? They have nursery facilities and nursing mother rooms usually but. There's the doctors offices aren't accessible, you'd really be surprised how few people really think about somebody over the age of two or three needing a changing table.

Interviewer: Have you had to change or delay plans because there was no adult changing table?

Participant: Yes. We've had to go home. Before we got our big van we'd have to go home. Sometimes mid-drive. Like we were driving there and she soiled herself in the car and we'd have to turn around and go home and [inaudible 00:16:45].

Interviewer: If more adult changing tables were installed in Florida, what types of people do you believe will benefit the most?

Participant: I think actually like, I think a lot of people would benefit. I think a lot of special needs children that you know, I think when I found out that children with autism, the average age of potty training being completed is eight. That's a big child. So I think that we will see those children be able to access the community a lot better which

would be good for their development. I don't honestly have a good understanding of how many adults have care providers, but I do know what there's quite a few people I've talked to with older parents that need this type of changing table for their older parent who still can function in society but cannot, you know, is not, needs access for a changing table. And people with medical issues and things where, feeding tubes and things like that, where that's easier to do laid down.

But really just the, once, like I said, once a child gets, once a person's above like 30, 40 pounds, the lifting makes it problematic for them to be in public if they need to be changed. And the cleanup of somebody incontinent is really arduous if you can't do that in a bathroom, you know? So having a family type bathroom with an adult adjustable high changing table I think really would let a lot of children that are older that are not potty trained access to the community. Especially if they are in places like public parks, you know? Where you might want to take your child to socialize with other kids but you can't because if they have an accident you basically have to go home.

And there's no way to like, nobody wants to lay their child down in a bathroom floor of a public park outdoor restroom, you know, concrete block. You know? And, or a swimming pool, you know? Nobody wants to deal with those things, you know? Laying their child on the floor of a public restroom, it's disgusting and embarrassing, just humiliating. It makes you feel like nobody cares about your kid and it's such a simple thing that could, if you could just go into a room, close the door, clean them up like you do at home, get hem all changed and back on their way, it would take 10, 15 minutes, you know? It really, really is just about money and people caring.

Interviewer: And when you're out participating in society, how often do you encounter an adult changing table that's accessible to you?

Participant: The only time I've ever seen one was at Family Café.

Interviewer: Okay. And, [inaudible 00:20:01] but I still want to ask, do you think that this is adequate?

Participant: What's that?

Interviewer: Do you think that this is adequate?

Participant: Than an adult changing table is adequate or that I've never seen one is adequate?

Interviewer: That you've haven't seen one.

Participant: Yeah, no it's outrageous actually. You know? I understand people don't think about it, I understand that. But when I go into Target and I see they have, or [inaudible 00:20:31], and I see they have a family changing room but there's not even an infant changing table in there, or there's a really small one in an awkward place, I can see that. Unless building codes are required, they're just not going to do it.

It's, really honestly, not that expensive. And places like Disney, they have tons of money, they have tons of buildings, they build new roller coasters every year. They can absolutely build something that would be accessible for a wide, you know with lifts and things like that too, I mean there's a lot of things they can add. But even just the minimum of being able to have a hight adjustable table so that you didn't have to [inaudible 00:21:13] your kid up on a table, it's dangerous. And being able to have everything you needed for sanitary, taking care of that business. That's, you know, it's not adequate at all, it's not even thought about. And it is, it's discriminatory. I mean, it really is.

Interviewer: And is there anything else you'd like share with me about this?

Participant: Yeah, I mean it's a weird thing to try to advocate for because, first of all you have to sort of publicly acknowledge that your loved one needs this accommodation. And that's really a stumbling block, you know other things my child needs accommodated for are very easy for me to advocate for. But as she gets older this is embarrassing to her and so for me to advocate or even find if there's an accommodation creates a social stigma for her. So it really is something that I think if it could be talked about at a high level, you know, as this is just decent, you know, and a public sanitation issue, that, that's just about decency and public sanitation so that individuals weren't forced to advocate for this like we have to do so many other things.

Let me advocate for a service dog or a wheelchair, okay. But, you know, a place to change her is really, that violates her privacy for me to have to publicly advocate for that. So there's a reluctance for me as the caregiver to respect her privacy and yet advocate for her needs. So that's what I'd like to add.

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Participant: Hello.

Interviewer: Yes, hello. My name is [interviewer]. I'm calling from the University of Florida.

Participant: Oh, hi. I'm sorry I missed you last week.

Interviewer: That's perfectly fine. Do you have a moment to speak with us now?

Participant: Sure. Let me just turn my TV off, so I can pay attention to you.

Interviewer: Okay.

Participant: Go ahead.

Interviewer: Alright.

Participant: It's a survey, right?

Interviewer: Yes.

Participant: Okay.

Interviewer: So Powered Height Adjustable Adult Changing Tables is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no?

Participant: Yes. Yes.

Interviewer: Okay. So before we begin, you received an email from the Family Café in April inviting you to tell us about how the lack of powered height adjustable changing tables in public settings affects you or loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

We are calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the Commission's ruling. Everything you say will be confidential and will be reported with no identifying information. There's no compensation for completing the survey. But your answers will help the Florida Building Commission make informed decisions.

Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to know that this call will be

recorded for quality control purposes and will be transcribed, summarized, and aggregated with other participants. This survey should take 10 to 15 minutes.

So first, I'd like to ask you to tell us a little bit about yourself, and why the lack of adult changing tables is an important issue for you.

Participant: Okay. So, I have a now 19-year-old daughter with Cerebral Palsy, and she has pretty much lost the ability to stand. She can use the toilet, but for me when I take her out, I can't stand her up and pull pants up and down, do all those things.

This is interesting to me because I actually asked about this a couple of years ago at the Café, if they were gonna have something like this. So anyway, my thinking was that has always been that if there were a changing table or even a bench that I could lay her down on and undress her and then lift her onto the toilet, which is basically what we do at home, that that would make it possible for me to take her places and do things with here when it's just me.

Usually, it takes a two-person job to take her to the bathroom.

So, that's my side of it.

Interviewer: Okay. And would there be anything else you'd like to add to that opening statement?

Participant: I would throw in just, it's really not to do with us particularly, but we were in London last [inaudible 00:03:28] and everywhere we went in London, it was any of the public places, they had a special needs bathroom that was designated a special needs bathroom, like all the hotels, all the museums. You know, those kind of places had these. Many of them had lifts, some of them had, like the adult sized changing table. They had all sorts of things. I thought, you know, if they can do that in London, why can't we do it in the United States.

Interviewer: Okay.

Participant: That's my story.

Interviewer: All right, thank you.

So, have you heard about adult changing tables and, if so, where have you heard about them?

Participant: I think that I had seen something at the café. Somebody had a - Family Café like I said. I think it was last year, but they had like a demonstration place and that's where I talked to them about it and that there was a discussion about how it would be difficult to put them. If you were gonna have them they'd probably fold down across the toilet which would make it very difficult for us, it wouldn't help me at all, but, I have seen different things. I'm trying to remember, you know, what else I've seen, but, I mean, it has to be like, you know, waste-high or lower. Obviously, they wouldn't

be able to be super high. With me, they'd need to be seat high, wouldn't they? Chair-high.

Other than that, I'm not sure exactly where I've seen them, but that's what I remember.

Interviewer: Okay. So, how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: Fairly big because I kind of have to always bring somebody with me or bring her home to go to the bathroom. That's about the only way.

Interviewer: Oh.

Participant: I did it one day at FSTJ and in a regular disabled bathroom and I don't know how I got it done. It was virtually impossible. It took me half an hour of struggling with a hundred pound child. So, very difficult.

Interviewer: And how did this affect you or make you feel?

Participant: How did what? [crosstalk 00:05:48] That event?

Interviewer: How did this affect you or make you feel?

Participant: I don't know. Desperate and pathetic. I'm not sure how to define that. Frustrated for sure. And a little bit scared I was gonna drop her on the floor. So, there's that fear factor.

Interviewer: So how-

Participant: You've got a hazard. If it helps it to say it, it's a hazard to not have something like that. Truly. It really is.

Interviewer: So, how helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: I mean how helpful? On a scale one to ten, about a, probably a nine and a half anyway.

Interviewer: So, what types of things would you be able to do?

Participant: Well, it would give me the option of putting her on a table to pull her clothes down to go on the toilet, or it would give me the option of changing her laying down if she had a some kind of a pull-up or a pad that just needed changed. It would give both those options I think.

Interviewer: Okay. So, overall please describe how your quality of life would change if universal changing tables were more prevalent.

Participant: I think it would make it easier to take her a lot more places. I have a highly intelligent child who is going to college, but we run into these problems like how to take her to the bathroom and do all those things. I'm not even sure how to I'm going to send her off to college if it isn't, like, a few blocks from the house which is what we're doing now. So that, I mean, clearly it would make a huge impact for her, and getting her out in the world. Perhaps we think about that with a job for her, too. How's she going to go to the bathroom with a job, somewhere? I didn't even know how to do that. So, that answer.

Interviewer: Okay. So when choosing things to do or places to go, do you consider certain places will have changing tables for adults?

Participant: Well, the places I'd like to see would be like restaurants, which are actually just getting into a lot of them, getting into having a family restroom. Even that is frustrating because it's a family restroom. Isn't always available. You know there's the the zoo. You know, I mean, really any public place that has more than 100 people come through it in a day probably almost ought to have one. If they really wanted to be fully accessible to people. That's what I think.

Interviewer: And if you ask how helpful or accommodating are locations when you ask about adult changing tables?

Participant: Well they all look at me like I'm crazy, but I have enough trouble just asking if they have special needs bathrooms [inaudible 00:08:56]. Yeah, you know I think it is interesting to me. There's really, I don't know any public places really that have them here. I haven't seen them anywhere, and for sure in Jacksonville. You know, other than going to therapy with [name] that's about the only place I've ever, and that really that which is the one of the raised, like, workout benches that they had. They put them in the bathroom. That was really helpful when we took her there.

But, you know, I don't really see that anywhere. I've been places that I was thinking there need to be a place at the zoo, the Jacksonville Zoo, that had a like little restrooms, had like a bench in it and it was like a concrete bench or something. And that was about the only thing that I could use to help me out. I've not really seen anything anywhere else. So, if they're there, I'd love to know where.

Interviewer: And so you have touched on this before, but what do you do if you have no access to a changing table?

Participant: Uh, the floor? I literally changed my daughter in a, well I'm going to say in a place in airports that we weren't really supposed to go, but one of the employees let us do it. So I'm not going to say where that was. I don't want to have someone to come back and ask that question. But basically she let us into an area and stood guard to make sure we knew where to go and make sure nobody came in on top of us. It's tough. It's really, even with two of us to do the job this is not an easy task to do. I mean, that's me and my husband trying to take her usually. It's very difficult to be able to lay her down somehow. Anyway, I do it at home, so I can do it at home. I don't know.

Interviewer: Okay, thank you.

Participant: Sure.

Interviewer: So, are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Let me think. I'm really trying to think of places I go with her. I mean, it's sort of one of those things that we go out, and out to go shopping or something and she's got to go to the bathroom, we don't have a lot of choices but just to decide it's time to go home.

Interviewer: Mm-hmm (affirmative)

Participant: And that's pretty much, you know completely interrupting everything that we're trying to do. You know, things like, any good event. Say you want to go to the beach or something, I can't even imagine if there were a [inaudible 00:11:42] I can't even go with them. You can't go to an all day thing is what it really comes down to. You know-

Interviewer: Mm-hmm (affirmative)-

Participant: Anything more than about four or five hours you just cannot go to because you know there's going to be a problem. So, really, kind of limits your activity.

Interviewer: So have you delayed or changed plans because there is no adult changing table?

Participant: Yeah.

Interviewer: And so if more adult changing tables were installed in Florida, what types of people would benefit the most? And why do you think that?

Participant: I think that anybody who has a child or an adult who either can't stand or can't stand for long. I suspect there are probably going to get to be even elderly people who don't want to go out and do things, but they just can't make that transition to sit on the toilet, and that's hard to plan. You know, anybody who has to go somewhere with help almost would probably benefit. Honestly, I don't understand too because they should be able to be used for changing infants as well. I mean, there's really no reason you can't, that can't be used for little kids or adults either one. That's my perspective.

Interviewer: And when you're participating with society, how often do you encounter an adult changing table accessible to you? And do you think that this is adequate?

Participant: Any time we're going to go anywhere, we're going to have to think about how we're going to do that.

Interviewer: Mm-hmm (affirmative)-

Participant: We've, I think even when we were going down to South Florida and you try to go to a restroom on the way to where you're heading, you know like even a turnpike scenario, at least then you'll have a bathroom big enough to fit the wheelchair in and a couple of people to help, but it still gets really awkward and always seems to make it hard.

Interviewer: Mm-hmm (affirmative)-

Participant: I don't know. I don't know how to answer questions when they're open ended like this. I'm a little confused.

Interviewer: Yeah, it's whatever you want to share. There's again-

Participant: Yeah

Interviewer: It's whatever you want to tell us.

Participant: Yeah, yeah. I mean, you get pieces out of this. But, yeah, I mean, I can't, one of the things that was very frustrating was the little places and there's no separate either family or disabled bathrooms. You know, you've got the men's rooms that have one in them, and the lady's room may have one in. But you can't take your husband into a lady's room for these things. Or the, you know, take the wife and the daughter into the men's room. You get very creative at times with that. You know, dive in there together and then tell people I can't, I'm sorry I have to bring my husband in to help my daughter who can't stand and if you know you won't come out of the bathroom. If you hear a man's voice, don't panic. That's how tricky it gets trying to maneuver these things because if there were places that, to lay her down, I could get her laid down and do the job. But, I can't hold her up as well as manipulate everything else that's supporting. So, anywhere you have to give people more options.

I know I've heard at least one guy talk about using a catheter and going on an airplane and having to lay down in the galley, and have him pull the curtain so he could be [inaudible 00:15:31] there with his daughter. And it's like, okay, that was interesting. I've never heard of that, and I thought today that's not for my [inaudible 00:15:39] but, in airplanes are always very challenging and I don't know how I'm going to accomplish that on an airplane. That's another issue. Trying to take an overseas flight is really interesting when you try to take someone to the bathroom like that. There's no room to maneuver. I mean you're basically on the changing table, but I'm sorry I don't know how you're supposed to.

Interviewer: Yeah, so just regarding the adult changing table topic, is there anything else you'd like to share?

Participant: What size these things come? I would suppose if there were a way to make them be height adjustable, that would be a lovely thing. I don't know if that's a possible thing or not, but unless they were somewhere like close to the toilet, as opposed to across the big room from the toilet. That would be more helpful to me because I could lay

her on, pull her pants down, pick her up and put her on the toilet without having to walk, which is pretty much something I can, the only way I can do it.

Interviewer: Mm-hmm (affirmative).

Participant: So, that's both of the two things that occurred to me about it.

Interviewer: Okay, thank you.

Participant: Mm-hmm (affirmative).

Interviewer: And then so on another topic, when traveling, was there a time that the height of the bed was an accessibility problem for you or someone you take care of? Yes or no?

Participant: Travel is always a problem. It's just, you can't find a facility to use. You have no where to lay them down or ability to get, you know, it becomes a two person event. I mean, literally, in London I was shocked that we went into what they called special needs bathrooms. They were supposed to be only special needs, they weren't for families or anything like that. And they literally had lifts in there that you could use to lift somebody onto the toilet. I was floored. I didn't know how to use them because we don't have anything like that in the US, so that intrigued me.

They had, the London Zoo, literally had a, it was an outside, like a trailer kind of set up, but it had a ramp going up to it. It was a big long room. It had a huge changing table on it that we used and it had the toilet and it had a lift. It had everything. I just think that would be amazing to have places like stadiums, and zoos, and concert halls, and you know, even if they just had one of them that you could find at some point. All of those are challenging things for us.

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Participant: Hello.

Interviewer: Hello. My name is-

Participant: Hello?

Interviewer: Hello, ma'am can you hear me?

Participant: Yeah, a little bit now. How are you?

Interviewer: I'm doing well. My name is [name] and I'm calling from the University of Florida. You received an email from the Family Café back in April inviting you to tell us about how to heights of beds effects you or your loved ones while traveling. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. Is now a good time?

Participant: Yeah, yeah. How long is the survey you're doing? The follow-up?

Interviewer: It's about 10 to 15 minutes.

Participant: Okay. I can do like 10 I think is the limit. Yeah.

Interviewer: If you need to go anytime during the survey or for any reason at all, would it be okay if we call back?

Participant: Yeah, yeah.

Interviewer: Okay. So a powered height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing.

Was there a time that an adult changing table would have been helpful to you or someone that you take care of, yes or no?

Participant: Yes, yes, definitely.

Interviewer: All right. So, as I said, you received an email from the Family Café inviting you to tell us about how the... Sorry, wrong one... how adjustable changing tables in public settings affects you or loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards.

We're calling you because you completed an online survey, or online scheduling form rather, when the Family Café emailed you. Your input will help inform and shape the commission's ruling.

Everything you say will be confidential and we'll be recorded with no identifying information. There's no compensation for completing the survey, but your answers will help the Florida Building Commission make an informed decision. Your participation is voluntary. There are no right or wrong answers to these questions, and you don't have to answer any questions you do not wish to, as well as stopping the interview at any time.

Lastly, I want you to know this call will be recorded for quality control purposes, and will be transcribed, summarized, and aggregated with other participants. The survey should take about 10 to 15 minutes to complete.

Participant: Okay.

Interviewer: First off, I'd like you to tell me a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Yes, it's an important issue because I have a teenager that I change. We have had to lay him down in public bathrooms, on the ground, in order to that, my husband and I.

Interviewer: How have you heard about adult changing tables?

Participant: I heard about them, I think through partners in policy making. And the Family Café survey. But yeah, I believe it was Partners in Policy Making.

Interviewer: How much of a problem is not having an adjustable adult changing table when you're participating in society?

Participant: It's a pretty important issue, it's a big problem... as far as having to put somebody who doesn't fit on a changing table on the floor, which is unhygienic in a public bathroom.

Number one and number two, having to bend over. Number one, space. There's not always enough space, even on the ground.

Number two, bending over an adult to change them. To wipe them, and change their diaper. Obviously, that adult, me or dad could fall and get hurt, or just obviously long term, it'll affect our back. It's very challenging.

Interviewer: Okay.

How helpful would it be to you if public spaces had adjustable adult changing tables available to use?

Participant: Very helpful.

Interviewer: What kind of things would you be able to do, places to go? Overall, describe how your quality of life would change if universal changing tables were more prevalent.

Participant: Our quality of life would be greatly improved. It would give us greater ability to be in the community.

Interviewer: Okay.

When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: Do I foresee them having it?

Interviewer: Not quite. Do you consider if certain places will have changing tables for adults?

Participant: Do I if they will have changing tables for adults?

Interviewer: Yes ma'am.

Participant: Well, I think it's important to have them in any public place. Restaurants, the service pauses along the turnpike, the highways. I think anywhere there needs to be wheelchair accessible. I think it would be helpful to have one of those in the handicap stalls, or the family restrooms, too, like at airports.

Interviewer: Mm-hmm (affirmative). Yep. All right, are there pl- I'm sorry, go ahead.

Participant: No, no. That was it.

Interviewer: Are there places to events you're unable to participate in? Do you feel a lack of accessibility to an adult changing table?

Participant: Yes, it's definitely hard. You know, public parks and also, private places, some restaurants. Some private entertainment parks, you know, like Disney World, so amusement parks. Water parks, things like that.

Interviewer: Have you had to later change plans because there was no adult changing table?

Participant: Yes, I've had to change plans because we couldn't change our son in the bathroom that was available.

Interviewer: If more adult changing tables were installed in Florida, what types of people do you feel benefit the most?

Participant: I think anyone with a physical disability. I think even parents of children without any handicaps, because the tables are bigger, so they can use them as well. You see what I'm saying?

Interviewer: Mm-hmm (affirmative).

Participant: You wouldn't need the baby table and the big table. The big table would help people of all ages and sizes.

Interviewer: When you're participating in society, how often do you encounter an adult changing table that's accessible to you?

Participant: How often do I encounter them?

Interviewer: Yes ma'am.

Participant: I don't know. I think, maybe once, I encountered one. I think we were able to use one once.

Interviewer: Do you think this is adequate?

Participant: No, no. It was okay, yeah. It was... yeah, it was a pleasant surprise, let's put it that way.

Interviewer: Is there anything else you'd like to share with me?

Participant: No, no. I just think it's great you are, uh, doing the survey, and hopefully there will be grants and funding. All of our population is aging. It's not just kids with special needs that are big, but obviously even older populations, as they have more... they age and have more needs, it will benefit them as well. I think that all society would benefit from having the adult size changing tables in public places, in the restrooms. So thank you.

Resp 34

Participant: Hello.

Interviewer: Hello. My name is [interviewer], and I'm calling from the University of Florida. You received an email from the Family Café in April inviting you to tell us how the lack of powered height adjustable changing tables in public settings affects you or loved ones.

Participant: Yes, you called earlier. Yes, go ahead.

Interviewer: Okay, so the university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We're calling because you completed the online scheduling form when the Family Café emailed you. Your input will help inform the commission's ruling.

Everything you say will be confidential and will be reported with no identifying information. There is no compensation for completing the survey, but your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There are no right or wrong answers to these questions. You do not have to answer any question you do not wish to answer, and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes, and will be transcribed, summarized, and aggregated with other participants. The survey should take 10 to 15 minutes. Okay.

Participant: Okay.

Interviewer: A powered height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of, yes or no?

Participant: Yes.

Interviewer: Okay. So, first I'd like to ask you to tell us a little about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Well, my work is with children with disabilities. Some of those are also adults, so we work with them up to the age of 30. Many of them are incontinent, and so we need that capability if we take them on a trip or go someplace where they would have a good time, but they also need to be changed.

Interviewer: Okay. Anything else you'd like to add?

Participant: No.

Interviewer: Okay. Have you heard about adult changing tables?

Participant: Yes.

Interviewer: Where have you heard about them, word of mouth, magazines, disability advocacy groups, et cetera?

Participant: Magazines, which apply to disability groups, yes.

Interviewer: Okay. How much of a problem is not having an adjustment adult changing table when you are participating in society?

Participant: Is there options or do I just say...

Interviewer: No, you just answer. It's a free response, so just answer as-

Participant: Free response, okay. You can always use a bed. Yes, okay, you can use a bed, but it's really easier if you can have something which is adjustable, and it's more comfortable for the person who needs to be changed.

Interviewer: Okay. Can you tell me about a specific example?

Participant: Well, we go one day a week to some sort of facility where we can either swim or do activities or participate with other abled individuals of the same age group. In all of those cases, it would be good if the restroom was... or at least the ADA restroom was equipped with something that went up and down.

Interviewer: Okay. Okay. How does this affect you or make you feel?

Participant: Well, it's difficult for the individuals who have disabilities who are of adult size for us to really be able to make them feel comfortable. The younger they are, of course, we do have... We go down to six-year-olds, so six to 11 years old we can pretty much manage. But it's the ones that are over that age. They have so much embarrassment in their life and difficulty socializing that this is just one more barrier to them being able to just have a good time.

Interviewer: Okay. How helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: It would be very helpful.

Interviewer: Okay. What types of things would you be able to do? Places to go?

Participant: Well, we would be able to use more of the public parks and theme parks in Florida if we knew that that was going to be available. We could also reassure the individuals who are coming with us that there will be facilities for them, and so we will be able to take care of any of their needs in that area.

Interviewer: Okay, so, overall, please describe how your quality of life would change if universal changing tables were more prevalent?

Participant: Well, I think it would take a lot of worry, and concern, and anxiety out of being able to take communities of individuals with disabilities who need to use a changing table. That's pretty significant considering they really want to do everything that everybody else can do. And without such a thing, they really... We really can't take a chance like that to go someplace where we don't know there'll be something.

Interviewer: Okay. When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: We do. It's not very common in North Florida, but we do.

Interviewer: How helpful or accommodating are these locations when you ask about adult changing tables?

Participant: They're very nice about it, but most of them say, "We have facilities for individuals in wheelchairs, but we don't have any place where you can change somebody." That's what most of them say.

Interviewer: Okay, so what do you do if you have no access to a changing table?

Participant: Well, generally, we will go to whatever vehicle that we have come in, and we will make do in the vehicle seats or in the back of the vehicle. We lay down pads and things to be able to get everybody clean and changed.

Interviewer: Can you give me a specific example?

Participant: Well, for instance, if we go to a park, a state park that has a springs in it, then before they go in the water, then we check and clean everything where they might have used. They might have either had a bowel movement, or they might just need to be cleaned up from urine. Then when we come back from swimming, then we do that again, so that they'll be comfortable on the way home or during lunch if that's the next thing we're going to be able to do.

Interviewer: Okay. How does this affect you or make you feel?

Participant: Well, the harder it is for the kids to be able to get clean and for us to be able to change them, then the more difficult it is for us to do additional activities, and, excuse me, then it limits the variety of activities that we can schedule.

Interviewer: Are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yes, we really can't use any of the city parks or the county parks that are near us because they just don't have anything except the wheelchair accessibility.

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Participant: Yes, we have crossed activities off our list because there was no place for the kids to get... for us to change the children and young adults.

Interviewer: Okay. If more adult changing tables were installed in Florida, what types of people would benefit the most?

Participant: Well, I mean, of course, it would primarily be people who are incontinent and need to wear some sort of appropriate diaper to keep them safe and to keep them clean. Those people, they have no way... it's not [inaudible 00:09:33] for them, so it would be really nice if we could go to more places and bring a wider variety of individuals.

Interviewer: When participating in society, how often do you encounter an adult changing table accessible to you? Like what percentage would you say?

Participant: Pretty low. Offhand, I would say 5%.

Interviewer: Okay. Okay. Is there anything else you'd like to share with me?

Participant: No. I think it's great that you guys are looking into this, thank you.

Resp 35

Participant: Hello.

Interviewer: Yes, hello. My name is [interviewer]. I'm calling from the University of Florida.

Participant: Mm-hmm (affirmative).

Interviewer: Okay. So just to begin, a powered height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of, yes or no?

Participant: Yes.

Interviewer: Okay, and so, just a brief overview of everything. You received an email from the Family Café in April inviting you to tell us about how the lack of powered height adjustable changing tables in public settings affects you or loved ones. The university is conducting research with the Florida Building Commission to assess and determine the need to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Café emailed you. Your input will help inform and shape the commission's ruling.

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So, first I'd like to ask you to tell us a little bit about yourself and why the lack of adult changing tables is an important issue for you.

Participant: Okay. Well, my name is [name]. I am both a mother of a child with a severe disability who requires assistance with toileting and diapering, and I'm also a speech pathologist who works with children, adolescents who would require the same services. So I have firsthand knowledge of how difficult it is to access public places without that kind of resource available. We oftentimes will have to use the floor and just take a blanket or a towel with us whenever we go on trips with our family, or just routine doctor's appointments, things like that, that we have to do. It's just very important to me, both as a mom and as a professional.

Interviewer: Would there be anything else you'd like to add to that opening statement?

Participant: No.

Interviewer: Okay, so have you heard about adult changing tables, and if so, where have you heard about them?

Participant: Some of the support groups that I'm in, for children with disabilities similar to my daughter's. Some of those parents report that they have access to adult changing tables and that it just makes their life a whole life easier and makes them able to go out in public and do things with their families as they would normally do. So that's mostly where I've heard of them, from support groups from people around the country and some globally.

Interviewer: Okay, thank you. So how much of a problem is not having an adjustable adult changing table when you are participating in society?

Participant: It's a significant problem. It really limits where you want to go and how long you're able to stay in a place. As my daughter has grown, it has just become more and more of an issue for me having to think about when I get to this place that we're going, what if we need to change her? How are we going to do that? So it limits where we go. It's just a pretty significant problem.

Interviewer: Would you mind telling me about a specific example?

Participant: Sure. We went to Disney World with our family in February. We have three members of our family who were using wheelchairs for various reasons. One was elderly, and then we had two children, young adults, who are disabled. So we had to take a towel and put our children on the floor at Disney World, in a public bathroom, with people everywhere. It's just very undignified, and it's not something that you would ever consider doing with a baby.

A typically developing baby, if you put them on the floor, people would probably call child services on you, and they would just really frown upon it I feel like. But parents of adolescents and adults with disabilities, we don't have a choice. It's either do that or don't go to places that the rest of the family wants to go. That was pretty difficult.

Interviewer: Just a follow-up about that example, how did that affect you or make you feel?

Participant: It was stressful for the adult parents. I guess it just really brings to light the issues that our kids, adolescents, teens, adults with disability face. That we still have a long way to go, so it's very disheartening.

Interviewer: So how helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: It would be really helpful. It would improve our daughter's quality of life tremendously. It would enable our family to do more together, and it would just, overall, have a very positive impact.

Interviewer: Thank you. When choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Participant: I do consider it. I don't know of any places that do have them right now, so it's more of a what's my alternative or what is... is there a spot or a space that's safe and out of view and that sort of thing that could be used instead? Because like I said, I don't personally know of any places that have one right now.

Interviewer: So if you ask, how helpful or accommodating are locations when you ask about adult changing tables?

Participant: Well, they don't have that available. They'll be apologetic and what else can we do kind of thing. At Disney World, they did have... I can't remember exactly what it was called, but it was kind of a parent lounge for kids who needed to take a break. I think it was a family style set up with a kitchen and a larger bathroom, so I was able to lay her on the floor on the towel there and not be in public and have her exposed to other people. That's really the only place that I've ever been offered an alternative or another option that was somewhat better than nothing.

Interviewer: So you touched on this a little bit in the beginning, but what do you do if you have no access to a changing table?

Participant: Well, we don't go to the place. That means we don't go a whole lot of places. We use the floor with a towel, or we use a vehicle, so clear out a space in the back of someone's SUV or van, which is very difficult to do. My daughter, part of her disability is heat intolerance, so taking her to a parked vehicle in the summertime and having her be in there for any length of time is rather dangerous and not a good option. But those would be the things that I would do.

Interviewer: Okay, and are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Participant: Yes, absolutely. If it's an event that's going to be all day, we would not be able to attend.

Interviewer: Have you delayed or changed plans because there was no adult changing table?

Participant: Absolutely.

Interviewer: So if more adult changing tables were installed in Florida, what types of people would benefit the most, and why do you think that?

Participant: Well, I think that people with disabilities in their family would benefit. It's not just the people who have the different ability or the lack of ability to use a regular restroom facility. It's really the entire family that is affected, and so that's a lot of people. I don't know the numbers, but it's certainly a significant amount of people.

As I see in my profession, the number is continuing to rise, especially people who are diagnosed with autism spectrum disorder. That is really on the rise, and so it's just going to continue to be more of a problem for families in the future. I think if Florida was able to go ahead and do something like this, that we would really be ahead of the rest of the country and ahead of the problem, which is always good. We would be an example to other states of how to serve our citizens.

Interviewer: So when you're participating in society, how often do you encounter an adult changing table accessible to you, and do you think that this is adequate?

Participant: I have never encountered one, so, no, I do not think that's adequate.

Interviewer: Okay, so regarding the topic of adult changing tables, is there anything else that you would like to share?

Participant: No, I don't think so.

Interviewer: Okay. On a different topic, when traveling, was there a time that the height of a bed was an accessibility problem for you or someone you take care of, yes or no?

Participant: No.

Interviewer: Okay. All right, so these are all the questions that we have for you, ma'am. Thank you so much for reaching out. We really appreciate taking the time to talk with you.

Participant: Thank you.

Interviewer: Yeah, but I hope you have a wonderful day, ma'am.

Participant: You too. Bye-bye.

Interviewer: Thank you. Bye.

Resp 36

Responder: Hello.

Interviewer: Yes. Hello. My name is [interviewer]. I'm calling from the University of Florida.

Responder: Hi. Yes.

Interviewer: So, just to start off, a powered high-adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves. For adults who manage mobility limitations or incontinence, they provide a safe, sanitary, and comfortable space for assisted changing. Was there a time that an adult changing table would have been helpful to you or someone you take care of? Yes or no?

Responder: Yes.

Interviewer: Okay. So just before we begin, you received an email from the Family Cafe in April inviting you to tell us about how the lack of powered high-adjustable changing tables in public settings affects your loved ones. The university is conducting research with the Florida Building Commission to assess and determine the needs to adjust the building code by interviewing people affected by current standards. We are calling you because you completed the online scheduling form when the Family Cafe emailed you, your info will help inform and shape the commission's ruling. Everything you say will be confidential and will be reported with no identifying information.

There is no compensation for completing the survey, but your answers will help the Florida Building Commission making informed decisions. Your participation is voluntary. There are no right or wrong answer to these questions. You do not have to answer any question you do not wish to answer and you can stop the interview at any time. I want you to know that this call will be recorded for quality control purposes and will be transcribed, summarized, and aggregated with other participants and the survey should take 10 to 15 minutes.

So first I'd like to ask you to tell us a little bit about yourself and why the lack of adult changing tables is an important issue for you?

Responder: I have a son who can't walk, can't talk, and he... Due to his conditional he also... There's no way for him to self transfer. He also can't be potty trained due to his disability, as well, so it's... Having the adult sized, adjustable-height changing table is a huge thing. Otherwise, we're on the floor, on a blanket, but the blanket is something you have to carry with you. So, you're laying on the floor and having to transfer to the is dangerous.

You know, it's a huge hygiene issue. You're down there with feces that's carrying Hep C, Hep A, Hep B. You've got... I mean, the hard floor is an issue for those who have muscle spasms and their body and head jerks. It's just... It's a dignity thing, just because you put in a stall with a, supposedly, accessible toilet, it's only for those

individuals who are paraplegics, not quadriplegics, not cerebral palsy advance, not Parkinson advance, not chorea and other movement disorders. So you're... These things are going to make... Let's say for Florida, the big attraction Disney World, how much of the population can't go because there's no inclusive changing areas?

So you're going to have to bring a blanket that you have to tote around that's been on the bathroom floor. And you have to try to lift your... You know, [inaudible 00:04:03] an adult onto the floor to change them. And even just from a lawsuit standpoint, so I injured myself trying to get him onto the floor because it's covered in the water or urine and I slip. Or he has a spasmodic episode while he's on the floor and cracks his head open. I mean, there's just so many issues, it's more than you can go into in one simple conversation.

I mean, it's protection, it's inclusivity, it's accessibility, and it's something that just needs to start happening everywhere. We need to start having an adjustable-height adult changing table and hoists and have actually accessible places for people to get out in the world and safely be able to use the restroom.

Interviewer: And would there be anything else that you would like to add to that opening statement, ma'am?

Responder: Just that... You know what, the US is far behind the UK, as far as having safe changing places for the severely disabled. And I'm glad to see that at least the state of Florida is trying to... Or the University of Florida is trying to make a change to that.

It's a big deal and it's far overdue.

Interviewer: Okay. So have you heard about adult changing tables and, if so, where have you heard about them?

Responder: Yes. I actually have heard about them and known about them through ChangingPlaces.org and they are an organization that, especially in the UK and are trying to start up here in the US, to get safe, inclusive restrooms for everyone.

Interviewer: Mm-hmm (affirmative)

Responder: Including adjustable-height adult changing tables.

Interviewer: Okay. So how much of a problem is not having an adjustable adult changing table when you are participating in society?

Responder: It means that my son can't. He can't... If there's no place to change him, and to safely do it and with dignity and to not expose him to feces and urine, how acceptable would life be to you if you had to lay on the floor to have someone change you? It's bad enough that he has to have someone change him, but now he has to do it on the bathroom floor? I mean, anyone who would put themselves for a moment mentally into those shoes, where they wouldn't have to lay on the floor of the bathroom, and then carry around with them the pad or the changing mat for the rest of the day that

they threw on that floor, that filth floor. And that laundry that every time you go out, on top of everything else you have to do to care for someone with a disability?

It makes the world inaccessible.

Interviewer: And would you mind telling me about a specific example?

Responder: Yes. So if I want to take my son to the zoo, like so many kids get to do on their field trips, with his special ed class, if it's going to be an outing longer than four hours, I already know I can't take him because I need to change him after that point, for his own hygiene.

So I don't live within route to even let him participate in something that, you know, all these kids get to do. An educational and a fun experience because I'm not willing to endanger ourselves by trying to unsafely be on the floor and I'm not going to expose him to the filth down there. And it's just not something that he needs to go through because people can watch him from under the stall. To be exposed and laying on a dirty floor? No. It's humiliating. It's unsafe. And it's unhygienic.

Interviewer: So how helpful would it be to you if public places had adjustable adult changing tables available to you?

Responder: It would be, quite literally, life changing. It would open doors to experiences that he currently doesn't have opportunities to participate in. It with make going to the doctors office, to a specialist, which is a two and a half hour drive one way. And even most hospitals don't have an adult-sized changing table restroom. So, yeah, it would make everyday life even better because not only would the things we have to do, therapy, doctors appointments, specialists, safer and healthier, but it would also allow him to do other things instead of every time he goes out into the world it's for a doctor's appointment.

It would be nice for him to be able to go out and go to the zoo, go to Disney Land, go to any place that everyone else takes for granted.

Interviewer: So when choosing things to do or places to go, do you consider if certain places will have changing tables for adults?

Responder: Absolutely.

Interviewer: And so if you ask how helpful or accommodating are these locations when you ask about adult changing tables?

Responder: Almost no place in the US has them right now. So I haven't come across anyone who has had them, at least in southern California. And as far as when you ask people, they don't understand the... They tell you, "Oh, yeah. We have a handicap restroom." Yeah. That's not accessible for my son. "Well, I'm sorry. I don't know what we can do." That's it.

That's all you get is a blank stare and, "I don't know how we can help you." But if anyone else, God forbid, went shopping to the mall and didn't have access to a restroom, or went to a restaurant and didn't have access to a restroom, it would be considered a health code violation in a restaurant. But you can deny it to someone who's already has enough challenges in their life.

They're already bound to a wheelchair and need assistance from another human being and you don't even give them the right to be able to go out and enjoy that meal because they can't be clean and have some dignity. It's just... If people would just stop and think about that for one second, if they didn't have restrooms, they were given the choice to lay on the floor, how important would it be?

Interviewer: And you've touched on this a little... Quite a bit, but what do you do if you have no access to a changing table?

Responder: If I have no access? It depends on the facility. If it's too filthy, then he has to sit in his own filth until we can get into a place that we can change him or get him home. If it's something where he has to be changed, right then and there, then we have to try to make do. Which means we don't go out anywhere to the doctor's office, because at least in the doctor's office, I can change him on the exam table because they have changeable mats and it can be wiped down, just like an adult changing table would.

So again, we don't go out because there's not a place to safely take care of him. He doesn't do anything but doctor's appointments and therapy.

Interviewer: So that ties into my next question, are there places or events that you are unable to participate in due to the lack of accessibility to an adult changing table?

Responder: Yeah. Anything you would need a restroom for, we can't go to. That's pretty much expected almost everywhere.

Interviewer: And just to follow up with that question, have you delayed or changed plans because there's no adult changing table?

Responder: Yeah. Like I said, we don't go places like the zoo, we don't go... I don't take him out with me, like I said, longer than four hours, and unless it's to a specialist or a doctor's appointment, because it has to be close to home so that if he needs to be changed, I can get him right home or I can be done with the activity in that amount of time and be home in order to have a safe place to change him.

So yeah, it's severely restricted to quality of life and what we can do.

Interviewer: If more adult changing tables were installed in Florida, what types of people would benefit the most and why do you think that?

Responder: What types of people wouldn't? So, I mean, aside from the people, the caregivers, and the people that need it, like I said before, how many lawsuits are wanting to

happen because someone unsafely tries to lift another grown human being down to the floor, a wet floor, a wet tile floor?

How many places aren't getting revenue because then we've like ours know we just can't go. I mean, it's not just as simple as even being inclusive, it's goes as far as economic value, safety. You know, it's a full faceted thing. Whenever you're overlooking something as basic as safe access to a restroom and now you have an entire sector of the population that isn't going to go shop at your places, isn't going to go recreate, it's going to travel to your destination because they know that it's not inclusive and there's nowhere safe. It affects everyone.

It affects the parent that see you changing your adult child, you know, or an adult. So, I'm a female, I take care of my son. I have to change my son, luckily he's still young but what about when he's 18 and I'm changing him on the floor and some mom has to explain to her three year old little girl what a penis is because I don't have the dignity because those stalls don't cover the bottom foot and a half of a stall.

I mean, this is... It's so far reaching and it's a ripple effect from not having this is just... It could go on and on.

Interviewer: And so when you're... I know you've said this before, but when you're participating in society, how often do you encounter an adult changing table accessible to you? And do you think that this is adequate?

Responder: I have not. I have not encountered one yet.

Interviewer: And so regarding the topics of adult changing tables, would there be anything else that you would like to share?

Responder: Yeah. I just think it's something that's long overdue. I think it's something that for a minimal amount of money to put in something, a room that'll fit... It's the size of a parking stall and you put in an adult-sized changing table, a toilet and a hoist, and a privacy screen. And how much could you change the lives of the people in those areas? How much more revenue? How much... How fewer lawsuits? How fewer indignities are people going to have to suffer?

And, you know, it is just all the things I've brought up, it's one room that could increase revenue, increase safety, increase tolerance, and increase the quality of an entire sect of the population wise.

Interviewer: And would there be anything else you'd like to share?

Responder: Nope. That's it. Just I thank you guys for conducting this research study and I really hope that the state of Florida does something groundbreaking with it. And that this can start a movement across the entire country. Because, like I said, the UK, they're starting to catch fire and they're getting a ton of these put in and we are so far behind. And we call ourselves... You know, we like to be egocentric and consider

ourselves the banner of progression for the world, here in the US, but we've completely forgotten about one basic human right.

You know? The ability to just go to use the restroom in a dignified and safe manner and we are not providing just even that. So, again, I really hope that this turns into something really great because there's tons of us, like myself and you guys, that are working towards this and I... You know, Europe's been working a hard time for a while to get it to where it starting to finally catch fire and, believe me, it's been lawsuits for people getting injured and it's been a lot of bad things for people to understand why this is a good thing for everyone, economically and safety-wise.

And, you know, it just... It's long overdue and thank you.

Interviewer: Yeah. No problem. But thank you so much for your time and thank you so much for taking the time to speak with us, we really appreciate it, ma'am. But I hope you have a wonderful day.

Responder: You too.

Interviewer: Thank you so much. Bye.

Responder: Bye.

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Participant: Hello, this is [name].

Interviewer: Hello, my name is [interviewer] and I'm calling from the University of Florida. You received an email from the family cafe in April inviting in to tell us about how the lack of power had [inaudible 00:00:26] tables in public settings affects you or loved ones. The university is conducting research with the Florida Building Commission to assess and determine the needs to adjust building code by interviewing people affected by current standards. Is now a good time to finish the survey? It's only about 10 to 15 minutes.

Participant: Yes, that's okay.

Interviewer: Okay, perfect. All right, so a power height adjustable adult changing table is a convenient and safe way for caretakers to assist individuals who may be unable to fully care for themselves? For adults who managed mobility limitations or incontinence, they provide a safe, sanitary and comfortable space for assisted changing. Was there a time that an adults' changing table would have been helpful to you or someone you take care of? Yes or no?

Participant: Yes.

Interviewer: All right. So, as I said, you received an email from a family cafe in April inviting you to tell us about the lack of power, how to adjustable changing tables in a public setting, and how it affects you or your loved ones. The university is conducting research about the... conducting research with rather the Florida Building Commission to assess and determine the need to adjust building code by interviewing people affected by current standards. We're calling you because you completed an online scheduling form when the Family Cafe emailed to you, and your input will help inform and shape the commission's ruling.

Everything you say will be confidential and will be reported with no identifying information. And while there's no compensation for the survey, your answers will help the Florida Building Commission make informed decisions. Your participation is voluntary. There is no right or wrong answers to these questions, and you don't have to answer any question you do not wish to answer. As well as he can stop interview at any time. And I also want you to know that the call will be recorded for quality control purposes as well as transcribed, summarized and aggregated with other participants. And as I said earlier, the survey should take about 10 to 15 minutes to complete.

Participant: Okay.

Interviewer: All right. So, first I'd like you to tell us a little about yourself and whether the lack of adult changing tables is an important issue for you.

Participant: Well, the reason I'm involved in is because I have an elderly parent, my mother who's in a wheelchair. And the caretakers that I have for her and myself when I'm with her

requires her for changing when she dirties herself and all. So, I found that that would be very convenient. It will be good if we could have more facilities like that, especially in public areas that are frequented by senior citizens, or people that like my mom or disabled, which is primarily in public areas. That's why.

Interviewer: Okay. And have you heard about adult changing tables? As well as, where have you heard about them? If you have.

Participant: I saw them online. I can't exactly pinpoint it now, but I did see one in a rest stop in North Florida, and I found it very interesting. And then it piqued my interest.

Interviewer: Okay. And how much of a problem is not having an adjustable adult changing table when you're out participating in society?

Participant: Well, it's a matter of an inconvenience. How inconvenient is an inconvenience? I mean, there's always ways around it. Right now there has to be ways around it because there aren't any facilities. But I would think, for example, traveling in airports and stuff like that, it would be a good place to have. But I think even just socially going to public places like parks and all that. Because the fact of the matter is when you're in elderly, when you're elderly or you're disabled a lot of the activities are passive activities that could mean like going out to parks and stuff like that, that don't have these facilities.

Interviewer: Okay. And how helpful would it be to you if public places had adjustable adult changing tables available to use?

Participant: If they were available to me?

Interviewer: Yes sir.

Participant: Oh yeah. I think that would be... it would be a great help for people that have to take care of people that require a system for changing themselves.

Interviewer: Okay. And you've already touched on this a little bit, but what types of things would you be able to give [inaudible 00:04:59] guess places you could-

Participant: I'm sorry. I didn't hear that.

Interviewer: All right. Can you hear me a bit better now?

Participant: Yes.

Interviewer: All right. You've already touched on this a little bit, but what types of things would you be able to do and places you'd be able to go if adult changing tables were available?

Participant: Well, I will be able to like if I knew where they were, I would be able to me myself take my mom, or my mom and the caretaker to those specific areas. Like I said, it

wouldn't... If I knew the facilities were there, it would make it easier to plan a trip for them. Right now my mom's basically home bound. So, there's not one particular place. It's just you'd have to follow the facilities, and then say, "Oh look, this has facilities, let's go do something there."

Interviewer: Okay. And when choosing things to do or places to go, do you consider if certain places we'll have changing tables for adults?

Participant: I'm sorry.

Interviewer: When choosing things to do or places to go, do you consider certain places will have changing tables for adults?

Participant: Yes.

Interviewer: Great. How helpful or accommodating are these locations when you ask about adult changing tables?

Participant: Well, they don't even know what it is. They ask, they say, "What are you talking about?" I mean, there's no... I mean, it's unheard of.

Interviewer: And what do you do-

Participant: I mean, there's no public education yet I think to the extent where people realize that they actually exist, and that they can be implemented.

Interviewer: And when you're out, what do you do if there's no access to an adult changing table?

Participant: Well, you... Right now they're called pampers and then you have to either finish what you're doing to get back to the house or you can... I can put my parent on a table or the caretaker can change her. Or they sit in and they have to wait. Because the alternative is to put somebody on a floor in a public restroom, and that's not very, very nice.

Interviewer: And are there places or events that you're unable to participate in due to the lack of accessible adult changing tables?

Participant: Yeah. I would say any place that doesn't have one would make it difficult to partake in that event.

Interviewer: And have you had-

Participant: Or I would say, the amount of time you could be at an event.

Interviewer: Okay. And have you had to change or delayed plans because there were no adult changing tables available?

Participant: No, not really. Because if I know they're not available, it's not an option. They're basically not available. I mean, they're... I've heard that there's an airport that might have one, or a rest stop that might have one, but in essence they don't exist. There needs to be a movement in order to make them happen.

Interviewer: And that's what we're trying to do here. And if there are more... Sorry. If more adult changing tables were installed in Florida, what types of people do you feel will benefit the most?

Participant: Disabled people that are not ambulatory, that need a full time caretaker. That can't help themselves and to the extent of eating or cleaning themselves and stuff. Let's see, even for... It's like a baby that... they have the baby changing tables everywhere, but this just happens to be an adult that has the same needs as a baby right now.

Interviewer: Okay. And when you're out participating in society, how often do you encounter an adult changing table that's accessible to you?

Participant: Never.

Interviewer: And this may be self evident, but I still want to ask. Do you think that this is adequate?

Participant: What is adequate? That they don't exist?

Interviewer: I guess so.

Participant: Yeah, no. Of course it's not adequate.

Interviewer: And is there anything else that you'd love to share with me?

Participant: No. I think it's something that... it's a small... it needs active people. It needs to be in the forefront of [inaudible 00:10:17]. It's something that might seem like it's a small group that needs it, but it's how the whole inception of the [inaudible 00:10:29] happened. It's for Americans with disabilities and these are Americans with disabilities, they need to be facilitated. And facilitating them is by providing these changing tables.

Interviewer: All right.

Participant: It's a matter of going on this step farther to get to where it has to be to help a portion of people of society that is in need of them.

Interviewer: Right. So, I want to thank you very much for your time and help talking with me today. I hope you have a great day, sir.

Participant: Okay. Thank you very much. Appreciate it. I hope that helps. Bye.