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Brief Report

“This is not built for me”: A qualitative study of adult-sized changing tables and public restroom accessibility

Geffen Treiman, MPH ^{*}, Maggie Cheng ¹, Madeline Oswald ¹

University of California Berkeley, School of Public Health, Berkeley, CA, USA

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ABSTRACT

Background: Adult-sized changing tables allow individuals with disabilities or medical conditions related to toileting to change with or without assistance. These tables are rarely found in public restrooms, and as a result, those who need them are often changed on floors, in vehicles, or are unable to stay in public spaces for more than a few hours.

Objective: This study aimed to understand how individuals who utilize adult-sized changing tables, or self-advocates, and caregivers for disabled people, access public restrooms and to report recommendations to improve inclusivity of public restrooms.

Methods: We virtually interviewed five self-advocates and sixteen caregivers in February and March 2023. We performed a qualitative analysis of the interview transcripts using MAXQDA 2022.

Results: Four major themes arose during interviews: social consequences, health effects, caregiver effects, and inaccessibility of restrooms in the healthcare setting. All caregivers have changed disabled individuals in vehicles, and 11 on public restroom floors, experiencing guilt and stress, and often receiving injuries. Several respondents reported limiting intake of fluids or using suppositories to prevent the need to toilet during unavoidable outings. Respondents most need height adjustable changing tables in healthcare settings, airports, and large recreational facilities.

Conclusions: Without adult-sized changing tables, individuals with disabilities are forced to risk their health and dignity to utilize public spaces.

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Many individuals with physical and developmental disabilities who need help with their toileting needs cannot use public restrooms. An estimated 61 million adults in the United States have a disability, with 3.6% of them unable to independently complete an activity of daily living such as using the toilet.^{1,2} Adult-sized changing tables allow individuals to take care of their toileting needs with or without a caregiver. These tables are rarely in public restrooms. Only five US states currently have a policy in place to require adult-sized changing tables in certain public facilities.³ None of the policies in place affect structures that have already been built, and are limited to future constructions or large scale renovations. As a result, many individuals who need these tables are changed on public restroom floors or backs of vehicles.³

Studies have shown that toileting care accounts for a significant burden for both caregivers and persons with disabilities, and can

delay hospital discharge after stroke or a traumatic brain injury.⁴ Additionally, access to public restrooms has been shown to be necessary for participation in the community; various minoritized groups have been limited in social participation through discriminatory bathroom legislation and barriers in the built environment.^{5,6} We conducted a qualitative analysis that consisted of interviewing caregivers and individuals who use adult-sized changing tables to understand the importance of these changing tables in public facilities, and report recommendations for initiatives or policies that pertain to public restrooms to improve inclusivity of public spaces.

Methods

Recruitment

The study was approved by the Institutional Review Board at the University of California, Berkeley. Recruitment occurred in January 2023. Purposive and theoretical sampling guided recruitment in ten different disability and caregiver Facebook groups with

^{*} Corresponding author.

E-mail address: geffentreiman@gmail.com (G. Treiman).

¹ M. Cheng and M. Oswald are undergraduate students.

permission from the group administrator. Individuals were screened via a questionnaire to ensure they were 18 years or older, were in the United States, and were either a self-advocate or a caregiver for an individual who needed help with toileting needs.

Interview guide development

The interview guide was designed in partnership with a caregiver of an individual who uses adult-sized changing tables. An individual who uses adult-sized changing tables was also consulted. Questions were refined based on a literature review of publicly available op-eds and news articles written by caregivers and individuals who use adult-sized changing tables. Questions were open ended and focused on experiences using public restrooms and collecting recommendations for improving accessibility.⁷ The interview guide was piloted on another caregiver and refined accordingly.

Interview procedures

Interviews occurred during February and March 2023 over Zoom, lasting 30 min to an hour. Interviews were conducted by the lead researcher G. T., who was a Master of Public Health candidate, and the reasons for doing the study were explained to participants. During interviews with caregivers, the care recipient was present if they were at least 18 years old, per caregiver preference. During self-advocate interviews, loved ones were present per participant preference. Interviews were audio recorded and transcribed verbatim. Participants who were non-verbal or unable to access Zoom completed a written interview in Qualtrics, for a total of two written interviews. No study participants dropped out of the study prior to interviews. No repeat interviews or follow ups were required.

Analysis

Transcripts were uploaded into MAXQDA 2022 qualitative analysis software. A preliminary code scheme was deductively defined using grounded theory based on available literature and contents of the interview and then inductively refined after a review of a subset of transcripts. The code book was an eclectic combination of emotion, descriptive, and in vivo coding. Two members of the research team separately coded three transcripts and refined the code scheme until inter-coder agreement was determined to be satisfactory (Rädiker & Kuckartz Kappa coefficient: 92%, Brennan & Prediger Kappa coefficient: 0.79). The remaining transcripts were coded per the final code scheme, and discrepancies were discussed and resolved.

Results

Participant demographics

16 caregivers were interviewed about 16 disabled individuals who used adult-sized changing tables. Disabled individuals had a mean age of 12.1 years old, ranging from 6 to 23 (See Table 1). Additionally, five self-advocates were interviewed with ages ranging from 30 to 55, for a total of 21 study participants. (See Table 2).

Where do caregivers change disabled individuals in public?

We identified the public locations where caregivers have changed care recipients (See Fig. 1). All 16 caregivers reported changing an individual in a vehicle or parking lot at least once. 10

Table 1
Caregiver and care recipient demographics.

Caregivers (N = 16)	
Age^a	N (%)
25–34	1
35–44	4
45–54	9
Gender	
Female	15 (94%)
Male	1
Race/ethnicity^a	
White	14 (88%)
Hispanic or Latino	1
Asian	1
Relationship to loved one	
Parent	16
Other	0
Care recipient (N = 16)	
Mean age (SD)	Range
12.1 (5.9)	6–23
Gender	N (%)
Female	5 (31%)
Male	11 (69%)

Demographic information of caregivers (N = 16) and care recipient (N = 16). Race/Ethnicity options included White, Black or African American, Native American or Alaska Native, Hispanic or Latino, Asian, Native Hawaiian or Pacific Islander, and Not Listed. Respondents could select multiple options.

^a Superscript denotes optional response.

Source: Demographic information of caregivers (N = 16) obtained from Qualtrics survey. Demographic information of care recipients (N = 16) obtained from caregivers during interviews.

Table 2
Self-advocate demographics.

Age (SD)	Range
41.4 (8.2)	30–55
Gender	N
Female	1
Male	4
Race/ethnicity^a	
White	4
Native American or Alaska Native	2

Demographic information of self-advocates (N = 5). Race/Ethnicity options included White, Black or African American, Native American or Alaska Native, Hispanic or Latino, Asian, Native Hawaiian or Pacific Islander, and Not Listed. Respondents could select multiple options.

^a Superscript denotes optional response.

Source/Notes: Demographic information of self-advocates obtained from Qualtrics survey.

caregivers have changed an individual on a baby changing table when that individual was over the weight limit. 11 have changed on a public restroom floor. Caregivers describe the experience of having to change someone on the floor as “humiliating,” “degrading,” “exhausting,” and “heartbreaking” but recognize they often have no other choice. Other reported locations for public changes include park benches, picnic tables, medical exam room tables, airport hallways, and public shower benches, with one caregiver stating, “I’ve changed him on a picnic table at a park, and several times on a park bench because it’s so much better to do that than to lay them on the floor or on the ground.”

We identified four major themes in the interviews: social consequences, health consequences, effects on caregivers, and inaccessibility of restrooms in the healthcare setting. Major themes and selected responses are included in the Appendix Exhibit A1.

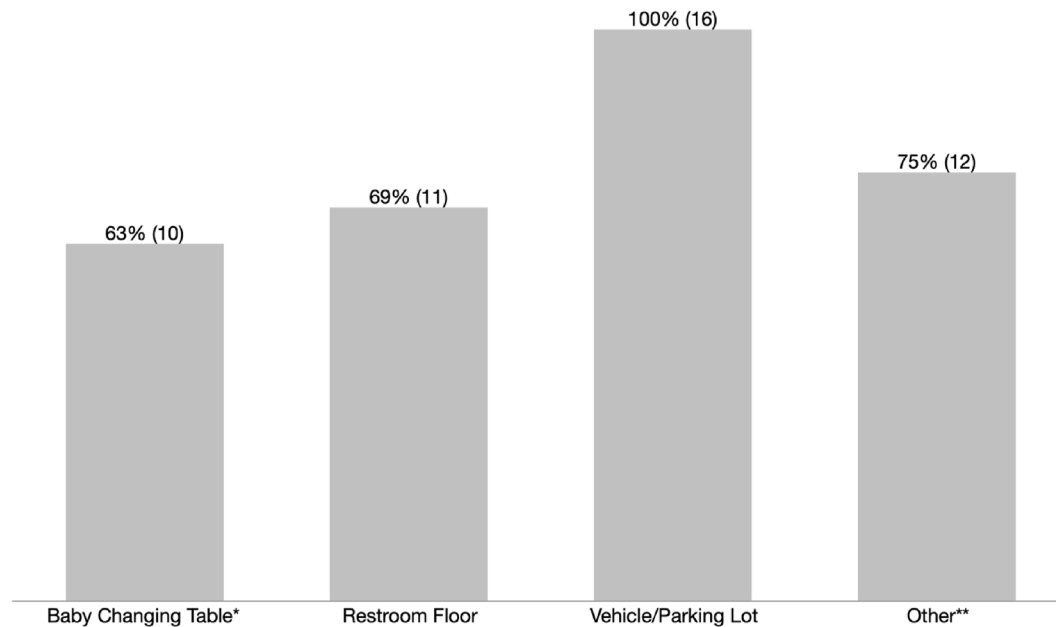


Fig. 1. Public places where caregivers have changed careiving recipient (N = 16).

Source/Notes: Prevalence of public locations in which caregivers reporting changing careiving recipient at least one time among participants (n = 16). *Changing on baby changing table when the individual is over recommended weight limit, too large (“legs hanging off”), or noticing baby changing table unable to support individual (“table started to buckle”). **Other public locations reported include park benches, picnic tables, medical examination tables, first aid stations, airplane floors, airport hallways, shower benches, grassy lawns in parks, restroom counter tops, folding tables, office conference rooms, and with individual in their wheelchair. Figure created in MAXQDA 2022 software.

Social consequences

Participants reported that without adult-sized changing tables, they cannot stay out for more than two or three hours at a time. One caregiver said “I know that that’s an eventuality that if we go to this place he will need to be changed and there won’t be a place to change him. So by that time it just won’t make sense to go at all. So I would say, we may sometimes go to parks that are very near our house.” One caregiver said “every single solitary decision we make about when or where we’re going, it’s innate. We are always thinking about our strategy for changing [her] because of her wheelchair.” Another said “My oldest son is getting married, so that’s going to be a day to enjoy. But also my very first thought is, what am I going to do about changing [my other son]?”

Caregivers also pointed out that having to leave early or stay home affects the entire family, including siblings of the individual who needs the changing table. One caregiver reported “I have avoided enrolling my younger son in sports because I wouldn’t be able to take his brother along and sit through a whole sports game because I know there’s nowhere to change. I try to just have my younger son ... ride bikes to get exercise instead of enrolling him in soccer.”

Additionally, caregivers reported a lack of privacy during changes, especially when there is not a family or single occupancy restroom. One participant overheard a stranger say, “That is so disgusting she would lay her child down on the floor like that,” after she changed her son on a towel on the restroom floor. Incongruent gender between caregiver and careiving recipient makes this process even more difficult if there is not a family restroom. Several other caregivers mentioned that many parking lots have cameras as well as feared potential legal repercussions: “I’m scared a police officer will see me changing my 16-year-old in the van and give a citation for indecent exposure or something.”

Health consequences

Injuries

There were several reports of injuries to the individual being changed. For example, one caregiver said “there have been a few times that she sat down too fast and hit her head because she knew what was coming. So she sits down and she flops back, and she’s hitting her head a few times, you know, on the floor of the bathroom.” Another recalled “it was at a facility for children with special needs, we went to the bathroom. Trying to get him onto the counter, he slipped, and he hit his head.” Difficulty of these changes and risk of injury is exacerbated when individuals have medical equipment such as trach tubes or catheters, or have spasticity, seizures, or recent surgeries.

Hacks and strategies

Participants were asked “how do you get around this problem of restrooms if you have to be out in public or travel?” Some caregivers reported giving suppositories or enemas prior to outings to limit the need to use a restroom. Other participants reported skipping boluses and limiting fluid intake, with one caregiver stating, “we skip her bolus when we take her to therapy ... solely because there’s no changing table [at the Children’s Hospital].”

To maintain privacy and sanitation during unavoidable public changes, 13 caregivers reported carrying around towels, mats, and folding tables to use during changes. Another stated “even if it’s only a day, we usually get a hotel room near to where we’re going, and then that way, we always go to the hotel, change him, and then go back out.” One caregiver said, “we strategically park in the back of the parking lot, even though he has a wheelchair tag because we want to give him that privacy when we do that diaper change.” Another common strategy was visiting a location ahead of time to see if there is a private closet or a folding table where the change could take place.

Effects on caregivers

Caregivers described injuries they have received when trying to change individuals without an adult changing table, with injuries to backs and shoulders being the most common. One caregiver said, "I have a bulging disk ... It's very hard on my body" and another said, "it's breaking my back, because I'm physically shlepping a 43-pound person to the ground."

Caregivers are under immense pressure to find a solution as well as make difficult decisions regarding going out of the house. Many described that the impossible task of finding a safe, private place for changes caused emotional and mental tolls. One caregiver stated, "any time we leave our home, and I don't know where I'm going to change him, it causes me extreme anxiety."

Caregivers also reported dedicating time and energy to increase adult-sized changing tables in public restrooms; 10 caregivers got involved in restroom specific advocacy efforts, one started a non-profit organization to fund an adult-sized changing table at her child's school, and another ran for city council.

Inaccessibility of restrooms in the healthcare setting

Hospitals and medical centers rarely had adult-sized changing tables in restrooms, according to caregivers. Many caregivers reported that their major hospital or medical center did not have adult-sized changing tables in the restrooms, with one caregiver stating, "these places that expect to have complex kids don't even have the diapering systems that he needs." Most caregivers performed changes on examination tables before or after appointments, though this may not be possible if the exam room is occupied by another patient or if the exam table is not height adjustable. One caregiver described a time the hospital front desk sent her and her son to the emergency room to change but "the ER didn't want [them] using their bed and having to clean it."

Self-advocate specific responses

We also interviewed five self-advocates, who are individuals who require restroom specific accommodations for either a disability or a chronic medical condition related to toileting. Four of the self-advocates identified as disabled. Three of five self-advocates needed an adult-sized changing table for their toileting needs. Four reported limiting fluid intake to avoid having to use public restrooms, with one self-advocate sharing, "I just dehydrate myself generally, so I don't have to use [public bathrooms]. I know it's not going to be accessible, so I won't try." Two self-advocates have changed themselves on a public restroom floor. One self-advocate with a neuromuscular condition who needs a bidet reported that he only goes out twice a year, but stated that if public restrooms had bidets, he would be able to go out all the time.

Self-advocates also emphasized the importance of single occupancy or family restrooms, citing privacy concerns. One participant stated, "there are limited family restrooms and if [my husband] needs to be there with me, we must either close the bathroom down or yell 'man in the restroom', and it's just awkward." Additionally, some self-advocates have had to leave stall doors ajar, because even "ADA stalls" cannot fit their wheelchair and their caregiver inside. Another participant said "people take audio recordings of me changing myself. Also, some people can post diaper sightings online."

Accommodations needed

Participants were asked what a restroom would need to include to be accessible. All 16 caregivers needed an adult changing table

for their disabled care recipient and three self-advocates needed one. Additional features mentioned were height adjustability, safety railings, and lifts and hoists. Single occupancy or family restrooms were important for privacy. Other features not specific to changing tables that were also mentioned include grab bars, handrails, bidets, sensory friendly and quiet hand dryers, sanitary place to dispose of trash, and signage.

Respondents would most like to see these accommodations in healthcare settings, especially in outpatient facilities where individuals do not have a hospital bed. Respondents also reported that they most need accessible restrooms in airports, rest stops, and large recreational facilities like arenas, stadiums, and amusement parks where patrons spend all day in and there is not easy re-entry. Participants recognized that these accommodations, particularly changing tables, may not be affordable to many smaller public facilities, but if they are placed strategically, people can find them. One participant said "it doesn't necessarily have to be right where you are. But if you know this one just close by, it makes a big difference."

Discussion

These findings paint a deeply concerning picture regarding the human rights and access to sanitation for individuals with disabilities who use adult-sized changing tables. Our results show that many disabled individuals experience shame, humiliation, a lack of privacy, and physical injuries during these public changes. Privacy and safety are necessary for dignified toileting as well as the human right to sanitation which is recognized by the United Nations General Assembly.^{8,9}

Toileting experiences specific to the healthcare setting such as skipping boluses on days of appointments, falling off counter tops during unsafe changes, and being directed to the emergency room show how persons with disabilities are forced to risk their health during the act of seeking care. This finding was both unexpected and disturbing when we consider that facilities such as hospitals and physical rehabilitation centers generally serve a larger population of disabled individuals compared to most other public settings. Notably, the Americans with Disabilities Act prohibits discrimination on the basis of disability in the healthcare setting.¹⁰ Furthermore, participants identified healthcare setting as an area where these tables would be most impactful.

We found that these violations to physical and psychological wellbeing are not limited to disabled people who use these tables, but affect both members of the caregiver-recipient dyad. The immense guilt as well as physical strain associated with toileting reported by caregivers is in line with previous studies.^{11,12}

We found that individuals who use adult-sized changing tables varied significantly in their mobility, level of independence or need for assistance from another individual, and requirement for additional features such as height adjustability and hoists. Thus, the seven principles of universal design should guide implementation of changing tables and be equitable, flexible in use, simple and intuitive, provide tolerance for error, require low physical effort, and provide appropriate size and space for use.¹³⁻¹⁵ Placing tables in private spaces such as single occupancy restrooms, including safety features such railings and padding, including hoists and lifts to minimize strain, and having large weight capacities will maximize these principles. Additionally, disabled individuals and their loved ones must be consulted in these efforts.

Limitations

The study had several limitations. First, 15 of the 16 caregivers interviewed were female, a limitation that is reflective of a lack of

gender diversity within the topic of research on caregiving. Another limitation of this study was the lack of racial diversity among participants. The caregivers interviewed were overwhelmingly White and no caregiver or self-advocate participants were Black. This study likely did not capture additional trauma, experiences of racism, and marginalization that could occur during these experiences.

While the interview guide was developed in partnership with both a caregiver and an individual who uses adult-sized changing tables, a focus group would have been a more robust method for developing the guide. Additionally, while multiple members of the research team have family members with disabilities, no members of the research team were disabled. Only five self-advocates were interviewed, indicating an area for further study, as caregiver experiences likely differ from experiences of individuals being changed. Finally, 10 of the 16 caregivers were involved in advocacy for adult changing tables, indicating potential self-selection bias.

Conclusion

This is the first study to systematically examine how disabled individuals who use adult-sized changing tables and their caregivers access public restrooms, where these accommodations are needed, and which features are required. 33 years after the Americans with Disabilities Act, many individuals with disabilities and their caregivers remain severely limited in their ability to participate in the community and face threats to their health and dignity. Key stakeholders in medicine and public health should advocate for regional and institutional policies that require and fund the inclusion of adult-sized changing tables in healthcare centers. Individuals interested in adult changing table related advocacy should first visit the Changing Spaces Campaign and Universal Changing Places websites which provide resources for reaching out to local representatives for policy support and requesting the installation of a changing table in various public facilities.^{16–18} Businesses and facility managers should visit the Momentum Refresh initiative, which provides mobile, adaptive restroom units equipped with adult-size changing tables and hoists.

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Conflicts of interest

The authors have no disclosures or conflicts of interests to declare.

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Appendix A. Supplementary material

Supplementary material to this article can be found online at <https://doi.org/10.1016/j.dhjo.2023.101520>.

References

1. *1 in 4 US Adults Live with a Disability*. Centers for Disease Control and Prevention; April 10, 2019. Published <https://www.cdc.gov/media/releases/2018/p0816-disability.html>. Accessed May 29, 2023.
2. Okoro CA. Prevalence of disabilities and health care access by disability Status and type among adults — United States, 2016. *MMWR Morb Mortal Wkly Rep*. 2018;67. <https://doi.org/10.15585/mmwr.mm6732a3>.
3. Treiman G. No dignity on the floor: a human rights argument for adult-sized changing tables in public restrooms in the United States. *Health Hum Rights*. 2023;25(1):213–221.
4. Yachnin D, Gharib G, Jutai J, Finestone H. Technology-assisted toilets: improving independence and hygiene in stroke rehabilitation. *J Rehabil Assist Technol Eng*. 2017;4:2055668317725686. <https://doi.org/10.1177/2055668317725686>.
5. Hochbaum R. *Bathrooms as a Homeless Rights Issue*. SSRN Electron J; 2019. <https://doi.org/10.2139/ssrn.3352868>. Published online.
6. Philips RR. The battle over bathrooms: Schools, courts, and transgender rights. *Theory Action*. 2017;10(4):100–117. <https://doi.org/10.3798/tia.1937-0237.1729>.
7. Rubin H J, Rubin I S. *Qualitative Interviewing (2nd Ed.): The Art of Hearing Data*. SAGE Publications, Inc.; 2005. <https://doi.org/10.4135/978145226651>.
8. Winkler IT. The human right to sanitation. *Univ Pa J Int Law*. 2015;37(4):1331–1406.
9. The office of the united nations high commissioner for human rights: about water and sanitation. OHCHR. <https://www.ohchr.org/en/water-and-sanitation/about-water-and-sanitation>. Accessed December 3, 2022.
10. Americans with disabilities act of 1990, AS AMENDED with ADA amendments act of. <https://www.ada.gov/pubs/adastatute08.htm#12101>; 2008. Accessed October 19, 2022.
11. Tuttle D, Griffiths J, Kaunnil A. Predictors of caregiver burden in caregivers of older people with physical disabilities in a rural community. *PLoS One*. 2022;17(11):e0277177. <https://doi.org/10.1371/journal.pone.0277177>.
12. Bollinger R, Somerville E, Keglovits M, Hu YL, Stark S. Feasibility of an automated bidet intervention to decrease caregiver burden. *Am J Occup Ther*. 2021;75(5):7505345020. <https://doi.org/10.5014/ajot.2021.043919>.
13. Story MF, Mueller JL, Mace RL. *The Universal Design File: Designing for People of All Ages and Abilities*. Revised Edition; 1998. Published online <https://eric.ed.gov/?id=ed460554>. Accessed August 10, 2023.
14. Null R. Introduction universal design: themes and experience. *Hous Soc*. 1995;22(1-2):1–4. <https://doi.org/10.1080/08882746.1995.11430214>.
15. The 7 principles | centre for excellence in universal design. <https://universaldesign.ie/what-is-universal-design/the-7-principles/>. Accessed August 10, 2023.
16. Universal Changing Places. <https://universalchangingplaces.com/>. [Accessed 11 September 2023].
17. Changing Spaces Campaign. <http://www.changingspacescampaign.org/>. [Accessed 27 October 2022].
18. Momentum Refresh. <https://momentumrefresh.org/>. [Accessed 11 September 2023].