The Hidden Crisis: Long COVID's Association with Housing Stability and Home Accessibility Among People with Disabilities

Kelsey Goddard, PhD, Andrew Myers, MA, Catherine Ipsen, PhD

PII: S1936-6574(24)00081-5

DOI: https://doi.org/10.1016/j.dhjo.2024.101650

Reference: DHJO 101650

To appear in: Disability and Health Journal

Received Date: 18 December 2023

Revised Date: 3 June 2024

Accepted Date: 6 June 2024

Please cite this article as: Goddard K, Myers A, Ipsen C, The Hidden Crisis: Long COVID's Association with Housing Stability and Home Accessibility Among People with Disabilities, *Disability and Health Journal*, https://doi.org/10.1016/j.dhjo.2024.101650.

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

© 2024 Published by Elsevier Inc.



Running Head: Long COVID's association with housing

The Hidden Crisis: Long COVID's Association with Housing Stability and Home Accessibility Among People with Disabilities

*Kelsey Goddard, PhD^a Andrew Myers, MA^b Catherine Ipsen, PhD^b

* Corresponding Author

^a University of Kansas, Institute for Health and Disability Policy Studies (KU-IHDPS) 1000 Sunnyside Ave., Room 1052 Lawrence, KS 66045 United States Phone: (785) 864-7085 ksg@ku.edu

^b University of Montana, Research and Training Center on Disability in Rural Communities (RTC:Rural)
253 Corbin Hall
Missoula, MT 59812
catherine.ipsen@mso.umt.edu; andrew.myers@mso.umt.edu

Conflict of Interest statement: The authors have no conflicts of interest to report.

Funding & Acknowledgement: The National Survey on Health and Disability (NSHD) is administered by the University of Kansas Institute for Health & Disability Policy Studies (KU-IHDPS) and funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR project #90IFRE0050). The contents of this manuscript do not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the federal government.

Key words (3-5): Long COVID, COVID-19 pandemic, housing stability, home accessibility Abstract word count (250 max): 250 Manuscript word count (4,000 max): 4,896 Number of references: 34 Number of tables: 3 Number of figures: 0

Abstract

| 2 | Background: The COVID-19 pandemic has given rise to the emerging phenomenon known as |
|----|--|
| 3 | Long COVID, characterized by persistent symptoms long after the acute infection has passed. |
| 4 | However, the relationship of Long COVID on housing stability and home accessibility remains |
| 5 | underexplored. |
| 6 | Objective: This manuscript aims to comprehensively examine the association of Long COVID |
| 7 | on housing stability and accessibility, identifying challenges faced by people with Long COVID |
| 8 | and potential strategies to address them. |
| 9 | Methods: The study employs a cross-sectional mixed-methods approach, combining quantitative |
| 10 | and qualitative methods. It analyzes data from 1,533 people with disabilities, 514 with Long |
| 11 | COVID and 1,019 without Long COVID, to compare demographics, housing stability, financial |
| 12 | concerns, housing problems, and home accessibility. Qualitative analysis extracts thematic |
| 13 | insights from 13 participant narratives. |
| 14 | Results: Individuals with Long COVID exhibit significantly higher rates of housing instability |
| 15 | (21.1% v. 8.1%, $p < .001$) and financial concerns, such as worries about high rent or mortgage |
| 16 | (50.4% v. 40.0%, p < .001), compared to those without Long COVID. They also report more |
| 17 | frequent issues with pests (30.0% v. 23.5%, p < .01) and mold (22.0% v. 12.7%, p < .001) in |
| 18 | their homes. Qualitative analysis reveals financial setbacks, difficulties in obtaining support, and |
| 19 | the challenges of home accessibility. |
| 20 | Conclusions: Associations between Long COVID and challenges related to housing stability and |
| 21 | home accessibility highlight the need for systemic changes, financial support, and advocacy. This |
| 22 | research contributes to understanding Long COVID's challenges, informing policy development, |
| 23 | and promoting compassionate responses, ensuring the well-being of people with Long COVID. |

| 24 | Introduction |
|----|--|
| 25 | In the wake of the COVID-19 pandemic, our understanding of the virus's far-reaching |
| 26 | consequences continues to evolve. Despite advancements in COVID-19 diagnosis, treatment, |
| 27 | and prevention, ^{1–3} the emergence of Long COVID introduces a complex and multifaceted |
| 28 | challenge to many disabled people who already face significant housing barriers. ^{4,5} The Centers |
| 29 | for Disease Control and Prevention (CDC) notes a significant prevalence, with 1 in 13 U.S. |
| 30 | adults (7.5%) now grappling with this condition, defined as symptoms lasting 3 months or more |
| 31 | after the initial virus contraction. ⁶ Amid this growing understanding, one area that remains |
| 32 | largely unexplored in the context of Long COVID is its potential impact on housing stability and |
| 33 | home accessibility, specifically for people with disabilities. |
| 34 | The persistent and varied symptoms, including debilitating fatigue, cognitive impairment, |
| 35 | and shortness of breath, ³ have the potential to disrupt an individual's ability to maintain stable |
| 36 | housing and navigate their home environment effectively. ^{7,8} These symptoms can significantly |
| 37 | impair daily functioning, making it challenging to manage employment ⁹ and fulfill financial |
| 38 | obligations, ¹⁰ thereby heightening the risk of eviction, foreclosure, or failing to meet the ongoing |
| 39 | demands of home maintenance. ⁷ Long COVID can exacerbate existing disabilities or introduce |
| 40 | new ones, ¹¹ necessitating adaptations in the living space ranging from minor modifications (e.g., |
| 41 | grab bars) to more significant accommodations (e.g., wheelchair ramps, specialized room |
| 42 | layouts), or even necessitate relocation to a more suitable living environment. ¹² |
| 43 | For individuals with disabilities, stable housing is not merely a place to live but a critical |
| 44 | factor in the ability to manage health conditions, maintain independence, and engage in |
| 45 | community life. Research shows that maintaining housing stability, which encompasses the |
| 46 | ability to stay in one's home without the threat of eviction or foreclosure, and having a home that |
| | |

47 is accessible and accommodating is essential for overall well-being and recovery.^{13,14} In this 48 context, housing stability not only refers to the physical suitability of the living environment but 49 also its financial affordability, ensuring that individuals can maintain their homes over the long 50 term without the threat of displacement. Therefore, addressing the housing needs of individuals 51 with Long COVID, particularly those with disabilities, requires a nuanced understanding of the 52 condition's impact on the essential role of adaptive, stable housing.

While existing literature extensively covers the immediate impacts of the COVID-19 53 pandemic on housing stability,^{15–18} a gap exists in understanding Long COVID's influence on 54 55 such critical, long-term aspects of people's lives. This manuscript aims to address this knowledge 56 gap through comparative and qualitative analyses, examining the relationships and experiences related to housing stability and home accessibility among individuals with Long COVID. We 57 hypothesize that individuals with Long COVID experience greater housing instability and 58 59 accessibility challenges compared to those without Long COVID, as evidenced by increased rates of financial concerns, housing-related problems, and the need for home adaptations to 60 61 accommodate new or exacerbated disabilities. Utilizing both quantitative and qualitative data, we delve into risk factors, potential interventions, and policy recommendations to mitigate these 62 63 challenges, contributing valuable insights for public health responses and policy development within the broader context of Long COVID. 64

65

Methods

66 Data Source and Sample

67 This cross-sectional study utilized unweighted data from the 2022 National Survey on
68 Health and Disability (NSHD), an internet-based survey of people with disabilities in the United
69 States, conducted from May to September of 2022. Given the inherent challenges in defining and

enumerating a representative population of individuals with disabilities—stemming from the
limitations of federal question sets which do not fully capture this demographic^{19,20}—the NSHD
adopted a purposive convenience sampling method. This approach aimed to engage a broad and
more inclusive array of respondents.

The target population for the NSHD consists of adults residing in the United States who self-identify as having "any physical or mental condition, impairment, or disability that affects daily activities and/or requires the use of special equipment/devices." This disability screening measure aims to capture a wide spectrum of experiences and conditions often overlooked by more restrictive federal definitions.

79 The recruitment process involved collaboration with over 60 national disability 80 organizations, leveraging their networks to distribute the survey broadly. These organizations 81 utilized various communication channels, including emails, newsletters, and social media, to 82 reach potential respondents, thereby enhancing the survey's visibility and reach within the 83 disability community.

The survey garnered responses from 2,725 adults with disabilities, reflecting a broad 84 array of experiences and conditions. However, due to the limitations in federal question sets, we 85 86 cannot confirm the representativeness of our sample within the broader disability population. This uncertainty underscores the complexity of defining a representative sample in this context. 87 Additionally, because we used a convenience sampling approach, we do not have data on the 88 89 survey's response rates. Participants were incentivized with a drawing for one of ten \$100 gift cards. All study procedures were approved by the University of [masked] Institutional Review 90 Board. 91

92 **Quantitative Measures**

| 93 | Long COVID status. Respondents were classified into "Long COVID" ($n = 514$) and |
|-----|--|
| 94 | "non-Long COVID" ($n = 1,019$) groups based on their response to the question, "Have you |
| 95 | experienced any COVID-19 symptoms for three months or longer following a suspected or |
| 96 | confirmed COVID-19 infection – also known as Long COVID? Examples of symptoms include |
| 97 | fatigue or extreme tiredness, cognitive problems, abnormal heart rate, shortness of breath, loss |
| 98 | of taste or smell, depression or other mental health conditions." Due to the survey design, |
| 99 | participants who did not confirm having contracted COVID-19 or responded "I don't know" |
| 100 | were not asked the Long COVID question, leading to the exclusion of 1,192 respondents. |
| 101 | Sociodemographic characteristics. Information collected included housing status [own, |
| 102 | rent, live long-term with friends or family, and other situation], living situation [alone or with |
| 103 | others], gender, race, ethnicity, age, self-reported health, and employment status. |
| 104 | Housing variables. "Housing instability," adapted from the Social Needs Screening |
| 105 | Tool, ²¹ was categorized based on participants' responses to their current living situation. |
| 106 | Individuals who reported a lack of a steady place to live or concerns about losing their place of |
| 107 | residence within the next six months were identified as having housing instability. "Housing cost |
| 108 | burdens," adapted from the American Housing Survey (AHS),22 encompassed perceptions of |
| 109 | high rent or mortgage payments and real estate taxes, with "high" being a subjective term based |
| 110 | on participants' own assessments rather than a predefined threshold. This category also included |
| 111 | utility bills, unsteady income, reliance on others for housing expenses, unexpected expenses, and |
| 112 | high debt, each scored as either present (1) or absent (0). "Housing-related problems," adapted |
| 113 | from the Social Needs Screening Tool, ²¹ included pests, mold, lead paint or pipes, lack of heat, |
| 114 | malfunctioning appliances, missing or non-functioning smoke detectors, and water leaks, |
| 115 | recorded as "yes" (1) if present. "Housing accessibility," an internally developed measured, was |

assessed based on the question, "How well do you think the layout and features of the place you *live now support you?*", rated from "not at all" (1) to "very well" (5). Quantitative data analyses
were conducted using cross-tabulations in SPSS (Version 28). Differences between the Long
COVID and non-Long COVID groups were tested using chi-square tests.

120 Qualitative Methods

121 We focused exclusively on individuals with Long COVID and conducted 13 in-depth remote interviews using Zoom and telephone, drawing from a purposively selected sample of 122 123 NSHD respondents. This sample was carefully chosen to represent a diverse range of 124 demographics, including housing status, gender, race, ethnicity, and geographical region. Our 125 semi-structured interview guide, refined through pilot interviews and expert feedback, was developed to ensure comprehensive coverage of relevant themes, such as the participants' 126 127 employment status, financial situations, and home environment interactions. During the 128 interviews, the flexibility of our approach allowed for thorough exploration and spontaneous follow-up questions, enriching the data collected. Each interview was recorded and transcribed 129 130 verbatim to maintain the integrity and accuracy of the participants' responses, and participants received a \$50 gift card for their contributions. The interviews were conducted from January to 131 October 2023. Following the interviews, a single coder performed an initial thematic analysis on 132 the transcripts,²³ identifying potential themes and categorizing the data. These initial themes 133 134 were then meticulously refined in relation to the data set and existing literature. To ensure the 135 robustness of our findings, two additional members of the research team reviewed the initial 136 coding. This collaborative effort aimed to validate and refine the identified themes, ensuring themes accurately reflected the participants' experiences with Long COVID. 137

138

Results

139 **Demographics**

140

- 141 Table 1 compares demographics of individuals with Long COVID (n = 514) to those
- 142 without (n = 1,019). The Long COVID group had significantly more females (p < .01).
- 143 Individuals with Long COVID were also significantly more likely to report poor/fair health and
- 144 not working (p < .001). Demographics of interview participants are also included in Table 1.
- 145 **Quantitative Findings**
- 146 147

148 Long COVID and non-Long COVID groups. Housing instability was markedly higher among

Table 2 presents a comparative analysis of housing stability and cost burdens between

- 149 the Long COVID group (21.1%) compared to non-Long COVID groups (8.1%). Participants
- 150 with Long COVID reported greater concerns about high rent or mortgage payments (50.4% vs.
- 40.0%), utility bills (55.7% vs. 45.5%), unsteady income (54.8% vs. 35.2%), relying on others 151
- 152 for housing payments (46.6% vs. 30.8%), and large, unexpected expenses (80.3% vs. 36.2%).
- 153 They also reported more concern about high credit card, student loan, or other debt (51.3% vs.
- 154 38.1%). However, concerns about high real estate taxes were similar, with 31.0% of respondents
- 155 in the Long COVID group and 27.1% in the non-Long COVID group expressing concern.
- 156 Regarding housing-quality issues, individuals with Long COVID reported more pest problems
- 157 (30.0% vs. 23.5%) and more prevalent mold issues (22.0% vs. 12.7%). Other housing concerns
- 158 showed minor differences. Concerning home accessibility, 17.6% of individuals in the Long
- 159 COVID group reported encountering unsupportive housing layouts and features, significantly
- 160 higher than the 11.4% reported among the non-Long COVID group.
- 161 **Qualitative Findings**
- 162 While Table 2 provides a comprehensive overview of housing stability and home 163 accessibility among individuals with Long COVID, our qualitative investigation reveals the

164 intricate ways in which Long COVID is associated with housing stability, financial burdens,

165 housing issues, and home accessibility. Seven overarching themes, each accompanied by distinct

166 key topics (shown in Table 3), offer unique insights into the challenges faced by these

167 individuals. The subsequent narrative presents detailed descriptions and representative quotations

168 for each theme, enhancing the depth of our findings.

169 Direct Impacts of Long COVID

Theme 1: Employment and financial impact on housing stability. The theme of 170 171 employment and financial impact highlights the profound effects of Long COVID on 172 participants' ability to work. Changes to employment status, resulted in significant income loss 173 and subsequent instability, which, in turn, affected housing stability. As participant #15724 states: "I've been unable to work as a result [of Long COVID] ... I was a geriatrician, a 174 physician for old people. And I was very busy, never worked less than 40 hours a week. I got 175 infected at work and have been sick ever since. And that was three and a half years ago." 176 177 The issue of high-deductible health insurance plans adds another layer to the financial 178 strain, as participant #15724 highlights: "I was a healthy person going into this. I was a long-179 distance runner. I had no reason to think that I would really need my health insurance. So, I had a high deductible plan... For the final year I was on [my employer-sponsored insurance], I spent 180 between \$10,000 or \$12,000." 181 182 The struggle to meet financial obligations extended beyond healthcare, affecting various

aspects of participants' lives such as bills, medications, and the pursuit of nutritious food. As

184 participant #11561 illustrates: "Aside from the little GoFundMe funds that I have gotten, which

all went to bills, there's no extra money for buying an electric wheelchair or getting a new car or

186 *finding a [more accessible] house... You just kind of feel stuck.*"

Participants also described the painful reality of depleting savings and liquidating assets like 401(k)s and personal belongings, a sentiment captured by participant #15340: "For a while, 188 189 I was paying my rent and the bare minimum expenses... just out of my savings account. I cashed 190 in my 401k. I cashed in savings bonds that I've had since birth... So, I was just blowing through 191 all the savings that I had amassed at this point in my life."

192 Finally, the necessity of lifestyle adjustments to cope with financial and health-related limitations is evident in participants' experiences, as participant #15724 describes: "I very much 193 194 decreased my expenditures. We sold our house and moved to a much smaller place... Basically, 195 we changed our lifestyle so that we could survive on just one income."

Theme 2: Home accessibility challenges. Participants detailed significant difficulties 196 with home accessibility, particularly with stairs, which became major obstacles in their daily 197 198 lives due to physical limitations and fatigue from Long COVID. Participant #15340 provides a 199 vivid account: "The stairs are definitely difficult. They're a lot of energy. Like do I have the energy to go up one more time...? And it's like no, I don't. I'm down here. I'm done for the day. It 200 201 just makes things a little bit more complicated... There's no running water down here. So, if I need to wash my hands or get a get a drink, I've got to go upstairs... And I'm not able to hold my 202 203 bladder as well as I used to. So, there was one or two accidents that I just cleaned up and don't 204 think about. Like everybody has an accident. It just sucks that I have to have them so young." 205 Kitchen accessibility was another critical issue, with many participants finding it 206 challenging to prepare meals due to the lack of suitable modifications (e.g., lack of accessible 207 countertops, cabinets, and appliances). As participant #15340 shares: "I'll get something on the 208 stove to start boiling and then just come in the other room and sit down. And wait until I hear it

start boiling because I can't stand there. And I mean, I used to cook a lot... And now I just don't
have the energy."

211 Bathroom accessibility posed additional hurdles, with participants facing challenges 212 using shower facilities, bathtubs, and the absence of assistive devices, significantly affecting 213 their personal hygiene and safety. Participant #11561's experience encapsulates these challenges: 214 "[Bathing] is so exhausting that I can only shower like once a week. And then it usually takes me about an hour and a half, or almost two hours, just for the actual showering part, not even 215 216 drying or getting dressed or doing anything. Because, at that point, I am laying on my bed 217 recovering after. And I have to use bath wipes and a shower cap type of thing on the other days." 218 Theme 3: Effects of home inaccessibility on daily life. Participants discussed the need 219 to manage their energy carefully due to fatigue and physical limitations caused by Long COVID, 220 necessitating prioritization of tasks to ensure well-being. As participant #15340 illustrates: "I 221 need to kind of gamble with my energy a lot of the times and what I can do. If my laundry doesn't 222 get done today, or if I need to finish it in the morning, that's not that big of a deal. But I had to 223 get the trash done today... I'm going to be on my bed the rest of today."

Inaccessible homes necessitated reliance on family members, friends, or caregivers for daily tasks and mobility within the home. Participants often found themselves unable to move around or use certain rooms without assistance, contributing to a heightened sense of dependence. As participant #11561 illustrates: *"There are about ten steps down to our driveway to get to one of the vehicles. I can't get down them by myself. My husband has to help me... Or like if my sister or my aunt or somebody is taking me to an appointment, they help me down the stairs. And they have to bring the walker and the wheelchair down for me... I can't do it alone."*

The combination of inaccessible rooms and limited mobility raised the risk of injuries,

particularly due to falls. Participants shared various instances of falls, broken bones, and 232

233 accidents within their homes. As participant #11561 states: "I don't think I've reciprocal walked

234 upstairs in at least a year and a half. It's always a one step because I lose my balance. And, with

235 the neuropathy, I can't always tell if I'm on the step. I had four falls in a year when I first got

236 sick. One of them resulting in a broken foot."

Inaccessibility within their homes prevented participants from engaging in community 237 238 activities and events, leading to feelings of being trapped and isolated, exacerbating their sense 239 of loneliness and exclusion. As participant #11561 notes: "I physically can't go outside of my 240 house by myself. And it is isolating... My whole existence is in my house... And it's literally all I have. My whole life is in this box. I live in a box." 241

242 One participant described a particularly challenging period when they became bed-

243 bound, highlighting the critical impact of home inaccessibility on the risk of institutionalization.

244 Participant #15642's account is telling: "I actually had considered and asked my health care

245 professional if I needed to move into a [nursing] home because I was completely bed bound. I

246 was in basically keeping bottles of Ensure around me just so I could drink it and not have to get

up, and I was literally wearing a diaper because I lost all control of my muscles." 247

Downstream Consequences 248

Theme 4: Deteriorating housing conditions. The theme of deteriorating housing 249 250 conditions sheds light on the struggles many participants faced in maintaining their homes, a 251 challenge directly linked to the physical limitations imposed by Long COVID. The inability to 252 perform even minor repairs or routine upkeep due to debilitating symptoms was a common 253 thread in participants' experiences, highlighting a significant aspect of their daily lives disrupted

by the illness. Participant #15724 vividly captured this sentiment: "We're constantly in a

situation where we have little things that need to be done around the house. We don't have the

ability to do it, and we can't find anyone to hire to do it... Things that are really, really little, but

257 we're just not capable of."

Compounding these challenges, participants also dealt with the breakdown of essential household appliances, adding layers of stress and practical difficulties to their already strained lives. As participant #15761's experience exemplifies: "*Of course, my washing machine broke during all this*… *And not having the money to buy another one, I'm having to go to the*

laundromat... I may or may not get [my laundry] back in the house that same day. But it won't
get put away that same day... Lifting, moving, picking up, bending... I've got arthritis in every
bone in my body now."

265 Moreover, some participants shared distressing accounts of how deteriorating housing conditions exacerbated their physical and emotional turmoil. As participant #14062 illustrates: 266 "The situation in my house that got so bad was they were doing some sewer repair outside. And 267 268 it tore up the street. And all the rats in the neighborhood came above ground... And at this point, 269 the dysautonomia was to such a degree that I would literally sometimes collapse. I could not 270 stand up. I was laying in tarps because the diarrhea never stopped... And then I look up, and 271 there's rats climbing my curtains and coming over the picture molding above my bed... So now I 272 have PTSD every night because this is what I picture when I'm falling asleep."

273 Efforts to Mitigate and Barriers

Theme 5: Home modifications and daily living aids. This theme explores how
participants adapted their living environments to better manage the limitations imposed by Long
COVID. Many participants undertook home modifications to enhance accessibility and support

their daily activities (e.g., installing railings, shower chairs, and raised toilets), reflecting a
proactive approach to mitigating the impact of their physical restrictions. As participant #15724
shares: "My wife actually built a fold out countertop so I can pull up a stool and sit at the
counter to do cooking or cutting things. Because, otherwise, if there's not a countertop that sticks
out, then my [legs] would not be able to go under the countertop, and I really wouldn't be able to
do it."

In addition to structural changes, participants incorporated various mobility aids (e.g.,
walkers and wheelchairs) to assist with navigation and reduce physical strain within their homes.
As participant #15340 illustrates: *"I've got these little dolly cart things that I got from some furniture store*. And I use those to get laundry or if I order a package... I use those to get from
one end of the house to the other. And I've got one on each floor so that I can use them. It's just
easier on my body when I can just lean onto something and just push it."
The theme also touches on participants' decisions to relocate to more suitable living

spaces. Downsizing or choosing homes with accessibility in mind was a critical step for some, as participant #15724 illustrates: "I had been in a colonial [house] where there was a long walk from my bedroom to the stairs to downstairs, and then another long walk to the kitchen. The setup was bad. And now I'm in a split level. I have only five steps and about 20 feet between me and the kitchen... So, that makes a really big difference that I don't have to walk far to get to the kitchen or the bathroom."

Theme 6: Financial constraints on home modifications. This theme underscores the financial hurdles participants encountered when considering necessary home modifications to accommodate their needs due to Long COVID. The cost of adapting homes for increased accessibility proved prohibitive for many, highlighting a significant gap between the need for

such modification and the ability to afford them. Participant #11561's statement encapsulates this

301 challenge: "We've tried to look into some different options for [home] modification. But it's

302 *expensive. And we don't have the finances to be able to really make any modifications.*"

Additionally, the theme touches of the difficulties of acquiring mobility aids, such as wheelchairs, which are crucial for maintaining independence and quality of life. As participant #15724 highlights: *"I looked into the process of getting a wheelchair and discovered that I had zero chance of it being approved by my insurance."*

Theme 7: Lack of support from agencies and healthcare. This theme delves into the 307 308 challenges participants encountered while navigating support systems, emphasizing the 309 difficulties in securing aid from both healthcare and social service agencies amidst the complexities of Long COVID. Participant experiences reveal a systemic struggle in accessing 310 311 private and Social Security disability benefits, with bureaucratic hurdles significantly impeding 312 their ability to obtain crucial financial support. As participant #15724's states: "The system basically is designed to automatically deny everyone on first pass and force everyone to hire a 313 314 lawyer... It wasn't until a couple months before my administrative judge hearing that I heard from someone that there was a form called a residual functional capacity form ... And it doesn't 315 appear that most doctors know anything about that." 316 317 The theme also captures participants' efforts to seek state and private rental assistance, 318 illustrating the temporary relief and subsequent challenges when such assistance runs its course.

319 As participant #15340 reflects: "Once [rental assistance] ran out, I wasn't able to afford my rent

anymore... So, I had to move. Right now, I am living in my grandparents' basement because it's

321 rent free... Because I definitely can't afford rent right now."

Moreover, the theme sheds light on the dissatisfaction and frustration with government 323 agencies, particularly when it comes to healthcare and personal assistance services. Participant 324 grievances about the inadequacies of Medicaid and other services illustrate the broader issue of 325 unmet needs within this community. As participant #14062 notes: "My situation here at the 326 house became so bad that last year, I called Adult Protective Services... I called the suicide crisis hotline. And I asked the crisis line to report me as a victim of neglect. Because... No one. No one 327 has come to help me." 328

329

Discussion

330 People with pre-existing disabilities have long grappled with housing instability and accessibility concerns.²⁴ These persistent housing problems²⁵ are potentially exacerbated by 331 Long COVID, emphasizing its role in a broader narrative of housing inequities.^{26–28} We should 332 333 view the experiences of individuals with Long COVID as a catalyst for addressing broader issues 334 and developing comprehensive solutions that benefit all individuals with disabilities. This study 335 emphasizes the pressing need to address these long-standing concerns, both within the context of 336 Long COVID and as part of a larger initiative to create inclusive and accessible housing for all. 337 Our findings indicate an association between individuals with Long COVID and 338 experiences of housing instability, which may be associated with high costs and unsteady 339 income. Healthcare practitioners should be aware of the financial challenges faced by these patients and consider referring them to financial counseling or support services, including 340 341 Medicaid or other assistance programs, which can provide critical support in accessing various necessary services.²⁹ 342

Policy changes, such as extended rent and mortgage relief programs³⁰ or enhanced job 343 protection for individuals with prolonged COVID symptoms,³¹ are crucial to address these 344

financial barriers. Additionally, systemic changes are needed to ensure economic stability for
individuals with disabilities, ensuring they have access to affordable housing options. Tailored
financial support, potentially accessible through Medicaid or specific grants designed for
individuals with disabilities, could alleviate some of the economic pressures contributing to
housing instability.

350 Furthermore, our study reveals that some people with Long COVID report struggling to maintain their homes due to physical limitations, impacting both housing stability and overall 351 health. Healthcare providers should assess the living conditions³² and recommend necessary 352 353 home health or rehabilitation services. Policymakers should also consider implementing 354 incentives or programs to assist Long COVID patients in maintaining their living environments. In this regard, systemic changes could include policies that mandate or incentivize the 355 construction of accessible housing units,²⁷ ensuring that new developments meet the needs of 356 357 individuals with varying levels of mobility and physical ability.

358 Our findings also highlight that some people with Long COVID encounter home 359 accessibility challenges, which may significantly affect their energy levels, reduce their 360 independence, and increase their risk of injuries. To effectively address these challenges, 361 collaborative efforts between healthcare practitioners, occupational therapists, and physical therapists are essential.³³ These professionals can provide a holistic approach to care, ensuring 362 363 that the individual's living environment is conducive to their recovery and daily functioning. 364 Healthcare providers also play a critical role in assisting patients in navigating resources for adaptive equipment and home modifications,³⁴ with potential support from Medicaid or similar 365 programs to facilitate these adaptations. This support from healthcare providers is vital in 366

367 supporting individuals with Long COVID adapt to their new limitations, promoting safety and368 autonomy within their living spaces.

On a broader scale, policymakers must recognize the importance of supporting home adaptations for individuals with Long COVID by expanding insurance coverage and grant programs, including Medicaid. Such initiatives would not only provide financial relief but also ensure that more people have access to the necessary modifications that can significantly improve their quality of life. By fostering an environment where comprehensive support is readily available, we can make a meaningful difference in the lives of those affected by Long COVID, helping them navigate their challenges more effectively.

376

Limitations

One limitation is the potential bias in self-reported data, which might affect the study's accuracy. The cross-sectional study design precludes causal inferences and examination of changes over time. Qualitative data, while valuable, may not capture the full diversity of Long COVID experiences, and subjectivity in qualitative data analysis may lead to different interpretations. Additionally, the researchers did not inquire whether respondents were currently experiencing Long COVID symptoms, which limits our understanding of the impacts of Long COVID on housing.

Moreover, the study's findings could be influenced by various confounding factors that were not controlled for, such as preexisting health conditions, socioeconomic status, and access to healthcare services. For instance, preexisting health conditions might exacerbate the severity of Long COVID symptoms, thereby increasing the individual's housing instability or need for accessible housing. Therefore, future research should consider these potential confounding factors to provide a more nuanced understanding of the observed relationships. Finally, the study

390 did not extensively explore regional or contextual factors influencing housing stability and

391 accessibility, which could offer additional insights into the barriers and facilitators of housing

392 equity for people with Long COVID.

Additionally, we acknowledge the inherent limitations of making inferences from nonprobability samples to the broader population. While our sample may not be representative of the general population, it is nevertheless fit for the purpose of this study, which involves examining relationships between population characteristics and key outcomes rather than focusing on the prevalence of those outcomes. This approach allows us to explore the complex dynamics and specific challenges faced by individuals with Long COVID in relation to housing stability and accessibility.

400

Conclusion

401 This manuscript underscores the profound connection between Long COVID and issues 402 with housing stability and accessibility, which persist beyond the initial infection. Individuals 403 with Long COVID may grapple with heightened rates of housing instability, financial stress, and 404 home accessibility challenges. Implementing systemic changes and tailored financial support is 405 crucial to enhance living conditions and alleviate the shortage of accessible housing. This 406 research contributes to a broader understanding of Long COVID challenges and advocates for a 407 more inclusive response to the pandemic's aftermath. We hope our findings spur further 408 investigations, shape policy development, and promote a compassionate, evidence-based 409 approach to support individuals with Long COVID.

| 410 | | References |
|-----|----|---|
| 411 | 1. | Lerner AM, Robinson DA, Yang L, Williams CF, Newman LM, Breen JJ, et al. Toward |
| 412 | | understanding COVID-19 recovery: National Institutes of Health workshop on postacute |
| 413 | | COVID-19. Ann Intern Med. 2021 Jul 20;174(7):999–1003. |
| 414 | 2. | Yong SJ. Long COVID or post-COVID-19 syndrome: Putative pathophysiology, risk factors, |
| 415 | | and treatments. Infect Dis (Lond). 2021;1–18. |
| 416 | 3. | Crook H, Raza S, Nowell J, Young M, Edison P. Long covid—mechanisms, risk factors, and |
| 417 | | management. BMJ. 2021 Jul 26;n1648. |
| 418 | 4. | Greiman L, Fleming SP, Ward B, Myers A, Ravesloot C. Life starts at home: Bathing, |
| 419 | | exertion and participation for people with mobility impairment. Arch Phys Med Rehabil. |
| 420 | | 2018 Jul 1;99(7):1289–94. |
| 421 | 5. | Greiman L, Koon L, Schulz JA, Nary D. A usable home: A qualitative investigation of the |
| 422 | | relationship between home usability and community participation for people with |
| 423 | | disabilities. Disabil Health J. 2022 Jan 1;15(1, Supplement):101211. |
| 424 | 6. | Centers for Disease Control and Prevention. Nearly one in five American adults who have |
| 425 | | had COVID-19 still have "Long COVID" [Internet]. 2022 [cited 2023 Nov 9]. Available |
| 426 | | from: https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2022/20220622.htm |
| 427 | 7. | Packard SE, Susser E. Association of Long COVID with housing insecurity in the United |
| 428 | | States, 2022-2023. medRxiv. 2023;preprint:1-29. |
| 429 | 8. | Karpman M, Fiol O, Popkin SJ, McCorkell L, Waxman E. Employment and Material |
| 430 | | Hardship among Adults with Long COVID in December 2022. Urban Institute; 2022. |

| 431 | 9. Perlis RH, Lunz Trujillo K, Safarpour A, Santillana M, Ognyanova K, Druckman J, et al. |
|-----|--|
| 432 | Association of Post-COVID-19 condition symptoms and employment status. JAMA Netw |
| 433 | Open. 2023 Feb 15;6(2):e2256152. |
| 434 | 10. Durstenfeld MS, Peluso MJ, Peyser ND, Lin F, Knight SJ, Djibo A, et al. Factors Associated |
| 435 | With Long COVID Symptoms in an Online Cohort Study. Open Forum Infectious Diseases. |
| 436 | 2023 Feb 1;10(2):ofad047. |
| 437 | 11. O'Brien KK, Brown DA, McDuff K, St. Clair-Sullivan N, Solomon P, Chan Carusone S, et |
| 438 | al. Conceptualising the episodic nature of disability among adults living with Long COVID: |
| 439 | a qualitative study. BMJ Glob Health. 2023 Mar;8(3):e011276. |
| 440 | 12. Swarnakar R, Yadav SL. Rehabilitation in long COVID-19: A mini-review. World Journal of |
| 441 | Methodology. 2022 Jul 7;12(4):235. |
| 442 | 13. Chen KL, Miake-Lye IM, Begashaw MM, Zimmerman FJ, Larkin J, McGrath EL, et al. |
| 443 | Association of promoting housing affordability and stability with improved health outcomes: |
| 444 | A systematic review. JAMA Netw Open. 2022 Nov 2;5(11):e2239860. |
| 445 | 14. Adamkiewicz G, Spengler JD, Harley AE, Stoddard A, Yang M, Alvarez-Reeves M, et al. |
| 446 | Environmental conditions in low-income urban housing: Clustering and associations with |
| 447 | self-reported health. Am J Public Health. 2014 Sep;104(9):1650–6. |
| 448 | 15. Foley E. COVID-19 and housing security: Assessing equity & efficiency across North |
| 449 | Carolina's emergency rental assistance programs. Sanford School of Public Policy at Duke |
| 450 | University; 2021. |
| 451 | 16. Versey H. The impending eviction cliff: Housing insecurity during COVID-19. Am J Public |
| 452 | Health. 2021;111:e1. |
| | |

- 453 17. Wagler A, Schober GS, Chavez-Baray SM, Ayala J, Dessauer PR, Moya EM. Food and
- 454 housing security at a US Hispanic-Serving Institution: An examination before and during the
- 455 COVID-19 pandemic. Public Health Front. 2022;10:918955.
- 456 18. Pollack CE, Leifheit KM, McGinty EE, Levine AS, Barry CL, Linton SL. Public support for
- 457 policies to increase housing stability during the COVID-19 pandemic. Am J Prev Med. 2021
- 458 Dec 1;61(6):919–22.
- 459 19. Hall JP, Kurth NK, Ipsen C, Myers A, Goddard K. Comparing measures of functional
- difficulty with self-identified disability: Implications for health policy. Health Affairs. 2022
- 461 Oct 1;41(10):1433–41.
- 462 20. Salinger MR, Feltz B, Chan SH, Gosline A, Davila C, Mitchell S, et al. Impairment and
- 463 Disability Identity and Perceptions of Trust, Respect, and Fairness. JAMA Health Forum.
 464 2023 Sep 22:4(9):e233180.
- 465 21. American Academy of Family Physicians. AAFP Short-Form Social Needs Screening Tool
- 466 [Internet]. 2019 [cited 2024 Mar 24]. Available from: https://sirenetwork.ucsf.edu/tools-
- 467 resources/resources/aafp-short-form-social-needs-screening-tool
- 468 22. U.S. Census. 2019 AHS Items Booklet [Internet]. 2018 [cited 2024 Mar 24]. Available from:
- 469 https://www2.census.gov/programs-
- 470 surveys/ahs/2019/2019%20AHS%20Items%20Booklet.pdf
- 471 23. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006 Jan
 472 1;3(2):77–101.
- 473 24. Schaak G, Stone L, Arienti F, Zovistoski A. Priced out: The housing crisis for people with
 474 disabilities. Policy Commons; 2017.

| 475 | 25. Burns SP. | Mendonca R. | Pickens ND. | Smith RO. | America's h | nousing | affordability | crisis: |
|-----|---------------|-------------|-------------|-----------|-------------|---------|---------------|---------|
| | | | | | | | | |

- 476 Perpetuating disparities among people with disability. Disabil Soc. 2021;36(10):1719–24.
- 477 26. Nishita CM, Liebig PS, Pynoos J, Perelman L, Spegal K. Promoting basic accessibility in the
- 478 home: Analyzing patterns in the diffusion of visitability legislation. J Disabil Policy Stud.
- 479 2007 Jun 1;18(1):2–13.
- 27. Maisel JL, Center I, Smith E, Change C, Steinfeld E, Center I, et al. Increasing home access:
 Designing for visitability. AARP Public Policy Institute. 2008;14:1–34.
- 482 28. Chattopadhyay J. Public opinion about visitability mandates in the United States: Favorable
- 483 but divisible. Hous Policy Debate. 2023 Sep 3;33(5):1228–48.
- 484 29. Downey MM, Neff J, Dube K. Don't just call the social worker: Training in structural
- 485 competency to enhance collaboration between healthcare social work and medicine. J Soc &
 486 Soc Welfare. 2019;46:77.
- 30. Yae R, Aurand A, Threet D, Foley E. Emergency rental assistance programs in response to
 COVID-19. National Low Income Housing Coalition; 2020.
- 489 31. Terman S. Protecting workers' jobs and income during COVID-19 [Internet]. Rochester, NY;
- 490 2020 [cited 2023 Nov 13]. Available from: https://papers.ssrn.com/abstract=3675811
- 491 32. Anderst A, Hunter K, Andersen M, Walker N, Coombes J, Raman S, et al. Screening and
- 492 social prescribing in healthcare and social services to address housing issues among children
- and families: a systematic review. BMJ Open. 2022 Apr 1;12(4):e054338.
- 494 33. Wasilewski MB, Cimino SR, Kokorelias KM, Simpson R, Hitzig SL, Robinson L. Providing
- 495 rehabilitation to patients recovering from COVID-19: A scoping review. PM R. 2022
- 496 Feb;14(2):239–58.

- 497 34. Pynoos J, Steinman BA, Nguyen AQD. Environmental assessment and modification as fall-
- 498 prevention strategies for older adults. Clin Geriatr Med. 2010 Nov;26(4):633–44.

| Table 1. 1 articipant demographics. | Long COVID (<i>n</i> = 514) | Non-Long COVID (<i>n</i> = 1019) | Interview Participants (n = 13) |
|---|------------------------------------|---|---------------------------------------|
| Housing Status | | | |
| Own | 46.4% | 46.8% | <i>n</i> = 6 |
| Rent | 36.9% | 37.6% | <i>n</i> = 5 |
| Long-term w/ friends/family (not paying rent) | 13.1% | 13.0% | N/A |
| Other Situation | 3.6% | 2.6% | <i>n</i> = 2 |
| Lives Alone | 23.5% | 24.6% | <i>n</i> = 6 |
| Gender** | | | |
| Female | 70.8% | 63.6% | <i>n</i> = 9 |
| Male | 17.4% | 25.5% | N/A |
| Transgender | 0.2% | 0.4% | N/A |
| Non-Binary | 6.1% | 4.5% | <i>n</i> = 2 |
| Two-Spirit | 0.8% | 0.1% | n = 1 |
| Agender | 1.2% | 1.8% | N/A |
| Other ^a | 3.6% | 4.1% | n = 1 |
| Race | | | |
| American Indian/Alaska Native | 1.9% | 1.1% | <i>n</i> = 3 |
| African American | 3.1% | 3.3% | n = 2 |
| Asian | 2.3% | 2.8% | n = 1 |
| Native Hawaiian/Pacific Islander | 0.0% | 0.1% | N/A |
| White | 87.6% | 88.9% | <i>n</i> = 5 |
| Multi-Racial | 5.2% | 3.7% | <i>n</i> = 2 |
| Ethnicity | | | |
| Hispanic/Latine | 7.0% | 5.6% | <i>n</i> = 1 |
| Poor/Fair Health*** | 68.6% | 40.4% | <i>n</i> = 10 |
| Employment Status*** | | | |
| Not Working | 38.4% | 26.5% | <i>n</i> = 7 |
| Working for Pay | 42.6% | 49.2% | <i>n</i> = 5 |
| Self-Employed | 8.4% | 7.7% | N/A |
| Both Self-Employed & Working for Pay | 3.9% | 4.2% | N/A |
| Not Working, Retired | 6.6% | 12.4% | <i>n</i> = 1 |
| Geographical Region | | | |
| South | 27.2% | 24.5% | <i>n</i> = 3 |
| West | 28.4% | 28.8% | <i>n</i> = 3 |
| Midwest | 26.3% | 24.3% | <i>n</i> = 3 |
| Northeast | 18.1% | 22.2% | <i>n</i> = 4 |
| Territories | 0.0% | 0.2% | N/A |
| Mean Age* | 44.8 | 45.8 | 43.7 |
| - | (18-79; SD | (18-92; SD | (23-63; SD |
| | = 12.7) | = 15.0) | = 12.5) |

Table 1. Participant demographics.

*p < .05; **p < .01; ***p < .001^a Includes other genders as identified by participants.

| Table 2. (| Comparative | analyses. |
|------------|-------------|-----------|
|------------|-------------|-----------|

| | Long COVID $(n = 514)$ | Non-Long COVID (<i>n</i> = 1019) |
|---|------------------------|---|
| Housing stability and cost burdens | | |
| Experiencing Housing Instability*** | 21.1% | 8.1% |
| Worried About High Rent or Mortgage*** | 50.4% | 40.0% |
| Worried About High Utility Bills*** | 55.7% | 45.5% |
| Worried About Unsteady Income*** | 54.8% | 35.2% |
| Worried About Relying on Others to Help Cover Housing Payments*** | 46.6% | 30.8% |
| Worried About Large Unexpected Expenses*** | 80.3% | 36.2% |
| Worried About High Credit Card, Student Loan, or Other Debt*** | 51.3% | 38.1% |
| Worried About High Real Estate Taxes | 31.0% | 27.1% |
| Housing-quality problems | SO. | |
| Problems with Pests** | 30.0% | 23.5% |
| Problems with Mold*** | 22.0% | 12.7% |
| Problems with Lead Paint/Pipes | 3.7% | 3.1% |
| Problems with Lack of Heat | 3.7% | 2.6% |
| Problems with Oven, Stove, or Refrigerator Not Working | 7.6% | 5.5% |
| Problems with Smoke/CO2 Detectors Missing or Not Working | 10.9% | 9.0% |
| Problems with Water Leaks | 11.3% | 9.7% |
| Housing accessibility | | |
| Unsupportive Housing Layout and Features*** | 17.6% | 11.4% |

Table 3. Qualitative themes and key topics. Theme 1: Employment and Financial Impact on Housing Stability Loss of Work and Income Health Insurance Costs Monthly Financial Struggles Depletion of Savings and Retirement Funds **Financial Adjustments Theme 2: Home Accessibility Challenges** Stair Challenges Kitchen Accessibility **Bathroom Limitations** Theme 3: Effects of Home Inaccessibility on Daily Life **Decreased Energy Restricted Independence** Increased Risk of Injury Decreased Community Participation / Isolation Increased Risk for Institutionalization **Theme 4: Deteriorating Housing Conditions** Maintenance Challenges Appliance Breakdown Traumatic Experience **Theme 5: Home Modifications and Daily Living Aids** Home Modifications Use of Mobility Aids Housing Relocation **Theme 6: Financial Constraints on Home Modifications** Financial Constraints on Home Adaptations Financial Constraints on Obtaining Mobility Aids Theme 7: Lack of Support from Agencies and Healthcare Barriers in Obtaining Financial Support and Disability Benefits Barriers in Maintaining Rental Assistance Absence of Assistance