Journal Pre-proof

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Please cite this article as: Caldwell J, Daniels E, Stober K, Unmet Needs for Long-Term Services and Supports and Associations with Health Outcomes, *Disability and Health Journal*, https://doi.org/10.1016/j.dhjo.2024.101678.

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Unmet Needs for Long-Term Services and Supports and Associations with Health Outcomes

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Keywords: Unmet Needs, LTSS, Health, BRFSS, Texas

Word count for abstract: 249
Word count for complete manuscript: 3,802
Number of tables: 2
Number of references: 43

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Abstract

Background. The availability of population-level data on unmet needs for long-term services and supports (LTSS) is limited at state and national levels. Data on unmet LTSS needs can improve our understanding of disparities and relationships with health outcomes.

Objective. 1) Explore differences in unmet LTSS needs by socio-demographic characteristics, including age, sex, race/ethnicity, metropolitan status, sexual orientation, and socio-economic status; and 2) Examine associations between unmet LTSS needs and health/preventative healthcare outcomes.

Methods. We used the 2021 Behavioral Risk Factor Surveillance System (BRFSS) core survey and state-added LTSS questions to analyze a sample of adults with LTSS needs in Texas (N=1,232). We compared socio-demographic characteristics between adults with and without unmet LTSS needs. We conducted modified-Poisson regressions to estimate unadjusted and adjusted risk ratios (with 95% confidence intervals) for each health/preventative healthcare outcome among adults with unmet LTSS needs. Health outcomes included health status, healthy days-physical health, healthy days-mental health, suicide ideation, and multiple chronic conditions. Preventative healthcare outcomes included routine check-up and flu vaccine.

Results. Among adults with LTSS needs, those with unmet LTSS needs were statistically significantly more likely to be younger (age<65), female, higher educational attainment, and non-straight sexual orientation. After controlling for socio-demographic variables, having unmet needs for LTSS was significantly associated with poorer physical and mental health outcomes and suicide ideation.

Conclusions. Improved data collection on unmet needs LTSS can assist policymakers, particularly at the state level in guiding reforms to reduce disparities in access to home and community-based services (HCBS) and improve health outcomes.

Key Words: Unmet Needs, Long-Term Services and Supports, Home and Community-Based Services, Health Outcomes, BRFSS

Background

An estimated 14 million individuals in the U.S. need long-term services and supports (LTSS).[1,2] LTSS refers to a wide range of health and social services provided to individuals who need help with activities of daily living, such as eating, bathing, and dressing, or with instrumental tasks, such as medication management, meal preparation, and supports for community participation and employment. Nearly half of the individuals currently needing LTSS are under the age 65.[2] The number of individuals with LTSS needs is projected to more than double in the coming decades, however, largely due to the aging baby boom generation and other factors including rising rates of chronic conditions and the Covid-19 pandemic [3,4]

The U.S. lacks a coordinated system for financing and delivering LTSS which contributes to considerable unmet needs. The vast majority of individuals needing LTSS rely on unpaid assistance from family and friends, supplemented by Medicaid for those who are eligible. Only about 13% of individuals with LTSS needs receive any form of paid assistance.[2] Nationally, an estimated 53 million family caregivers provide supports to individuals with disabilities and older adults.[5]

Medicaid is the primary funder of paid LTSS in the U.S. However, eligibility for Medicaid HCBS is tied to strict income and asset limits. Moreover, there is a longstanding institutional bias within the Medicaid program where the provision of nursing homes is mandatory while preferred Home and Community-Based Services (HCBS) are optional for states to provide. Despite this bias, significant progress has been made in "rebalancing" Medicaid LTSS systems (i.e., shifting from institutional to HCBS). Nationally, in 2019 approximately 58.6% of total Medicaid spending was allocated to HCBS versus institutional settings.[6] Yet, striking variations exist across states and different populations needing LTSS. While states allocated 78.9% of their

2

59 total Medicaid LTSS spending for individuals with intellectual and developmental disabilities

60 (IDD) to HCBS, they only allocated 32.9% on HCBS for older adults and adults with physical

61 disabilities.[6]

62   States also have considerable flexibility in how they design their Medicaid HCBS systems

63 (i.e., eligibility, scope of services and supports provided, amount/duration, and delivery) which

64 contributes to unmet needs. Nationally, approximately 656,000 individuals are on waiting lists

65 for Medicaid HCBS waiver programs.[7] One study examining Medicaid HCBS recipients across

66 multiple states found that nearly a third of individuals reported unmet needs for assistance with

67 daily activities, assistive technology, home modifications, transportation, and other services.

68 Moreover, disparities in access to HCBS and quality of supports exist for individuals with

69 diverse identities and socio-demographic characteristics, including gender, age, race/ethnicity,

70 LGBTQ+ identities, and metropolitan residence.[8–13]

71   Previous research suggests that unmet needs for LTSS are associated with worse community

72 living and health outcomes. Limited access to HCBS contributes to undesirable and preventable

73 placements in institutional settings.[14] Unmet needs for HCBS have been associated with reduced

74 community participation, interactions with family and friends, satisfaction with activities during

75 the day, and feelings of control over life.[15] Access and quality of HCBS are also important social

76 determinants of health. Unmet needs for LTSS have been associated with lower rates of routine

77 preventative care [15,16], higher emergency department (ED) utilization and hospitalizations[15,17,18],

78 and mortality.[19,20] Less is known about impacts on mental health. Established associations

79 between depression and unmet LTSS need warrants further exploration on potential mental

80 health outcomes.[21,22]

81   However, our understanding of unmet needs for LTSS and impacts on health outcomes is

82   limited due to the availability of population-level data. National surveys asking adults across the

83   lifespan about needs and unmet need for LTSS have not been administered since the mid-1990s,

84   at which point approximately 21% of LTSS users were determined to have some unmet needs.[23]

85   Some national surveys assess LTSS needs and unmet needs for older adults but do not survey

86   adults with disabilities under 65.[24] Representative state-level data on LTSS needs and unmet

87   needs is also critical for policymakers to plan, particularly given the wide variations in state

88   Medicaid LTSS systems. Some states have led the way in conducting surveys and adding

89   questions to existing population surveys to assess LTSS needs and unmet needs. In 2007,

90   Massachusetts implemented a call-back survey tied to their Behavioral Risk Factor Surveillance

91   (BRFSS) Survey. More recently, California conducted a follow-up LTSS survey tied to the

92   California Health Interview Survey (CHIS)[25] and with the support of the Commonwealth Fund,

93   two states (Washington and Texas) added questions to their BRFSS.[26]

94   The current study examines LTSS unmet need questions that were implemented in Texas

95   during the 2021 BRFSS cycle. Our specific aims are to: 1) Explore differences in unmet LTSS

96   needs by socio-demographic characteristics, including age, sex, race/ethnicity, metropolitan

97   residence, sexual orientation, and socio-economic status; and 2) Examine associations between

98   unmet LTSS needs and health outcomes, including physical and mental health status and routine

99   preventative healthcare.

100   **Methods**

101   *Data Source*

102   We analyzed data from the 2021 Texas Behavioral Risk Factor Surveillance System

103   (BRFSS).[27] The BRFSS is a state-based, cross-sectional random digit dial telephone survey that

104   is administered annually to adults over the age of 18 residing in non-institutional settings across

105   all 50 states and 4 territories in a collaboration with the Centers for Disease Control and

106   Prevention (CDC). BRFSS is designed to collect data about population health-related risk

107   behaviors, chronic health conditions, and use of preventative health services.[27]

108   BRFSS consists of core questions and rotating core questions that are included in the

109   surveys administered across all states and territories. In 2021, the CDC offered 19 standardized

110   modules concerning varying topics that states could elect to include in that year's

111   implementation. Beyond the adoption of certain modules, states have the option to pay to add

112   their own questions for respondents in their state only.

113   However, the state-added questions are not sponsored by the CDC; for example, ahead of

114   the administration of the 2021 BRFSS survey, Brandeis University and the Long-Term Quality

115   Alliance (LTQA) collaborated with Texas and Washington state to pilot the addition of LTSS-

116   related questions, sponsored by a grant from the Commonwealth Fund.[28] Specifically, the state-

117   added questions included items on LTSS need, unmet need, and whether received LTSS was

118   unpaid or paid, and source of payment. Additionally, the 2021 Texas BRFSS added questions

119   related to suicide ideation and attempts. The response rate for 2021 in Texas was 35.6%.

120   ***Sample***

121   The 2021 Texas BRFSS data set included a total of 10,817 adults aged 18 and above. Our

122   analytic sample include the individuals who indicated they had LTSS by responding

123   affirmatively to 4 LTSS need questions, and also responded to the unmet LTSS need questions;

124   we also excluded responses which had missing values for age. The final analytical sample thus

125   includes 1,232 individuals.

126   ***Measures***

127 *LTSS need, unmet need and type*

128   *LTSS Need*. LTSS need was measured by affirmative responses to either of the two

129 standard disability core questions: (1) 'Do you have a difficulty dressing or bathing?' and (2)

130 'Because of a physical, mental, or emotional condition, do you have difficulty doing errands

131 alone such as visiting a doctor's office or shopping?' These core questions are modeled after the

132 activities of daily living (ADL) and instrumental activities of daily living (IADL) questions

133 included in the American Community Survey (ACS), and therefore offer the opportunity for

134 direct comparison.

135   In addition, LTSS need was measured by affirmative responses to either of two state-

136 added disability questions concerned with ADL and IADL: (1) 'In the last month, because of a

137 physical, mental, or emotional condition, do/did you have any difficulty completing tasks such as

138 housework, preparing meals, getting dressed, eating/drinking, getting around your home, and

139 using the toilet without assistance from another individual and/or use of special equipment?' and

140 (2) 'In the last month, because of a physical, mental, or emotional condition, do/did you have any

141 difficulty completing tasks such as housework, preparing meals, managing medications,

142 shopping, or managing money without assistance from another individual and/or use of special

143 equipment?' These state-added questions were only asked of respondents who were identified as

144 having a disability via the six disability core questions and/or a chronic condition from core

145 questions asking about heart attacks, heart disease, stroke, asthma, cancer, COPD, depression,

146 kidney disease and diabetes.

147   *Receipt of LTSS Supports*. The type of LTSS was categorized as paid only or paid and

148 unpaid, and only unpaid, based on responses to the state-added question, 'Are your supports

149 paid, unpaid (for example, a family friend or family member), or both?'

150   *Unmet LTSS Need.* LTSS unmet need was measured based on affirmative responses to

151 either of two state-added questions: (1) 'In the last month, did you ever go without completing

152 specific tasks like bathing/showering, getting dressed, eating/drinking, getting around your

153 home, and using the toilet?' and (2) 'In the last month, did you ever go without completing

154 specific tasks like housework, preparing meals, managing medications, shopping, or managing

155 money?'

156 *Health Outcomes*

157   *Health Status.* We classified adults as having fair or poor general health status based on

158 their response to the question 'Would you say that in general your health is – Excellent, Very

159 good, Good, Fair, or Poor?' This was transformed into a dichotomous variable, with responses of

160 'fair' or 'poor' coded as 0 and responses of 'good,' 'very good,' and 'excellent' coded as 1.

161   *Healthy Days- Physical health.* We counted the frequency of physically healthy days that

162 adults reported in response to the question, 'Now thinking about your physical health, which

163 includes physical illness and injury, for how many days during the past 30 days was your

164 physical health not good?' A dichotomous variable was calculated based on respondents who

165 reported experiencing 14 or more days of 'not good' physical health.

166   *Healthy Days – Mental Health.* We counted the frequency of mentally healthy days that

167 adults reported in response to the question, 'Now thinking about your mental health, which

168 includes stress, depression, and problems with emotions, for how many days during the past 30

169 days was your mental health not good?' A dichotomous variable was calculated based on

170 respondents who reported experiencing 14 or more days of 'not good' mental health.

171   *Suicide Ideation*. We classified adults as having thought about attempting suicide if they

172   affirmatively answered the question, 'During the past 12 months, have you ever seriously

173   considered attempting suicide?'

174   *Multiple Chronic Conditions*. We classified adults as having multiple chronic conditions

175   if they reported having two or more of the following chronic conditions: cardiovascular disease,

176   asthma, cancer, chronic obstructive pulmonary disease/ emphysema/ chronic bronchitis, kidney

177   disease, diabetes, arthritis/ gout/ lupus/ fibromyalgia, high cholesterol, high blood pressure, and

178   BMI>30kg/m2.

179   <u>*Preventative Healthcare Outcomes*</u>

180   *Routine Checkup*. We classified adults as not having a routine checkup if they reported

181   not having a routine checkup in the past year.

182   *Flu Vaccine*. We classified adults as not having been vaccinated for influenza if they had

183   not received a flu shot in the past year.

184   <u>*Covariates*</u>

185   We included the following sociodemographic characteristics as covariates in all of our

186   multivariate analyses: age, gender, race and ethnicity (non-Hispanic White, non-Hispanic Black,

187   Hispanic, non-Hispanic Other Race, Unknown), sexual orientation (straight, gay/ lesbian/

188   bisexual, unknown), education (<high school, high school graduate or higher), household income

189   (<$35,000; ≥$35,000), health insurance (yes/no), and metropolitan status (yes/no).

190   **Analysis**

191   We compared demographic and socioeconomic characteristics between adults by unmet

192   LTSS need using chi-square tests for categorical variables and t-test for continuous variables. We

193   calculated the prevalence for each health and healthcare outcome among adults by unmet LTSS

194   needs. We conducted modified-Poisson regressions to estimate unadjusted and adjusted risk

195   ratios (with 95% confidence intervals) for each health and healthcare outcome among adults with

196   and without unmet LTSS need. Multivariate analyses adjusted for age, race and ethnicity,

197   education, income, health insurance status, paid/unpaid LTSS, sexual orientation, and

198   metropolitan status. We conducted multiple imputations by chained equations to impute values

199   for LTSS supports (missing 50.9%), income (missing 24.8%), and metropolitan status (missing

200   5.3%) that had missing data; we added 10 imputations for each missing value.[29] In order to

201   address missing values for race/ethnicity and sexual orientation, we created an unknown

202   category for each variable. All analyses were conducted using Stata version 18 applying *svy*

203   commands to account for the complex sampling design of the BRFSS.

204   **Results**

205   An overview of the characteristics of the analytic sample of participants is presented in

206   Table 1. Among adults with LTSS need, and compared to adults without unmet LTSS need,

207   adults with unmet LTSS need were, on average, younger, with a higher female share, a higher

208   share of non-Hispanic Whites, a lower share of Hispanics, a higher share of recipients of unpaid

209   supports, a higher share of high-school graduates and above, and a higher share of individuals

210   with a gay/lesbian/bisexual sexual orientation. In particular, non-older adult status (age<65) was

211   shown to be a strong and statistically significant determinant of unmet LTSS need, together with

212   female status, higher educational attainment, and non-straight sexual orientation, albeit to a

213   lesser extent.

214   **[Table 1]**

215   Table 2 displays an overview of health and healthcare outcomes among adults by unmet

216   LTSS need status. Among adults with LTSS need, and compared to adults without unmet LTSS

9

217 need, adults with LTSS need had poorer physical and mental health outcomes and worse suicide

218 ideation outcomes. In particular, the association between unmet LTSS need and worse mental

219 health outcomes is strong and statistically significant, as is the association between unmet LTSS

220 need and suicide ideation.

221 **[Table 2]**

222 **Discussion**

223 *Differences in Unmet LTSS Needs across the Sample Population*

224   Using a sample of community-dwelling adults with reported LTSS need in Texas, this

225 study identified demographic differences associated with having unmet LTSS need. To start,

226 younger people were more likely to have unmet needs than adults over the age of 65. This

227 finding is not surprising, as persistent ableism and institutional bias in the current Medicaid

228 system may restrict options for younger adults with disabilities, particularly psychiatric

229 disabilities, to access waiver services and paid support in the community [30,31].

230   However, the identification of this difference in Texas calls for improved national-level

231 surveillance of unmet LTSS needs among adults of all ages. About half of all adults with LTSS

232 needs living in the community are under the age of 65, [32–34], but access to data is more readily

233 available for older adults because of survey initiatives like the National Health and Aging Trends

234 Study (NHATS) (see [15,16]. Collecting more state-level, as well as national-level data, on unmet

235 needs for younger adults would help identify individuals who are falling through the cracks.

236   These findings also highlight that women are more likely to have unmet LTSS needs than

237 men, a difference that can partially be explained by the fact that women tend to live longer. In

238 addition, however, the historically gendered nature of caregiving may also be influencing these

239 differences. Women are more likely to provide care to spouses and other family members than

10

240   men [5], so it is plausible that younger and older women alike, particularly those in heterosexual

241   partnerships, do not have comparable access to family caregivers.

242   While this study did not find significant differences in unmet LTSS needs by race or

243   ethnicity, it is important to note that the small sample sizes of participants who identified as

244   racial and/or ethnic minorities may have impacted the possibility for such differences to be

245   detected. Existing literature suggests that racial and ethnic disparities in LTSS needs and unmet

246   needs may exist, [13] so future studies with larger, representative samples are needed. Other non-

247   significant and unanticipated associations warrant this call for further research as well. For

248   instance, the association between education and unmet needs requires further consideration. In

249   addition, whether or not an individual received paid supports had no significant bearing on the

250   likelihood of having unmet LTSS needs. It is again possible that the small number of individuals

251   who received any amount of paid support in the sample (less than 20%), impacted the lack of

252   statistical significance.

253   Lastly, it is of note that individuals who identified their sexual orientation as lesbian, gay,

254   bisexual (LGB) or other (as opposed to "straight") were significantly more likely to experience

255   unmet LTSS needs than their straight counterparts. Aging adults who identify as sexual

256   orientation minorities may have worse social support than their straight peers, as they are less

257   likely to be partnered or have children, and more likely to face discrimination in long-term care

258   residential settings [35]. It is essential that future research and policy planning take cultural

259   considerations relating to sexual orientation and gender identity minorities into account.

260   *Negative Health Outcomes*

261   This study expanded on previous studies in the determination of how unmet LTSS needs

262   are associated with adverse health outcomes. First and foremost, this study revealed that people

263   with unmet LTSS needs have a significantly elevated risk of experiencing dire mental health

264   consequences. Holding all else constant, individuals with unmet LTSS needs have a 313%

265   greater risk of seriously considering suicide than those who do not have unmet needs. They have

266   a 49% greater risk of experiencing poor mental health for 2 weeks or more in a given month. By

267   nature, these are conservative estimates. People who have died by suicide are not represented,

268   and people experiencing chronic mental health concerns may be underrepresented if they are less

269   able or likely to participate in BRFSS. While existing literature supports the notion that

270   functional disability, in combination with aging, may be associated with higher rates of suicidal

271   ideation [36], our findings indicate that access to LTSS needs may be an important contributing

272   factor.

273   Poor mental health and suicidality cannot be mitigated or fully treated in a vacuum of

274   healthcare; individuals need services and support to live in the community. In this sense, HCBS

275   can serve as both primary prevention and intervention in relation to the mental health crises

276   impacting disabled and aging adults. These findings underscore the wide-reaching benefit of

277   expanding access to Medicaid, particularly as it relates to the mental health care of individuals

278   who need and use HCBS.

279   In addition to mental health, adults with unmet LTSS needs have a significantly higher

280   risk of experiencing poor physical health for 14 days or more in a given month, which is

281   consistent with findings from other studies that examined aging or disability populations

282   separately.[15,19] This may be related to access to routine care.[19] It is worth noting that the

283   unadjusted risk ratios indicated individuals with unmet LTSS needs had a significant risk of not

284   accessing a routine checkup in the past year; however, the adjusted risk ratios are not statistically

285   significant using a 95% confidence interval. Future research with larger, multi-state or national

286   samples, should examine this relationship further.

287   *Covid- 19 Considerations*

288   Data for this study was collected over the course of 2021, so it is important to

289   contextualize findings within the Covid-19 pandemic. Emerging evidence continues to prove that

290   Covid-19 has had disproportionately adverse effects on the physical health, mental health, and

291   mortality rates among disabled and aging communities. [37,38]. Rates of unmet LTSS needs have

292   been impacted by issues relating to Covid-19 infection, reduced healthcare access, social

293   isolation, inadequate supply of direct-care workers, and general limitations in paid and unpaid

294   care.[37,39] At the same time, policy measures enabled by the COVID-19 public health emergency

295   impacted LTSS receipt, though it affected institution-based LTSS differently than HCBS.[40]

296   *Limitations*

297   The overall 2021 Texas BRFSS sample is limited by the sampling frame and survey

298   modality. BRFSS is a random digit dial telephone survey that is only administered to adults

299   living in non-institutional settings. As such, adults with psychiatric, cognitive, and/or intellectual

300   and developmental disabilities who live in congregate settings, like group homes, nursing homes,

301   or intermediate care facilities, are not included within the sampling frame. In addition, BRFSS is

302   not household-based, so adults with intellectual and developmental disabilities who live in

303   family homes are not guaranteed to be represented.

304   Beyond the general BRFSS sample, the final analytic sample for this study relied upon a

305   combination of core and state-added questions to identify individuals with LTSS needs. The

306   core BRFSS questions used to determine unmet need mirrors the language used by the American

307   Community Survey (ACS), whereby participants are asked about "difficulty" completing self-

308   care and independent living tasks. These questions have evidenced limitations in capturing all

309   relevant participants with disabilities and LTSS needs; in particular, individuals with psychiatric

310   disabilities, chronic illnesses, intellectual disabilities, sensory disabilities, and learning

311   disabilities may be more likely to respond negatively to these questions, which would exclude

312   eligible respondents from the analytic sample.[41,42]

313   Due to this shortcoming of the core BRFSS questions, this study also included

314   participants who responded affirmatively to Texas-added questions on LTSS need in the analytic

315   sample. However, these questions were piloted for the first time in this 2021 administration of

316   BRFSS and were not subjected to cognitive testing. Other states can look to Texas' developed

317   questions and refine their own for future testing and use.

318   This study also used state-added questions to evaluate the rate and impact of unmet

319   LTSS. These questions only captured unmet LTSS need related to activities of daily living, like

320   eating and bathing, and do not include instrumental activities of daily living, like transportation,

321   cooking, and financial management. Future work on how having unmet needs relating to social

322   determinants of health impacts health outcomes is needed. In addition, BRFSS data used in this

323   study is population-level and does not allow for more granular analysis of unmet needs of

324   individuals receiving Medicaid HCBS.

325   Finally, these findings should be interpreted with some degree of caution because they do

326   not illustrate causality, but rather reflect a statistically significant association between unmet

327   need and risk for health outcomes. It is possible that bi-directional relationships between these

328   variables, as well as unaccounted-for confounding variables, may bias results.

329   **Conclusions**

330   This study underscores the importance of meeting LTSS needs for older adults and

331 individuals with disabilities. Most individuals with LTSS needs have needs that are not being

332 met. Policymakers should address the institutional bias in Medicaid and improve access to

333 HCBS, including targeted efforts to reduce systemic gaps and inequities. CMS recently issued

334 regulations aimed at ensuring access to Medicaid services, including HCBS. Having state-level

335 data on unmet needs of individuals receiving Medicaid HCBS as well as those in the general

336 population will help states and advocates identify gaps and disparities in access. In addition,

337 given the major role unpaid family caregivers play in providing LTSS, improved policies and

338 practices are needed to support family caregivers. The Recognize, Assist, Include, Support, and

339 Engage (RAISE) Family Caregivers Council led by the Administration for Community Living

340 (ACL) recently developed the first National Strategy to Support Family Caregivers which

341 includes recommended actions that can be taken at the federal, state, and local levels. Moreover,

342 more needs to be done to strengthen the paid direct care workforce. Exacerbated by the Covid-19

343 pandemic and wages that have not kept pace with other industries, individuals with disabilities

344 are facing a crisis in recruiting and retaining direct care workers. This crisis is contributing to

345 gaps in services and unmet needs that have significant implications for the health and well-being

346 of individuals with disabilities.

347   Lastly, this study demonstrates the importance of collecting representative data on unmet

348 LTSS needs. The BRFSS could be one existing survey to build upon to provide state-level data.[43]

349 A next step could be for CDC in partnership with ACL and CMS to cognitively test a set of

350 questions for a formal CDC optional module on LTSS that states could use. At the national level,

351 additional questions could be added to other existing surveys or development of a new national

352   survey of people with disabilities could be pursued that is inclusive of individuals with

353   disabilities across lifespan.

354 **References**

355 1. Hado E, Komisar H. Long-Term Services and Supports: Fact Sheet. *Wash DC AARP Public*
356 *Policy Inst August Httpswww Aarp Orgcontentda Maarpppi201908long-Term-Serv--*
357 *Supports Doi*. Published online 2019.

358 2. Kaye HS, Harrington C, LaPlante MP. Long-term care: who gets it, who provides it, who
359 pays, and how much? *Health Aff (Millwood)*. 2010;29(1):11-21.

360 3. Mitra M, Long-Bellil L, Moura I, Miles A, Kaye HS. Advancing Health Equity And
361 Reducing Health Disparities For People With Disabilities In The United States: Study
362 examines health equity and health disparities for people with disabilities in the United States.
363 *Health Aff (Millwood)*. 2022;41(10):1379-1386.

364 4. U.S Commission on Long-Term Care. *Commission on Long-Term Care: Report to*
365 *Congress*.; 2013. http://ltccommission.org/ltccommission/wp-
366 content/uploads/2013/12/Commission-on-Long-Term-Care-Final-Report-9-26-13.pdf

367 5. AARP, National Alliance for Caregiving. *Caregiving in the U.S. 2020*.; 2020.
368 https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-
369 united-states-01-21.pdf

370 6. Murray C, Tourtellotte A, Lipson D, Wysocki A. *Medicaid Long-Term Services and*
371 *Supports Annual Expenditures Report: Federal Fiscal Year 2019*. Mathematica Policy
372 Research; 2021.

373 7. Burns A, Watts MO, Ammula M. *A Look at Waiting Lists for Home and Community-Based*
374 *Services from 2016 to 2021*. KFF; 2022. https://www.kff.org/medicaid/issue-brief/a-look-at-
375 waiting-lists-for-home-and-community-based-services-from-2016-to-2021/

376 8. Christ A, Dickman H. *An Equity Framework for Evaluating California's Medi-Cal Home*
377 *and Community-Based Services for Older Adults & People with Disabilities*. Justice in
378 Aging; 2022. https://justiceinaging.org/wp-content/uploads/2022/12/An-Equity-Framework-
379 for-Evaluating-CAs-HCBS-System.pdf

380 9. Fabius CD, Thomas KS, Zhang T, Ogarek J, Shireman TI. Racial disparities in Medicaid
381 home and community-based service utilization and expenditures among persons with
382 multiple sclerosis. *BMC Health Serv Res*. 2018;18(1):1-9.

383 10. Fabius CD, Parker LJ, Thorpe RJ. The influence of race and gender on receiving assistance
384 with daily activities among older Americans. *Innov Aging*. 2022;6(2):igab060.

385 11. Gorges RJ, Sanghavi P, Konetzka RT. A national examination of long-term care setting,
386 outcomes, and disparities among elderly dual eligibles. *Health Aff (Millwood)*.
387 2019;38(7):1110-1118.

388 12. Harrington C, Kang T. Disparities in service use and expenditures for people with
389 intellectual and developmental disabilities in California in 2005 and 2013. *Intellect Dev*
390 *Disabil*. 2016;54(1):1-18.

13. Shippee TP, Fabius CD, Fashaw-Walters S, et al. Evidence for action: Addressing systemic racism across long-term services and supports. *J Am Med Dir Assoc*. 2022;23(2):214-219.

14. Kaye HS. Gradual rebalancing of Medicaid long-term services and supports saves money and serves more people, statistical model shows. *Health Aff Proj Hope*. 2012;31(6):1195-1203. doi:10.1377/hlthaff.2011.1237

15. Chong N, Akobirshoev I, Caldwell J, Kaye HS, Mitra M. The relationship between unmet need for home and community-based services and health and community living outcomes. *Disabil Health J*. 2022;15(2):101222.

16. Allen SM, Piette ER, Mor V. The adverse consequences of unmet need among older persons living in the community: dual-eligible versus Medicare-only beneficiaries. *J Gerontol B Psychol Sci Soc Sci*. 2014;69(Suppl_1):S51-S58.

17. DePalma G, Xu H, Covinsky KE, et al. Hospital readmission among older adults who return home with unmet need for ADL disability. *The Gerontologist*. 2013;53(3):454-461.

18. Xu H, Covinsky KE, Stallard E, Thomas III J, Sands LP. Insufficient help for activity of daily living disabilities and risk of all-cause hospitalization. *J Am Geriatr Soc*. 2012;60(5):927-933.

19. He S, Craig BA, Xu H, et al. Unmet need for ADL assistance is associated with mortality among older adults with mild disability. *J Gerontol Ser Biomed Sci Med Sci*. 2015;70(9):1128-1132.

20. Weaver RH, Roberto KA. Effects of long-term services and supports on survival of poor, highly vulnerable older adults. *The Gerontologist*. 2019;59(5):936-946.

21. Rivera E, Hirschman KB, Naylor MD. Reported needs and depressive symptoms among older adults entering long-term services and supports. *Innov Aging*. 2020;4(3):igaa021.

22. Xiang X, An R, Heinemann A. Depression and unmet needs for assistance with daily activities among community-dwelling older adults. *The Gerontologist*. 2018;58(3):428-437.

23. LaPlante MP, Kaye HS, Kang T, Harrington C. Unmet need for personal assistance services: estimating the shortfall in hours of help and adverse consequences. *J Gerontol B Psychol Sci Soc Sci*. 2004;59(2):S98-S108.

24. LTQA. *Data Resources to Determine the LTSS Needs of Working Age Adults with Disabilities*. Long-Term Quality Alliance; 2018. https://www.ltqa.org/white-paper-disability-data-resources/

25. Kietzman K, Chen L. *Unmet Needs for Help at Home: How Older Adults and Adults With Disabilities Are Faring in California*. UCLA Center for Health Policy Research; 2022.

26. LTQA, CLPC. *Final Report: LTSS Need, Receipt, and Unmet Need in the Washington State Population Age 18-64 with Disabilities*. Long-Term Quality Alliance, Community Living

426   Policy Center; 2023. https://www.ltqa.org/ltss-need-receipt-and-unmet-need-in-the-
427   washington-state-population-age-18-64-with-disabilities/

428   27. CDC. *Behavioral Risk Factor Surveillance System*. Centers for Disease Control and
429   Prevention; 2023. https://www.cdc.gov/brfss/index.html

430   28. LTQA. *Measuring Unmet LTSS Need and Service Use Among Adults Under Age 65 with*
431   *Disabilities*. Long-Term Quality Alliance; 2022. https://www.ltqa.org/measuring-unmet-ltss/

432   29. Rubin DB. Multiple imputation. In: *Flexible Imputation of Missing Data*. CRC press; 2018.

433   30. Friedman C, VanPuymbrouck L. The relationship between disability prejudice and Medicaid
434   home and community-based services spending. *Disabil Health J*. 2019;12(3):359-365.

435   31. Ne'eman A, Stein M, Grabowski DC. Nursing Home Residents Younger Than Age Sixty-
436   Five Are Unique And Would Benefit From Targeted Policy Making: Study examines
437   policies that could benefit nursing home residents younger than sixty-five. *Health Aff*
438   *(Millwood)*. 2022;41(10):1449-1459.

439   32. Colello KJ. *Overview of Long-Term Services and Supports*. Congressional Research Service;
440   2021.

441   33. Kaye HS, Harrington C, LaPlante MP. Long-term care: who gets it, who provides it, who
442   pays, and how much? *Health Aff Proj Hope*. 2010;29(1):11-21.
443   doi:10.1377/hlthaff.2009.0535

444   34. Kaye HS, Harrington C. Long-term services and supports in the community: Toward a
445   research agenda. *Disabil Health J*. 2015;8(1):3-8.

446   35. SAGE, Human Rights Campaign Foundation. *Long-Term Care Eequality Index 2021*.; 2021.
447   https://www.sageusa.org/wp-content/uploads/2021/06/sage-lei-2021-report-final.pdf

448   36. Bickford D, Morin RT, Woodworth C, et al. The relationship of frailty and disability with
449   suicidal ideation in late life depression. *Aging Ment Health*. 2021;25(3):439-444.

450   37. Akobirshoev I, Vetter M, Iezzoni LI, Rao SR, Mitra M. Delayed Medical Care And Unmet
451   Care Needs Due To The COVID-19 Pandemic Among Adults With Disabilities In The US:
452   Study examines delayed medical care and unmet care needs attributable to the COVID-19
453   pandemic among US adults with disabilities. *Health Aff (Millwood)*. 2022;41(10):1505-1512.

454   38. Kaye HS, Caldwell J. Excess Deaths Of Medicaid Home And Community-Based Services
455   Recipients During COVID-19. *Health Aff (Millwood)*. 2023;42(1):115-120.

456   39. Blum JD, Mathis SR. Forgotten on the frontlines: The plight of direct care workers during
457   COVID-19. *U Det Mercy Rev*. 2020;98:325.

458   40. Reinhard SC, Flinn B, Blakeway Amero C. COVID-19's Impact on Community-based
459   Long-Term Services and Supports. *Generations*. 2022;46(1):1-12.

460   41. Hall JP, Kurth NK, Fall EC. Discrepancy among behavioral risk factor surveillance system,
461   social security, and functional disability measurement. Published online 2012.

462   42. Hall JP, Kurth NK, Ipsen C, Myers A, Goddard K. Comparing Measures Of Functional
463   Difficulty With Self-Identified Disability: Implications For Health Policy: Study compares
464   measures of functional difficulty with self-identified disability. *Health Aff (Millwood)*.
465   2022;41(10):1433-1441.

466   43. Wu C, Lewis C. *Creating a New Model to Measure the Need for Long-Term Services and
467   Supports Among Working-Age Adults with Disabilities*. The Commonwealth Fund; 2023.
468   https://www.commonwealthfund.org/blog/2023/creating-new-model-measure-need-long-
469   term-services-and-supports-among-working-age-adults

470

471 **[Appendix]**

Appendix

Table A1. Study Sample Characteristics by Unmet LTSS Need Status (Unimputed Sample)

Characteristics	Total Sample	Unmet LTSS Need		Unadjusted		Adjusted	
		No	Yes				
	N (%)	N (%)	N (%)	RR	95% CI	RR	95% CI
Total sample, N (row %)	1,232 (100)	535 (37.5)	697 (62.5)				
Estimated sample, N (row %)	1,942,393 (100)	728,876 (37.5)	1,213,517 (62.5)				
Age, Mean (SD)	53.6 (1.1)	59.8 (1.3)	49.8 (1.5)	0.99***	[0.99,0.99]	-	-
Age ≤65	-	-	-	-	-	1.29*	[1.06,1.58]
Gender							
Male	462 (36.2)	220 (43.3)	242 (32.0)	Ref.	-	Ref.	-
Female	770 (63.8)	315 (56.7)	455 (68.0)	1.21*	[1.03,1.42]	1.06	[0.91,1.23]
Race/Ethnicity							
NH White	644 (45.3)	256 (43.0)	388 (46.7)	Ref.	-	Ref.	-
NH Black	124 (12.6)	59 (12.5)	65 (12.7)	0.97	[0.78,1.22]	0.98	[0.79,1.22]
Hispanic	367 (36.0)	178 (38.9)	189 (34.2)	0.92	[0.78,1.09]	0.90	[0.74,1.09]
NH Other	53 (2.7)	22 (2.6)	31 (2.7)	0.98	[0.71,1.36]	0.92	[0.66,1.27]
Unknown	44 (3.5)	20 (3.0)	24 (3.8)	1.06	[0.77,1.44]	0.77	[0.29,2.03]
LTSS Supports							
Paid	219 (15.7)	86 (11.0)	133 (18.5)	Ref.	-	Ref.	-
Unpaid only	384 (33.4)	128 (22.6)	256 (40.0)	1.01	[0.87,1.17]	0.93	[0.78,1.11]
Missing	629 (50.9)	321 (66.4)	308 (41.5)	Ref.	-		-
Income							
<$35,000	381 (30.5)	149 (28.2)	232 (31.9)	0.97	[0.83,1.14]	0.92	[0.79,1.08]
≥$35,000	576 (44.6)	239 (43.3)	337 (45.4)	Ref.	-	Ref.	-

Missing	275 (24.8)	147 (28.5)	128 (22.7)	-	-	-	-
Education							
High school or higher	1,003 (76.8)	408 (68.6)	595 (81.7)	1.34*	[1.06,1.69]	1.17	[0.72,1.65]
Less than high school	225 (22.9)	125 (30.8)	100 (18.2)	Ref.	-	-	Ref.
Missing	4 (0.3)	2 (0.6)	2 (0.1)	-	-	-	-
Metropolitan Status							
Non-metropolitan	157 (11.6)	62 (13.5)	95 (10.5)	Ref.	-	Ref.	-
Metropolitan	1,023 (83.1)	445 (81.5)	578 (84.0)	1.12	[0.84,1.49]	0.90	[0.72,1.12]
Missing	52 (5.3)	28 (5.0)	24 (5.5)	-	-	-	-
Sexual orientation							
Straight	1,006 (77.4)	450 (84.8)	556 (72.9)	Ref.	-	Ref.	-
Gay/ lesbian/ bisexual	92 (11.3)	21 (5.8)	71 (14.6)	1.12*	[1.03,1.23]	1.17*	[1.03,1.32]
Unknown	134 (11.4)	64 (9.5)	70 (12.5)	-	-	0.94	[1.59,1.49]

Source: Texas BRFSS 2021.
Note: Abbreviations, LTSS = Long Term Services and Supports; NH = Non-Hispanic; Ref. = Reference group; RR = Risk Ratio. * p<0.05, ** p<0.01, *** p<0.001. Percentage in parentheses are column shares. Percentage might not add up to 100% due to rounding. Calculated using sampling weights. Adjusted and unadjusted columns represent models using row variable as an independent variable for unmet LTSS need. Adjusted model includes all table covariates.

Table A2. Health and Healthcare Outcomes by Unmet LTSS Need (Unimputed Sample)

Characteristics	Total Sample	Unmet LTSS Need		Unadjusted		Adjusted	
		No	Yes				
	N (%)	N (%)	N (%)	RR	95% CI	RR	95% CI
Total sample, N (row %)	1,232 (100)	535 (37.5)	697 (62.5)				
Estimated sample, N (row %)	1,942,393 (100)	728,876 (37.5)	1,213,517 (62.5)				
General Health is Poor/Fair Only	734 (58.4)	294 (56.9)	440 (59.3)	1.04	[0.88,1.23]	1.20	[1.00,1.45]
Physical Health not Good (14+ Days)	546 (42.3)	201 (35.8)	345 (46.2)	1.26	[1.00,1.59]	1.48**	[1.14,1.91]

Mental Health not Good (14+ Days)	459 (40.1)	141 (27.5)	318 (47.8)	1.73***	[1.32,2.26]	1.46**	[1.10,1.92]
Seriously Considered Suicide	117 (11.3)	21 (3.3)	96 (16.1)	4.76***	[2.33,9.71]	4.04***	[1.82,8.97]
Multiple Chronic Conditions	964 (69.6)	408 (70.6)	556 (69.0)	0.98	[0.85,1.12]	1.13	[0.96,1.32]
Routine Checkup in the Last Year	990 (73.7)	451 (82.3)	539 (68.5)	0.86*	[0.77,0.97]	0.94	[0.84,1.05]
Flu Vaccine in the Last Year	486 (41.0)	272 (42.6)	314 (40.0)	0.94	[0.75,1.17]	1.03	[0.82,1.29]

Source: Texas BRFSS 2021.

Note: Abbreviations, LTSS = Long Term Services and Supports; NH = Non-Hispanic; Ref. = Reference group; RR = Risk Ratio. * $p<0.05$, ** $p<0.01$, *** $p<0.001$. Percentage in parentheses are column shares. Percentage might not add up to 100% due to rounding. Calculated using sampling weights. Adjusted and unadjusted columns represent models using row variable as a dependent variable and unmet LTSS need as an independent variable. Adjusted column accounts for age, gender, race/ethnicity, unpaid supports, income, educational attainment, and sexual orientation as described in Table 1.

Table 1. Study Sample Characteristics by Unmet LTSS Need Status

Characteristics	Total Sample	Unmet LTSS Need		Unadjusted		Adjusted	
		No	Yes				
	N (%)	N (%)	N (%)	RR	95% CI	RR	95% CI
Total sample, N (row %)	1,232 (100)	535 (37.5)	697 (62.5)				
Estimated sample, N (row %)	1,942,393 (100)	728,876 (37.5)	1,213,517 (62.5)				
Age, Mean (SD)	53.6 (1.1)	59.8 (1.3)	49.8 (1.5)	0.99***	[0.99,0.99]	-	-
Age ≤65	-	-	-	-	-	1.48**	[1.22,1.80]
Gender							
Male	462 (36.2)	220 (43.3)	242 (32.0)	Ref.	-	Ref.	-
Female	770 (63.8)	315 (56.7)	455 (68.0)	1.21*	[1.03,1.42]	1.17*	[1.01,1.36]
Race/Ethnicity							
NH White	644 (45.3)	256 (43.0)	388 (46.7)	Ref.	-	Ref.	-
NH Black	124 (12.6)	59 (12.5)	65 (12.7)	0.97	[0.78,1.22]	0.96	[0.76,1.20]
Hispanic	367 (36.0)	178 (38.9)	189 (34.2)	0.92	[0.78,1.09]	0.91	[0.77,1.07]
NH Other	53 (2.7)	22 (2.6)	31 (2.7)	0.98	[0.71,1.36]	0.90	[0.64,1.26]
Unknown	44 (3.5)	20 (3.0)	24 (3.8)	1.06	[0.77,1.44]	1.01	[0.73,1.38]
LTSS Supports							
Paid	405 (32.9)	194 (36.2)	215 (30.1)	Ref.	-	Ref.	-
Unpaid only	825 (67.1)	340 (63.8)	481 (69.0)	1.10	[0.90,1.34]	0.98	[0.80,1.25]
Missing	2 (0.0)	1 (0.0	1 (0.0)	Ref.	-		-
Income							
<$35,000	772 (62.8)	149 (28.2)	232 (31.9)	0.97	[0.82,1.14]	1.06	[0.90,1.25]
≥$35,000	458 (37.2)	239 (43.3)	337 (45.4)	Ref.	-	Ref.	-
Missing	2 (0.0)	147 (28.5)	128 (22.7)	-	-	-	-

Education

High school or higher	946 (77.0)	408 (68.6)	595 (81.7)	1.34*	[1.06,1.69]	1.34*	[1.07,1.67]
Less than high school	282 (23.0)	125 (30.8)	100 (18.2)	Ref.	-	-	Ref.
Missing	4 (0.0)	2 (0.6)	2 (0.1)	-	-	-	-

Metropolitan Status

No	153 (12.5)	73 (14.0)	81 (11.6)	Ref.	-	Ref.	-
Yes	1,077 (87.5)	460 (86.0)	616 (88.4)	1.09	[0.82,1.45]	1.10	[0.84,1.43]
Missing	2 (0.0)	2 (0.0)	0 (0.0)	-	-	-	-

Sexual orientation

Straight	1,006 (77.4)	450 (84.8)	556 (72.9)	Ref.	-	Ref.	-
Gay/ lesbian/ bisexual	92 (11.3)	21 (5.8)	71 (14.6)	1.12*	[1.03,1.23]	1.24**	[1.06,1.46]
Unknown	134 (11.4)	64 (9.5)	70 (12.5)	-	-	1.26*	[1.03,1.56]

Source: Texas BRFSS 2021.

Note: Abbreviations, LTSS = Long Term Services and Supports; NH = Non-Hispanic; Ref. = Reference group; RR = Risk Ratio. * $p<0.05$, ** $p<0.01$, *** $p<0.001$. Percentage in parentheses are column shares. Percentage might not add up to 100% due to rounding. Calculated using sampling weights and multiple imputations. Adjusted and unadjusted columns represent models using row variable as an independent variable for unmet LTSS need. Adjusted model includes all table covariates.

Table 2. Health and Healthcare Outcomes by Unmet LTSS Need

Characteristics	Total Sample	Unmet LTSS Need		Unadjusted		Adjusted	
		No	Yes				
	N (%)	N (%)	N (%)	RR	95% CI	RR	95% CI
General Health is Poor/Fair Only	716 (58.6)	304 (57.2)	411 (59.5)	1.04	[0.88,1.23]	1.16	[0.99,1.35]
Physical Health not Good (14+ Days)	515 (44.4)	190 (38.3)	317 (48.1)	1.26	[1.00,1.59]	1.29*	[1.03,1.63]
Mental Health not Good (14+ Days)	489 (41.6)	145 (28.6)	328 (49.3)	1.73***	[1.32,2.26]	1.51**	[1.17,1.94]
Seriously Considered Suicide	139 (11.7)	18 (3.5)	112 (16.5)	4.76***	[2.33,9.71]	4.10***	[1.96,8.59]
Multiple Chronic Conditions	856 (69.6)	378 (70.7)	480 (69.0)	0.98	[0.85,1.12]	1.03	[0.90,1.17]
Routine Checkup in the Last Year	914 (75.8)	438 (83.0)	484 (71.4)	0.86*	[0.77,0.97]	0.91	[0.82,1.01]
Flu Vaccine in the Last Year	504 (41.4)	228 (43.0)	278 (40.4)	0.94	[0.75,1.17]	1.08	[0.87,1.33]

Source: Texas BRFSS 2021.

Note: Abbreviations, LTSS = Long Term Services and Supports; NH = Non-Hispanic; Ref. = Reference group; RR = Risk Ratio. * p<0.05, ** p<0.01, *** p<0.001. Percentage in parentheses are column shares. Percentage might not add up to 100% due to rounding. Calculated using sampling weights and multiple imputations. Adjusted and unadjusted columns represent models using row variable as a dependent variable and unmet LTSS need as an independent variable. Adjusted column accounts for age, gender, race/ethnicity, unpaid supports, income, educational attainment, and sexual orientation as described in Table 1.