The relationship between unmet need for home and community-based services and health and community living outcomes

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Title: The Relationship between Unmet Need for Home and Community-Based Services and Health and Community Living Outcomes

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1 **Title:** The Relationship between Unmet Need for Home and Community-Based Services and

2 Health and Community Living Outcomes

3

4 Abstract:

<u>Background:</u> Few studies have examined user-reported perspectives about the quality and
sufficiency of home and community-based services (HCBS) and their relationship to key health
and community living outcomes.

8

<u>Objective:</u> To examine the association between unmet need for HCBS and health and community
living outcomes in a multi-state, multi-program sample of Medicaid HCBS users.

11

12 Methods: We used data from the 2017-2018 National Core Indicators-Aging and Disability 13 (NCI-AD) survey, collected among older adults and adults with physical disabilities who were 14 receiving Medicaid HCBS across 13 states (N = 10,263). We conducted descriptive analysis on 15 the demographic, functional, and health characteristics of the sample, and examined the prevalence of unmet need for HCBS across five domains: 1) assistance with daily activities, 2) 16 17 assistive technology, 3) home modifications, 4) transportation, and 5) sufficiency of services for 18 meeting user needs and goals. We used logistic regressions to estimate adjusted odds ratios for 19 the association between unmet need for HCBS and health care utilization (ED visits, 20 hospital/rehab stays, preventative care) and community living outcomes (active in the 21 community, interacting with family/friends, satisfaction, control). 22 23 Results: Across the five domains, prevalence of unmet need ranged from 21% (unmet need for 24 assistance with self-care or other daily activities) to 54% (unmet need for assistive technology).

Individuals who experienced unmet need had consistently worse health and community living

26 outcomes than those who reported no unmet need, after adjusting for key user demographic,

27 functional, and social characteristics (p<0.05).

28

<u>Conclusions:</u> Unmet need for HCBS is consistently and significantly associated with poor health
 and community living outcomes among Medicaid users.

31 Introduction

32 Long-term services and supports (LTSS) refer to a wide range of health and social 33 services provided to individuals with disabilities and older adults who need assistance with daily 34 living (i.e. eating, bathing, dressing, medication management, meal preparation, mobility). In the U.S., LTSS is primarily financed through the Medicaid program, which accounts for over half of 35 36 national LTSS spending.¹ An estimated 12 million individuals need LTSS and most prefer to receive supports at home versus in institutional settings, such as nursing homes.^{2, 3} Medicaid 37 38 Home and Community-Based Services (HCBS) provide an alternative to institutional care, 39 allowing users to receive LTSS in their own homes and communities.

40 The Americans with Disabilities Act of 1990 (ADA), as reaffirmed by the landmark U.S. 41 Supreme Court Olmstead decision, established that individuals have a right to live in the most integrated setting appropriate to their needs.⁴ Access to HCBS is essential to ensuring this right. 42 43 High-quality HCBS provides a tailored set of services to meet users' care and support needs under their own direction, according to their personal preferences and goals.⁵ Services can 44 45 include in-home personal care, adult day, employment supports, and assistance with meals, 46 transportation, assistive devices, and home modifications. While HCBS is not medical care, 47 services support users' health and well-being by ensuring a safe living environment, assisting with management of chronic health conditions, and coordinating health care services. HCBS 48 49 allow individuals with disabilities to live independently, participate in the community, and age 50 with dignity and respect. This includes facilitating participation in valued activities and 51 relationships, as well as employment. Access to HCBS may also reduce unnecessary placements in more costly nursing homes and other institutional settings.⁶⁻⁹ 52

53 Access to Medicaid HCBS is limited. The Medicaid program has a longstanding 54 institutional bias in which nursing home care is a mandatory benefit, while HCBS are optional for states to provide.¹⁰⁻¹¹ Over the past few decades, access to Medicaid HCBS has significantly 55 56 expanded. Enforcement of the ADA, coupled with state and federal policies have shifted the balance of LTSS from institutional to community-based settings.^{1, 12-13} Broader access to 57 58 Medicaid HCBS is significant because it expands services to individuals who were previously 59 ineligible for Medicaid LTSS. For example, state Medicaid waivers may extend HCBS services 60 to certain target populations (e.g., individuals with physical disabilities and older adults) at 61 higher income thresholds than standard Medicaid rules allow.

62 Nationally, approximately 56% of total Medicaid LTSS spending is now devoted to 63 HCBS.¹² However, access varies widely between states and across populations that need HCBS. 64 Moreover, states have significant flexibility in designing their Medicaid HCBS systems, which contributes to variation in program eligibility and the types and amount of services and supports 65 provided.¹⁴ Most states cap enrollment in their Medicaid HCBS programs and maintain wait lists. 66 67 Nationally, over 820,000 individuals are on wait lists for services covered under 1915 (c) HCBS 68 waivers (which is the primary Medicaid authority states use to provide HCBS) and 1115 waivers, and the average wait time exceeds three years.¹⁵⁻¹⁶ 69

70 Because unmet need for LTSS is not routinely assessed in any national population survey that includes adults of all ages, unmet need for LTSS is not well understood.² In the mid-1990s, 71 21% of LTSS users in the U.S. were found to have unmet need.¹⁷ Using a broader definition of 72 73 LTSS, a 2007 survey among the working-age population in Massachusetts found that unmet need was as high as 70%.¹⁸ In a 2011 national survey among older adults, 32% of those 65 and older 74 75 who had difficulty or received help with self-care or household activities reported experiencing an adverse consequence related to unmet need.¹⁹ Among participants in Medicaid HCBS 76 programs, studies across various states have found unmet need ranges from 24% to 58%.²⁰⁻²² 77

Previous studies have found that unmet need for HCBS is associated with multiple adverse outcomes including mortality, hospitalization, and institutionalization.²³⁻²⁶ Among those living in community settings, adverse outcomes of unmet LTSS need include the inability to get out of bed or out into the community, medication mistakes, falls, inadequate nutrition, missed healthcare appointments, discomfort due to infrequent bathing or changing clothes, and inability to reach the toilet in time.^{17, 27-30}

84 Relatively few studies have examined self-reported perspectives about the quality and 85 sufficiency of HCBS programs and their relationship to key health outcomes. Moreover, few studies have examined the impact of unmet needs on community living outcomes, such as the 86 87 ability to participate in the community and maintain desired relationships with family and 88 friends. Prior studies have been limited to data sources focused on older adults receiving Medicare, but not younger adults with disabilities receiving Medicaid HCBS.¹⁹ Other studies 89 90 have been limited to data from single states and/or individuals with disabilities but who are not 91 necessarily Medicaid HCBS users. Our study builds on previous research by 1) assessing the 92 prevalence of unmet need for HCBS in a multi-state sample of Medicaid HCBS users and 2)

- 93 examining the association between unmet need for HCBS and key health and community living
- 94 outcomes.
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96 Methods

97 Conceptual Framework

98 *Figure 1* presents the conceptual framework for the relationship between unmet need for 99 HCBS and health and community living outcomes. In this model, individual characteristics and 100 HCBS system-level factors determine the scope and level of services accessed by users. 101 Individual characteristics include demographics, health characteristics, level of assistance needed 102 for daily activities, type of residence, and personal preferences and goals. System-level factors 103 include the design, administration, and quality of Medicaid HCBS program(s) and infrastructure 104 (note: these characteristics are not directly measured in our study). Across a range of service 105 domains, users may experience unmet need for HCBS when the level, quality, and/or scope of 106 services they receive are insufficient for meeting their needs. Users may receive some but not 107 enough of the supports and services they need in each HCBS domain or report receiving no 108 services at all. Unmet need for HCBS may put individuals who rely on these services to support 109 their health, well-being, and community integration at greater risk for poor health and 110 community outcomes.

111

112 Data

113 We used secondary data from the 2017-2018 wave of the National Core Indicators Aging 114 and Disability (NCI-AD) survey. NCI-AD is coordinated by participating states, ADvancing 115 States (formerly the National Association of States United for Aging and Disabilities 116 [NASUAD]), and Human Services Research Institute (HSRI). States volunteer to participate in 117 NCI-AD and choose the publicly funded program(s) to include in their survey sample. Each state 118 must have at least 400 total respondents to participate. State health agencies conduct the survey 119 among a sample of older adults and individuals with physical disabilities who access LTSS through the selected programs in their state.³¹ The survey collects a wide range of respondent-120 121 reported information on quality of services and outcomes. Data is collected through in-person 122 interviews and a subset of questions allow for proxy responses from family, friends, or hired 123 caregivers (e.g. questions on health care events). Several items are derived from state 124 administrative records and linked to the survey data, including the primary source of funding for 125 services.

126 Although the target populations for NCI-AD are older adults and adults with physical 127 disabilities who use publicly funded LTSS, it is important to note that the individuals sampled 128 differ across states. While NCI-AD sets general parameters for sampling, individual state 129 agencies are responsible for administering the NCI-AD. Therefore, sampling and recruitment 130 procedures may vary by state. States sample respondents from their own set of LTSS programs, 131 each with varying eligibility criteria. For example, states can choose to draw their samples from 132 among Medicaid HCBS recipients, Older Americans Act program participants, nursing home 133 residents, and/or state-funded HCBS program participants.

The 2017-2018 NCI-AD represents data collected in one survey cycle (June 1, 2017 – May 31, 2018) and the data in this study includes responses from 13 states (CO, IN, KS, MN, MS, NE, NJ, NV, OR, TN, TX, VT and WI). The data was de-identified at the state level to protect state and respondent identities. See *Table 1* in the supplemental materials for further details on the Medicaid HCBS program sampled in each state and corresponding sample sizes.

140 Study sample

Of the 15,789 respondents to the NCI-AD, we limited our sample to the 10,284 identified
as participating in Medicaid HCBS programs. Of those, 21 were removed because of missing
data on all of the outcomes of interest, leaving a final sample size of 10,263 community-dwelling
Medicaid HCBS recipients.

145

146 *Measures*

147 Outcome Variables - Health Care Utilization & Community Living Outcomes. Health 148 care utilization and community living outcomes were measured as binary variables (yes/no). The 149 health care utilization outcomes included measures of whether respondents reported 1) one or 150 more emergency room visit(s), 2) one or more overnight stay(s) in a hospital or rehabilitation 151 facility, 3) at least one physical exam or wellness visit, and 4) at least one dental visit over the 152 prior year. Community living outcomes included measures of whether respondents reported 153 being 1) as active in the community as they would like to be, 2) able to see or talk to friends and 154 family when they wanted to, 3) satisfied with how they spend their time during the day, and if 155 they 4) felt in control of their life. Of note, NCI-AD allows proxy responses for survey items 156 used to construct the health care utilization outcomes but not the community living outcomes.

157 Independent Variables – Unmet Need. The key independent variables were binary 158 (yes/no) indicators of unmet need for HCBS. Unmet need was assessed across five domains: 1) 159 assistance with self-care or other daily activities, 2) assistive technology, 3) home modifications, 160 4) transportation, and 5) services that fully meet user needs and goals. Respondents had 1) unmet 161 need for assistance with self-care or other daily activities if they did not always receive enough 162 help with self-care activities (e.g., bathing, dressing, eating) or other daily activities (e.g., 163 preparing meals, shopping, taking medications) when needed. Respondents had 2) unmet need 164 for assistive technology if they needed but did not have any of the following items: walker, 165 scooter, wheelchair, hearing aids, glasses, or CPAP machine. Similarly, respondents had 3) 166 unmet need for home modifications if they needed but did not have any of the following items: 167 bathroom grab bars, other bathroom modifications, specialized bed, ramp or chairlift, remote 168 monitoring system, or emergency response system. For transportation, respondents had 4) unmet 169 need if they reported not always having transportation to medical appointments or activities 170 outside of the home. Finally, respondents had 5) unmet need for services that met their needs and 171 goals if they reported that their long-term care services did not fully meet all of their needs and 172 goals.

173 Covariates. We examined several demographic and health characteristics of the sample 174 and included these as covariates in our multivariate analyses. Demographic characteristics 175 included age, gender, race/ethnicity (white, Black, and other non-Hispanic, Hispanic, unknown), 176 and location (rural or urban area based on respondent zip codes). This information was derived 177 from state administrative records, and where missing, was asked during the interview. We also 178 included two variables on living arrangements: whether the respondent lived alone and residence 179 type (home or senior living, congregate setting [e.g., group home or assisted living], other). 180 Health characteristics included self-reported health status (excellent, very good, or good; fair; 181 poor; only included as a covariate in models for community living outcomes) and functional 182 status based on reported level of need (none, some, a lot) for assistance with self-care and other 183 daily activities.

184

185 Analysis

We conducted descriptive analysis to describe the demographic, functional, and health
characteristics of the sample overall and by unmet need status (i.e., any unmet need vs. no unmet

- 188 need) to examine how individual characteristics might be associated with unmet need. We also
- 189 performed bivariate analyses to determine the observed prevalence of each outcome by unmet
- 190 need status. We used logistic regressions to estimate the adjusted odds ratios (with 95%
- 191 confidence intervals) for the association between unmet need indicators and the health care
- 192 utilization and community living outcomes, as hypothesized in our conceptual framework.
- 193 Multivariable models adjusted for the person-level characteristics described above, as these
- 194 factors may also influence health and community living outcomes. We performed all analyses in
- 195 Stata version 16 MP and a p-value of <0.05 was the accepted level of significance. This study
- 196 was reviewed and approved by the authors' Institutional Review Board.

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197 **Results**

198 *Table 1* presents descriptive statistics on the community-dwelling Medicaid HCBS users 199 in the study sample, overall and by unmet need status. About 80% of users reported unmet need 200 in at least one domain, and unmet need for assistive technology and home modifications were 201 most common. In general, those with any unmet need were younger than those without unmet 202 need. HCBS users who were non-Hispanic white represented a greater proportion of those with 203 no unmet need compared to those with any unmet need, and the inverse relationship was true for 204 all other racial/ethnic groups. Living at home/senior living and living alone was more common 205 among individuals reporting unmet need. Individuals with any unmet need were more likely to 206 report their health status as poor.

Figure 2 compares the observed prevalence of each health and community living
outcome among HCBS users with any unmet need to those with no unmet need in any of the five
domains. Individuals with at least one type of unmet need had greater prevalence of ER use and
overnight hospital or rehab stays (52% vs. 34% and 36% vs. 24%, respectively). Individuals with
no unmet need were more likely to receive preventative care services (i.e., a physical or dental
exam). With respect to community living, users with no unmet need were consistently more
likely to experience each positive outcome than those with any unmet need.

214 Table 2 presents results from multivariate analysis that examines the association between 215 unmet need and health care utilization outcomes, adjusted for respondent characteristics. In 216 general, unmet need was associated with greater likelihood of an ER visit and a hospital/rehab 217 stay in the past year and reduced likelihood of both types of preventative care in the past year. 218 Among the various types of unmet need, lack of adequate assistive technology was associated 219 with the greatest likelihood of having an ER visit and a hospital/rehab stay, and lowest likelihood 220 of receiving a physical exam in the last year. Unmet need for transportation was associated with 221 the lowest likelihood of receiving a dental exam in the last year.

Table 3 presents the adjusted association between the various types of unmet need and community living outcomes. Unmet need was consistently associated with lower likelihood of experiencing each community living outcome. Comparing across types of unmet need, unmet need for transportation was related to the lowest likelihood of being active in the community and interacting with friends and family. Services that did not fully meet recipient needs and goals

- 227 was associated with the lowest likelihood of user satisfaction with how time is spent and feeling
- in control of life.

229 **Discussion**

230 This study examines the prevalence of unmet needs and associated health and community 231 living outcomes in a multi-state, multi-program sample of older adults and individuals with 232 physical disabilities receiving Medicaid HCBS. Using a novel dataset that assesses LTSS 233 outcomes across a standard set of user-reported measures, we found that unmet need for HCBS is 234 common among older adults and adults with physical disabilities who receive Medicaid HCBS. 235 While our study does not focus on the causes for unmet need, our conceptual framework presents 236 HCBS system-level characteristics as a factor in the ability of HCBS programs to meet users' 237 service and support needs. The prevalence of unmet needs for HCBS is unsurprising given the 238 optional nature of most services under state Medicaid programs, enrollment caps, and limits on 239 service allocations. Access to HCBS may also be linked to systemic racial and ethnic barriers, and barriers by geographic location.³²⁻³³ Furthermore, challenges with provider networks and the 240 241 availability of qualified direct care workers may also impact access to high-quality HCBS. Demographic shifts have increased reliance on direct care workers as the need for LTSS grows 242 and the supply of potential family caregivers falls.³⁴ At the same time, many direct care workers 243 244 experience poor job quality, including low wages, limited benefits, and insufficient training, leading to high employee turnover and job vacancies.³⁵⁻³⁸ These workforce issues may impact the 245 quality of HCBS and lead to unmet need and other adverse outcomes.³⁸⁻³⁹ 246

247 Our finding that nearly a third of HCBS users reported that their services did not fully 248 meet their service needs and goals is particularly concerning given that the Centers for Medicaid 249 and Medicare Services requires person-centered planning for all individuals receiving Medicaid 250 HCBS. Person-centered planning is a facilitated, individual-directed, positive approach to 251 planning and coordinating a person's services and supports based on their individual aspirations, needs, preferences, and values.^{5, 40} The extent to which person-centered thinking, planning, and 252 253 practice is implemented effectively varies considerably across HCBS programs and states. Lack 254 of high-quality person-centered planning may impact the degree to which services and supports 255 can be customized to fully meet individual needs. To address this variation, policy makers should 256 adopt and enforce a set of standardized person-centered planning practices and measures to improve the quality of service planning among HCBS users.⁵ Future studies should examine the 257 258 barriers and facilitators of person-centered planning among Medicaid HCBS recipients and

assess the extent to which service plans are implemented and reflected in the supports that usersreceive.

261 Our study found that unmet need for HCBS was consistently associated with adverse 262 health and community living outcomes, supporting the relationships hypothesized in our 263 conceptual framework. The link between unmet need and user outcomes provides actionable 264 evidence for policy makers to systematically assess and address individual users' specific need 265 for HCBS. A crucial concern in the growth of HCBS is whether community-based supports 266 result in improved outcomes for users over institutional care. Among individuals dually eligible 267 for Medicaid and Medicare, both all-cause hospitalizations and potentially avoidable hospitalizations are more common among HCBS users than nursing home residents.⁴¹ Results 268 269 from our study suggest that addressing unmet needs among HCBS users could be one pathway 270 for reducing avoidable hospitalizations and improving health and well-being, which could reduce 271 overall health care costs for this population. This finding is particularly relevant for state and 272 federal initiatives seeking to better integrate and coordinate LTSS and acute care for individuals 273 receiving Medicaid LTSS. There has been significant growth in Managed Long-Term Services 274 and Supports (MLTSS), which is the delivery of LTSS through capitated managed care 275 organizations that are also typically responsible for acute care and other services such as behavioral health.⁴²⁻⁴³ With meaningful stakeholder engagement, oversight, and quality metrics, 276 277 these payment and delivery models could offer health plans better incentive to reduce unmet 278 HCBS needs and potentially improve related health outcomes among their beneficiaries.⁴⁴

279 This study has several limitations. The cross-sectional design limits our ability to make 280 causal inferences about the relationship between unmet need and outcomes for HCBS users. 281 For example, because the cross-sectional data does not ensure the temporal precedence of unmet 282 need, there is possibility for reverse causality. Although the multivariate analysis controlled for 283 certain respondent health and functional characteristics, it is possible that health and community 284 living outcomes may contribute to a user's unmet need for HCBS. State-level administration of 285 the NCI-AD survey presents another limitation for generalizability of the study findings. 286 Participating states did not have identical sampling strategies and selected respondents from their 287 own set of unique Medicaid HCBS programs, each with their own user eligibility requirements.³³ 288 The study sample may not be representative of the Medicaid HCBS user population in each state 289 or across states.

Because the data was aggregated across states (without the presence of a state identifier), the extent to which various state Medicaid program characteristics might differentially impact unmet need among HCBS users, user outcomes, or the relationship between the two is unknown. Prior research involving the Medicaid population has found wide variation between states in terms of program sufficiency and quality. Finally, because some survey items allowed for proxy responses, not all data collected by NCI-AD was user-reported. There may be cases where proxy responses do not accurately or fully capture user experiences.

297 Despite these limitations, the findings from this study emphasize the heightened risk of 298 adverse health and community living outcomes related to unmet needs for HCBS among 299 Medicaid beneficiaries. This study calls attention to the importance of user perspectives and 300 community engagement as important measures for assessing the sufficiency, quality, and 301 outcomes of HCBS programs. It also underscores the importance of person-centered approaches 302 that incorporate the perspectives, needs, and desires of individuals receiving HCBS and the 303 potential impact on health and community living outcomes. As states are working to shift LTSS 304 programs away from institutional services and toward HCBS, additional efforts are needed to 305 ensure that Medicaid HCBS programs are addressing the service needs of their beneficiaries. 306 Programs should implement quality measures that track the extent to which recipients' needs are 307 being met, in addition to whether the services they receive have been designed to further their 308 individual life goals.

309	References	
310	1. O'Malley Watts, M., Musumeci, M., Chidambaram, P. (2020). Medicaid home and	
311	community-based services enrollment and spending [Issue Brief]. Henry J Kaiser Family	
312	Foundation. https://www.kff.org/medicaid/issue-brief/medicaid-home-and-community-	
313	based-services-enrollment-and-spending/	
314	2. Kaye, H. S., Harrington, C., & LaPlante, M. P. (2010). Long-term care: Who gets it, who	
315	provides it, who pays, and how much?. Health affairs, 29(1), 11-21.	
316	3. Harrell R, Lynott J, Guzman S, Lampkin C. (2014). What is livable? Community preferences of	
317	older adults. AARP Public Policy Institute.	
318	https://www.aarp.org/content/dam/aarp/research/public_policy_institute/liv_com/2014/what-is-	
319	livable-report-AARP-ppi-liv-com.pdf	
320	4. Olmstead v. L. C., 527 U.S. 581 (1999).	
321	5. National Quality Forum. (2016). Quality in home and community-based services to support	
322	community living: Addressing gaps in performance measurement. Washington, DC.	
323	https://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-	
324	Based_Services_to_Support_Community_LivingAddressing_Gaps_in_Performance_Measure	:
325	ment.aspx	
326	6. Kane, R. L., Lum, T. Y., Kane, R. A., Homyak, P., Parashuram, S., & Wysocki, A. (2013). Does	
327	Home- and Community-Based Care Affect Nursing Home Use? Journal of Aging & Social	
328	Policy, 25(2), 146-160. doi:10.1080/08959420.2013.766069	
329	7. Spillman, B. (2016). Does home care prevent or defer nursing home use? Report to the	
330	Department of Health and Human Services, Assistant Secretary for Planning and Evaluation.	
331	https://aspe.hhs.gov/basic-report/does-home-care-prevent-or-defer-nursing-home-use	
332	8. Segelman, M., Intrator, O., Li, Y., Mukamel, D., Veazie, P., & Temkin-Greener, H.	
333	(2017). HCBS spending and nursing home admissions for 1915 (c) Waiver Enrollees.	
334	Journal of Aging & Social Policy, 29(5), 395-412.	
335	9. Xu, H., & Intrator, O. (2020). Medicaid Long-term Care Policies and Rates of Nursing Home	
336	Successful Discharge to Community. J Am Med Dir Assoc, 21(2), 248-253.e241.	
337	doi:10.1016/j.jamda.2019.01.153	
338	10. Reaves, E. L., & Musumeci, M. (2015). Medicaid and long-term services and supports: A	
339	primer. Washington, DC: The Kaiser Family Foundation.	

340	https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-
341	primer/
342	11. Ryan, J., & Edwards, J. C. (2015). Rebalancing Medicaid long-term services and
343	supports. Health Affairs Health Policy Brief, 1-7.
344	12. Murray, C., Tourtellotte, A., Lipson, D., & Wysocki, A. (2021). Medicaid Long-Term
345	Services and Supports annual expenditures report: Federal fiscal years 2017 and 2018.
346	Mathematica Policy Research. https://www.medicaid.gov/medicaid/long-term-services-
347	supports/downloads/ltssexpenditures-2017-2018.pdf
348	13. Thach N.T., Wiener J.M. (2018). An overview of long-term services and supports and Medicaid
349	Final Report to the Office of the Assistant Secretary for Planning and Evaluation. 2018.
350	https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicaid-final-
351	report
352	14. Ng T., Stone J., Harrington C. (2015) Medicaid home and community-based services:
353	how consumer access is restricted by state policies. J Aging Soc Policy. 27(1):21-46.
354	doi:10.1080/08959420.2015.969078
355	15. Kitchener, M., Ng, T., & Harrington, C. (2004). Medicaid 1915 (c) home and
356	community-based services waivers: a national survey of eligibility criteria, caps, and
357	waiting lists. Home health care services quarterly, 23(2), 55-69.
358	16. Musumeci, M., O'Malley Watts, M., Chidambaram, P. (2020). Key state policy choices about
359	medicaid home and community-based services. Kaiser Family Foundation.
360	https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-
361	community-based-services/
362	17. LaPlante, M. P., Kaye, H. S., Kang, T., & Harrington, C. (2004). Unmet need for
363	personal assistance services: estimating the shortfall in hours of help and adverse
364	consequences. The Journals of Gerontology Series B: Psychological Sciences and Social
365	Sciences, 59(2), S98-S108.
366	18. Mitra, M., Bogen, K., Long-Bellil, L. M., & Heaphy, D. (2011). Unmet needs for home
367	and community-based services among persons with disabilities in
368	Massachusetts. Disability and health journal, 4(4), 219-228.
369	19. Freedman, V. A., & Spillman, B. C. (2014). Disability and care needs among older
370	Americans. The Milbank Quarterly, 92(3), 509-541.

371	20. Brown, R., Carlson, B. L., Dale, S., Foster, L., Phillips, B., & Schore, J. (2007). Cash and
372	counseling: Improving the lives of Medicaid beneficiaries who need personal care or
373	home-and community-based services. Mathematica Policy Research.
374	https://www.mathematica.org/our-publications-and-findings/publications/cash-and-
375	counseling-improving-the-lives-of-medicaid-beneficiaries-who-need-personal-care-or-
376	home-and-communitybased-services
377	21. Graham, C., Liu, P-J., Kaye, S. (2016). Evaluation of Cal MediConnect: Key Findings from a
378	Survey with Beneficiaries. Berkeley, CA: UCSF Community Living Center and UC Berkeley
379	Health Research for Action Center.
380	https://www.thescanfoundation.org/sites/default/files/uc_duals_phonesurvey_2016.pdf
381	22. NASUAD, HSRI. (2017). National Core Indicators for Aging and Disability Adult
382	Consumer Survey 2015-2016 national results. https://nci-ad.org/upload/reports/NCI-
383	AD_2015-2016_National_Report_FINAL.pdf
384	23. He, S., Craig, B. A., Xu, H., Covinsky, K. E., Stallard, E., Thomas III, J., & Sands, L.
385	P. (2015). Unmet need for ADL assistance is associated with mortality among older
386	adults with mild disability. Journals of Gerontology Series A: Biomedical Sciences and
387	Medical Sciences, 70(9), 1128-1132.
388	24. DePalma, G., Xu, H., Covinsky, K. E., Craig, B. A., Stallard, E., Thomas III, J., & Sands,
389	L. P. (2013). Hospital readmission among older adults who return home with unmet need
390	for ADL disability. The Gerontologist, 53(3), 454-461.
391	25. Xu, H., Covinsky, K. E., Stallard, E., Thomas III, J., & Sands, L. P. (2012). Insufficient
392	help for activity of daily living disabilities and risk of all-cause hospitalization. Journal of
393	the American Geriatrics Society, 60(5), 927-933.
394	26. Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). Unmet care needs and
395	key outcomes in dementia. Journal of the American Geriatrics Society, 53(12), 2098-
396	2105.
397	27. Allen, S. M., & Mor, V. (1997). The prevalence and consequences of unmet need:
398	Contrasts between older and younger adults with disability. Medical care, 1132-1148.
399	28. Allen, S. M., Piette, E. R., & Mor, V. (2014). The adverse consequences of unmet need
400	among older persons living in the community: dual-eligible versus Medicare-only

401	beneficiaries. Journals of Gerontology Series B: Psychological Sciences and Social
402	Sciences, 69(Suppl_1), S51-S58.
403	29. Desai, M. M., Lentzner, H. R., & Weeks, J. D. (2001). Unmet need for personal
404	assistance with activities of daily living among older adults. The Gerontologist, 41(1),
405	82-88.
406	30. Komisar, H. L., Feder, J., & Kasper, J. D. (2005). Unmet long-term care needs: an
407	analysis of Medicare-Medicaid dual eligibles. INQUIRY: The Journal of Health Care
408	Organization, Provision, and Financing, 42(2), 171-182.
409	31. NASUAD, HSRI. (2019). National Core Indicators for Aging and Disabilities Adult
410	Consumer Survey 2017-2018 national results part 1. https://nci-
411	ad.org/upload/reports/NCI-AD_2017-2018_National_Report_Part_1_FINAL_12-24-
412	<u>19.pdf</u>
413	32. Gorges, R. J., Sanghavi, P., & Konetzka, R. T. (2019). A National Examination Of Long-Term
414	Care Setting, Outcomes, And Disparities Among Elderly Dual Eligibles. Health Affairs, 38(7).
415	1110-1118. doi:10.1377/hlthaff.2018.05409
416	33. Harrington, C., & Kang, T. (2016). Disparities in Service Use and Expenditures for
417	People With Intellectual and Developmental Disabilities in California in 2005 and
418	2013. Intellectual and developmental disabilities, 54(1), 1–18.
419	https://doi.org/10.1352/1934-9556-54.1.1
420	34. Redfoot, D., Feinberg, L., & Houser, A. N. (2013). The aging of the baby boom and the
421	growing care gap: A look at future declines in the availability of family caregivers (pp. 1-
422	12). Washington, DC: AARP Public Policy Institute.
423	35. Campbell, S., Drake, A.D.R., Espinoza, R., & Scales, K. (2021). Caring for the Future:
424	The Power and Potential of America's Direct Care Workforce. Bronx, NY.
425	https://phinational.org/resource/caring-for-the-future-the-power-and-potential-of-
426	americas-direct-care-workforce/
427	36. National Core Indicators. (2020). National Core Indicators 2019 Staff Stability Survey
428	Report. https://www.nationalcoreindicators.org/upload/core-
429	indicators/2019StaffStabilitySurveyReport_FINAL_1_6_21.pdf

430	37. Kelly, C. M., Morgan, J. C., & Jason, K. J. (2013). Home Care Workers: Interstate
431	Differences in Training Requirements and Their Implications for Quality. Journal of
432	Applied Gerontology, 32(7), 804-832. https://doi.org/10.1177/0733464812437371
433	38. Institute of Medicine (US) Committee on the Future Health Care Workforce for Older
434	Americans. (2008). Retooling for an Aging America: Building the Health Care
435	Workforce. National Academies Press (US).
436	39. Robison, J., Shugrue, N., Porter, M., Fortinsky, R. H., & Curry, L. A. (2012). Transition
437	from home care to nursing home: Unmet needs in a home-and community-based program
438	for older adults. Journal of Aging & Social Policy, 24(3), 251-270.
439	40. National Quality Forum. (2020). Person centered planning and practice final
440	report. Washington, DC.
441	http://www.qualityforum.org/Publications/2020/07/Person_Centered_Planning_and_Prac
442	tice_Final_Report.aspx
443	41. Konetzka, R. T., Jung, D. H., Gorges, R. J., & Sanghavi, P. (2020). Outcomes of
444	Medicaid home-and community-based long-term services relative to nursing home care
445	among dual eligibles. Health Services Research, 55(6), 973-982.
446	42. Lewis, E., Eiken, S., Amos, A., Saucier, P. (2018). The growth of managed long-term services
447	and supports programs: 2017 update. Truven Health Analytics.
448	https://www.medicaid.gov/medicaid/downloads/mltssp-inventory-update-2017.pdf
449	43. Medicaid and CHIP Payment and Access Commission. (2018). Tailoring MLTSS
450	programs for individuals with intellectual and developmental disabilities. Washington,
451	DC. https://www.macpac.gov/publication/tailoring-mltss-programs-for-individuals-with-
452	intellectual-and-developmental-disabilities/
453	44. Dobson, C., Gibbs, S., Mosey, A., Smith, L. (2017). Demonstrating the value of Medicaid
454	managed long-term services and supports programs.
455	https://www.chcs.org/resource/demonstrating-value-medicaid-managed-long-term-services-
456	supports-programs/

Table 1. Sample Descriptives

		Total Any Unmet Need		t Need	No Unmet Need			
		Ν	%	Ν	%	Ν	%	
Ν		9,913	-	8,040	-	1,873	-	
Gender (n=9,867)	Male	3,514	35.6	2,849	35.6	665	35.7	
	Female	6,353	64.4	5,153	64.4	1,200	64.3	
Age (n= 9,887)	18-54	2,207	22.3	1,818	22.7	389	20.8	
	55-64	2,184	22.1	1,891	23.6	293	15.7	
	65-74	2,231	22.6	1,851	23.1	380	20.3	
	75-84	1,918	19.4	1,468	18.3	450	24.1	
	85+	1,347	13.6	991	12.4	356	19.1	
Race/ethnicity (n=9,913)					X			
White, non-	Hispanic	5,481	55.3	4,219	52.5	1,262	67.4	
Black, non-	Hispanic	1,843	18.6	1,583	19.7	260	13.9	
	Hispanic	1,411	14.2	1,256	15.6	155	8.3	
Other, non-	Hispanic	623	6.3	514	6.4	109	5.8	
T	Jnknown	555	5.6	468	5.8	87	4.6	
Rural/Urban status (n=9,811)	Rural	545	5.6	412	5.2	133	7.2	
	Urban	9,266	94.4	7,549	94.8	1,717	92.8	
Needs help w. self-care (n=9,861)	None	1,954	19.8	1,477	18.5	477	25.5	
	Some	4,301	43.6	3,583	44.8	718	38.4	
	A lot	3,606	36.6	2,930	36.7	676	36.1	
Needs help w. other daily activities (n=9,3	352)		\sim					
	None	488	5	365	4.6	123	6.6	
	Some	5,811	59	4,819	60.4	992	53.1	
	A lot	3,553	36.1	2,799	35.1	754	40.3	
Health status (n=9,819)		3						
Excellent/very go	od/good	4,376	44.6	3,201	40.2	1,175	63	
	Fair	3,443	35.1	2,916	36.7	527	28.3	
	Poor	2,000	20.4	1,837	23.1	163	8.7	
Residence type (n=9,751)								
Home/seni	or living	7,802	80	6,551	82.8	1,251	67.9	
Congrega	te setting	1,739	17.8	1,184	15	555	30.1	
	Other	210	2.2	174	2.2	36	2	
Living arrangement (n=9,073) Liv	es alone	2,734	31.2	2,325	32.4	409	25.5	
Lives wi	th others	6,039	68.8	4,845	67.6	1,194	74.5	
Unmet need for:	Ν			%				
Help w. self-care/other daily activities (n=		2,124			21.1			
Services meeting needs & goals (n=10,049)			3,016			30.0		
Assistive technology (n=9,922)			5,389			54.3		
Home modifications (n=9,876)			5,050			52.2		
Transportation (n=10,064)			2,612			26.7		

Notes: Some individuals in the sample had missing data for the variables included in this table. Sample sizes among individuals without missing data for each variable are noted in parentheses.

	Model A:	Model B:	Model C:	Model D:
	ER visit	Hospital/rehab stay	Physical exam	Dental exam
Sample included:	7,850	7,834	7,724	7,712
	Odds	ratio (95% confidence interval)		
Unmet Need for:				
Help w. self-care/other daily activities	1.31**(1.16 - 1.48)	1.12 (0.99 - 1.27)	0.95 (0.81 - 1.12)	1.16*(1.02 - 1.31)
Services meeting needs & goals	1.13*(1.01 - 1.26)	1.19**(1.06 - 1.33)	0.82**(0.71 - 0.95)	0.94 (0.84 - 1.05)
Assistive technology	1.60**(1.46 - 1.77)	1.54**(1.39 - 1.71)	0.74**(0.65 - 0.84)	0.85**(0.77 - 0.94)
Home modifications	1.30**(1.17 - 1.43)	1.16**(1.04 - 1.29)	0.89 (0.78 - 1.03)	0.83**(0.75 - 0.92)
Transportation	1.07 (0.96 - 1.20)	1.17**(1.05 - 1.32)	0.76**(0.66 - 0.88)	0.70**(0.63 - 0.78)
Female	1.22**(1.10 - 1.34)	1.07 (0.97 - 1.19)	1.16*(1.02 - 1.32)	1.08 (0.98 - 1.19)
Age (ref. 65-74)				
18-54	0.99 (0.86 - 1.14)	0.77 * * (0.67 - 0.90)	0.68**(0.57 - 0.83)	1.89**(1.64 - 2.18)
55-64	1.11 (0.97 - 1.27)	0.98 (0.85 - 1.13)	0.89 (0.73 - 1.07)	1.38**(1.21 - 1.59)
75-84	0.98 (0.84 - 1.13)	0.99 (0.85 - 1.15)	0.90 (0.73 - 1.10)	0.89 (0.77 - 1.04)
85+	0.86 (0.73 - 1.01)	0.78**(0.65 - 0.92)	0.99 (0.79 - 1.24)	0.80**(0.68 - 0.95)
Race/ethnicity (ref. White, non-Hispanic)				
Black, non-Hispanic	0.82**(0.72 - 0.93)	0.78**(0.68 - 0.89)	1.05 (0.88 - 1.25)	0.92 (0.81 - 1.05)
Hispanic or Latino	0.79**0.69 - 0.91)	0.71**(0.61 - 0.82)	0.89 (0.74 - 1.07)	1.15 (1.00 - 1.32)
Other, non-Hispanic	0.75**(0.61 - 0.92)	0.81*(0.65 - 1.00)	0.71**(0.55 - 0.91)	1.01 (0.82 - 1.23)
Unknown	1.20 (0.97 - 1.49)	0.95 (0.76 - 1.18)	1.14 (0.85 - 1.55)	1.07 (0.87 - 1.33)
Lives in urban area	1.28*(1.04 - 1.58)	1.10 (0.88 - 1.37)	1.35*(1.05 - 1.74)	1.19 (0.96 - 1.47)
Needs help w. self-care (ref. none)				
A lot	1.39**(1.18 - 1.63)	1.42**(1.20 - 1.69)	1.42**(1.15 - 1.74)	1.08 (0.92 - 1.27)
Some	1.28**(1.11 - 1.47)	1.24**(1.07 - 1.45)	1.20*(1.01 - 1.44)	1.19*(1.03 - 1.37)
Needs help w. other daily activities (ref. none)			
A lot	1.13 (0.87 - 1.46)	1.04 (0.79 - 1.38)	1.17 (0.85 - 1.61)	0.74*(0.57 - 0.96)
Some	0.97 (0.75 - 1.24)	0.97 (0.74 - 1.27)	1.13 (0.83 - 1.53)	0.81 (0.63 - 1.04)
Residence type (ref. home/senior living)				
Congregate setting	1.19*(1.04 - 1.36)	1.12 (0.97 - 1.29)	0.60**(0.50 - 0.72)	1.42**(1.23 - 1.63)
Other	0.80 (0.54 - 1.18)	0.95 (0.63 - 1.42)	0.54**(0.34 - 0.86)	0.89 (0.60 - 1.31)
Lives alone	1.16**(1.04 - 1.29)	1.04 (0.92 - 1.16)	0.85*(0.73 - 0.98)	1.07 (0.96 - 1.19)

Table 2. Multivariate Logistic Regression Results: Health Outcomes

Notes: *p<0.05 **p<0.01

	Model A:	Model B:	Model C:	Model D:
	Active in community	Interact w. family/friends	Satisfied w. time spent	In control of life
Sample included:	6,702	6,450	6,746	6,681
Unmet Need for:				
Help w. self-care/other daily activities	0.56** (0.48 - 0.65)	0.64** (0.53 - 0.78)	0.57** (0.49 - 0.65)	0.68** (0.59 - 0.78)
Services meeting needs & goals	0.69** (0.61 - 0.79)	0.63** (0.53 - 0.75)	0.46** (0.41 - 0.52)	0.42** (0.37 - 0.48)
Assistive technology	0.75** (0.67 - 0.83)	0.90 (0.76 - 1.06)	0.82** (0.73 - 0.91)	0.85* (0.76 - 0.96)
Home modifications	0.71** (0.63 - 0.80)	0.88 (0.73 - 1.04)	0.85** (0.75 - 0.95)	0.90 (0.79 - 1.02)
Transportation	0.47** (0.41 - 0.53)	0.51** (0.43 - 0.60) 💧	0.58** (0.51 - 0.65)	0.63** (0.55 - 0.71)
Female	0.81** (0.73 - 0.91)	1.06 (0.90 - 1.25)	0.92 (0.82 - 1.03)	0.91 (0.80 - 1.02)
Age (ref. 65-74)				
18-54	0.93 (0.79 - 1.10)	1.18 (0.94 - 1.48)	0.85 (0.73 - 1.00)	0.95 (0.81 - 1.13)
55-64	0.92 (0.79 - 1.08)	1.07 (0.86 - 1.33)	0.86* (0.73 - 1.00)	1.05 (0.89 - 1.23)
75-84	1.11 (0.94 - 1.32)	1.43** (1.10 - 1.84)	1.18 (0.99 - 1.41)	1.19 (0.99 - 1.43)
85+	1.04 (0.86 - 1.27)	1.61** (1.20 - 2.15)	1.24* (1.02 - 1.52)	1.20 (0.98 - 1.49)
Race/ethnicity (ref. White, non-Hispanic)				
Black, non-Hispanic	0.96 (0.83 - 1.11)	1.82** (1.45 - 2.28)	1.23** (1.07 - 1.42)	1.57** (1.34 - 1.83)
Hispanic or Latino	0.69** (0.58 - 0.82)	1.87** (1.43 - 2.45)	1.50** (1.27 - 1.77)	1.22* (1.03 - 1.44)
Other, non-Hispanic	1.20 (0.93 - 1.55)	1.27 (0.87 - 1.84)	1.37* (1.05 - 1.78)	1.14 (0.87 - 1.49)
Unknown	0.86 (0.67 - 1.10)	1.49* (1.02 - 2.18)	0.98 (0.77 - 1.25)	0.96 (0.75 - 1.24)
Lives in urban area	0.93 (0.73 - 1.17)	1.08 (0.78 - 1.50)	0.82 (0.64 - 1.04)	0.86 (0.67 - 1.11)
Needs help w. self-care (ref. none)				
A lot	0.71** (0.60 - 0.85)	1.33* (1.03 - 1.71)	1.03 (0.86 - 1.23)	0.94 (0.78 - 1.14)
Some	0.88 (0.76 - 1.03)	1.09 (0.88 - 1.36)	1.01 (0.87 - 1.18)	0.91 (0.77 - 1.08)
Needs help w. other daily activities (ref. none)				
A lot	1.12 (0.85 - 1.48)	0.80 (0.52 - 1.24)	1.04 (0.78 - 1.38)	0.94 (0.70 - 1.28)
Some	1.21 (0.93 - 1.57)	0.86 (0.57 - 1.31)	1.08 (0.82 - 1.41)	1.10 (0.82 - 1.48)
Health Status (ref. Excellent/very good/good)				
Fair	0.66** (0.59 - 0.74)	0.85 (0.71 - 1.03)	0.67** (0.59 - 0.76)	0.59** (0.52 - 0.67)
Poor	0.36** (0.31 - 0.43)	0.72** (0.58 - 0.89)	0.41** (0.36 - 0.48)	0.41** (0.35 - 0.48)
Residence type (ref. home/ senior living)				
Congregate setting	1.17* (1.00 - 1.37)	0.55** (0.44 - 0.69)	1.05 (0.89 - 1.24)	0.72** (0.61 - 0.85)
Other	1.10 (0.71 - 1.70)	0.45** (0.26 - 0.77)	0.97 (0.62 - 1.51)	0.63* (0.41 - 0.98)
Lives alone	1.00 (0.89 - 1.14)	0.97 (0.80 - 1.16)	0.97 (0.86 - 1.10)	1.69** (1.48 - 1.93)

Table 3. Multivariate Logistic Regression Results: Community Living Outcomes

Notes: *p<0.05 **p<0.01



Figure 1. Conceptual Framework for the Relationship between Unmet Need for HCBS and Health and Community Living Outcomes

Black and white version

Figure 1. Conceptual Framework for the Relationship between Unmet Need for HCBS and Health and Community Living Outcomes



Color version



Black and white version

