

Journal Pre-proof

Experiences of health care services among people with cognitive disabilities and mental health conditions

Elizabeth M. Stone, Elizabeth Wise, Elizabeth A. Stuart, Emma E. McGinty



PII: S1936-6574(23)00129-2

DOI: <https://doi.org/10.1016/j.dhjo.2023.101547>

Reference: DHJO 101547

To appear in: *Disability and Health Journal*

Received Date: 23 June 2023

Revised Date: 23 October 2023

Accepted Date: 30 October 2023

Please cite this article as: Stone EM, Wise E, Stuart EA, McGinty EE, Experiences of health care services among people with cognitive disabilities and mental health conditions, *Disability and Health Journal* (2023), doi: <https://doi.org/10.1016/j.dhjo.2023.101547>.

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

© 2023 Published by Elsevier Inc.

Experiences of health care services among people with cognitive disabilities and mental health conditions

Elizabeth M. Stone, PhD, MSPH^{ab}, Elizabeth Wise, MD^c, Elizabeth A. Stuart, PhD^d, Emma E. McGinty, PhD, MS^e

- a. Center for Health Services Research
Rutgers Institute for Health, Health Care Policy, and Aging Research
112 Paterson St., New Brunswick, NJ 08901
- b. Department of Psychiatry
Rutgers Robert Wood Johnson Medical School
671 Hoes Lane, Piscataway, NJ 08854
- c. Department of Psychiatry and Behavioral Sciences
Johns Hopkins School of Medicine
600 N. Wolfe St., Baltimore, MD 21287 USA
- d. Department of Biostatistics
Johns Hopkins Bloomberg School of Public Health
615 N. Wolfe St., Baltimore, MD 21205 USA
- e. Division of Health Policy and Economics
Department of Population Health Sciences
Weill Cornell Medicine
402 E. 67th St., New York, NY 10065

Corresponding author:

Elizabeth Stone
112 Paterson Street
New Brunswick, NJ 08901
1-618-541-0522
elizabeth.stone@rutgers.edu

Keywords: cognitive disability; mental health; health care experiences; health services

Funding: This work was supported by the Johns Hopkins Institute for Health and Social Policy, the Johns Hopkins Wendy Klag Center for Autism and Developmental Disabilities, and the National Institute of Mental Health (T32MH109436 and F31MH131311).

Conflict of Interest: Authors have no conflicts of interest to report.

Data statement: All data used in this manuscript is publicly available through the Agency for Healthcare Research and Quality.

Abstract word count: 249

Manuscript word count: 2,871

Number of references: 28

Number of figures/tables: 3 (1 figure, 2 tables)

Journal Pre-proof

Experiences of health care services among people with cognitive disabilities and mental health conditions

Abstract

Background: People with cognitive disabilities such as intellectual and developmental disabilities face significant barriers to accessing high-quality health care services. Barriers may be exacerbated for those with co-occurring mental health conditions.

Objective: This study compares patient experiences of health care services between adults with and without cognitive disabilities and, among people with a cognitive disability, those with and without co-occurring mental health conditions.

Methods: Cross-sectional analyses were conducted using 2021 Medical Expenditure Panel Survey data, a national U.S. survey, to examine differences in Consumer Assessment of Healthcare Providers and Systems measures.

Results: Adults with cognitive disabilities reported lower satisfaction with health care services compared to the general population (7.71 (95% confidence interval (CI): 7.47-7.95) vs. 8.31 (95% CI: 8.27-8.36) on scale from 0-10). Adults with cognitive disabilities were less likely to report that providers listened carefully to them (odds ratio (OR): 0.64, 95% CI: 0.48-0.86), explained things in a way that was easy to understand (OR: 0.50, 95% CI: 0.35-0.72), showed respect for what they had to say (OR: 0.48, 95% CI: 0.34-0.66), spent enough time with them (OR: 0.57, 95% CI: 0.42-0.77), or gave advice that was easy to understand (OR: 0.43, 95% CI: 0.28-0.66) compared to the general population. Among adults with cognitive disabilities, there were no differences based on co-occurring mental health conditions.

23 **Conclusions:** Adults with cognitive disabilities report lower satisfaction with health care
24 services driven by worse experiences with the health care system. Policies to increase provider
25 capacity to support this population should be prioritized.

26 **Keywords:** cognitive disability; mental health; health care experiences; health services

Journal Pre-proof

27 **Introduction**

28 Individuals with intellectual and developmental disabilities (IDD) such as autism
29 spectrum disorder (ASD) and Down syndrome experience significant health disparities,
30 including increased rates of co-occurring mental and physical health conditions and decreased
31 life expectancy, compared to the general population.¹⁻³ In their 2006 review, Krahn and
32 colleagues describe a “cascade of disparities” affecting individuals with IDD wherein disparities
33 in the prevalence of co-occurring conditions are intensified by disparities in attention to
34 treatment or management of those co-occurring conditions, disparities in preventive services for
35 comorbid co-occurring conditions, and disparities in access to health care services overall.⁴

36 Barriers to high-quality health care services for individuals with IDD are well
37 documented. Few health care service providers receive training in how to support patients with
38 IDD.^{4,5} This contributes to a lack of knowledge of how to accommodate services to meet the
39 needs of patients with IDD (e.g., using alternative communication strategies) and stigmatizing
40 attitudes about treating people with IDD.^{4,6} People with IDD also frequently require services that
41 are spread across highly fragmented health care and social service systems, necessitating
42 significant resources to navigate.⁵

43 The ability to access high-quality health care services may be even more difficult for
44 individuals with co-occurring conditions, including the approximately one-third of individuals
45 with IDD who also have a mental health condition, such as depression or anxiety.^{3,7,8} In
46 particular, mental health conditions are also highly stigmatized and often present differently in
47 individuals with IDD compared to those in the general population.^{9,10} For example, “acting out”
48 and disorganized behavior, common symptoms of posttraumatic stress disorder among
49 individuals with IDD, are observed less frequently in the general population.¹⁰ This frequently

50 results in people with co-occurring IDD and mental health conditions not being adequately
51 served in either the IDD or the mental health sectors.^{7,8}

52 To date, research on the quality of the experiences of health care services for individuals
53 with IDD with and without co-occurring mental illness is largely qualitative. Quantitative
54 analyses are typically focused on small, local samples.^{4,11-15} These studies report disparities in
55 accessing health care services among individuals with IDD and poor experiences with those
56 services, including a lack of provider knowledge or training in treating this population, a lack of
57 understanding of medical procedures among individuals with IDD, and a lack of shared-decision
58 making between providers and their patients with IDD.^{4,11-15} One large-scale quantitative
59 analysis of combined Behavior Risk Factor Surveillance Survey and National Core Indicators
60 Consumer Survey data found that adults with IDD had lower rates of preventive health care
61 services (i.e., physical exam, flu shot, cancer screening) compared to individuals with no
62 disability.¹⁶

63 One reason for the limited research in this area is the inability to specifically identify
64 people with IDD in national surveys. Instead, these surveys use functional measures of disability
65 such as limitations in physical activity, cognition, hearing, or vision. In this study, we identify
66 individuals in a large, national survey with cognitive limitations with and without co-occurring
67 mental health conditions and assess their experiences of health care services using Medical
68 Expenditure Panel Survey (MEPS) data measures on Consumer Assessment of Healthcare
69 Providers and Systems (CAHPS).^{17,18} Among other groups, the identified population with
70 cognitive disability likely includes individuals with IDD, especially those with intellectual
71 disability, which is characterized by significant limitations in intellectual functioning and
72 adaptive behaviors and is often present in individuals with other developmental disabilities.²⁰

73 **Methods**

74 *Data source*

75 The Medical Expenditure Panel Survey (MEPS) is a large, nationally representative
76 survey of civilian, non-institutionalized individuals and families in the U.S. fielded by the
77 Agency for Healthcare Research and Quality (AHRQ).¹⁹ Survey sampling is done at the
78 household level; typically one adult will participate in the computer-assisted personal
79 interviewing process on behalf of the entire household.²¹ The publicly available household
80 component data includes information on individual household members' demographic
81 characteristics, health conditions, health status, use of medical care services, charges and
82 payments, access to care, satisfaction with care, and health insurance coverage.¹⁹ Information
83 related to health care services including diagnoses is confirmed and supplemented by and
84 additional MEPS sample of the providers who provided care to individuals in the household
85 survey.¹⁹

86 Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan
87 Survey measures are included as part of the larger MEPS survey.¹⁸ These twelve items are part
88 of a subset of questions given to all adults in sampled households as a paper-and-pencil
89 questionnaire. Proxy responses for these items are allowed.¹⁸ Specific CAHPS items are
90 described in detail below.

91

92 *Study population*

93 This cross-sectional analysis used a sample of 22,779 adults (age 18 and older) in 2021,
94 the most recent year the CAHPS measures were available. Individuals were divided into four
95 groups for analysis. First, adults with (N=1,497) and without (N=21,282) a cognitive disability

96 were identified. Consistent with previous literature, individuals were considered to have a
97 cognitive disability if they met criteria for cognitive limitation: “(1) experienced confusion or
98 memory loss, (2) had problems making decisions, or (3) required supervision for their own
99 safety.”^{18,22} Second, among adults with a cognitive disability, those with (N=689) and without
100 (N=808) co-occurring mental health conditions were identified. People were considered to have
101 a co-occurring mental health condition if they reported being diagnosed with a psychiatric
102 condition or a psychiatric condition was identified as a reason for receipt of a medical service.
103 These were identified using ICD-10 codes for schizophrenia, mood disorders, anxiety and other
104 mental health conditions as defined in the Healthcare Effectiveness Data and Information Set
105 (HEDIS) Mental Illness Value Set (ICD-10 codes F20-F25, F28-F34, F39-F45, F48, F50-F52,
106 F59, F60, F63-F66, F68, F90, F91, F93-F95, F98, F99, G44, R37, R45, Z87).²³

107

108 *Measures*

109 The primary independent variable was diagnostic category, first defined as adults with
110 (vs. without) cognitive disability and then defined as adults with a cognitive disability with (vs.
111 without) a co-occurring mental health condition. Outcomes of interest were the twelve CAHPS
112 measures. First was a measure of overall satisfaction with health care services received in the
113 previous 12 months. To measure overall satisfaction, individuals who went to a doctor’s office or
114 clinic to get care at least once in the prior 12 months were asked to rate their health care from all
115 doctors and other health providers, from 0 (worst health care possible) to 10 (best health care
116 possible). Next were three measures related to accessing health care services: ability to get care
117 right away, ability to get an appointment as soon as needed, and ability to see a specialist when
118 needed. The final eight measures related to experiences of health care services were: health

119 providers listened carefully, explained things in a way that was easy to understand, showed
120 respect for what the individual had to say, spent enough time with the individual, gave
121 instructions about what to do for a specific condition, gave advice that was easy to understand,
122 asked individuals how they were going to follow advice, and offered help filling out forms. All
123 items except for the overall rating were measured on a four-response Likert scale (“never,”
124 “sometimes,” “usually,” or “always”). For the main analysis, these items were dichotomized with
125 responses of “always” or “usually” indicating agreement and “sometimes” or “never” indicating
126 disagreement. For example, an individual who responded “usually” to the item “How often
127 health providers listened carefully to you” was coded as agreeing with the statement, “Health
128 providers listened carefully to me.” Full item wording for all CAHPS measures is listed in
129 Appendix A.

130 Demographic measures controlled for in analyses included age, sex, race/ethnicity,
131 annual household income, educational attainment, employment, marital status, region, and
132 insurance coverage. Insurance coverage groups were not mutually exclusive (i.e., individuals
133 could report both Medicare and Medicaid coverage) and included only individuals who reported
134 each type of coverage for the full calendar year. Individuals who indicated having no insurance
135 coverage at any point in the year were considered to be uninsured.

136 *Statistical analysis*

137 Chi-squared tests were used to assess differences in demographic characteristics across
138 diagnostic categories. We used linear (for overall satisfaction with health care services) and
139 logistic (for all other measures) regression to assess the relationship between the three diagnostic
140 categories and the CAHPS measures controlling for demographic characteristics. Logistic
141 regression results are reported as odds ratios for each of the two comparisons (1. individuals with

142 a cognitive disability vs. general population 2. among those with a cognitive disability, those
143 with vs. without a co-occurring mental health condition).

144 We conducted two sensitivity analyses. First, we conducted an analysis using
145 multinomial logistic regression to examine differences across the full Likert response scale for
146 items dichotomized in the main analysis. Second, we conducted all analyses excluding
147 individuals aged 65 and older who may have been more likely to be classified as having a
148 cognitive limitation due to an age-related condition (e.g., dementia) and therefore more closely
149 approximate the IDD population. All analyses included MEPS survey weights, which account for
150 sampling and nonresponse and allow for generalizability to the full U.S. civilian,
151 noninstitutionalized population.¹⁹ Analyses were conducted using Stata version 15.²⁴ The study
152 was approved by the (blinded for review) Institutional Review Board.

153 Results

154 Of the 22,779 U.S. adults included in the 2021 MEPS, 6.6% (N=1,497) had a cognitive
155 disability. Nearly half (46%, N=689) of those with a cognitive disability had a co-occurring
156 mental health condition. Individuals with cognitive disabilities differed significantly from
157 individuals in the general population across demographic characteristics (Table 1). Relative to
158 the general population, people with cognitive disabilities were older, more likely to be female,
159 more likely to be White, Black, or a race/ethnicity other than those listed and less likely to be
160 Asian or Hispanic, had lower annual household income, lower educational attainment, were
161 more likely to be unemployed, more likely to be widowed or divorced and less likely to be single
162 or married, and more likely to have Medicare and/or Medicaid coverage and less likely to have
163 private insurance or to be uninsured. Among those with a cognitive disability, individuals with
164 co-occurring mental health conditions were younger, more likely to be White and less likely to
165 be Black, more likely to have an annual household income below \$25,000, more likely to be
166 single, and less likely to have Medicare insurance coverage and more to have Medicaid than
167 those without a co-occurring mental health condition.

168 Individuals with a cognitive disability rated their overall satisfaction with health care
169 services as significantly lower than individuals in the general population (7.71 (95% confidence
170 interval (CI): 7.47-7.95) vs. 8.31 (95% CI: 8.27-8.36) on a scale from 0 (worst) to 10 (best
171 health care possible) (Figure 1). There was no significant difference in the overall satisfaction
172 with health care services between individuals with a cognitive disability with and without co-
173 occurring mental health conditions (7.69 (95% CI: 7.43-7.94) vs. 7.80 (95% CI 7.48-8.11)). Full
174 regression results are listed in Appendix B.

175 For measures relating to experience of healthcare services, there were no differences
176 between adults with cognitive disabilities and the general population on the three items related to
177 accessing care (Table 2). However, people with a cognitive disability reported significantly
178 worse experiences on five of the eight remaining measures compared to people in the general
179 population. Those with a cognitive disability reported decreased odds of health providers
180 listening carefully to them (OR: 0.64, 95% CI: 0.48-0.86), explaining things in a way that was
181 easy to understand (OR: 0.50, 95% CI: 0.35-0.72), showing respect for what they had to say
182 (OR: 0.48, 95% CI: 0.34-0.66), spending enough time with them (OR: 0.57, 95% CI: 0.42-0.77),
183 or giving advice that was easy to understand (OR: 0.43, 95% CI: 0.28-0.66) compared to the
184 general population. Among adults with a cognitive disability, there were no significant
185 differences on measures of healthcare experiences related to presence of a co-occurring mental
186 health condition.

187 Results of sensitivity analyses were largely consistent with the main analysis. People with
188 cognitive disabilities reported worse experiences of healthcare services (i.e., were significantly
189 more likely to respond with a response other than “always”) compared to the general population
190 on all measures except for providers asking them to describe how they would follow instructions
191 (Appendix C). Among those with a cognitive disability, differences were observed on measures
192 of providers explaining things or giving advice in a way that was easy to understand and asking
193 patients to describe how they would follow instructions with people with a co-occurring mental
194 health condition being less likely to respond that this “always” occurred compared to those
195 without a mental health condition.

196 In analyses excluding individuals aged 65 and older, individuals with and without
197 cognitive disabilities no longer differed significantly on the measure of providers listening

198 carefully to them; all other differences were similar to that of the primary analysis (Appendix D).
199 Like the main analysis, there were no significant differences between individuals with cognitive
200 disabilities with and without co-occurring mental health conditions on any measure in this
201 sensitivity analysis.

Journal Pre-proof

202 Discussion

203 We found that, in a national sample of U.S. adults, those with cognitive disabilities
204 reported lower satisfaction with health care services relative to the general population, primarily
205 driven by worse experiences with health care services. There were no significant differences in
206 experiences of health care services based on a co-occurring mental health condition among
207 adults with cognitive disabilities.

208 We found the greatest differences in quality of health care services were related to
209 provider communication and time spent with patients with cognitive disabilities. This is
210 consistent with prior qualitative work examining barriers to accessing high-quality care among
211 people with IDD. A 2022 review of access to health care services for adults with IDD and
212 communication disorders found that ineffective provider communication was a widespread and
213 significant barrier for this population.¹⁵ Poor patient-provider communication then contributed to
214 further negative outcomes for the patient with IDD including disruptions in continuity of care,
215 increased emergency department utilization, and patient safety risks.¹⁵

216 Findings here are also consistent with recent work related to providers' ability and
217 willingness to accommodate patients with disabilities more generally. A recent survey of a
218 national sample of primary care and specialty providers found that less than half of providers felt
219 "very confident" in their ability to provide the same level of care to patients with disabilities as
220 they did for patients without disabilities, and the greatest barrier to providing care for patients
221 with disabilities was lack of time.^{25,26}

222 Study findings suggest that priority should be placed on increasing provider time and
223 skills to effectively communicate with and meet the needs of people with cognitive disabilities,
224 including those with IDD. Training providers in the basics of working with patients with

225 cognitive disabilities, such as strategies for improving communication with patients with
226 communication or language disorders specifically could help to improve providers' ability to
227 support this population.¹⁵ One potentially helpful strategy for health care providers could be the
228 FRAME mnemonic framework, where each letter provides a general direction for
229 communication with patients with IDD (e.g., F = familiarize yourself with how the patient
230 prefers to communicate).²⁷ Provider payment policies should also reflect the increased time and
231 effort needed for high-quality appointments with patients with complex needs such as individuals
232 with IDD or other cognitive disabilities. One example, particularly relevant for individuals with
233 co-occurring mental health conditions, is the use of the interactive complexity add-on code
234 which allows mental health providers to bill for appointment complexity related to
235 communication (including the use of alternative communication devices) in conjunction with
236 billing for the primary service being delivered.²⁸

237 Findings from this analysis should be considered in light of its limitations. First, this is a
238 cross-sectional analysis, so causal claims cannot be made. MEPS respondents are limited to the
239 non-institutionalized U.S. population, so these findings may not generalize to significant number
240 of people with cognitive disabilities in institutional settings such as hospitals or nursing facilities
241 who may have different experiences with health care. Individuals who respond (or have a
242 household member that responds as a proxy) to MEPS may also have greater resources (e.g.,
243 time), fewer health or disability concerns (e.g., less severe cognitive or physical disabilities), or
244 other differences compared to individuals who do not respond that also may affect experiences of
245 health care services. The measures of health care experiences themselves ask respondents to rate
246 experiences based on health service utilization over the prior year. This may mask differences
247 between experiences with different types of providers (e.g., primary care vs. mental health)

248 across the groups examined. Additionally, MEPS does not have a direct measure of IDD; as
249 operationalized in this analysis, individuals meeting criteria for cognitive limitations may also
250 include people with age-related limitations such as dementia and exclude individuals with a
251 developmental disability who do not have cognitive limitations. Despite these limitations, we
252 found similar results in a sensitivity analysis excluding individuals aged 65 and older who may
253 be more likely to have been identified as having a cognitive disability because of an age-related
254 condition. Data limitations are part of a larger dearth of national data on individuals with
255 disability generally and specifically IDD.¹

256

257 Conclusion

258 In a large, nationally representative sample of U.S. adults, people with cognitive
259 disabilities reported lower satisfaction with health care services related to worse experiences with
260 services overall compared to respondents in the general population. Individuals with cognitive
261 disabilities with and without co-occurring mental health conditions largely reported similar
262 experiences of health care services. Policies to increase provider training and capacity to provide
263 health care services for people with cognitive disabilities, including IDD, should be prioritized.

264 **References**

- 265 1. Escudé C. Advancing Health Equity For People With Intellectual And Developmental
266 Disabilities. *Health Affairs Forefront*. 2022.
- 267 2. Morin D, Mérineau-Côté J, Ouellette-Kuntz H, Tassé MJ, Kerr M. A comparison of the
268 prevalence of chronic disease among people with and without intellectual disability.
269 *American journal on intellectual and developmental disabilities*. 2012;117(6):455-463.
- 270 3. Mazza MG, Rossetti A, Crespi G, Clerici M. Prevalence of co-occurring psychiatric
271 disorders in adults and adolescents with intellectual disability: A systematic review and
272 meta-analysis. *Journal of Applied Research in Intellectual Disabilities*. 2020;33(2):126-
273 138.
- 274 4. Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access
275 for people with intellectual disabilities. *Mental retardation and developmental disabilities
276 research reviews*. 2006;12(1):70-82.
- 277 5. Ervin DA, Hennen B, Merrick J, Morad M. Healthcare for persons with intellectual and
278 developmental disability in the community. *Frontiers in public health*. 2014;2:83.
- 279 6. Pelleboer-Gunnink H, Van Oorsouw W, Van Weeghel J, Embregts P. Mainstream health
280 professionals' stigmatising attitudes towards people with intellectual disabilities: a
281 systematic review. *Journal of Intellectual Disability Research*. 2017;61(5):411-434.
- 282 7. Pinals DA, Hovermale L, Mauch D, Anacker L. Persons with intellectual and
283 developmental disabilities in the mental health system: part 1. clinical considerations.
284 *Psychiatric Services*. 2021:appi. ps. 201900504.

- 285 8. Pinals DA, Hovermale L, Mauch D, Anacker L. Persons with intellectual and
286 developmental disabilities in the mental health system: part 2. policy and systems
287 considerations. *Psychiatric Services*. 2021:appi. ps. 201900505.
- 288 9. Ditchman N, Werner S, Kosyluk K, Jones N, Elg B, Corrigan PW. Stigma and
289 intellectual disability: Potential application of mental illness research. *Rehabilitation*
290 *Psychology*. 2013;58(2):206.
- 291 10. Fletcher R, Loschen E, Stavrakaki C, First M. DM-ID: diagnostic manual—intellectual
292 disability: a textbook of diagnosis of mental disorders in persons with intellectual
293 disability. *Journal of Mental Health Research in Intellectual Disabilities*. 2007;29.
- 294 11. Doherty AJ, Atherton H, Boland P, et al. Barriers and facilitators to primary health care
295 for people with intellectual disabilities and/or autism: an integrative review. *BJGP open*.
296 2020;4(3).
- 297 12. Williamson HJ, Contreras GM, Rodriguez ES, Smith JM, Perkins EA. Health care access
298 for adults with intellectual and developmental disabilities: A scoping review. *OTJR:*
299 *occupation, participation and health*. 2017;37(4):227-236.
- 300 13. Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A. Discrimination and other
301 barriers to accessing health care: perspectives of patients with mild and moderate
302 intellectual disability and their carers. *PloS one*. 2013;8(8):e70855.
- 303 14. Durbin A, Sirotich F, Lunskey Y, Durbin J. Unmet needs of adults in community mental
304 health care with and without intellectual and developmental disabilities: A cross-sectional
305 study. *Community mental health journal*. 2017;53(1):15-26.

- 306 15. Shady K, Phillips S, Newman S. Barriers and facilitators to healthcare access in adults
307 with intellectual and developmental disorders and communication difficulties: An
308 integrative review. *Review Journal of Autism and Developmental Disorders*. 2022:1-13.
- 309 16. Havercamp SM, Scott HM. National health surveillance of adults with disabilities, adults
310 with intellectual and developmental disabilities, and adults with no disabilities. *Disability
311 and health journal*. 2015;8(2):165-172.
- 312 17. Agency for Healthcare Research and Quality. CAHPS: Assessing Healthcare Quality
313 From the Patient's Perspective. Retrieved from:
314 [https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/about-cahps/cahps-program-
315 brief.pdf](https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/about-cahps/cahps-program-brief.pdf). Accessed 4/27/2023.
- 316 18. Agency for Healthcare Research and Quality. MEPS HC-233 2021 Full Year
317 Consolidated Data File Documentation. Retrieved from:
318 https://meps.ahrq.gov/data_stats/download_data/pufs/h233/h233doc.shtml. Accessed
319 10/19/2023.
- 320 19. Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey: Survey
321 Background. Retrieved from:
322 https://www.meps.ahrq.gov/mepsweb/about_meps/survey_back.jsp. Accessed 4/27/2023.
- 323 20. Li Q, Li Y, Zheng J, Yan X, Huang J, Xu Y, Zeng X, Shen T, Xing X, Chen Q, Yang W.
324 Prevalence and trends of developmental disabilities among US children and adolescents
325 aged 3 to 17 years, 2018–2021. *Scientific Reports*. 2023; 13(1):17254.

- 326 21. Agency for Healthcare Research and Quality. MEPS-HC Panel Design and Data
327 Collection Process. Retrieved from:
328 https://meps.ahrq.gov/mepsweb/survey_comp/hc_data_collection.jsp. Accessed
329 10/19/2023.
- 330 22. Reichard, A., & Stolzle, H. Diabetes among adults with cognitive limitations compared to
331 individuals with no cognitive disabilities. *Intellectual and Developmental Disabilities*,
332 2011;49(3), 141-154.
- 333 23. National Committee for Quality Assurance. HEDIS Volume 2: Technical Specifications
334 for Health Plans. 2016.
- 335 24. StataCorp. 2017. Stata Statistical Software: Release 15. College Station, TX: StataCorp
336 LLC.
- 337 25. Iezzoni LI, Rao SR, Ressler J, et al. Physicians' Perceptions Of People With Disability
338 And Their Health Care: Study reports the results of a survey of physicians' perceptions of
339 people with disability. *Health Affairs*. 2021;40(2):297-306.
- 340 26. Iezzoni LI, Rao SR, Ressler J, et al. US Physicians' Knowledge About The Americans
341 With Disabilities Act And Accommodation Of Patients With Disability: Study examines
342 what physicians know about the Americans With Disabilities Act and what is done to
343 accommodate patients with a disability. *Health Affairs*. 2022;41(1):96-104.
- 344 27. Burns MI, Baylor CR, Morris MA, McNalley TE, Yorkston KM. Training healthcare
345 providers in patient-provider communication: What speech-language pathology and
346 medical education can learn from one another. *Aphasiology*. 2012;26(5):673-688.

- 347 28. Centers for Medicare and Medicaid Services. Billing and Coding: Psychiatry and
348 Psychology Services. Retrieved from: [https://www.cms.gov/medicare-coverage-
database/view/article.aspx?articleid=57480&ver=10&bc=0](https://www.cms.gov/medicare-coverage-
349 database/view/article.aspx?articleid=57480&ver=10&bc=0) . Accessed 5/7/2023.

Journal Pre-proof

350 **Figure Legends**

351 **Figure 1.** Overall satisfaction with health care services by diagnostic group, 2021

Journal Pre-proof

Table 1. Weighted demographic characteristics of US adults by diagnostic group, 2021*

	General pop.	Cognitive disability	p-value	Cognitive disability		
				No mental health condition	Mental health condition	p-value
N	21,282	1,497		808	689	
Age, y (mean, SD)	47.8 (18.1)	60.4 (21.7)	<0.001	63.4 (18.1)	56.6 (19.3)	<0.001
Sex						
Female	50.9	58.3	<0.001	57.0	59.8	0.400
Male	49.1	41.7	<0.001	43.0	40.2	0.400
Race/ethnicity						
White, non-Hispanic	61.2	66.4	0.002	63.0	70.6	0.016
Black, non-Hispanic	11.9	15.2	0.010	17.4	12.5	0.047
Asian, non-Hispanic	6.4	2.9	<0.001	3.6	2.1	0.232
Other, non-Hispanic	3.1	4.9	0.023	4.0	5.9	0.202
Hispanic	17.4	10.6	<0.001	12.0	8.9	0.084
Household annual income						
< \$25,000	14.9	43.0	<0.001	40.0	46.8	0.038
\$25,000-\$49,999	18.0	21.8	0.012	22.4	21.0	0.632
\$50,000-\$74,999	16.6	12.9	0.002	14.1	11.3	0.226
\$75,000-\$99,999	13.5	8.5	<0.001	8.0	9.1	0.612
\$100,000+	37.0	13.8	<0.001	15.4	11.7	0.155
Highest degree attained						
Less than high school	11.5	22.0	<0.001	23.7	19.9	0.195
High school	48.1	57.6	<0.001	57.6	57.7	0.964
Bachelor's degree	25.0	12.7	<0.001	10.9	15.0	0.091
Graduate degree or higher	15.5	7.6	<0.001	7.8	7.4	0.832
Employment						
Employed	65.4	21.2	<0.001	21.6	20.8	0.794
Unemployed	34.6	78.8	<0.001	78.4	79.2	0.794
Marital status						
Single	29.8	24.9	0.002	20.3	30.7	0.001
Married	52.1	34.1	<0.001	38.4	28.7	0.004
Widowed	5.9	19.4	<0.001	21.1	17.3	0.128
Divorced	12.2	21.6	<0.001	20.3	23.3	0.234
Region						
Northeast	17.4	16.8	0.672	15.6	18.3	0.289
Midwest	20.5	25.1	0.006	24.9	25.3	0.913
South	38.2	37.7	0.738	38.7	36.4	0.505

West	23.8	20.4	0.017	20.9	19.9	0.740
Insurance coverage [†]						
Medicare	22.6	61.1	<0.001	67.4	53.1	<0.001
Medicaid	15.9	42.6	<0.001	38.3	48.0	0.004
Private insurance	67.6	35.3	<0.001	36.3	34.0	0.506
Uninsured	7.5	1.3	<0.001	1.8	0.7	0.130

* All values are percentages unless otherwise noted. Totals may not add to 100 because of rounding. Weighted percentages are representative of the U.S. civilian, noninstitutionalized population.

[†] Insurance coverage indicates full calendar year coverage or uninsured. Medicare, Medicaid, and private insurance categories are not mutually exclusive.

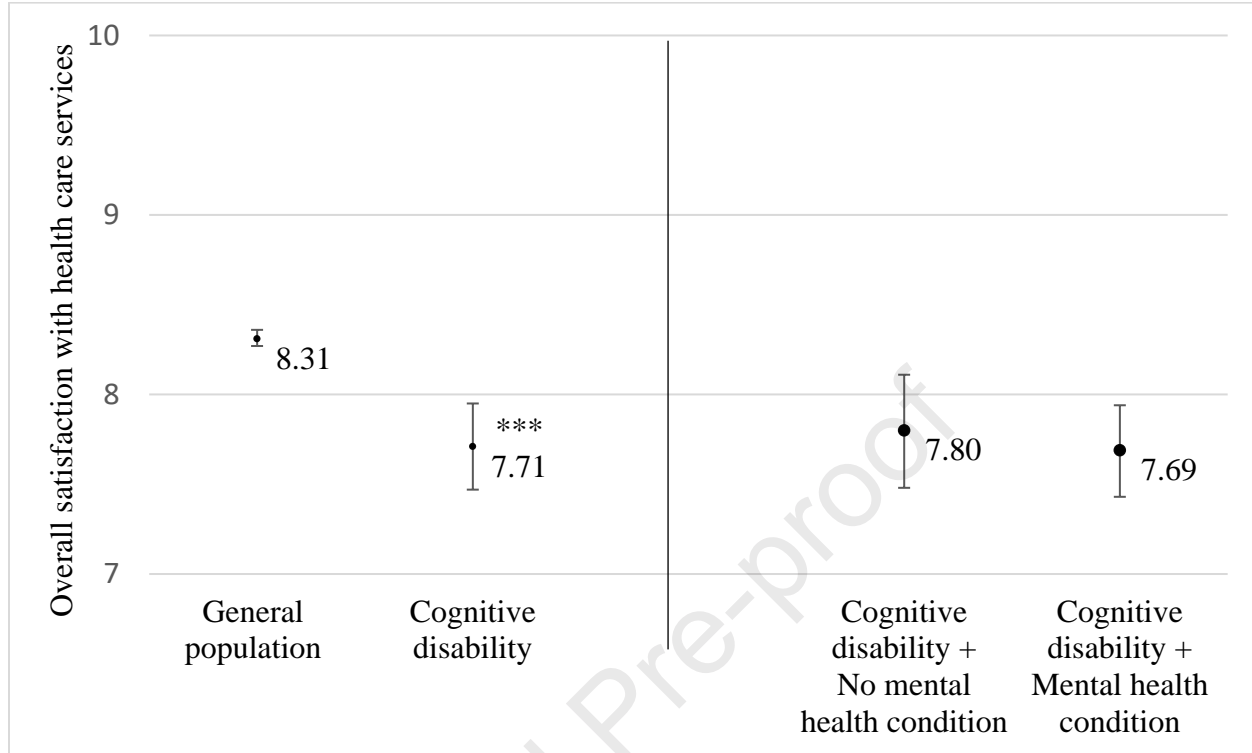
Table 2. Odds ratios for agreement with Consumer Assessment of Healthcare Providers and Systems (CAHPS) measures by diagnostic group, 2021*

	Cognitive disability vs. general population			Among those with a cognitive disability: With vs. without co-occurring mental health condition		
	OR	95% CI	p-value	OR	95% CI	p-value
N	22,779			1,497		
I received care right away.	0.95	0.66-1.35	0.756	0.87	0.48-1.56	0.634
I got an appointment for health care as soon as I thought it was needed.	1.06	0.82-1.38	0.645	1.20	0.77-1.88	0.417
It was easy to see a specialist when needed.	0.97	0.73-1.28	0.810	1.08	0.66-1.77	0.761
Health providers listened carefully to me.	0.64	0.48-0.86	0.003	0.65	0.37-1.14	0.135
Health providers explained things in a way that was easy to understand.	0.50	0.35-0.72	<0.001	1.13	0.64-1.99	0.664
Health providers showed respect for what I had to say.	0.48	0.34-0.66	<0.001	0.68	0.38-1.22	0.190
Health providers spent enough time with me.	0.57	0.42-0.77	<0.001	0.98	0.85-1.64	0.932
Doctors or other health providers gave instructions about what to do about a specific illness or health condition. [†]	NA	NA	NA	NA	NA	NA
The advice given by doctors or other health providers easy to understand.	0.43	0.28-0.66	<0.001	0.93	0.49-1.78	0.831
Doctors or other health providers asked me to describe how I was going to follow their instructions.	0.86	0.69, 1.08	0.203	0.70	0.48-1.06	0.095
I was offered help with filling out forms at the doctor or other provider's office.	0.83	0.63-1.10	0.198	0.95	0.57-1.59	0.854

* Models adjust for age, sex, race/ethnicity, income, education, employment, marital status, region, and insurance coverage. Full model results in Appendix B.

† No one included in the sample indicated agreement with this measure.

Journal Pre-proof

Figure 1. Overall satisfaction with health care services by diagnostic group, 2021[†]

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

[†] Mean rating of quality of all health care services in the last 12 months from 0 (worst health care possible) to 10 (best health care possible). Estimates adjusted for age, sex, race/ethnicity, income, education, employment, marital status, region, and insurance coverage. Full model results available in Appendix B.