

Health Care Experiences of Adults with Disabilities Enrolled in Medicaid Only: Findings from a 2014-2015 Nationwide Survey of Medicaid Beneficiaries

Persons who qualify for Medicaid on the basis of a disability are a diverse population group, consisting of individuals with a wide range of physical impairments, functional limitations, and intellectual and mental health disabilities.¹ In 2015, Medicaid provided coverage for 10.2 million non-elderly individuals on the basis of a disability.² Most of those individuals were adults ages 18 and older residing in a community setting. Medicaid beneficiaries with a disability may be enrolled in Medicaid alone or be dually enrolled in Medicaid and Medicare. This brief focuses on adult Medicaid beneficiaries who are not dually enrolled and qualified for Medicaid on the basis of a disability.

According to the Medicaid and CHIP Payment and Access Commission (MACPAC), research is limited on the health care experiences of adults with disabilities enrolled only in Medicaid (i.e., not dually enrolled in Medicare and Medicaid); however, population-based surveys indicate that they have access to care that is comparable to that of other insured persons with disabilities.³ A recent analysis found that non-elderly adults

¹The health care needs of this subgroup vary depending on the individual. Some beneficiaries are relatively healthy individuals who have a disability that require functional accommodations (e.g., deafness or blindness) and others may have a disability resulting in complex health needs that require ongoing medical or mental health services. In addition, some beneficiaries have a need for long term services and supports; others do not.

² <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CMS-Statistics-Reference-Booklet/Downloads/2015CMSStatistics.pdf>. (See Table I.16.) Numbers reflect average monthly enrollment. The total number of people with disabilities includes some children. The 10.2 million also includes Qualified Medicare Beneficiaries (QMB) and Specified Low-Income Medicare Beneficiaries (SLMB).

³ March 2012 Report to Congress on Medicaid and CHIP. MACPAC. URL: https://www.macpac.gov/wp-content/uploads/2015/01/Medicaid_and_Persons_with_Disabilities.pdf.

Key Findings

- Approximately 8 in 10 adults with disabilities covered by Medicaid alone (i.e. not dually enrolled in Medicare) reported they could always or usually get needed care (78%), and reported they always or usually received care quickly (82%).
- Roughly 2 in 10 adults with disabilities reported they were unable to get needed care. Coverage related barriers (e.g., beneficiary said Medicaid would not approve, cover or pay for care) were the most commonly reported reason for being unable to get care.
- Despite greater health care needs and more functional limitations, adults with disabilities when compared with beneficiaries overall reported similar or slightly better patient care experiences on most indicators in this brief, including:
 - How well doctors communicate (always or usually good: 89% vs. 90%);
 - Customer service interactions (always or usually positive: 76% vs. 76%);
 - Getting special medical equipment (always or usually easy: 55% vs. 51%).
- Adults with disabilities reporting a doctor or HMO as their usual source of care gave the highest ratings for their overall care (81% gave a score of 7-10). Adults reporting no usual source of care gave the lowest ratings (62% gave a score of 7-10).

with disabilities enrolled in Medicaid in 2015 were more than 2.5 times as likely to have three or more functional limitations, and more than 1.5 times as likely to have 10 or more health care visits in a year compared to people with disabilities who were privately insured - a finding likely indicative of their greater health care needs.⁴

Persons with disabilities account for a sizable share of Medicaid spending. For example, while about 15 percent of Medicaid beneficiaries were eligible for coverage on the basis of a disability, they represented 40 percent of Medicaid expenditures in federal fiscal year 2015.⁵ Understanding the health care experiences of persons with disabilities will support performance improvement efforts to maximize the independence, well-being, and health of people with disabilities and their families and caregivers.

The 2014-2015 Nationwide Adult Medicaid Consumer Assessment of Healthcare Providers and Systems (NAM CAHPS) survey, conducted by the Center for Medicaid and CHIP Services (CMCS), is well suited to examine access and experiences of care of adults with disabilities.⁶ The survey provides comparative information on experiences of care across states and socio-demographic subgroups. This brief focuses on adult beneficiaries (ages 18-64) who qualified for Medicaid on the basis of a disability, were living in the community, and were not dually enrolled in Medicare and Medicaid (henceforth called adults with disabilities).⁷ Indicators of access and experiences of care for this group are compared with those of all adult Medicaid beneficiaries. The intent is to provide states, the federal government, and stakeholders with information that can be used to guide continuous quality improvement efforts. Additional information on the survey, the analytic approach used in this brief, and the survey questions analyzed in this brief can be found in Appendices A and B.

BACKGROUND

Public health coverage programs, such as Medicare and Medicaid, play an important role for people with disabilities. The Supplemental Security Income (SSI) program, established in 1972, provides cash assistance to low-income persons with disabilities and the elderly. In most states, SSI eligibility qualifies an individual for Medicaid coverage; approximately two-thirds of those who qualify for Medicaid on the basis of a disability do so based on SSI eligibility.⁸ Persons with a permanent disability are eligible for Medicare if they qualify for Social Security Disability Insurance (SSDI) but they must wait two years to enroll in Medicare.⁹ Medicaid often serves as the first source of coverage for low-income individuals with a disability until they are eligible for Medicare.

⁴ Kaiser Family Foundation, March 2017. <http://kff.org/medicaid/issue-brief/medicaid-restructuring-under-the-american-health-care-act-and-nonelderly-adults-with-disabilities/>. This analysis also included dually eligible nonelderly adults.

⁵ <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/ActuarialStudies/Downloads/MedicaidReport2016.pdf>

(see Figure 1. Data include children and adults with disabilities, as well as medical care and long term services and supports [home-based and institutional services]).

⁶ The NAM CAHPS survey is considered a CAHPS-like survey since additional questions were added to the questionnaire. The CAHPS® health plan survey 5.0 was used as the initial basis for development of the NAM CAHPS survey. For additional information on the CAHPS family of surveys see: <http://www.ahrq.gov/cahps/index.html>.

⁷ The sampling frame was constructed from each state's Medicaid Statistical Information System (MSIS) eligibility file, where available. For the few states that did not have up-to date MSIS files, the state provided CMS with a standardized data extract from its internal eligibility system to create a comparable sampling frame. After sorting the file by four mutually exclusive beneficiary subgroups based on program eligibility, the contractor used a systematic sample selection with a random start point to select the number of enrollee records within each state and stratum as needed to provide confidence intervals with margins of error under 5 percent at the 95 percent confidence level. The total sample was composed of over 1.2 million cases, averaging approximately 29,000 sampled enrollees per state.

⁸ March 2012 Report to Congress of Medicaid and CHIP. MACPAC. URL: https://www.macpac.gov/wp-content/uploads/2015/01/Medicaid_and_Persons_with_Disabilities.pdf.

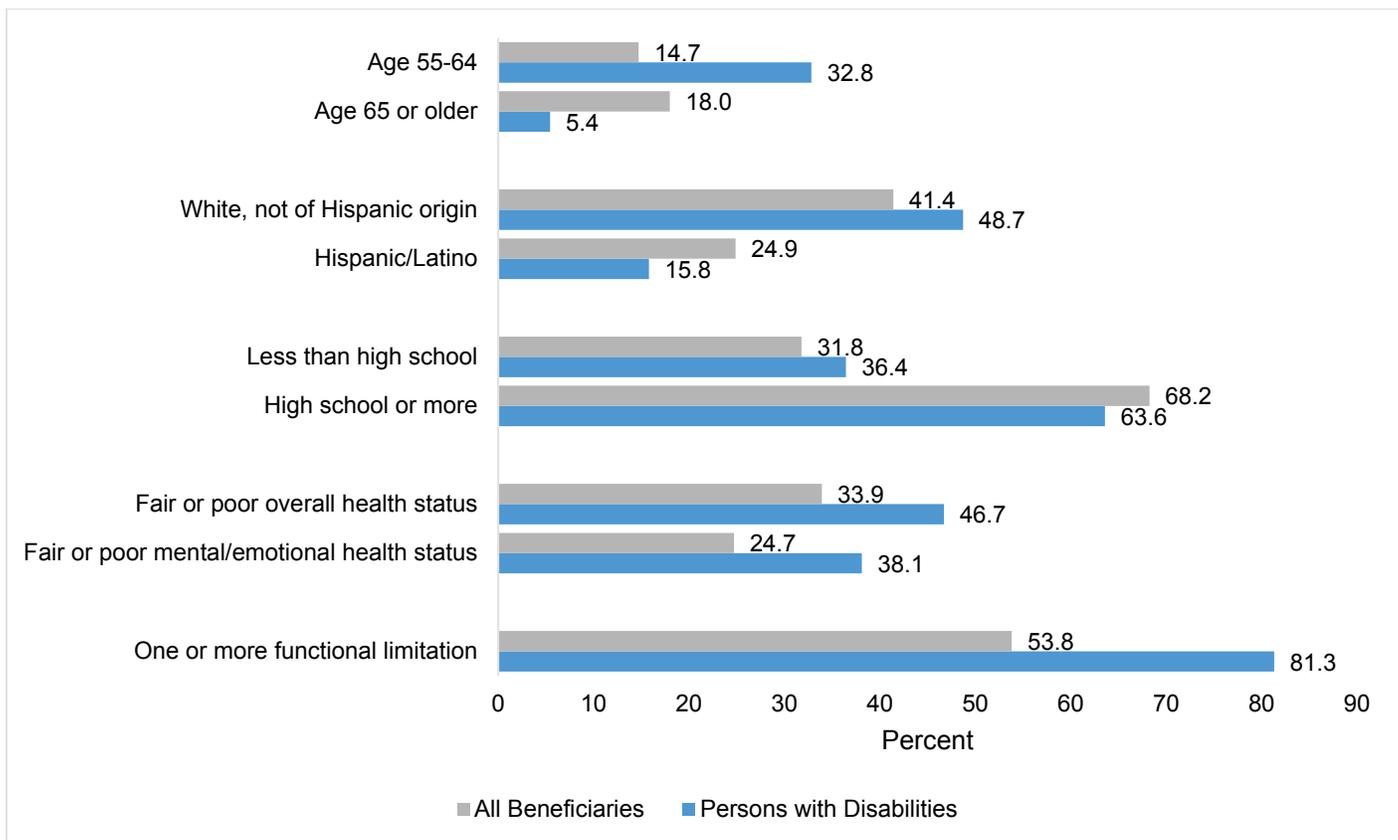
⁹ Medicare also includes coverage for some individuals with a disability under 65 years of age.

THE SURVEY POPULATION & SURVEY MEASURES

Of the 272,679 NAM CAHPS survey respondents, roughly one-fourth (n=76,704) were adults covered by Medicaid on the basis of a disability who were not full-benefit dual enrollees. Estimates of self-reported indicators of access and experiences of care were calculated using survey weights to represent the population of adult Medicaid beneficiaries in the participating states as well as each state’s Medicaid population with disabilities.¹⁰

Adult beneficiaries covered by Medicaid on the basis of a disability were diverse demographically and in their health needs (see Figure 1). They were similar to all adult Medicaid beneficiaries in some respects and yet differed in others. For example, they were relatively similar in level of formal education; but they differed in that a larger percentage of adults with disabilities than all adults were ages 55-64 (33 percent vs. 15 percent), reported fair/poor overall health (47 percent vs. 34 percent) and reported fair/poor mental or emotional health (38 percent vs. 25 percent).

Figure 1. Demographic Characteristics, NAM CAHPS Survey: All Adult Beneficiaries and Adult Beneficiaries with Disabilities^a



^a **Note:** “All Adult Beneficiaries” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service. The finding that 5.4 percent of adults with disabilities were ages 65+ and not dually-enrolled is likely because they 1) lacked the work history or citizenship status to qualify for Medicare and/or 2) turned 65 during the time period when the survey was conducted in 2014-2015 (i.e., after the sample was drawn in 2013).

¹⁰Alaska, New Hampshire, North Dakota, and Wisconsin did not participate in the 2014-2015 NAM CAHPS survey.

Adult Medicaid beneficiaries who qualified for coverage on the basis of a disability also differed from the general population of adult beneficiaries in the percentage reporting one or more functional limitation. The NAM CAHPS instrument included six questions based on updated U.S. Department of Health and Human Services (HHS) survey data collection standards to define disability status.¹¹ The six item question set was developed to define disability from a functional perspective. The responses to these questions indicate that 81 percent of adult Medicaid beneficiaries with disabilities reported one or more functional limitation; while only about half of the general population of adult Medicaid beneficiaries reported one or more functional limitation (see Figure 1).

Four composite measures of consumer experience were developed from the NAM CAHPS survey. Composite measures are groupings of two or more questionnaire items that measure the same dimensions of experience with care. The Agency for Healthcare Research and Quality (AHRQ), which oversees the CAHPS program, recommends the use of a standard set of composite measures for CAHPS public reporting to succinctly summarize patient experience for a set of items. The following composites were developed from the questionnaire items in Appendix B using the specifications and case-mix adjustments (for age, education, and health) provided by AHRQ:^{12,13}

- **Getting needed care** composite combines responses from two questions (Q36, Q17);
- **Getting care quickly** composite combines responses from two questions (Q4, Q7);
- **How well doctors communicate** composite combines responses from four questions (Q28, Q29, Q30, Q31);
- **Health plan information and customer service** composite combines responses from two questions (Q39, Q40).¹⁴

HEALTH CARE EXPERIENCES OF ADULTS WITH DISABILITIES

Helping individuals with disabilities manage their needs requires access to care and coordination of care across a wide-range of services. Although a larger percentage of adults who qualified for Medicaid coverage on the basis of a disability than all adult beneficiaries reported fair/poor health, adults with disabilities reported similar or slightly better access to health care than adult beneficiaries overall (Table 1). Among adults with disabilities, 78 percent reported they could usually or always get needed care, as compared to 75 percent of all beneficiaries. Adults with disabilities also reported usually or always getting timely care more frequently than all beneficiaries (82 percent vs. 79 percent).

¹¹ HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. <https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status>.

¹² Instructions for Analyzing Data for CAHPS® Surveys: Using the CAHPS Analysis Program Version 4.1. https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/surveys-guidance/2015_Instructions_for_Analyzing_Datav2.pdf

¹³ For more information about the NAM CAHPS composite measures, see the Methodological Brief on Understanding Composite Measures (link to be inserted).

¹⁴ Based on cognitive testing of the NAM CAHPS survey, respondents who did not have a health plan would likely have answered this question based on their overall experience of care.

Table 1. Getting Needed Care and Getting Care Quickly

Medicaid Beneficiaries		
Composite Measure	Adults with Disabilities	All Adults
Getting needed care	Percent	Percent
Never + Sometimes	22.2	24.9
Usually	26.3	26.5
Always	51.5	48.6
Getting care quickly		
Never + Sometimes	18.0	20.7
Usually	23.0	24.1
Always	59.0	55.2

Note: “All Adults” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service.

Two factors that can affect getting needed care are how well doctors communicate with patients and customer service, both of which can impact patient help-seeking behaviors as well as compliance with advice from providers. Adults with disabilities reported usually or always having good doctor-patient communication (89 percent) as did adult beneficiaries overall (90 percent; see Table 2). They also reported slightly more frequent positive customer service interactions than beneficiaries overall (78 percent vs. 76 percent responded usually or always).

Table 2. Communication with Doctors and Customer Service

Medicaid Beneficiaries		
Composite Measures	Adults with Disabilities	All Adults
How well doctors communicate	Percent	Percent
Never + Sometimes	11.3	10.4
Usually	17.7	18.2
Always	71.1	71.4
Health plan information and customer service		
Never + Sometimes	22.5	23.6
Usually	21.2	21.8
Always	56.3	54.6

Note: “All Adults” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service.

For individuals with functional limitations or medical needs, coverage for medical supplies and equipment is essential. In the NAM CAHPS survey, beneficiaries were asked if they had a need for medical equipment such as a cane, wheelchair, diabetic testing supplies, or a nebulizer. As expected, a larger share of adults with disabilities than adults overall reported a need for special medical equipment (49 percent vs. 39 percent, Table

3). However, the percentage of adults with disabilities, as compared with adults overall, who reported it usually or always was easy to obtain the needed equipment did not differ greatly (55 percent vs. 51 percent).

Table 3. Access to Special Medical Equipment

Medicaid Beneficiaries		
Survey Item	Adults with Disabilities	All Adults
Getting special medical equipment	Percent (SE)	Percent (SE)
Never + Sometimes	45.2 (0.4)	49.1 (0.3)
Usually	16.8 (0.3)	15.4 (0.2)
Always	38.1 (0.4)	35.5 (0.3)

Note: The denominator for this indicator is the subset of respondents who reported needing medical equipment in the last 6 months. “All Adults” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service. SE = standard error.

RATINGS OF CARE

Once obtaining care, adults with disabilities reported relatively high ratings for their personal doctors and specialists, as did adult Medicaid beneficiaries overall (see Table 4). On a scale of 0-10, with 10 being the highest rating, at least 8 in 10 adults with disabilities gave their personal doctor and their specialist a rating of 7-10 (85 percent and 86 percent, respectively). However, a lower percentage of both adults with disabilities and adults overall rated all their care in the 7-10 range (76 percent and 77 percent, respectively).

Table 4. Ratings of All Health Care, Personal Doctor, and Specialist

Medicaid Beneficiaries		
Survey Items	Adults with Disabilities	All Adults
Ratings of all health care	Percent (SE)	Percent (SE)
0-6	24.4 (0.3)	22.7 (0.2)
7-8	28.1 (0.3)	31.0 (0.2)
9-10	47.5 (0.3)	46.4 (0.2)
Ratings of personal doctor		
0-6	14.6 (0.2)	13.4 (0.2)
7-8	21.0 (0.3)	22.7 (0.2)
9-10	64.4 (0.3)	63.9 (0.2)
Ratings of specialist		
0-6	13.8 (0.3)	13.7 (0.2)
7-8	22.2 (0.4)	23.5 (0.3)
9-10	64.0 (0.4)	62.8 (0.3)

Note: “All Adults” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service.

To explore whether ratings of care varied by beneficiaries’ usual source of medical care (USC), this analysis compared ratings of care for three groups of beneficiaries (see Table 5). Adults with disabilities reporting a

doctor or health maintenance organization (HMO) as their usual source of care gave the highest ratings across all three indicators, followed by those reporting a clinic, health center, or outpatient hospital department as their usual source of care. Those reporting no usual source of care gave the lowest ratings across all three indicators.¹⁵

Table 5. Ratings of Health Care and Doctors by Usual Source of Care: Adults with Disabilities

Medicaid Beneficiaries			
Survey Items	Doctors office or HMO	Clinic, Health Center or Outpatient Department	No USC
Ratings of all health care	Percent (SE)	Percent (SE)	Percent (SE)
0-6	18.9 (0.2)	22.4 (0.3)	38.1 (0.6)
7-8	31.4 (0.3)	31.8 (0.3)	26.7 (0.6)
9-10	49.7 (0.3)	45.8 (0.4)	35.2 (0.6)
Ratings of personal doctor			
0-6	11.2 (0.2)	13.8 (0.3)	26.9 (0.8)
7-8	22.3 (0.3)	23.4 (0.3)	22.3 (0.7)
9-10	66.5 (0.3)	62.8 (0.4)	50.9 (0.9)
Ratings of specialist			
0-6	12.1 (0.3)	14.4 (0.4)	20.8 (0.9)
7-8	23.6 (0.3)	23.5 (0.5)	23.6 (1.0)
9-10	64.4 (0.4)	62.1 (0.5)	55.7 (1.1)

Note: Responses to two NAM CAHPS survey items (Q23 and Q25) were combined to define usual source of care (USC). The non-missing responses to Q25 were grouped into three categories: (1) Doctor’s office or HMO; (2) Clinic or health center + Hospital outpatient department; and (3) Hospital emergency room + Some other place + don’t go to one place most often. The third category was recoded as “No USC.” For respondents with missing data for Q25, USC was coded as “No USC” if they answered “No” in Q23. Respondents who answered “Yes” in Q23 but were missing data for Q25 were set to missing and excluded from the analysis.

GEOGRAPHIC VARIATION IN THE EXPERIENCES OF ADULTS WITH DISABILITIES

This brief also provides state-specific data on the health care experiences of adults with disabilities covered by Medicaid alone (see Appendix Tables D, E, and F). Figure 2 summarizes geographic variation on five indicators of health care experiences: getting needed care, getting care quickly, how well doctors communicate, health plan information and customer service, and access to special medical equipment.

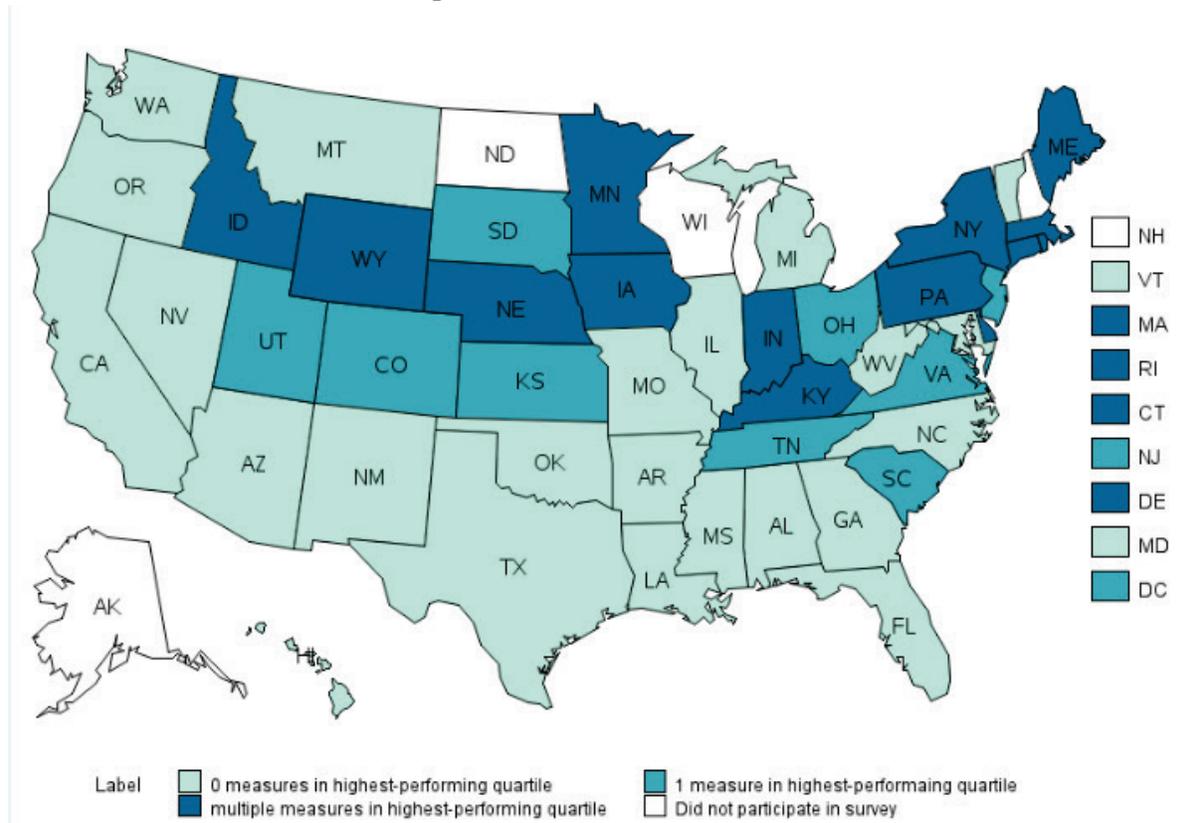
For the purpose of this analysis, states were designated as “higher performing” on an indicator if the percentage of adults with disabilities in the state reporting rates of “Never + Sometimes” were at or below the lowest quartile (based on the 25th percentile). The lowest quartile was established to define the threshold for higher performance; it does not necessarily represent optimal performance but indicates a smaller share of adults with disabilities in these states reported problems in health care experiences than in other states.

¹⁵ Having no USC was defined as self reporting no USC, or reporting a hospital emergency room, some other place as USC or don’t go to one place most often.

States were grouped into three categories based on the number of indicators in the higher performing quartile. About half of the states had at least one of the five indicators in the higher performing quartile. Of these states:

- Fourteen states were considered “higher performing” because they had rates in the higher performing quartile for at least two of the five indicators: Connecticut, Delaware, Idaho, Indiana, Iowa, Kentucky, Maine, Massachusetts, Minnesota, Nebraska, New York, Pennsylvania, Rhode Island, and Wyoming. Of the higher performing states, Minnesota was the only state to achieve higher performing status across all five indicators.
- Ten states had one indicator in the higher performing quartile: District of Columbia,¹⁶ Colorado, Kansas, New Jersey, Ohio, South Carolina, South Dakota, Tennessee, Utah, and Virginia.

Figure 2. State Performance on Five Experience of Care Indicators: Adult Beneficiaries with Disabilities



Note: The five experience of care indicators were: getting needed care, getting care quickly, how well doctors communicate, health plan information and customer service, and access to special medical equipment.

BARRIERS TO OBTAINING NEEDED CARE

Approximately 20 percent of adult beneficiaries covered by Medicaid on the basis of a disability reported that they could not get the care they or a doctor believed necessary. Among those who reported not being able to get needed care, the most commonly reported reason was that their health plan would not approve, cover, or pay for care (see Table 6). The other barriers to care cited by at least 10 percent of adults with disabilities were prolonged wait times, lack of transportation, and doctors not accepting beneficiaries’ insurance. Of these

¹⁶ For the purpose of this analysis, the District of Columbia was counted as a state.

barriers, lack of transportation was the reason with the largest gap between adults with disabilities and all adult beneficiaries (12 percent vs. 9 percent).

Table 6. Reasons for Barriers to Needed Care

Medicaid Beneficiaries		
Survey Item	Adults with Disabilities	All Adults
Main reason for not being able to get needed care	Percent (SE)	Percent (SE)
My health plan wouldn't approve, cover, or pay for care	45.5 (0.8)	43.9 (0.6)
The wait took too long	13.5 (0.6)	12.9 (0.4)
Couldn't get transportation to doctor's office	12.2 (0.5)	8.6 (0.3)
Doctor refused to accept my insurance	11.0 (0.5)	10.4 (0.4)
Couldn't afford care	8.5 (0.5)	14.3 (0.4)
Didn't know where to go to get care	7.0 (0.4)	6.4 (0.3)
Doctor doesn't speak my language	1.5 (0.2)	1.2 (0.1)
Couldn't take time off work or get child care	0.7 (0.1)	2.4 (0.2)

Note: "All Adults" includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service.

SUMMARY AND CONCLUSION

The NAM CAHPS survey data provide a resource to support states, CMS, and providers in better understanding and improving the experiences of adults covered by Medicaid on the basis of a disability. Putting people first and improving the customer experience are key goals of CMS, and there is an emerging body of evidence that an individual's experiences in the health care system affects health care use and health outcomes.¹⁷

On four of the five indicators of health care experiences examined in this analysis (i.e., getting needed care, getting timely care, how well doctors communicate, health plan information and customer service), roughly 8 in 10 adult Medicaid beneficiaries with a disability reported favorable experiences (i.e., responded always or usually good) and gave relatively high ratings (i.e., ratings of 7-10) of their experiences with their personal doctors and specialists. Ratings were slightly lower for their health care experiences overall. Moreover, descriptive statistics indicate that even though adults with disabilities had greater health needs than the general population of adults, they reported similar experiences in the health care system as did adult Medicaid beneficiaries overall.

Data showing that 2 in 10 adults with a disability enrolled in Medicaid only (i.e., not full-benefit dual enrollees) face challenges getting needed care or getting timely care are of concern. Although further research is needed to better understand the factors presenting barriers to care, the NAM CAHPS data indicate that coverage related barriers were the most commonly reported reason for being unable to get care (i.e., respondents said Medicaid would not approve, cover or pay for care). Lack of transportation was one of the five top barriers identified, and was more frequently cited by adults with disabilities than Medicaid beneficiaries overall. Finally, evidence that beneficiaries without a usual source of medical care gave the lowest ratings of care suggests that efforts to

¹⁷ The CAHPS Ambulatory Care Improvement Guide: Practical Strategies for Improving Patient Experience. Section 2: Why Improve Patient Experience? <https://www.ahrq.gov/sites/default/files/wysiwyg/cahps/quality-improvement/improvement-guide/2-why-improve/cahps-section-2-why-improve-patient-experience.pdf>

ensure that beneficiaries are connected to a medical home may assist in improving patient experience in the health care system.

Although Medicaid provides coverage for medically necessary supplies and equipment, nearly half (45%) of adults with disabilities (i.e., not full-benefit dual enrollees) with a need for special medical equipment reported problems getting the equipment. Since the survey question described several examples of medical equipment, it is unknown whether this finding is capturing problems with a particular type of equipment or reflects a more general problem. Future research is needed to better understand access issues related to medical equipment. Despite the unknowns, the large share of beneficiaries reporting a problem is of concern.

In 2016, CMS issued a Medicaid home health final rule which included a federal framework for defining medical supplies, equipment and appliances coverable under the Medicaid state plan. This rule also clarified in regulation that for coverage of medical supplies, equipment and appliances, items must be “suitable for use in any setting in which normal life activities take place, other than inpatient settings.”¹⁸ Research is needed to assess whether this regulation is improving access to medical equipment.

Twenty-three states and the District of Columbia were identified as “higher” performing states because of the relatively small share of beneficiaries with disabilities reporting problems on one or more of the five indicators of health care experiences. These states may have lessons that can be shared with other states to drive improvements in health care access and experiences. Future assessments are needed to examine how the higher performing states achieved their results in order to share best practices with other states. Almost all states have used different waiver authorities in Medicaid to cover home and community-based services (HCBS) for beneficiaries who would otherwise require services in an institution. Case-management, personal care and transportation services are among the types of HCBS that states are offering under waivers to improve the ability of beneficiaries to live in their communities. Evaluations of these programs can help determine whether state innovations in service delivery have contributed to the results achieved by the higher performing states.

Medicaid, working at the state and federal level, is striving to improve health care access and experiences of care for all beneficiaries. Given increasing recognition that feedback from consumers can help in improving person-centered care, the NAM CAHPS data and findings can be used to inform improvement efforts that may be tailored toward specific subgroups of adults with disabilities. For example, evidence that 2 in 10 adults with disabilities (i.e., not full-benefit dual enrollees) reported that they were unable to get needed care can be explored further by age group, specific functional limitation, transportation services, or usual source of care. Constructing a profile of the population reporting challenges is the first step in the improvement process and developing strategies for improvement is the next step. The NAM CAHPS survey data can be used to support the ongoing cycle of efforts to improve access to quality care for adults with disabilities.

This brief was prepared and paid for by the Centers for Medicare & Medicaid Services.

¹⁸ 42 CFR §440.70: <https://www.federalregister.gov/documents/2016/02/02/2016-01585/medicaid-program-face-to-face-requirements-for-home-health-services-policy-changes-and>

Appendix A. About this Brief

The Centers for Medicare & Medicaid Services (CMS) contracted NORC at the University of Chicago and its partner, Thoroughbred Research Group, to conduct the first-ever nationwide adult Medicaid (NAM) Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey. NAM CAHPS surveyed a representative sample of adult beneficiaries age 18 and older who were not residing in an institutional setting and were continuously enrolled in Medicaid from October 2013 through December 2013, prior to state Medicaid expansions that occurred on or after Jan 1, 2014.

The goal of the 2014-2015 NAM CAHPS survey was to obtain national and state estimates of adult Medicaid beneficiaries' experience of care, including access to and utilization of services, across different financing and delivery models and population groups. The CAHPS® health plan survey 5.0 was used as the initial basis for development of the NAM CAHPS questionnaire. NAM CAHPS is a CAHPS-like survey since additional questions were added to the questionnaire. These data will serve as baseline information that can be used in later assessments of the experiences of adult Medicaid beneficiaries.

The sample for the 2014-2015 NAM CAHPS survey was designed to capture four sub-groups of adult Medicaid beneficiaries. The main stratifiers were state (including the District of Columbia) and the following four mutually exclusive beneficiary groupings:

- adults dually eligible for Medicaid and Medicare (Full-benefit Dual Enrollees);
- adults (non-dual) with disabilities based on program eligibility criteria (Adults with Disabilities);
- all other adults (non-dual, non-disabled) enrolled in a managed care organization (Managed Care, or MC); and,
- all other adults (non-dual, non-disabled) who obtained care from a fee-for-service (FFS) provider or were enrolled in a primary care case management arrangement (FFS-PCCM).

Beneficiaries in the subgroups of Full-benefit Dual Enrollees and Persons with Disabilities may be enrolled in either a managed care organization or obtain care from a FFS-PCCM provider.

Forty six states and the District of Columbia participated in the 2014-2015 NAM CAHPS survey. Data collection occurred from December 2014 through July 2015, across four waves. The questionnaire was administered first through mail, and then with telephone follow-up where necessary, and was available in both English and Spanish. This effort resulted in an overall response rate of 23.6%, with 272,679 beneficiaries completing the survey. Learn more about the NAM CAHPS at <https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/adult-cahps/index.html>

Overview of Analytic Approach

All statistics presented in this brief are descriptive in nature. Estimates were calculated using survey weights. Survey weights incorporate the selection probability of each sample person, and adjust for differential response rates to produce robust statistical estimates at the state level. The standard error, a measure of the statistical accuracy of the percent, was calculated using the Taylor series linearization method, which takes into account the complex sample design via the concatenated STATE_STRATUM variable. The standard error was used to calculate a 95 percent confidence interval for each estimate and then bivariate comparisons were made by comparing 95 percent confidence intervals. Note that standard errors were not calculated and significance testing was not performed for the composite measures. All other comparisons discussed in the text are statistically significant at $p < .05$. For further information on weighting and variance estimation please see the Methodology Brief on Deriving Weighted Estimates and Calculating Standard Errors for States and Subpopulations for the NAM CAHPS Survey.

APPENDIX B. SURVEY QUESTIONNAIRE ITEMS

Q4. In the last 6 months, when you needed care right away, how often did you get care as soon as you needed?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

Q7. In the last 6 months, how often did you get an appointment for a check-up or routine care at a doctor's office or clinic as soon as you needed?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

Q16. Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate all your health care in the last 6 months?

Q17. In the last 6 months, how often was it easy to get the care, tests, or treatment you needed?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

Q18. In the last 6 months, how often was it easy to get special medical equipment, such as a cane, a wheelchair, diabetic testing supplies, or a nebulizer, you needed?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always
- 5 Did not need special medical equipment in the last 6 months

Q21. In the last 6 months, were you ever not able to get medical care, tests, or treatments you or a doctor believed necessary?

- 1 Yes
- 2 No → If no, Go to Question 23

Q22. What is the main reason you were not able to get medical care, tests, or treatments you or a doctor believed necessary? Choose one.

- 0 Couldn't afford care
- 1 My health plan wouldn't approve, cover, or pay for care
- 2 Doctor refused to accept my insurance
- 3 Doctor doesn't speak my language
- 4 Couldn't get transportation to doctor's office
- 5 Couldn't take time off work or get child care
- 6 Didn't know where to go to get care
- 7 The wait took too long

Q23. Is there a place that you usually go to when you are sick or need advice about your health care?

- 1 Yes → If no, Go to Question 25
- 2 No

Q25. What kind of place do you go to most often for your medical care? Choose one.

- 1 Clinic or health center
- 2 Doctor's office or HMO
- 3 Hospital emergency room

- 4 ○ Hospital outpatient department
- 5 ○ Some other place
- 6 ○ Don't go to one place most often

Q28. In the last 6 months, how often did your personal doctor explain things in a way that was easy to understand?

- 1 ○ Never
- 2 ○ Sometimes
- 3 ○ Usually
- 4 ○ Always

Q29. In the last 6 months, how often did your personal doctor listen carefully to you?

- 1 ○ Never
- 2 ○ Sometimes
- 3 ○ Usually
- 4 ○ Always

Q30. In the last 6 months, how often did your personal doctor show respect for what you had to say?

- 1 ○ Never
- 2 ○ Sometimes
- 3 ○ Usually
- 4 ○ Always

Q31. In the last 6 months, how often did your personal doctor spend enough time with you?

- 1 ○ Never
- 2 ○ Sometimes
- 3 ○ Usually
- 4 ○ Always

Q34. Using any number from 0 to 10, where 0 is the worst personal doctor possible and 10 is the best personal doctor possible, what number would you use to rate your personal doctor?

Q36. In the last 6 months, how often did you get an appointment to see a specialist as soon as you needed?

- 1 ○ Never
- 2 ○ Sometimes
- 3 ○ Usually
- 4 ○ Always

Q38. We want to know your rating of the specialist you saw most often in the last 6 months. Using any number from 0 to 10, where 0 is the worst specialist possible and 10 is the best specialist possible, what number would you use to rate that specialist?

Q39. In the last 6 months, how often did your health plan's customer service give you the information or help you needed?

- 1 ○ Never
- 2 ○ Sometimes
- 3 ○ Usually
- 4 ○ Always
- 5 ○ Did not try to get information or help → If No, Go to Question 41

Q40. In the last 6 months, how often did your health plan's customer service staff treat you with courtesy and respect?

- 1 ○ Never
- 2 ○ Sometimes
- 3 ○ Usually
- 4 ○ Always

APPENDIX C. NATIONWIDE ADULT MEDICAID POPULATION SURVEY CHARACTERISTICS

	Adults with Disabilities	All Adults
Race/Ethnicity	Percent (SE)	Percent (SE)
White, not of Hispanic origin	48.7 (0.3)	41.4 (0.2)
Persons of color, not of Hispanic origin	35.5 (0.3)	33.7 (0.2)
Hispanic/Latino	15.8 (0.3)	24.9 (0.2)
Age		
18-34	26.7 (0.3)	32.1 (0.2)
35-44	14.1 (0.2)	20.2 (0.2)
45-54	21.0 (0.2)	15.0 (0.1)
55-64	32.8 (0.3)	14.7 (0.1)
65 or older	5.4 (0.1)	18.0 (0.1)
Education		
Less than high school	36.4 (0.3)	31.8 (0.2)
High school or more	63.6 (0.3)	68.2 (0.2)
Self-reported Health		
Fair or poor overall health status	46.7 (0.5)	33.9 (0.3)
Fair or poor mental/emotional health status	38.1 (0.3)	24.7 (0.3)
Functional limitations		
One or more functional limitation	81.3 (0.3)	53.8 (0.2)

Note: “All Adults” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service.

APPENDIX D. ACCESS TO CARE, BY STATE

			Getting Needed Care (Never + Sometimes)	Getting Care Quickly (Never + Sometimes)
			Percent	Percent
All Adults (Nationwide)			24.9	20.7
Adults with Disabilities				
	Nationwide		22.2	18.0
	Alabama		23.6	18.9
	Arkansas		23.0	19.6
	Arizona		25.6	21.6
	California		31.5	26.7
	Colorado		19.5	15.8
	Connecticut		19.4	17.4
	District of Columbia		20.1	18.7
	Delaware		17.6	14.5
	Florida		26.9	18.9
	Georgia		21.8	16.4
	Hawaii		21.5	18.3
	Iowa		17.1	15.4
	Idaho		18.2	16.7
	Illinois		22.6	16.3
	Indiana		17.7	14.9
	Kansas		18.6	15.1
	Kentucky		20.5	14.9
	Louisiana		27.9	19.3
	Massachusetts		15.7	14.6
	Maryland		20.9	17.4
	Maine		16.3	14.1
	Michigan		18.9	15.7
	Minnesota		16.5	13.7
	Missouri		21.2	16.1
	Mississippi		20.7	16.7
	Montana		19.8	17.4
	North Carolina		19.2	15.9
	Nebraska		13.6	12.8
	New Jersey		21.4	17.4
	New Mexico		28.0	20.2
	Nevada		23.9	20.0
	New York		18.9	14.9
	Ohio		20.1	17.5
	Oklahoma		22.7	16.2

	Getting Needed Care (Never + Sometimes)	Getting Care Quickly (Never + Sometimes)
Oregon	25.3	19.8
Pennsylvania	17.2	14.0
Rhode Island	16.9	13.5
South Carolina	22.9	16.4
South Dakota	20.3	17.8
Tennessee	18.8	15.4
Texas	26.2	21.2
Utah	19.2	15.4
Virginia	19.1	14.7
Vermont	19.8	17.4
Washington	23.8	21.3
West Virginia	20.6	15.9
Wyoming	16.1	13.1

Note: “All Adults” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service.

APPENDIX E. EXPERIENCES OF CARE, BY STATE

		Communications with Doctors (Never + Sometimes)	Health Plan Information & Customer Service (Never + Sometimes)
		Percent	Percent
All Adults (Nationwide)		10.4	23.6
Adults with Disabilities			
	Nationwide	11.3	22.5
	Alabama	14.8	25.2
	Arkansas	13.3	28.0
	Arizona	12.8	27.1
	California	14.7	28.0
	Colorado	10.3	23.1
	Connecticut	8.9	23.6
	District of Columbia	8.2	24.7
	Delaware	7.4	19.1
	Florida	13.3	24.1
	Georgia	9.4	26.3
	Hawaii	10.6	24.5
	Iowa	7.6	21.4
	Idaho	9.6	24.8
	Illinois	10.1	23.5
	Indiana	10.6	20.0
	Kansas	10.0	22.1
	Kentucky	10.2	18.8
	Louisiana	11.0	22.6
	Massachusetts	10.3	18.6
	Maryland	10.0	20.4
	Maine	9.0	21.7
	Michigan	11.2	21.9
	Minnesota	7.0	19.4
	Missouri	11.7	27.6
	Mississippi	9.4	21.2
	Montana	9.4	23.1
	North Carolina	11.9	21.1
	Nebraska	7.8	22.0
	New Jersey	9.6	19.3
	New Mexico	10.9	22.5
	Nevada	11.7	27.7
	New York	8.9	19.6
	Ohio	10.7	17.9

	Communications with Doctors (Never + Sometimes)	Health Plan Information & Customer Service (Never + Sometimes)
Oklahoma	12.1	25.3
Oregon	12.2	22.7
Pennsylvania	9.7	17.5
Rhode Island	9.1	22.8
South Carolina	10.2	19.9
South Dakota	8.7	27.2
Tennessee	11.9	19.5
Texas	13.1	23.1
Utah	8.9	23.7
Virginia	9.7	20.1
Vermont	11.7	25.6
Washington	12.5	25.1
West Virginia	9.6	24.1
Wyoming	8.3	26.1

Note: “All Adults” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollee; managed care; and fee-for-service.

APPENDIX F. ACCESS TO SPECIAL MEDICAL EQUIPMENT FINDINGS BY STATE

		Access to Special Medical Equipment (Never + Sometimes)
		Percent (SE)
All Adults (Nationwide)		49.1 (0.3)
Adults with Disabilities		
	Nationwide	45.2 (0.4)
	Alabama	52.1 (1.7)
	Arkansas	49.7 (1.7)
	Arizona	54.3 (2.0)
	California	50.2 (2.0)
	Colorado	34.9 (1.5)
	Connecticut	37.3 (1.9)
	District of Columbia	42.4 (2.0)
	Delaware	43.3 (2.1)
	Florida	49.3 (1.9)
	Georgia	51.5 (1.7)
	Hawaii	51.7 (1.6)
	Iowa	37.6 (1.7)
	Idaho	39.3 (1.7)
	Illinois	45.7 (1.8)
	Indiana	38.6 (1.6)
	Kansas	42.5 (1.8)
	Kentucky	39.8 (1.9)
	Louisiana	53.5 (1.8)
	Massachusetts	36.9 (2.0)
	Maryland	46.4 (2.0)
	Maine	39.9 (2.1)
	Michigan	45.1 (1.8)
	Minnesota	36.5 (1.8)
	Missouri	43.8 (1.6)
	Mississippi	44.9 (1.7)
	Montana	40.1 (1.7)
	North Carolina	41.2 (1.8)
	Nebraska	35.1 (1.6)
	New Jersey	45.3 (2.1)
	New Mexico	44.8 (2.0)
	Nevada	48.2 (1.9)
	New York	42.1 (1.9)
	Ohio	40.8 (1.7)
	Oklahoma	50.0 (1.7)

Access to Special Medical Equipment (Never + Sometimes)	
Oregon	43.6 (1.9)
Pennsylvania	39.5 (1.9)
Rhode Island	44.3 (2.1)
South Carolina	48.6 (1.7)
South Dakota	42.2 (1.7)
Tennessee	41.5 (1.7)
Texas	52.5 (2.1)
Utah	41.3 (1.7)
Virginia	40.5 (1.9)
Vermont	42.9 (2.0)
Washington	42.8 (2.0)
West Virginia	40.5 (1.6)
Wyoming	35.9 (2.3)

Note: “All Adults” includes individuals in the four NAM CAHPS sample stratum: persons with disabilities; full-benefit dual enrollees; managed care; and fee-for-service.