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OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

ISSUE BRIEF

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USE OF MEDICAID PERSONAL CARE SERVICES IN 2019 AND 2020

KEY POINTS

- We examined the number and characteristics of Medicaid enrollees with comprehensive benefits who received personal care services (PCS) between March and December of 2019 and March through December of 2020. We found 3 percent fewer Medicaid enrollees received PCS in 2020 than in 2019, declining from 1.7 million to 1.6 million monthly Medicaid enrollees on average. The average rate of PCS use per month also declined by 7 percent between 2019 and 2020, from 251 users per 10,000 Medicaid enrollees to 234 users.
- Among PCS users, an average of 44,000 per month used school-based PCS in 2019, declining by 57 percent, to an average of 19,000 per month in 2020. The average rate of school-based PCS use declined by 59 percent, from 7 users per 10,000 Medicaid enrollees to 3 users.
- While the average monthly number and rate of Medicaid PCS users declined between 2019 and 2020, the average rate of days with PCS use per month increased by almost 6% among all PCS users and approximately 3% among users of school-based PCS.
- Medicaid enrollees who were age 65 and older, female, or lived in urban areas used PCS at the highest rates during both the 2019 and 2020 study periods. Between the two periods, rates of PCS use declined for all age groups (except those age 85 and older), enrollees of both sexes, and enrollees living in both urban and rural areas.
- Between the 2019 and 2020 study periods, the average rate of PCS use increased for Medicaid enrollees with traumatic brain injury or non-psychotic mental disorders due to brain damage but decreased for enrollees with other types of chronic or disabling conditions, decreasing the most for those with cystic fibrosis or other metabolic disorders, mental or behavioral health conditions, and intellectual and developmental disabilities.

BACKGROUND

Home and community-based services (HCBS) are a range of medical and non-medical services, including personal care services (PCS), provided in the home and community. PCS include various types of human assistance for activities of daily living (ADLs) such as eating and bathing, and instrumental activities of daily living (IADLs), including meal preparation and light housework.[1] Typically PCS are provided to individuals with disabilities and chronic conditions, and can be delivered in both community-based and institutional settings. State Medicaid programs cover PCS delivered in community settings using several authorities, for example, state plans, section 1915(c) waiver programs, or section 1115 demonstrations.

Delivery of PCS in community-based settings, which many rely on to support their daily functioning, was disrupted in 2020 due to the COVID-19 pandemic. Although states and the Centers for Medicare and Medicaid Services (CMS) used Medicaid emergency authorities to implement temporary changes to their HCBS programs to maintain or expand access to services and support providers,[2,3] the pandemic exacerbated workforce shortages, forced some providers to close, and caused individuals to decline care so as to limit exposure to the

virus.[4,5] The purpose of this study was to examine trends in Medicaid-funded PCS use during 2019 and 2020, distinguishing between a pre-COVID-19 pandemic period (March through December of 2019) and a COVID-19 pandemic period (March through December of 2020)[i] by key demographic factors and chronic or disabling condition. This issue brief presents findings from descriptive analyses of PCS use nationally.

METHODS

Data

For these analyses, we used data from the 2019–2020 Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF) Research Identifiable Files (RIF). States, the District of Columbia, and territories report Medicaid data to T-MSIS, including those on enrollment, demographics, service use, and payment. TAF RIF are T-MSIS data that have been optimized for research, are organized by year and include nonvoid and nonduplicate final action claims.[6] Specifically, we used the TAF RIF demographic and eligibility (DE) file and the other services (OT) file. The DE file includes demographic, eligibility, and enrollment information for all individuals enrolled in Medicaid for at least one day during the calendar year. The OT file includes fee-for-service claims, managed care encounters, and financial transaction records (including capitation payments, service tracking claims, and supplemental payments) that Medicaid paid for.

To assess data quality, we used measures featured in the Data Quality (DQ) Atlas.[ii] We used DQ Atlas state data quality assessments of the following topics: Total Medicaid Enrollment, Claims Volume - OT, Procedure Codes - OT Professional, and Linking Claims to Beneficiaries.[iii] We excluded states with unusable data on 1 or more topics (Alabama, Arkansas, Rhode Island, Tennessee, and Utah) from our analyses for the year(s) their data were determined to be unusable.[iv] More information on data quality can be found in ***Appendix Table A***.

Identification of Medicaid PCS Users

We limited these analyses to individuals enrolled in Medicaid with comprehensive benefits for at least one day per month.[v] Comprehensive benefits include those that meet the Minimum Essential Coverage standard of the Patient Protection and Affordable Care Act.[7] We identified and classified claims for PCS using an HCBS taxonomy developed for use with Medicaid Analytic eXtract (MAX) data, modified for use with TAF RIF.[8] To identify Medicaid enrollees who received PCS, we identified all PCS claims in the OT file using national and state-specific procedure codes. National procedure codes are listed in ***Table 1***. In addition, we identified a subset of PCS delivered in a school setting based on the place of service code.[vi] Using procedure codes allowed us to identify enrollees using PCS specifically, rather than identifying enrollees using HCBS by Medicaid program authority, such as section 1915(c) waiver programs or section 1915(i) state plan option, as has been the case in previous work.[9,10] For more information on identifying and classifying HCBS claims in the TAF RIF, see the Office of the Assistant Secretary for Planning and Evaluation's issue brief Identifying and Classifying Medicaid Home and Community-Based Services Claims in the Transformed Medicaid Statistical Information System, 2016-2020.

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[i] For both periods, we analyzed March through December to align with the starting month of the COVID-19 pandemic (March).

[ii] For more information, see the DQ Atlas: https://www.medicaid.gov/dq-atlas/welcome.

[iii] We also performed an analysis that was not a measure in DQ Atlas, which assessed the percentage of service use records that did not link to an eligibility record.

[iv] We excluded Utah for 2019 and 2020 and Arkansas for 2020 due to unusable procedure codes on professional claims. We measured the percentage of service use records that did not link to an eligibility record and found Alabama and Rhode Island had unusable data in 2019 and Tennessee had unusable data in 2020; we excluded these states during those years. The differences in states with unusable data across the time periods could impact the results we observed.

[v] We applied the study inclusion criteria for each month in 2019 and 2020.

[vi] We used only the place of service code to identify school-based services at the time of our analysis. More recent guidance on identifying school-based services in TAF is available from DQ Atlas at https://www.medicaid.gov/dq-atlas/landing/briefs.

Table 1. Identifying personal care services and school-based personal care services		
Service	**Requirement**	**Codes**
Personal care services	Requires 1 relevant procedure code	**Procedure codes** T1019 – Personal care services, per 15 minutes T1020 – Personal care services, per diem 99509 – Home visit for assistances of daily living and personal care S5125 – Attendant care services, per 15 minutes S5126 – Attendant care services, per diem
School-based personal care services	Requires 1 relevant procedure code AND the school place-of-service of code	**Procedure codes listed above for personal care services** **AND** **Place-of-service code** 03 – School
Note: Personal care services and personal care services (school-based) were identified using procedure and place of service codes. This list reflects national procedure codes, but we also included state-specific procedure codes.		

Measure Calculation

Throughout this brief, we compare two time periods: March 2019 through December 2019 and March 2020 through December 2020. We selected these two time periods to compare Medicaid-funded PCS use at the start of the COVID-19 pandemic (2020) with the same time period from the prior year (2019). We used several measures to assess PCS use among Medicaid enrollees during these time periods: (1) the number of enrollees receiving PCS per month; (2) the rate of enrollees receiving PCS per month; and (3) the rate of PCS days received per month.[vii] We calculated averages of these measures for both the 2019 and 2020 time periods. Measure descriptions are provided in ***Table 2***.

For each month in 2019 and 2020, we calculated each measure for all Medicaid enrollees who met study inclusion criteria, as well as by select demographic characteristics (age,[viii] sex [male/female], race/ethnicity,[ix] and geographic location [rural/urban][x]) and type of chronic or disabling condition. To stratify PCS use by chronic or disabling condition category, we identified enrollees with specific chronic or disabling conditions[xi] by

[vii] School-based services tend to peak in the winter months, so excluding the months of January and February could influence the patterns in school-based PCS more than overall PCS.

[viii] Age group categories included the following: ≤ 18, 19–64, 65–84, and 85+.

[ix] Race/ethnicity categories included the following: non-Hispanic White; non-Hispanic Black; non-Hispanic Asian; non-Hispanic American Indian and Alaska Native; non-Hispanic Hawaiian/Pacific Islander; Multiracial, non-Hispanic; Hispanic; and Unknown.

[x] Using the zip and county codes for an enrollee found in the TAF RIF, we identified the urbanicity of an enrollee's residence by using the Area Health Resources Files.

[xi] Chronic or disabling condition categories included the following: Alzheimer's Disease, Mental and Behavioral Health Condition, Chronic Kidney Disease, Cystic Fibrosis and Other Metabolic Disorders, Epilepsy, Intellectual or Developmental Disability, Musculoskeletal Condition, Sensory Conditions, Stroke/Transient Ischemic Heart Attack, Traumatic Brain Injury (TBI) and Nonpsychotic

year using the Chronic Conditions Data Warehouse (CCW) Chronic Condition algorithms,[xii] developed by CMS. These algorithms use diagnosis, procedure, and other codes to identify each type of condition. More information on the chronic or disabling conditions can be found in ***Appendix Table B***.

Table 2. Measures of PCS use

Measure	Measure description
(1) Number and percentage of enrollees receiving PCS per month	• This measure captures the number of unique Medicaid enrollees with at least 1 claim for any PCS in the month. • This measure is presented in 2 ways: - The average number of enrollees receiving PCS in a given month for the 2019 and 2020 study periods, calculated as the mean number of enrollees who had a claim for PCS in each month of the period - The distribution of PCS users within a given demographic category or the percentage of PCS users with a given chronic or disabling health condition, calculated by dividing the sum of the number of enrollees in each category who had a claim for PCS in each month of the period by the sum of Medicaid enrollees with comprehensive benefits who used any PCS in each month of the period
(2) Rate of enrollees receiving PCS per month	• The numerator for this measure is the number of Medicaid enrollees with at least 1 claim for any PCS in the month. • The denominator is the total number of monthly Medicaid enrollees with comprehensive benefits in the demographic or chronic or disabling condition category for which the measure is calculated. • Where we present the average rate, we provide the average rate of enrollees using HCBS in a given month during the 2019 and 2020 study periods, calculated as the sum of enrollees who had a claim for PCS in each month of the period divided by the sum of enrollees with comprehensive benefits in each month of the period.
(3) Rate of PCS days per month	• The numerator is the unique number of PCS claims per month, counting only 1 claim per enrollee per day within the month, and the denominator is the number of enrollees using PCS during the month (Measure 1). • Where we present the average rate, we provide the average rate of PCS days for enrollees using PCS in a given month during the 2019 and 2020 study periods, calculated as the sum of PCS days in each month of the period divided by the sum of enrollees who had a claim for PCS in each month of the period.

FINDINGS

PCS Use

An average of 1.7 million Medicaid enrollees with comprehensive benefits received PCS each month during March through December of 2019 (***Appendix Table C***). This number fell by 3 percent to 1.6 million enrollees

Mental Disorders Due to Brain Damage, and Other Chronic or Disabling Condition. The Other Chronic or Disabling Conditions category included other health conditions not captured by the specific categories noted here, such as asthma, diabetes, and hypertension. More information on the chronic or disabling conditions, including the full list of health conditions included in the Other Chronic or Disabling Conditions category, can be found in ***Appendix Table B***.

[xii] Available at https://www2.ccwdata.org/web/guest/condition-categories-chronic.

per month during March through December of 2020. Of this total number of PCS users, an average of 44,000 per month used school-based PCS during 2019; this number fell by 57 percent, to 19,000 enrollees per month, during 2020.

The average monthly rate of users per 10,000 Medicaid enrollees declined for both PCS and school-based PCS between the 2019 and 2020 study periods (***Figure 1***). For PCS, it declined from 251 users per 10,000 Medicaid enrollees to 234 users; for school-based PCS, it declined from 7 users per 10,000 Medicaid enrollees to 3 users. The decrease in the average rate of service users per 10,000 Medicaid enrollees was larger for school-based PCS (58.6 percent decrease) than for all PCS (7.0 percent decrease) (***Figure 1***). The average rate of service days per 1,000 Medicaid service users increased for both PCS (5.9 percent) and school-based PCS (3.3 percent) between the 2019 and 2020 study periods (***Figure 1***).

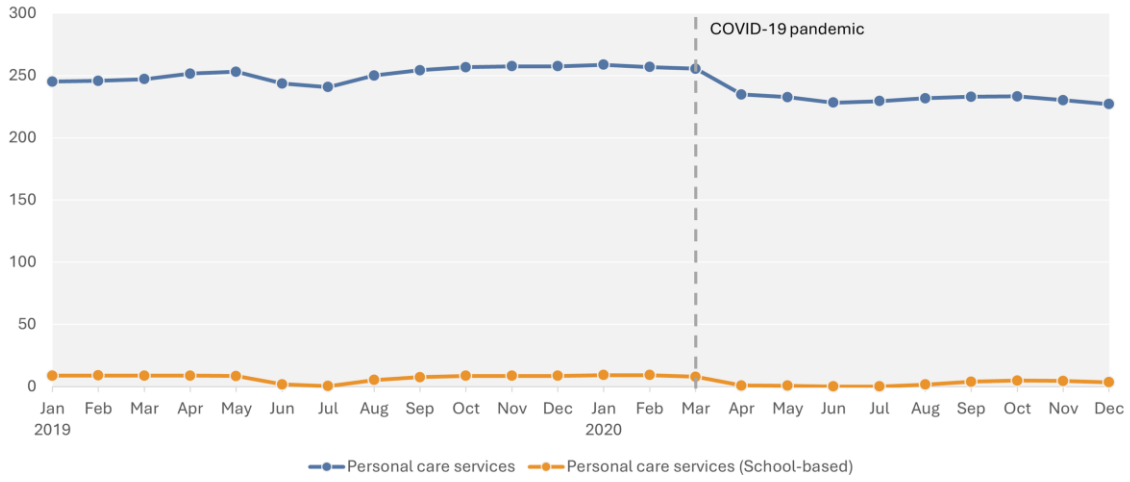
Figure 1. Percent change in the rate of PCS users per 10,000 Medicaid enrollees and rate of PCS days per 1,000 Medicaid HCBS users, March 2019–December 2019 and March 2020–December 2020

Average Rate of Service Users per 10,000 Medicaid Enrollees	Mar 2019 –Dec 2019	Mar 2020 –Dec 2020	Percent change
Personal care services	251.1	233.5	-7.0%
Personal care services (School-based)	6.7	2.8	-58.6%
Average Rate of Service Days per 1,000 Medicaid Service Users			
Personal care services	6,686.6	7,079.0	+5.9%
Personal care services (School-based)	4,887.2	5,046.4	+3.3%

Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.
Note:
This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month. The metric calculation is described in ***Table 2***.

Between March and April 2020, the first two months of the COVID-19 pandemic, the rate of PCS users and school-based PCS users per 10,000 Medicaid enrollees declined by 8.1 percent and 89.3 percent, respectively (***Figure 2***). The rate of PCS users and school-based users remained lower throughout the rest of 2020 after the steep decline between March and April.

Figure 2. Rate of PCS users per 10,000 Medicaid enrollees during each month, 2019–2020



Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.
Notes:
The overall rate of Medicaid enrollees using PCS is per 10,000 Medicaid enrollees.

This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month.

PCS Use by Select Enrollee Demographic Characteristics

Enrollee Age, Sex, and Rural/Urban Location

Approximately half of Medicaid enrollees using PCS were age 65 and older (49 percent in 2019 and 51 percent in 2020); this age group used PCS at the highest rate (around 1,400 users per 10,000 enrollees per month during both study periods) (***Appendix Table D***). The rate of PCS users declined the most for enrollees ages 18 and younger, but there was a decline for all other age groups except those age 85 and older. Around 61 percent of PCS users were female during both the 2019 and 2020 study periods, and females used PCS at a higher rate than males. The rate of decline was slightly larger for male than female PCS users. The majority of Medicaid enrollees using PCS lived in urban areas (83 percent) in both the 2019 and 2020 periods. PCS users living in urban areas used PCS at higher rates than those living in rural areas. However, the rate of decline was larger for PCS users living in rural areas than in urban areas.

Enrollee Race and Ethnicity

The distribution of Medicaid enrollees receiving PCS by race and ethnicity remained similar between the 2019 and 2020 study periods. Non-Hispanic White enrollees made up the largest share of PCS users, followed by Hispanic enrollees of any race and non-Hispanic Black enrollees (***Appendix Table E***). Rates of Medicaid enrollees receiving PCS declined between the 2019 and 2020 study periods for those in all race and ethnicity categories, ranging from a decline of 4.3 percent for non-Hispanic Asian enrollees to a decline of approximately 16 percent for non-Hispanic multiracial enrollees (***Figure 3***). The average rate of PCS days per 1,000 Medicaid PCS users increased for all race and ethnicity categories (***Appendix Figure 1***).

Figure 3. Percent change in the rate of PCS users per 10,000 Medicaid enrollees, by race/ethnicity, March 2019–December 2019 and March 2020–December 2020

Race/Ethnicity	Mar 2019 –Dec 2019	Mar 2020 –Dec 2020	Percent change
Asian, non-Hispanic	596.1	570.5	-4.3%
Black, non-Hispanic	257.8	245.0	-5.0%
Hawaiian/Pacific Islander, non-Hispanic	312.4	295.8	-5.3%
Hispanic, all races	269.0	248.6	-7.6%
White, non-Hispanic	238.7	219.2	-8.2%
American Indian and Alaska Native, non-Hispanic	187.2	171.2	-8.5%
Unknown	171.0	150.8	-11.8%
Multiracial, non-Hispanic	123.5	103.6	-16.1%

Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.
Notes:
The overall rate of Medicaid enrollees using PCS is per 10,000 Medicaid enrollees in each demographic category.

This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month. The measure calculation is described in ***Table 2***.

PCS Use by Enrollee Chronic or Disabling Condition Category

The distribution of Medicaid enrollees receiving PCS by chronic or disabling condition category remained similar between the 2019 and 2020 study periods (***Appendix Table F***).[xiii] The largest share of users had an other or disabling chronic condition. Between the 2019 and 2020 study periods, the rate of PCS users per 10,000 Medicaid enrollees increased only among enrollees with traumatic brain injury (TBI) or nonpsychotic mental disorders due to brain damage (***Figure 4***). Among Medicaid enrollees with other types of conditions, rates of PCS users per 10,000 Medicaid enrollees declined, ranging from a 0.4 percent decline among those with Alzheimer's disease to 9.6 percent among those with cystic fibrosis or other metabolic disorders. The average rate of PCS days per 1,000 Medicaid PCS users increased for people with all chronic or disabling conditions except for TBI or nonpsychotic mental disorders due to brain damage (***Appendix Figure 2***).

[xiii] We identified chronic conditions for all PCS users using Medicaid TAF data only. We are likely to be missing chronic conditions for dually eligible individuals whose diagnoses are more likely to be documented in Medicare claims.

Figure 4. Percent change in the rate of PCS users per 10,000 Medicaid enrollees, by chronic or disabling condition, March 2019–March 2019 and March 2020–December 2020

Disabling or chronic condition	Mar 2019 –Dec 2019	Mar 2020 –Dec 2020	Percent change
TBI or Nonpsychotic Mental Disorders due to Brain Damage	1,041.3	1,058.6	+1.7%
Alzheimer's Disease	1,565.6	1,559.1	-0.4%
Sensory Conditions	1,173.1	1,145.5	-2.4%
Musculoskeletal Condition	1,420.0	1,369.7	-3.5%
Epilepsy	1,152.6	1,092.0	-5.3%
Stroke/Transient Ischemic Heart Attack	1,807.7	1,709.1	-5.5%
Chronic Kidney Disease	1,168.0	1,097.2	-6.1%
Other Disabling or Chronic Condition	605.6	564.8	-6.8%
Intellectual or Developmental Disability	872.0	807.4	-7.4%
Mental or Behavioral Health Condition	376.3	347.8	-7.6%
Cystic Fibrosis or Other Metabolic Disorders	584.3	528.1	-9.6%

Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.
Notes:
The overall rate of Medicaid enrollees using PCS is per 10,000 Medicaid enrollees in each demographic category.
This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month. The measure calculation is described in ***Table 2***.

DISCUSSION

Between March and December 2019 and March and December 2020, PCS use declined, with a greater decline in a subset of school-based PCS. Specifically, the number of PCS users declined from an average of 1.7 million Medicaid enrollees to 1.6 million enrollees per month, and the rate declined from an average of 251 users per 10,000 Medicaid enrollees to 234 users. The number of school-based PCS users declined from an average of 44,000 Medicaid enrollees to 19,000 enrollees per month, and the rate declined from an average of 7 users per 10,000 Medicaid enrollees to 3 users.

Although the average number and rate of PCS users declined, the average rate of service days among PCS users increased between the 2019 and 2020 study. It is possible that users with the greatest need were able to continue receiving PCS despite the disruptions and risks during the March through December 2020 period, whereas users with less need may have stopped using services for various reasons, such as difficulty in finding workers available for limited hours during the COVID-19 pandemic. In addition, state efforts, through opportunities like Appendix K modifications to existing section 1915(c) waiver programs, may have allowed some users to expand their access during 2020.[14]

Previous evidence indicates that the COVID-19 pandemic exacerbated direct care workforce shortages and provider closures,[4,11] and caused individuals to decline services due to the risk of infection from the virus,[12] thus limiting access to HCBS. Direct care workers struggled to access personal protective equipment, testing, and vaccines early in the pandemic due to not being categorized as essential workers.[5] These issues likely had an impact on the ability for some individuals to receive face-to-face PCS due to the risks to themselves and

their PCS providers, which could account for some of the decline in the average rate of users. As noted for the patterns of service days, it is possible that people with fewer needs stopped using services, which might have influenced the decline in users. The more dramatic decline in the use of school-based PCS relative to overall PCS was likely due to school closures during the 2020 period that prohibited people from receiving services in a school setting.[13] In addition, due to a public health emergency related to the COVID-19 pandemic, the number of Medicaid enrollees grew steadily from March 2020 to April 2023, at which point states restarted redeterminations and began disenrolling people who were no longer eligible.[15] The continued increase in enrollees during the 2020 study period could also partially explain the decline in the number of PCS users per 10,000 Medicaid enrollees, because many of the people who remained enrolled between March 2020 and April 2023 were not eligible for or did not have a need for PCS.

Although the distribution of PCS users by demographic characteristics, including age, sex, race and ethnicity, and chronic or disabling condition, were similar during the 2019 and 2020 study periods, there were some differences in the change in the rate of PCS use between the two study periods by enrollee characteristics that help shed light on those enrollees with a higher risk of losing access to PCS. They include people with intellectual and developmental disabilities, mental or behavioral health conditions, or cystic fibrosis or other metabolic disorders, whose rates of PCS use declined considerably. The change in the rate of PCS use by chronic or disabling condition might also have been partly driven by the decline in school-based PCS users between 2019 and 2020, because people receiving school-based PCS might have had a higher prevalence of these conditions.

Limitations

The analyses presented in this brief have some limitations. First, the quality of the data reported by states may affect the reliability of certain information. For example, if a procedure code was not reported accurately, we may have been unable to identify PCS claims. ***Appendix Table A*** shows states and territories with data that we determined to be unusable, of high concern, or unclassified based on key DQ Atlas measures that we assessed to determine whether to exclude a state from our analyses.[xiv] Although we excluded from the study states with unusable data based on one or more of the DQ Atlas measures assessed, we included states with data determined to be of high concern to allow for analyses of PCS use across a greater number of states. The differences in states with unusable data across the study periods could impact the results we observed.

In addition, some states continue to have severe data quality issues with their race and ethnicity data,[xv, xvi] in part due to reporting difficulties or states receiving incomplete race and ethnicity information from enrollees.[16] Because we did not exclude states due to poor race and ethnicity data quality, the unreliability of many states' race and ethnicity data should be considered when interpreting findings presented in this brief.

In addition, PCS possibly could be over- or undercounted based on issues related to capturing and classifying codes associated with PCS, but we do not know the overall impact of these issues on the counts of users and service days. In particular, we identified codes that might lead to an overestimate of PCS users in a few states because they are not necessarily distinct to PCS, and we could be missing state-specific procedure codes of which we were not aware that could lead to an underestimate of PCS users for certain states. For example, in New Jersey, state procedure code Z1610 "Initial Nursing Assessment Visit" is included in the PCS taxonomy category but is distinct from other codes in the PCS list in that it has no designation for a personal care visit or

[xiv] It is outside the scope of this study to account for all data quality issues or policy quirks of any given state. For a systematic accounting of known data quality issues, refer to the DQ Atlas: https://www.medicaid.gov/dq-atlas/welcome.

[xv] More information on states' race and ethnicity data can be found in the DQ Atlas: https://www.medicaid.gov/dq-atlas/landing/topics/single/map?topic=g3m16&tafVersionId=32.

[xvi] Information on the data quality of race and ethnicity data for the 2020 preliminary TAF RIF is not available in the DQ Atlas.

attendant services; in New York, state procedure code 2817 "Long Term Personal Care (Hosp Based)" is included in the PCS taxonomy category but appears to reflect services in a hospital. The addition of these codes could lead to an overestimate of PCS users in New Jersey and New York. It is not clear how these potential over-identification issues balance out with missing procedure codes from the PCS taxonomy list.

Our analysis focused on PCS paid by Medicaid and for users who had service claims. We were unable to identify enrollees who received unpaid PCS, received PCS paid for by a funding source other than Medicaid, or who had unmet needs for PCS. Also, as with all claims-based analyses, we were able to identify only those enrollees with a chronic or disabling condition who received Medicaid-covered treatment related to their condition. As a result, we may have underestimated the number of PCS users who had a chronic or disabling condition, as those who did not seek treatment are not identifiable in the data. Specifically, we are likely to be missing chronic conditions for dually eligible individuals whose diagnoses were more likely to be documented on Medicare claims as opposed to Medicaid claims.

We did not exclude enrollees who died or those who moved to a different state during the month. Those who died during the month are represented in both the numerator (where their service use occurred before their death) and denominator of the measures presented in this brief. Similarly, we did not exclude enrollees who moved to a different state during the month, which may have resulted in some enrollees being double counted in the denominator when aggregating up to the national level. Based on an exploratory analysis, we expect a counteracting effect of including these two groups in the denominator during the 2020 study period, given higher mortality rates and fewer interstate moves observed in the 2020 data. Taken together, we expect that the rates presented in this brief may therefore slightly underestimate the true rates of PCS use had we excluded from the denominator enrollees who died and moved.

Last, we did not address patterns of use for other types of HCBS beyond PCS. We expect that the patterns we observed for PCS during the 2020 period could differ for other types of HCBS, such as service types that can more easily be provided remotely without face-to-face contact.

CONCLUSION

This brief presents trends in Medicaid-funded PCS use during 2019 and 2020, showing the number of Medicaid enrollees using HCBS and the declining rate of PCS use between the March 2019 through December 2019 study period and the March 2020 through December 2020 study period. Analyses presented in this brief are among the first to use an HCBS taxonomy for TAF data, developed based on a taxonomy created for use with older Medicaid eXtract (MAX) data.[8] Additional work should be done to validate this taxonomy for use in identifying HCBS claims and the individuals who use HCBS. In addition, future research should examine use of other types of HCBS and cover a longer time horizon. As the quality of TAF data continues to improve, future research should further explore differences in service use among subpopulations of Medicaid HCBS users. Last, future work should explore the underlying causes of PCS use trends presented in this brief.

APPENDIX: SUPPLEMENTAL TABLES AND FIGURES

Appendix Table A. Supplemental data quality information

State	Total Medicaid enrollment	Linking claims to beneficiaries	OT Claims File	
			Claims volume	Procedure codes (Professional)
Alabama	---	Unusable (2019)	---	---
Arkansas	---	---	---	Unusable (2020)
Massachusetts	---	---	High concern (2019, 2020)	---
Minnesota	---	---	High concern (2019, 2020)	---
New Jersey	---	---	High concern (2019, 2020)	---
North Dakota	---	---	---	High concern (2020)
Puerto Rico	Unclassified (2019, 2020)	---	High concern (2019, 2020)	---
Rhode Island	High concern (2019)	Unusable (2019)	High concern (2019)	---
Tennessee	---	High concern (2019) Unusable (2020)	---	---
Utah	---	---	---	Unusable (2019, 2020)
Virgin Islands	Unclassified (2019, 2020)	---	High concern (2019, 2020)	---

Source: Transformed Medicaid Statistical Information System Analytic Files, 2019–2020, version 5.
Notes:
TAF version 5 aligns with the 2019 Release 1 file and 2020 preliminary file in the DQ Atlas.

It is outside the scope of this study to account for all data quality errors or policy quirks of any given state. For a systematic accounting of known data quality issues, refer to the DQ Atlas: https://www.medicaid.gov/dq-atlas/welcome.

To assess data quality, we used measures featured in the DQ Atlas. For more information, see the DQ Atlas: https://www.medicaid.gov/dq-atlas/welcome. We considered the data quality for a state based on DQ Atlas thresholds for the following topics: Total Medicaid Enrollment, Claims Volume - OT, Procedure Codes - OT Professional, and Linking Claims to Beneficiaries. We did not include in the analysis states with unusable data on 1 or more topics. The differences in states with unusable data across the time periods could impact the results.

Appendix Table B. Chronic and disabling conditions	
Condition category	**Chronic condition algorithms included in category**
Alzheimer's Disease	Alzheimer's disease, Alzheimer's disease and related disorders or senile dementia
Chronic Kidney Disease	Chronic kidney disease
Cystic Fibrosis or Other Metabolic Disorders	Cystic fibrosis and other metabolic developmental disorders
Epilepsy	Epilepsy
Intellectual or Developmental Disability	Autism spectrum disorders, intellectual disabilities and related conditions, learning disabilities, and other developmental delays
Mental or Behavioral Health Condition	Attention-deficit/hyperactivity disorder, alcohol use disorder, anxiety, behavior or conduct disorders, depression, mood disorders (including bipolar disorder), opioid use disorder, other drug use disorders, other mental health conditions, psychotic disorders, trauma or stress-related disorders, and Tourette's syndrome and tic disorders
Musculoskeletal Condition	Cerebral palsy, hip/pelvic fracture, muscular dystrophy, mobility impairments, osteoporosis, rheumatoid arthritis/osteoarthritis, and spinal cord injury
Other Disabling or Chronic Condition	Acquired hypothyroidism, acute myocardial infarction, anemia, asthma, atrial fibrillation, benign prostatic hyperplasia, cataract, colorectal cancer, chronic obstructive pulmonary disease and bronchiectasis, diabetes, endometrial cancer, female/male breast cancer, fibromyalgia and chronic pain and fatigue, glaucoma, heart failure, human immunodeficiency virus and/or acquired immunodeficiency syndrome, hyperlipidemia, hypertension, ischemic heart disease, leukemias and lymphomas, liver disease, cirrhosis, other liver conditions (except viral hepatitis), lung cancer, migraine and chronic headache, multiple sclerosis and transverse myelitis, obesity, peripheral vascular disease, pressure and chronic ulcers, prostate cancer, sickle cell disease, spina bifida and other congenital anomalies of the nervous system, tobacco use disorders, viral hepatitis (general)
Sensory Conditions	Blindness and visual impairment, and Sensory - deafness and hearing impairment
Stroke/Transient Ischemic Heart Attack	Stroke/transient ischemic attack
TBI or Nonpsychotic Mental Disorders Due to Brain Damage	TBI and nonpsychotic mental disorders due to brain damage

Note: We identified all chronic and disabling conditions using CMS's standardized approach for identifying individuals with mental health and substance use disorder conditions in claims data, which is available from the CCW at: https://www2.ccwdata.org/web/guest/condition-categories-chronic.

Appendix Table C. Average number and rate of PCS users per month, March 2019–December 2019 and March 2020–December 2020				
	Average number of PCS users per month		Average rate of PCS users per month	
	March 2019–December 2019	March 2020–December 2020	March 2019–December 2019	March 2020–December 2020
Personal Care Services	1,651,606	1,603,153	251.1	233.5
Personal Care (school-based)	43,889	18,996	6.7	2.8

Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.
Notes:
The average rate of Medicaid enrollees receiving PCS each month is per 10,000 Medicaid enrollees.

This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month. The metric calculations are described in ***Table 2***.

Appendix Table D. Distribution of PCS users and average rate of PCS users per month, by demographic characteristic, March 2019–December 2019 and March 2020–December 2020				
Demographic category	Distribution of PCS users		Average rate of PCS users per month	
	March 2019–December 2019	March 2020–December 2020	March 2019–December 2019	March 2020–December 2020
Age ≤ 18	10%	8%	57.8	43.7
Ages 19–64	41%	41%	212.8	195.6
Ages 65+	49%	51%	1,429.2	1,383.2
Ages 65–84	36%	37%	1,275.8	1,222.7
Ages 85+	13%	13%	2,150.9	2,187.0
Female	61%	61%	279.1	261.6
Male	39%	39%	217.5	200.1
Urban	82%	83%	255.5	239.0
Rural	17%	17%	229.2	209.9

Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.
Notes:
The distribution of PCS users is calculated using the total number of Medicaid enrollees with comprehensive benefits who received PCS in each month. The average rate of Medicaid enrollees receiving PCS each month is per 10,000 Medicaid enrollees.

This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month. The measure calculation is described in ***Table 2***.

There were less than 1 percent of users who had an Unknown geographic classification.

Appendix Table E. Distribution of PCS users, by race/ethnicity, March 2019–December 2019 and March 2020–December 2020		
Race/ethnicity category	**March 2019–December 2019**	**March 2020–December 2020**
White, Non-Hispanic	34%	34%
Hispanic, All Races	22%	22%
Black, Non-Hispanic	19%	20%
Unknown	12%	11%
Asian, Non-Hispanic	10%	11%
American Indian and Alaska Native, Non-Hispanic	1%	1%
Hawaiian/Pacific Islander, Non-Hispanic	< 1%	< 1%
Multiracial, Non-Hispanic	< 1%	< 1%

Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.
Notes:
The distribution of PCS users is the number of PCS users in each month divided by the number of Medicaid enrollees with comprehensive benefits who used PCS in each month, on average, for each period.

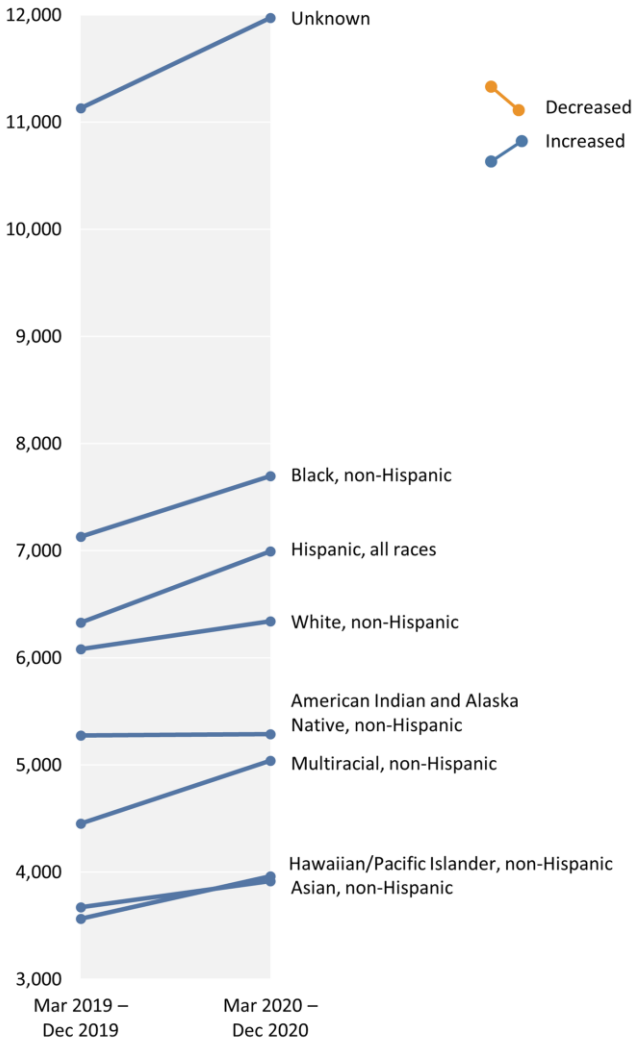
This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month. The measure calculation is described in ***Table 2***. Those with unknown race/ethnicity include those with missing values.

Appendix Table F. Percentage of PCS users with a chronic or disabling condition, by condition category, March 2019–December 2019 and March 2020–December 2020		
Chronic or disabling condition category	**March 2019–December 2019**	**March 2020–December 2020**
Other Disabling or Chronic Condition	74%	74%
Musculoskeletal Condition	34%	33%
Mental or Behavioral Health Condition	33%	32%
Chronic Kidney Disease	25%	24%
Intellectual or Developmental Disability	15%	13%
Alzheimer's Disease	11%	11%
Epilepsy	7%	7%
Stroke/Transient Ischemic Heart Attack	7%	6%
Sensory Conditions	4%	4%
TBI or Nonpsychotic Mental Disorders Due to Brain Damage	< 1%	< 1%
Cystic Fibrosis or Other Metabolic Disorders	< 1%	< 1%

Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.
Notes:
The distribution of PCS users is the number of PCS users in each month divided by the number of Medicaid enrollees with comprehensive benefits who used PCS in each month, on average, for each period.

This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month. The measure calculation is described in ***Table 2***.

Appendix Figure 1. Average rate of PCS days per 1,000 Medicaid PCS users, by race/ethnicity, March 2019–December 2019 and March 2020–December 2020



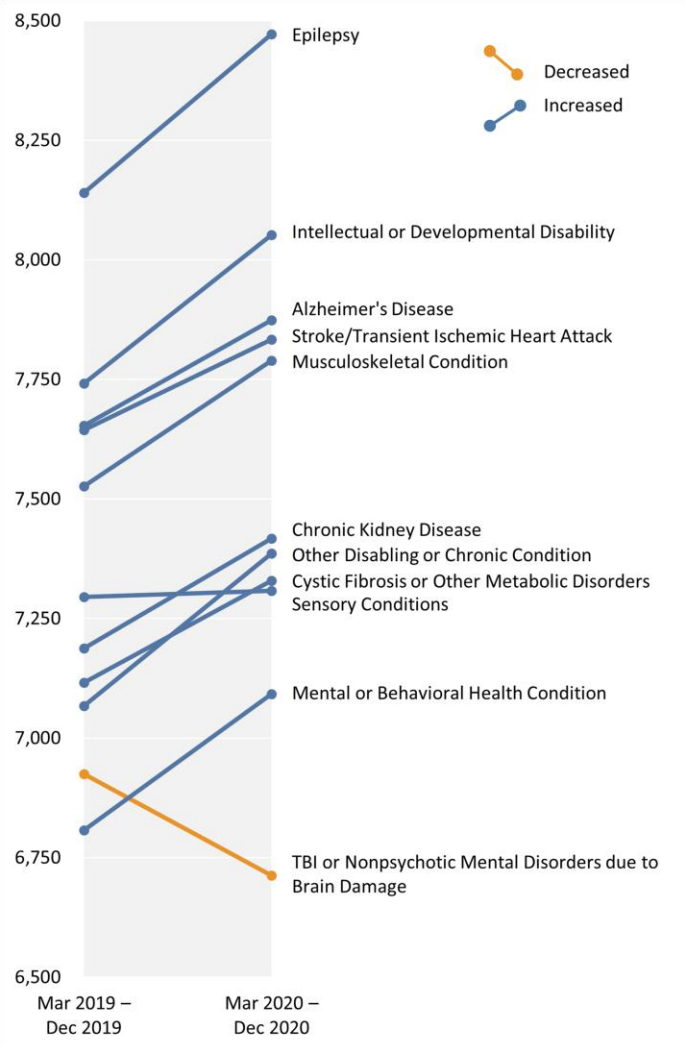
Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.

Notes:

The numerator of the rate of PCS days per month is the unique number of PCS claims per month, counting only 1 claim per enrollee per day within the month, and the denominator is the number of enrollees using PCS during the month.

This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. The measure calculation is described in ***Table 2***.

Appendix Figure 2. Average rate of PCS days per 1,000 Medicaid PCS users, by chronic or disabling condition, March 2019–December 2019 and March 2020–December 2020



Source: Transformed Medicaid Statistical Information System Analytic Files, 2018–2020, version 5.

Notes:

The overall rate of Medicaid enrollees using PCS is per 10,000 Medicaid enrollees.

This analysis includes individuals enrolled in Medicaid with comprehensive benefits who were enrolled for at least 1 day per month. Enrollees using PCS are those with at least 1 PCS claim during the month. The measure calculation is described in ***Table 2***.

CMS's standardized approach for identifying individuals with various chronic health conditions in claims data is available from the CCW. Chronic health conditions include Alzheimer's disease, behavioral health, chronic kidney disease, cystic fibrosis and other metabolic disorders, epilepsy, intellectual and developmental disabilities, musculoskeletal conditions, sensory conditions, stroke or transient ischemic heart attack, TBI and nonpsychotic mental disorders due to brain damage, and other chronic or disabling conditions (such as asthma, migraines, and other conditions not of primary concern to HCBS use).

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