



Examining Health Service Utilization in Medicaid Participants with Intellectual and Developmental Disabilities

Findings from Louisiana, Pennsylvania, and Wyoming

Authors:

- Claire Payne, *Guidehouse*
- Jack Meullenet, *Guidehouse*

Contributors:

- James Howgate, *Guidehouse*
- Madison Hluchan, *ASTHO*
- Orobosa Idehen, *ASTHO*
- Alex Kearly, *ASTHO*
- Adrianna Evans, *ASTHO*

This work was supported by Cooperative Agreement Number NU38OT000290, funded by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$6,900,000 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

Table of Contents

EXECUTIVE SUMMARY	1
• KEY OBSERVATIONS	1
INTRODUCTION	1
METHODS	2
RESULTS	4
• UTILIZATION DIFFERENCES BY IDD STATUS	8
THEMES AND CONSIDERATIONS	9

Executive Summary

ASTHO—with funding from CDC and in partnership with Guidehouse Consulting—led a multi-state Medicaid analysis project to assess utilization of various Medicaid services in adults with intellectual and developmental disabilities (IDD) and, where applicable, compare utilization in adults with and without IDD.

Our analysis explores utilization of a variety of professional services and their trends over time in adults with IDD across three states (Louisiana, Pennsylvania, and Wyoming), by examining Medicaid claims and encounters from Jan. 1, 2018 – Dec. 31, 2020, to answer the following questions:

1. Which types of services did participants with IDD utilize most?
2. For services the non-IDD population utilized, which types of services showed the largest utilization differences by IDD status?
3. What are the utilization differences in emergency department services by IDD status?

Key Observations

- In-home and community supports was the most-utilized service by the total number of IDD participants and volume per member in Pennsylvania and Louisiana, with utilization largely steady from 2018 to 2020.
- Participants with IDD also heavily utilized therapies and standard therapies during the study period. Participants utilizing these services increased from 2018 to 2019 in each state; however, the frequency per member was small.
- In Pennsylvania, participants with IDD utilized more standard therapies than other participants when controlling for age, race, ethnicity, and gender.
- In Louisiana, participants with IDD utilized more lower-level emergency department (ED) visits¹ than other participants when controlling for age, race, ethnicity, and gender.

Introduction

Individuals with intellectual disability and other developmental disabilities (IDD) often [experience health disparities](#) and [reduced access to care](#). The [term developmental disability \(DD\) refers to](#) a severe, chronic disability manifested before 22 years of age and resulting in substantial functional limitations in multiple areas of major life activity. [Intellectual disability \(ID\)](#) is a type of DD characterized by limitations in intellectual functioning and adaptive behavior originating before age 18. Between [1% – 3% of the U.S. population has ID](#), whereas [recent prevalence estimates for DD are 2 – 6 times that number](#) depending on how DD is defined.

ASTHO and CDC aimed to better understand which services participants with IDD utilize most and to identify differences in utilization compared to those without IDD, where possible. Our findings can

¹ Emergency department levels are defined by: [CPT® Code - New or Established Patient 99281-99285 - Codify by AAPC](#)

inform public health surveillance, preparedness, and response efforts, along with Medicaid service and policy planning to help address the needs of people with IDD compared to the non-IDD population.

Methods

We examined Medicaid claims and encounters for individuals aged 25-64 years from Jan. 1, 2018 – Dec. 31, 2020 from three states: Louisiana, Pennsylvania, and Wyoming. In some cases, sample sizes for Wyoming were below suppression limits, so we omitted certain statistics. We considered individuals with one or more claims with a diagnosis code (ICD-10-CM) of IDD at any point in the three-year period to have IDD.² The quality of information provided on Medicaid claims is dependent on the accuracy of medical providers submitting claims and reliance on human entry of codes.³ Individuals included in this analysis demonstrated at least six months of eligibility at any point during the pre-COVID-19 study period (March 2019 – February 2020) and six months of eligibility at any point during the COVID-19 study period (March 2020 – March 2021) to decrease the impact of [Medicaid “churn”](#), which follows the same procedure as our previous analyses, as detailed in previous publications.

We used a three-year study period, 2018 – 2020, to measure service utilization, and categorized individual services—Healthcare Common Procedure Coding (HCPCs) or Current Procedure Terminology (CPTs)—into 10 groups dependent on the services with the highest utilization either by total participants, units of measure (e.g., minutes, hours, per diem, visits) or volume per member for people with IDD. We excluded services related to routine procedures such as laboratory, radiology, and anesthesiology because they are commonly utilized and provide minimal insight into emerging trends or opportunities. Considering there can be dozens or even hundreds of similar services with distinct coding values, we applied a service category grouping to simplify the analysis and consolidate the findings. Due to the granular nature of Medicaid claims data, there are many individual services that we combined into the larger services categories.

We developed the categories by first leveraging those found in the [American Academy of Professional Coders \(AAPC\)](#) and the [Healthcare Common Procedure Coding System \(HCPCS\)](#). However, AAPC and HCPCS do not include definitions for state specific codes, which are common on Medicaid waivers. States have flexibility when defining a specific service code to service description, so Guidehouse applied additional categorization based on individual service descriptions. In addition, individual services have varying units of measure. Therefore, we normalized any services that had a unit of measure tied to minutes or hours to hour increments. We also kept services with a unit of measure of per diem or assessment/visit separate since they could not be normalized into a single unit of measure.

² A refined list of ICD-10-CM codes identified people with IDD for this analysis based on potentially disabling conditions listed in the Chronic Conditions Data Warehouse (CCDW) of CMS and algorithms applied in previous CDC-funded collaborations to exclude congenital malformations where a person would likely not survive to adulthood. We considered Medicaid participants as having IDD if they had ICD-10-CM codes related to IDD at any point from Jan. 1, 2018 – March 10, 2021.

³ We used three years to best account for potential under coding of diagnoses which can be a limitation when using Medicaid data.

The final 10 service categories selected were:

1. Alcohol and Drug Therapies
2. Standard Therapies
3. Therapies⁴
4. Day Care Services
5. In-Home and Community Supports
6. Nursing
7. Residential
8. Supported Employment/Skills and Job Development
9. Supports Coordination/Case Management
10. Emergency Department Visits

To measure the utilization of different services and any between IDD and overall Medicaid populations, we performed analyses that answered the following questions:

1. Which types of services did participants with IDD utilize most?
2. For services the whole population used, which types of services showed the largest utilization differences by IDD status?
3. What is the utilization of emergency department service based on IDD status?

To determine which services members with IDD utilized most, we aggregated service utilization to display the overall volume, number of participants utilizing, and volume per member utilizing for each service and year. We conducted regression analysis to compare utilization across IDD status in emergency department visits and standard therapies, adjusting for age group, race and ethnicity, and gender. We conducted statistical testing on these metrics to locate significant year-to-year changes and model differences in utilization by IDD status.⁵⁶

When analyzing the services that participants with IDD most widely utilized, we observed overall utilization for the entire IDD population by calculating the utilization per 1,000 member months (MMs), the number of unique participants utilizing within each service category, and the volume of utilization per participation to better understand the intensity of service use. MMs represent the number of individuals enrolled within Medicaid within a month. This metric is used as a normalization metric to allow comparison between populations with varying sizes.

⁴ Standard therapies are services that are not different from state to state. These codes are defined: [CPT® Code - Psychiatry Services and Procedures 90785-90899 - Codify by AAPC](#). In comparison, the therapies category has services that are different between states.

⁵ Chi-Squared analysis to test for year-over-year changes and Wilcoxon signed-rank to test for significance in changes in frequency per member utilizing.

⁶ Statistical significance defined as $p < .05$

Results

Table 1 displays the number of unique participants for each of the 10 most-utilized service categories in 2018, for each state. Therapies and standard therapies appeared in the top 10 service categories for all three states. Pennsylvania and Wyoming both feature supports coordination and day care services. Louisiana and Pennsylvania both feature in-home and community supports near the top of their lists. Uniquely, Louisiana features supported employment services in the top 10. We also evaluated (separately in comparison to the non-IDD population) emergency department claims and depending on the level of the emergency department visit there were different utilization metrics. The table displays unit types due to variability in how services are recorded within Medicaid claims data.

Table 1: Top 10 Service Categories in CY 2018 by State

#	Louisiana			Pennsylvania			Wyoming		
	Category	Unit Type	Unique Participants	Category	Unit Type	Unique Participants	Category	Unit Type	Unique Participants
1	In-Home and Community Supports	Hours	6,101	Supports Coordination/Case Management	Hours	29,842	Supports Coordination/Case Management	Session or Assessment	201
2	Standard Therapies	Session or Assessment	2,472	In-Home and Community Supports	Hours	19,560	Supports Coordination/Case Management	Hours	99
3	Standard Therapies	Hours	1,642	Standard Therapies	Hours	8,538	Day Care Services	Hours	70
4	In-Home and Community Supports	Per Diem	1,423	Residential	Per Diem	7,853	Nursing	Hours	67
5	Residential	Per Diem	1,413	Therapies	Hours	7,586	Therapies	Hours	59
6	Therapies	Hours	1,398	Day Care Services	Hours	5,055	Standard Therapies	Hours	56
7	Supported Employment/ Skills and Job Development	Hours	1,053	Standard Therapies	Session or Assessment	4,859	Standard Therapies	Session or Assessment	41
8	Nursing	Hours	707	Supported Employment/Skills and Job Development	Hours	4,769	Therapies	Session or Assessment	20
9	Supported Employment/Skills and Job Development	Per Diem	396	Supports Coordination/Case Management	Per Month	3,135	Alcohol and Drug	Session or Assessment	<10
10	Nursing	Session or Assessment	239	Nursing	Hours	2,495	In-Home and Community Supports	Per Diem	<10

In-home and community supports were the most widely used service by overall utilization and unique participants in Pennsylvania and Louisiana across all three years. Even though there was utilization within the per diem and assessment/visit unit of measure for in-home and community supports, this utilization was nominal in comparison to the hourly unit of measure.

Table 2 illustrates the utilization change over the calendar years for utilization per 1,000 member months (MMs) and unique participants for Louisiana and Pennsylvania. It shows fairly stable utilization per 1,000 and unique participants for Louisiana; however, there are larger observed changes for Pennsylvania between 2019 and 2020.

Table 2: Louisiana and Pennsylvania Hourly In-Home and Community Supports Utilization (2018-2020)⁷

Louisiana In-Home and Community Supports (Hours)					
2018		2019		2020	
Utilization per 1,000 MMs*	Unique Participants	Utilization per 1,000 MMs	Unique Participants	Utilization per 1,000 MMs	Unique Participants
98,323.5	6,101	98,194.2	6,282	97,736.6	6,241
Percent Change		-0.1%	3.0%	-0.5%	-0.7%

Pennsylvania In-Home and Community Supports (Hours)					
2018		2019		2020	
Utilization per 1,000 MMs	Unique Participants	Utilization per 1,000 MMs	Unique Participants	Utilization per 1,000 MMs	Unique Participants
153,120.2	19,560	154,176.3	21,388	114,535.3	20,578
Percent Change		0.7%	9.3%	-25.7%	-3.8%

*MMs denotes Medicaid Participants

While in-home and community supports is the most widely utilized service category, there is still high utilization of additional service categories for people with IDD. The three graphs in **Figure 1** show utilization per 1,000 MMs, unique participants utilizing a service category, and the frequency per member by service category. The interaction of the unique participants compared to the frequency per member intends to measure the intensity of service utilization (or the combination of observing the increases/decreases in both metrics compared to each other) in Louisiana. The frequency per member for the alcohol and drug therapies service category increased each year of the study timeframe, though 2020 saw fewer participants utilizing these services. Participants use standard therapies widely, the category displaying the largest volume of unique participants, with utilization increasing in 2019 and decreasing in 2020. The number of participants using standard therapies increased in 2019 and decreased in 2020, with frequency per member and utilization per 1,000 MMs decreasing each year with generally low frequency per member.

⁷ Wyoming not included in Table 2, as in-home and community supports was the not the most utilized service category.

The plot in **Figure 1** displays overall hourly service utilization for the IDD population in Louisiana per 1,000 MMs, by member, and the frequency of utilization per member. The supported employment service category saw decreasing utilization per 1,000 MMs throughout the study period. Nursing utilization per 1,000 MMs decreased in 2020 while more unique participants used nursing services. Day care services show overall low utilization per 1,000 MMs with few unique participants utilizing the service. However, the frequency per member was high, indicating that those utilizing day care services utilize a large amount. Additionally, we ran statistical significance for the changes in frequency per participant, denoted by the asterisk. The plots depict the utilization for the hourly unit of measure.

Figure 1: Louisiana Hourly Service Utilization by Participants with IDD Utilizing, Frequency per Member, and Utilization per 1,000 MMs⁸

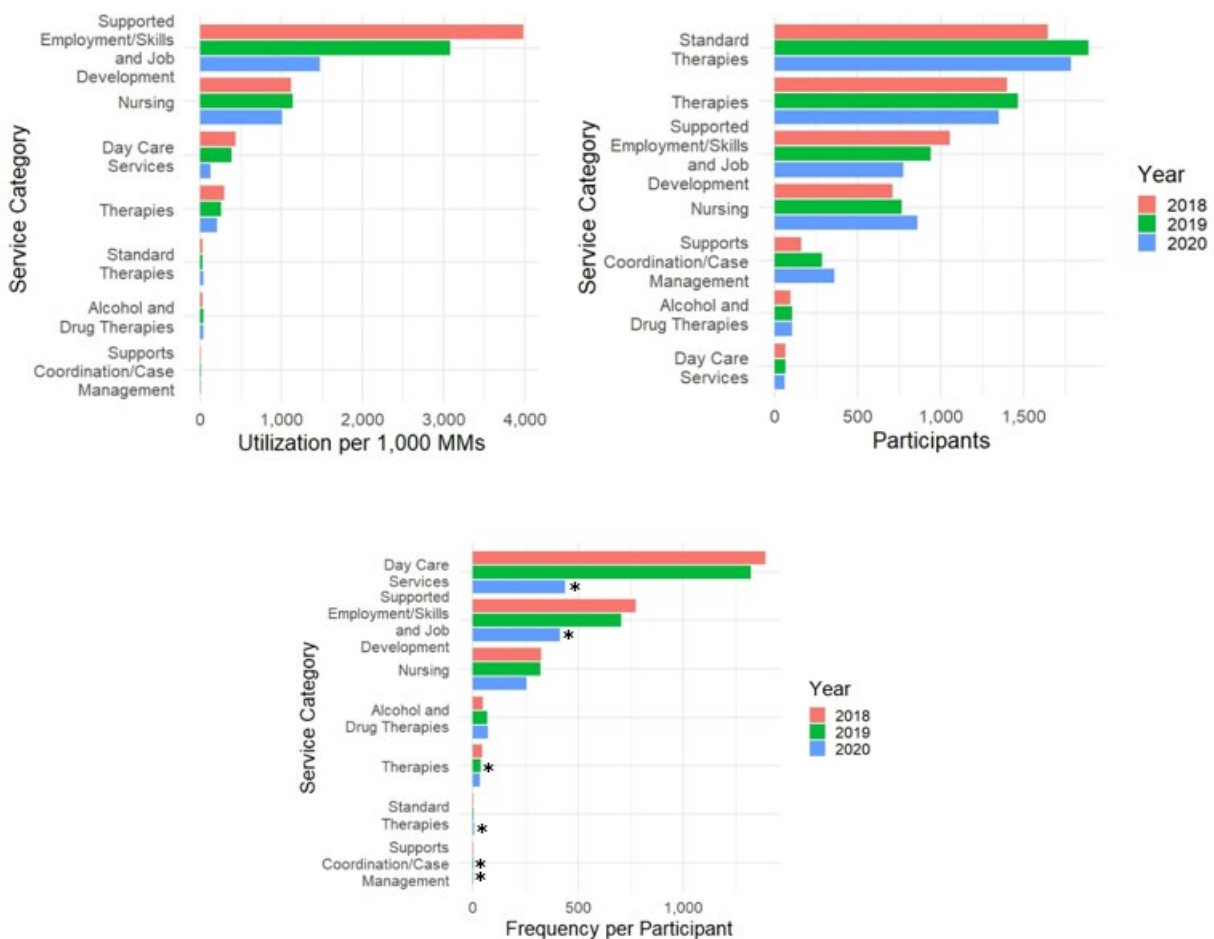


Figure 2 includes hourly service utilization for Pennsylvania for the remaining top utilized services, except in-home and community supports. Hourly alcohol and drug therapies was a small category of service and ended the study period lower than in 2018. Standard therapies had minor decreases in 2020.

⁸ The minimum value for utilization per 1,000 MMs was 2.36, for participants was 60, and for frequency per member was 2.34.

The smaller, more IDD-specific therapies were mostly utilized through hourly codes, with significant decreases in frequency per member. The number of participants utilizing hourly therapy codes stayed more level, indicating that many participants kept receiving therapy services but less often.

Day care services saw large decreases in utilization per 1,000 MMs in both 2019 and 2020, with decreasing numbers of participants and increasing frequency per member. Participants utilized nursing less often in 2019 before the category generally decreased in 2020. Hourly residential was heavily utilized, but—while not depicted in the plot—the per diem codes also decreased significantly each year. The size of the population using residential services increased in 2019 before decreasing in 2020. Supported employment was mainly utilized through hourly codes, which declined significantly in utilization per 1,000 each year. The number of participants utilizing supported employment services decreased less than the frequency in 2020, indicating most participants were still utilizing them. We ran statistical significance for the changes in frequency per participant, denoted by the asterisk.

Figure 2: Pennsylvania Hourly Service Utilization by Participants with IDD Utilizing, Frequency per Member, and Utilization per 1,000 MMs⁹

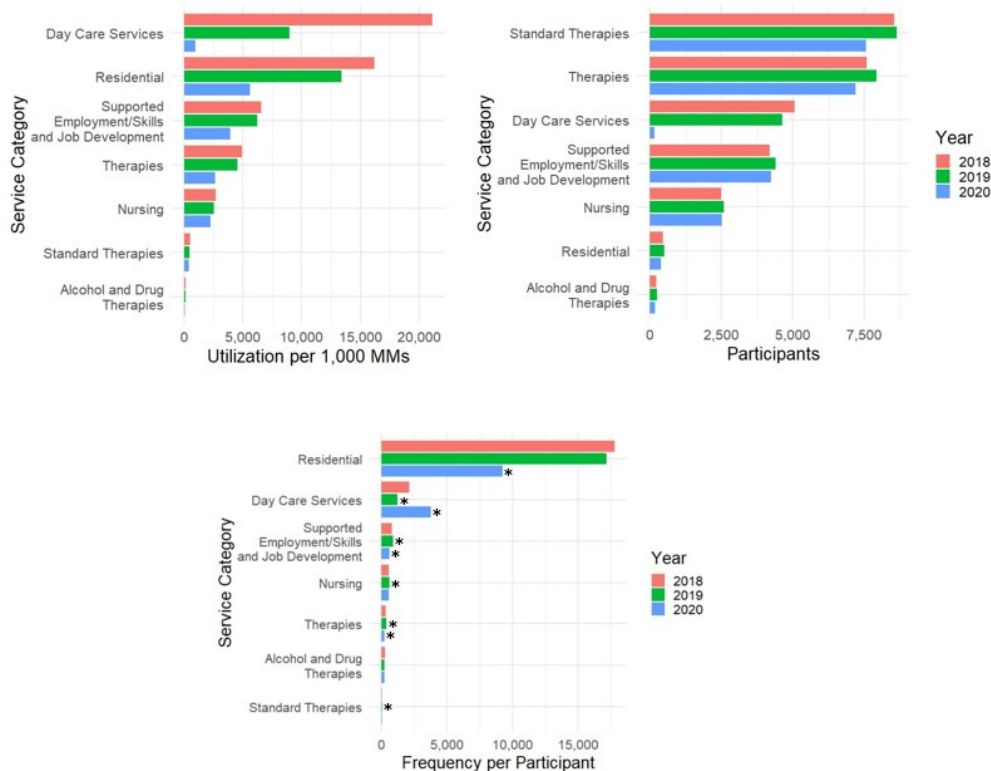


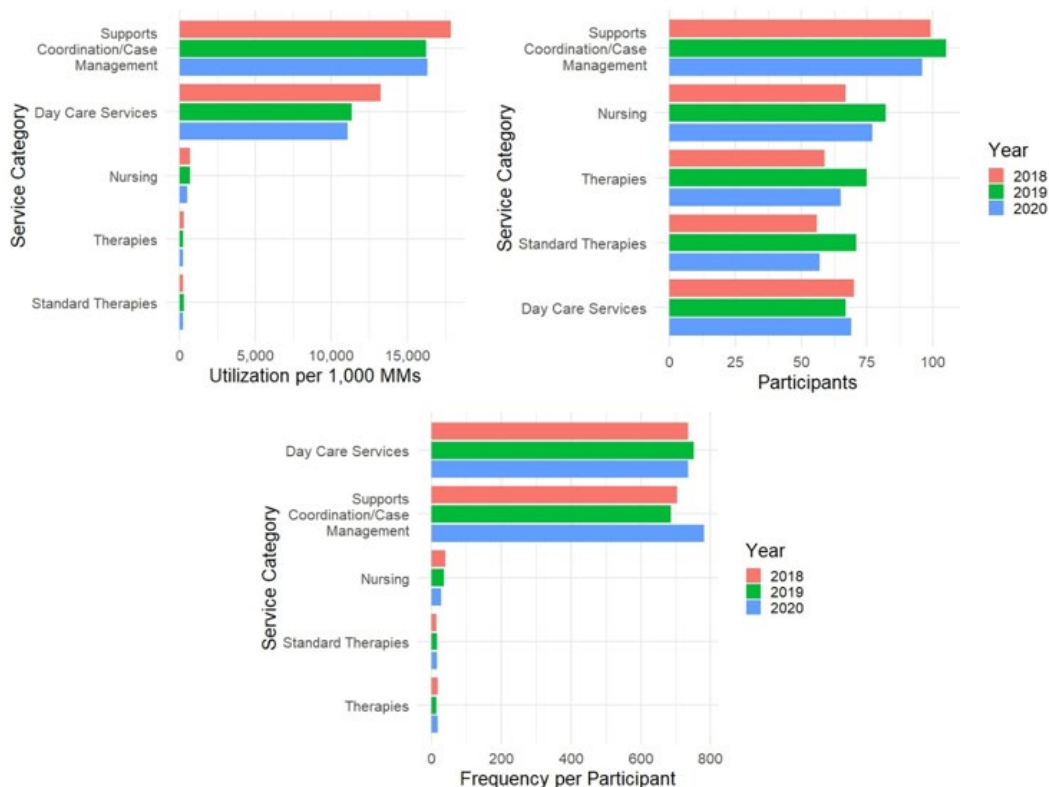
Figure 3 includes the top utilized services by number of unique participants in Wyoming. The IDD population is substantially smaller in Wyoming, which is representative of the smaller state population. Therefore, we did not find the observed patterns to be statistically significance in any categories. We are

⁹ The minimum value for utilization per 1,000 MMs was 56.33, for participants was 164, and for frequency per member was 29.23.

still able to observe that supports coordination/case management is the most widely utilized service. There is also consistency across the other four services, where anywhere from mid-60 to 75 participants are utilizing services.

The top left plot in **Figure 3** shows the overall utilization per 1,000 MMs patterns for the same set of Wyoming services. Day care and supports coordination/case management services were the most-utilized service categories by a large margin. There was no observed statistical significance for the frequency per participant.

Figure 3: Wyoming Hourly Service Utilization by Participants with IDD Utilizing, Frequency per Member and Utilization per 1,000 MMs¹⁰



Utilization Differences by IDD Status

Emergency department visits are widely utilized by both the IDD and Non-IDD populations. Since both populations use these services, we were able to compare if utilization patterns between both groups differed. In Louisiana, the most common emergency department visit level among participants with IDD was level 5. For the overall population, the most common visit was level 4. However, using a regression model, we find that IDD status was associated with 9% lower odds¹¹ of having a higher-level visit compared to similar participants with non-IDD status. In Pennsylvania, the most common ED visit level

¹⁰ The minimum value for utilization per 1,000 MMs was 203.6, for participants was 56, and for frequency per member was 13.9.

¹¹ From an ordinal logistic regression with controls for age group, race/ethnicity, and gender. 95% CI: 0.9 – 0.93

was level 5 for both IDD and non-IDD populations. The estimated odds ratio for Pennsylvania was 1.0, indicating that, after controlling for demographics, there was no significant difference in ED visit level associated with IDD status.¹² Wyoming's sample size was too small to draw conclusions.

To analyze standard therapy utilization by IDD status, we ran a regression on the number of standard therapies billed for an individual member from 2018 – 2020. For Louisiana, after controlling for age group, race, ethnicity, and gender, there was no significant difference¹³ between the IDD and overall Medicaid populations. For Pennsylvania, the difference was significant,¹⁴ indicating that participants from the IDD population used more standard therapy sessions in the study timeframe than similar participants of the overall Medicaid population.

Themes and Considerations

Medicaid claims data is an impactful and robust source of information when looking to better understand trends in utilization. Claims data provide details needed to identify critical services specific to populations of interest, potential gaps in care, or the need for increased service capacity. As seen in the analyses conducted as part of this report, we were able to confirm that members heavily and consistently utilized in-home and community supports even during the COVID-19 pandemic. This indicates the essentiality of these services to care for the IDD population. As a comparison, we also observed that unique participants widely used standard therapies, but the frequency per member was low. This may indicate access to these services is adequate. Retrospective analyses can offer leaders insights to evaluate where to focus resources, or in some case reallocate resources, to make the largest impact.

Of note, when analyzing Medicaid data sources, it is important to appreciate the best use cases of the information and ensure that we leverage the appropriate partners throughout the process. We learned that successful analysis requires building strong partnerships. This allows for the transparent and collaborative sharing of data across multiple partners, inclusive of Medicaid agencies, designated state operating agencies—including state units that serve behavioral health, IDD and other disability populations, HCBS disability champions, provider networks, academic institutions and utilizers of services. That collaboration enhances the development of beneficial analyses that have actionable insights.

In addition, Medicaid claims data is only able to provide insights related to services that have been delivered, and not services that are desired or needed. Therefore, it's important to supplement claims data analyses with engaging experts who are familiar with the service delivery and the populations to extrapolate the underlying explanations for the utilization patterns. As an example, Louisiana provided anecdotal commentary related to Hurricane Ida in 2021 and the impact on utilization of specific services due to access issues.

¹² From an ordinal logistic regression with controls for age group, race/ethnicity, and gender. 95% CI: 0.99 – 1.02

¹³ From a regression with a log-link function. 95% CI for coefficient of number of standard therapies: -0.78 – 0.39

¹⁴ From a regression with a log-link function. 95% CI for coefficient of number of standard therapies: -0.37 – -0.26

Potential considerations for state and territorial health agency staff when considering analyses using Medicaid populations and data include:

- Anticipate the complexity of establishing data sharing agreements by proactively engaging across agencies to develop a plan for easier sharing of information. Many Medicaid agencies have third parties, such as university systems and managed care organizations involved in data collection and aggregation. This further complicates data accessibility.
- Be mindful of the high degree of program variation across state Medicaid programs. While federal standards exist, states have high autonomy in design and operation of their programs. Anticipating these differences impacted our state engagement strategies and required effort to “stratify” when comparing state data. Common variations that complicate inter-state analyses include:
 - Differing eligibility categories
 - Managed care vs. fee-for-service operations
 - Service types and definitions
 - Specialized programs and waiver services
 - Claim and other data specifiers and coding nuances
- Be proactive but build consensus around a commitment to studying trends and learning from them post-emergency. Many states were under-resourced or faced other competing pressures (e.g., natural disasters, leadership turnover) that hindered their ability to participate, even though states acknowledged interest and anticipated value in learning from study findings. Both public health and Medicaid units are often in reactive positions, thus, pre-work is essential to build shared, long-standing commitment to studying observations from future public health emergencies.

Potential considerations for state and territorial health agency staff based on the outcomes of analyses include:

- Medicaid claim data are powerful and can be of considerable value during times of emergency when planning for emergencies. Claims data made available proactively through sharing agreements with response agencies can inform plans intended to continue in-home and community-based care delivery services for persons with IDD that are disproportionately affected by disasters.
- Routinely assess the expected level of utilization, compared to the observed level of utilization, for a given service. Comparing data on enrollment and claims data can illuminate gaps in care using utilization trends to better understand access issues. Combining population experts to provide context related to average service usage compared to the actual utilization can provide thoughtful insights on whether there are gaps in care.
- When designing studies focused on disability populations, including individuals with I/DD, consider the risk of skewing focus to individuals with high acuity or long-term care needs. Disabilities occur along a continuum of acuity. Therefore, considering Medicaid categories that capture mainstream, adult participants can expand observations to those individuals who have lower acuity but meet diagnostic criteria. This will help to consider the needs and trends among working adults with disabilities and/or individuals not receiving long-term care.