Research

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A Report on the Increased Payment Rates for HCBS for People with Intellectual and Developmental Disabilities During the COVID-19 Pandemic

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Abstract

Recognizing the crisis the COVID-19 pandemic represents to the Home- and Community-Based Services (HCBS) service system and the health, safety, and quality of life of people with intellectual and developmental disabilities (IDD), states temporarily amended their HCBS programs to strengthen service delivery. States are able to temporarily amend their HCBS 1915(c) waiver programs by submitting *Appendix K: Emergency Preparedness and Response Waivers* to the Centers for Medicare and Medicaid Services (CMS). The aim of this study was to examine if, and how, states increased their reimbursement rates for HCBS IDD waiver services during the COVID-19 pandemic. To do so, we analyzed 294 Appendix Ks which amended HCBS 1915(c) waivers for people with IDD between the start of the pandemic and April 2022. During the pandemic, 34 states and the District of Columbia increased reimbursement rates for 2,435 services provided by 82 HCBS waivers for people with IDD. Increase in reimbursement rates ranged from 3.5% to 160.7%, with an average increase of 23.3%. States most frequently increased reimbursement for supports to live in one's own home, residential habilitation, and health and professional services. In addition, 12 states and the District of Columbia offered one-time supplemental payments through 25 HCBS waivers for people with IDD. While increasing payments during the pandemic likely helped stabilize the HCBS service system during this period of crisis, what remains to be seen is how the IDD service system will function when this additional funding is discontinued.

Keywords: Home- and Community-Based Services (HCBS); people with intellectual and developmental disabilities (IDD); COVID-19 pandemic; reimbursement rates; human service providers.

People with intellectual and developmental disabilities (IDD) are especially at risk for contracting and dying of COVID-19 (Clift et al., 2021; Landes, Turk, Formica, et al., 2020; Landes, Turk, & Wong, 2020; Turk et al., 2020). This is not only because of their disabilities and/or medical conditions, but also because many people with IDD receive personal care which requires close contact and because many people with IDD live in congregate settings (Abrams et al., 2020; Brown et al., 2021; Clift et al., 2021; Landes, Turk, Formica, et al., 2020; Landes, Turk, & Wong, 2020; Turk et al., 2020). As a result of the increased risk to people with IDD, as well as precautions states implemented for all populations, the COVID-19 pandemic significantly disrupted Home- and Community-Based Services (HCBS) for people with IDD (Gathright, 2020).

HCBS is a form of Long-Term Services and Support (LTSS), that allows people with IDD to receive support in their homes and communities, rather than institutions. HCBS gives states the flexibility to tailor LTSS programs to suit the needs of populations in their states that may otherwise require institutional care. For example, states are able to decide HCBS eligibility criteria, how many people will be served, what services are included in their HCBS programs, the ways those services are provided, and cost limits. In 2018, $42.3 billion was spent on Medicaid HCBS waivers for people with IDD in the United States, with an average spending of $48,000 person with IDD (Larson et al., 2021). Unlike acute health care, HCBS often covers a wide range of wrap-around services, from personal care to employment supports to assistive technology. The largest proportion of HCBS expenditures for people with IDD are devoted to residential habilitation, supports to live in one's own home, and day habilitation (Friedman, 2023). However, some waivers are designed to excluded residential habilitation in favor of relying on unpaid natural supports in order to reduce costs. In fact, the flexibilities granted to

states by CMS to customize their HCBS programs often results in vast inconsistencies across states, waivers, and services in terms of how services are provided and how money is allocated.

The Impact of COVID-19 on HCBS

During the COVID-19 pandemic, many HCBS providers serving people with IDD lacked resources and funding, not only because of increased costs but also because they have had to close service lines (service types/categories) as a result of government safety orders. For example, in 2020, 68% of IDD providers closed service lines and 32% lost revenue as a result. Lost revenue was especially problematic given prior to the pandemic the average IDD provider only had enough money to maintain operations for a single month (American Network of Community Options and Resources [ANCOR] Foundation & United Cerebral Palsy, 2021; Avalere Health, 2020).

In addition to a lack of funding and resources, direct support professional (DSP) turnover also increased provider instability. While DSP turnover was already referred to as a 'crisis' prior to the pandemic, it further increased during the pandemic due to DSPs' added workloads, the increased risks DSPs faced, and DSPs' family caregiving responsibilities (ANCOR Foundation & United Cerebral Palsy, 2021; Gathright, 2020). As a result of vacancies, there was also an additional burden on unpaid family caregivers during the pandemic (Luterman, 2020). Moreover, many HCBS providers had to pay overtime to their staff, the costs of which were estimated at a million dollars a year for the average provider (ANCOR Foundation & United Cerebral Palsy, 2021).

As a consequence of these additional pressures on the HCBS system, the quality of people with IDD's services decreased, and many IDD providers were operating on the brink of disaster, with some permanently going out of business (ANCOR Foundation & United Cerebral

Palsy, 2021; Avalere Health, 2020; Embregts et al., 2022; Scheffers et al., 2021). Thompson and Nygren (2020) explain,

> Platitudinous calls to 'tighten the belt' and 'do more with less' are empty rhetoric to organizations that operate without profit or operational reserves. Funding delays and cuts will not only result in people with IDD having fewer choices and less opportunity to exercise self-determination in regard to where and how they live, as well as how their supports are delivered, but will eventually place the health and safety of people at risk. (p. 259)

Provider instability hinders the health, safety, and quality of life of people with IDD, and is also a risk to the long-term future of the HCBS service system – if droves of providers go out of business, people with IDD will have fewer opportunities to live, work, and thrive in their communities, rather than institutional settings (ANCOR Foundation & United Cerebral Palsy, 2021).

Emergency HCBS Funding

The COVID-19 pandemic had a significant impact on people with IDD and HCBS service delivery. To minimize disruptions to HCBS and promote the quality of services, the Centers for Medicare and Medicaid Services (CMS) provided states with the ability to temporarily increase their HCBS Funding during the pandemic. States are able to temporarily amend their HCBS 1915(c) waivers by submitting *Appendix K: Emergency Preparedness and Response Waivers* to CMS. Appendix Ks also allow states the opportunity to increase reimbursement rates for services as CMS (n.d.-a) notes "extraordinary circumstances may necessitate adjustments to the payment and utilization estimates contained in the approved [HCBS 1915(c)] waiver" (p. 10). In fact, increased HCBS spending reduces the risk that people

with be institutionalized and improves people's outcomes (Blackburn et al., 2016; Leslie et al., 2017; Muramatsu et al., 2007; Nord et al., 2020; Wang et al., 2020).

Despite the ability to make emergency pandemic changes to HCBS, these changes are optional and according to each state's discretion. In fact, even prior to the pandemic, one of the hallmarks of HCBS was the lack of consistency across programs and states, with a lack of standardization and states having the ability to make relatively subjective choices about how they provide HCBS to people with IDD. As a result, it is especially important to examine how states design and change their HCBS programs. Where states focus their limited supply of money is one indicator of their priorities – it highlights how they prioritize the needs of people with IDD in times of crisis and instability, and what types of services they believe people with IDD need. A comprehensive understanding of the changes states make, including areas of need and gaps in service delivery, is also necessary for advocacy efforts to ensure the services states provide truly mirror the needs of people with IDD during the pandemic and beyond, especially when the additional funding ends. For these reasons, the aim of this report was to examine if, and how, states increased their reimbursement rates for HCBS IDD waiver services during the COVID-19 pandemic. The secondary aim was to identify patterns in the reimbursement rates. To examine this, we analyzed Appendix Ks which amended HCBS 1915(c) waivers for people with IDD (n = 294).

Methods

This study analyzed the Appendix K: Emergency Preparedness and Response amendments states made to their HCBS waivers for people with IDD. Appendix K waivers were obtained from the Medicaid.gov website's *Approved HCBS 1915(c) Appendix K Datatable* on April 7, 2022 (Centers for Medicare and Medicaid Services, n.d.-b). The CMS Appendix K

Datatable organizes Appendix Ks based on which HCBS waivers they apply to. To be included in our study, the Appendix Ks needed to be specifically amending HCBS waivers for people with IDD – intellectual disabilities, developmental disabilities, and/or autism (see Friedman (2023) for a list of IDD 1915(c) waiver programs in 2021). In their Appendix Ks, states must also document the reason for amending their HCBS programs (i.e., pandemic/endemic, natural disaster, natural security emergency, environment, or other). Only COVID-19 pandemic Appendix Ks were utilized for this study. One HCBS IDD amendment by Louisiana was made because of Hurricane Laura and Hurricane Delta; this Appendix K was excluded from the analysis (no rates were amended in this Appendix K anyhow), however, all other Louisiana Appendix Ks for COVID-19 were retained. This process resulted in a collection of 294 Appendix K waivers which amended HCBS IDD waivers.

In Appendix K waivers, states are required to document how they will temporarily change their HCBS programs during the COVID-19 pandemic and what dates these changes are effective between (Centers for Medicare and Medicaid Services, n.d.-a). Specifically, in section K-2-f of Appendix K waivers, states document how they will temporarily increase payment rates for waiver services, if they choose to do so. We used this information to determine which services were amended and how rates were increased and/or how one-time supplemental payments were provided.

More specifically, when service reimbursement rates were increased, we used descriptive statistics to analyze the how rates increased across HCBS IDD waivers. In addition, in order to examine the different patterns in reimbursement rates, we used the additional data that could be gleaned from Appendix Ks and HCBS – the date ranges of the temporary changes and the types of services involved. We used the Appendix K effective dates (the date ranges the HCBS

program is temporarily changed) to aggregate reimbursement rate increases by quarters of the pandemic they were active. To determine how reimbursement rates differed based on service category, we organized services with increased rates into Rizzolo et al.'s (2013) HCBS IDD waiver service taxonomy. In their study, Rizzolo et al. (2013) reviewed service definitions for all services provided in HCBS IDD waivers and placed each into one of the following service categories: adult day health; community transition supports; day habilitation; family services (subcategories: family training and counseling, family supports); financial support services; health and professional services (subcategories: crisis, dental, clinical and therapeutic services, nursing and home health); individual goods and services; prevocational; recreation and leisure; residential habilitation (facility-based); respite; self-advocacy training and mentorship; specialized medical and assistive technologies; support coordination; supported employment; supports to live in one's own home (e.g., companion, homemaker, chore, personal assistance, supported living); and transportation. The author of this study used Rizzolo et al.'s (2013) taxonomy information to categorize each service that was amended using Appendix K according to Rizzolo et al.'s template (e.g., Alaska AK0260 waiver's "Residential Habilitation Group Home" service was listed in the template as falling into the "residential habilitation" service category and marked accordingly). After assignment, all services were reviewed again to ensure they were in the correct category. We then aggregated reimbursement rate increases by service category and analyzed these data using descriptive statistics.

The way states offered one-time supplemental payments using Appendix K was often not done consistently across states. States offered one-time supplemental payments either for: (1.) all claims; (2.) certain services only; or (3.) for other purposes that were not service specific. They then administered these payments either by flat rates (set dollar amounts) or a percentage of

costs. We created an excel document, reorganizing every one-time supplemental payment into which type of supplemental payment was offered (i.e., all claims, certain services [organized by Rizzolo et al.'s service category taxonomy as described above], or other purposes). Then we aggregated each of the three payment types by payment methodology (i.e., flat rate or percentage of costs) to determine the average supplemental payment.

Results

Increased Reimbursement Rates

During the COVID-19 pandemic, 34 states and the District of Columbia (77.8% of states with HCBS IDD waivers) increased reimbursement rates for a total of 2,435 services in 82 HCBS waivers for people with IDD. Increase in reimbursement rates ranged from 3.5% to 160.7%, with an average increase of 23.3% (*SD* = 19.0%; Figure 1).

Differences Based on Time Period

The increases in reimbursement rates for HCBS IDD services ranged slightly over different time periods of the pandemic (Figure 2). However, the increased rates most often hovered around an average 25-30% increase, with the lowest average being the second quarter of 2020 (April 1 to June 30, 2020) and the highest being the second quarter of 2021 (April 1 to June 30, 2021). The increase in reimbursement rates has slowly declined since the second quarter of 2021 (April 1 to June 30, 2021) and was 25.8% as of the second quarter of 2022 (April 1 to June 30, 2022). It remains to be seen if, or how, this downward trend will continue as the pandemic evolves.

Differences Based on Service Category

The service categories that were most commonly amended during the pandemic were supports to live in one's own home (*n* = 408), residential habilitation (*n* = 405), and health and

professional services (*n* = 332), while the least frequently amended were individual goods and services (*n* = 1), financial support services (*n* = 2), and family services (*n* = 12; Table 1).

In terms of rate increase, the largest average increases were for financial support services (33.0%), respite (31.5%), and health and professional services (27.8%; Figure 3). Meanwhile, the categories with the smallest average rate increases were self-advocacy training and mentorship (12.1%), support coordination (16.7%), and prevocational services (16.7%).

Differences by State

Arkansas, Florida, Iowa, Kansas, Mississippi, Montana, Nevada, New Jersey, Ohio, and South Dakota did not increase their HCBS rates at all using Appendix K (Table 2). The states that increased the largest number of services included Colorado (763), Pennsylvania (181), Georgia (145), Alabama (136), and Tennessee (129). Meanwhile, the states that had the largest average increases for their IDD HCBS reimbursement rates were District of Columbia (60.36% increase), Alaska (50.00% increase), Kentucky (50.00%), Michigan (50.00% increase), North Dakota (50.00% increase), Utah (50.00% increase), and Washington (50.00% increase).

One-time Supplemental Payments

During the COVID-19 pandemic, 12 states and the District of Columbia (28.9% of states with HCBS IDD waivers) offered one-time supplemental payments through 25 HCBS waivers for people with IDD. Supplemental payments were offered either via a flat rate payment – a set dollar amount – or based on the percentage of claims for that provider. Out of the 533 different supplemental payments, 4 were for all of providers' claims (across all services), 507 were for claims for specific service lines, and 22 were for other purposes (Table 3). Those that provided a supplemental payment for all of the provider's claims, offered a supplemental payment of 8.0% of those claims, on average.

Of those supplemental payments for specific service lines, the categories that most commonly included supplemental payments were: supports to live in one's own home (n = 143); supported employment (n = 99); and respite (n = 72). The categories least commonly associated with supplemental payments were: adult day health (n = 3); community transition supports (n = 5); and specialized medical equipment and assistive technology (n = 6). In terms of payment amounts for specific services, of those which were paid by flat rate, supports to live in one's own home had an average supplemental payment of $802 per DSP, respite of $604 per DSP, and financial support services of $110 per person with IDD served. Of those paid by percentage of claims for the service lines, specialized medical equipment and assistive technology (33.1%), adult day health (16.0%), and prevocational (14.0%) services paid the highest average percentage rates for supplemental payments, and community transition supports (5.0%), family services (5.0%), and respite (6.1%) paid the lowest average percentage rates.

The supplemental payments for other purposes included paying for direct care related services in general, working with COVID+ people, supporting staff recruitment, retention, training, and credentialing, purchasing personal protective equipment (PPE), and purchasing technology. For example, two waivers offered supplemental payments for providers to purchase PPE at $250 per person with IDD the providers served. Another example is three of Pennsylvania's waivers (i.e., Consolidated Waiver [PA0147], Person/Family Directed Support [PA0354], Community Living Waiver [PA1486]) offered providers either $50,000 or 1% of the provider's annual revenue, whichever is greater, for staff training, credentialing, and business associates programs.

Discussion

The COVID-19 pandemic significantly impacted the HCBS system for people with IDD. For this reason, the aim of this study was to explore if, and how, states increased payment for IDD HCBS during the pandemic, as well as potential trends among those payments. We found that between March 2020 and April 2022, 39 states and the District of Columbia (88.9% of states with HCBS IDD waivers) increased reimbursement rates and/or offered one-time supplemental payments for IDD HCBS. States increased the reimbursement rates for almost 2,500 HCBS services for people with IDD and offered more than 500 different supplemental payments. By increasing payment rates for HCBS, states are able to help promote continuity and stability, compensate for emergency staffing needs, and offset additional pandemic expenses, among other benefits.

Increased payment through Appendix K appeared to target many of HCBS IDD's pain points during the pandemic. For example, in order to help support those working directly with people with IDD, such as DSPs and nurses, reimbursement rates were frequently increased and supplemental payments offered for residential habilitation, supports to live in one's own home, and health and professional services. In fact, nursing and home health services saw the largest average increase across the service categories at 43%. Given people with IDD are the group most at risk for COVID-19 infection and death, nurses and home health aides played a critical role during the pandemic, not only in terms of helping prevent and stop the spread of COVID-19, but also helping to care for people with IDD who were infected with COVID-19 (Clift et al., 2021; Landes, Turk, Formica, et al., 2020; Landes, Turk, & Wong, 2020; Turk et al., 2020). Increased funding for nursing and home health can be used to reduce turnover, offer paid time off for quarantining, and help reduce the negative impact high workload has on staff's quality of life (Desroches et al., 2022; Ebrahimi et al., 2021).

In addition, rates for employment and day services were commonly increased during the pandemic. This was likely to compensate for people with IDD losing their jobs and in-person settings needing to close and/or be altered for social distancing and safety (ANCOR Foundation & United Cerebral Palsy, 2021; Luterman, 2020; Scheffers et al., 2021). The sudden and significant drop in revenue from the closing of day programs and sheltered workshops, even temporarily, destabilized human service providers and threatened their ability to operate (ANCOR Foundation & United Cerebral Palsy, 2021). While in-home day services meant services were more individualized for each person than in traditional congregate in-person day services, this likely contributed to increased costs due to increased staffing needs and the costs of developing more interactive and engaging education and programming that could occur remotely, especially for extended periods during lockdown (Bradley, 2020; Embregts et al., 2022). In addition, due to large technology disparities in the disability community, additional funding was likely needed to help acquire and run the technology needed to provide these services (Navas et al., 2021). At the same time as they were offering virtual services, many providers that owned or leased physical spaces for their in-person day services likely had to maintain the operating costs of those settings despite not offering services in them, leading to increased expenses.

In contrast, there were other service types where rate increases were less frequent – seemingly prioritized less during the pandemic given where money was allocated. For example, rates were not frequently increased for family services. Even prior to the pandemic, LTSS in the United States depended heavily on unpaid caregiving, which increases caregivers' physical and emotional stress, and negatively impacts their health (Gallanis & Gittler, 2012; Kunkel et al., 2003; Simon-Rusinowitz et al., 2005); this likely further intensified during the pandemic. While

increasing funding for other services, such as crisis and respite services, likely had a beneficial impact on families, more attention to family services in particular could help support family caregivers during the pandemic.

In addition, self-advocacy training and mentorship rates were not only less commonly amended altogether, when they were increased, they had one of the smallest rate increases at 12% on average. While self-advocacy training and mentorship services are relatively sparsely funded in IDD HCBS (Friedman, 2023), these services help promote self-determination, strengthen people with IDD's sense of identity and community, and help people cope during challenging circumstances (Friedman, 2017; Hayes & Balcazar, 2007). As such, they would be especially beneficial to people with IDD not only to help cope with the stress and trauma of the pandemic, but also as they faced ableism (discrimination against people with disabilities) during the pandemic, which disadvantaged and discriminated against people with disabilities (e.g., health care rationing, vaccine prioritization, masking and lockdown policies, etc.; American Association of People with Disabilities, 2020; American Psychological Association, 2020; Autistic Self Advocacy Network, 2020; Boyle et al., 2020; Contrera, 2021; Ervin & Hobson-Garcia, 2020; Luterman, 2020; Oakley et al., 2020; Pulrang, 2020).

It is important to note that five states – Florida, Iowa, Kansas, Mississippi, and New Jersey – did not increase reimbursement rates or offer one-time supplemental payments in their IDD HCBS programs through Appendix K. There were also large differences across the sates that did increase their reimbursement rates and/or offer supplemental payments. One could theorize a lack of expansion of funding through HCBS could evidence a lack of prioritization of the needs of people with IDD in these states. However, while states like Florida and Mississippi rank relatively low in terms of their commitment to IDD HCBS, as evidenced by low overall

spending, low spending per capita, low fiscal effort, and a large waiting list (Florida), New Jersey ranks high in terms of total spending and average spending per participant, and has no waiting list, and Iowa and Kansas are about average (Friedman, 2023; The Henry J. Kaiser Family Foundation, n.d.). In fact, there was no correlation between increased payment rates in Appendix K, and HCBS 1915(c) allocations, state population, or state personal income. Therefore, there is not necessarily a consistent trend as far as HCBS prioritization is concerned. In addition, Florida, Mississippi, and New Jersey had some of the highest COVID-19 death rates in the United States (The New York Times, 2022), indicating a need for increased support for people with IDD, despite the lack of increased reimbursements or one-time payments. Yet, there was no relationship between COVID-19 rates (Centers for Disease Control and Prevention, 2022) and how states implemented payment changes to their HCBS programs using Appendix K. Inconsistencies across states, waivers, and services is one of the hallmarks of HCBS – the flexibilities granted to states to tailor their programs and the lack of standardization, although beneficial, often results in what appears to be relatively arbitrary choices (Friedman, 2023); this trend seems to have continued with emergency Appendix K funding during the pandemic.

The lack of increased reimbursement rates and one-time payments in these states, as well as the discrepancies across states that did offer increased reimbursement rates and/or one-time payments, may be due to states using other policies, programs, or funding sources, beyond Appendix K, to supplement their IDD HCBS. How much states attempted to strengthen their HCBS service delivery for people with IDD in the form of increased funding is likely also influenced by state politics and attitudes towards not only COVID-19, but also “entitlement” programs like Medicaid, taxation (which helps funds Medicaid), and disability more broadly. For example, research has found that both ableism and racism (discrimination against people of

color) contribute to states' funding of Medicaid and HCBS, with more ableist states funding HCBS at lower rates and institutionalizing more people with IDD, and more racist states spending less per person on Medicaid (Friedman, 2019; Friedman & VanPuymbrouck, 2019; Leitner et al., 2018).

Implications for Policy and Practice

Across all HCBS IDD waivers and their services, reimbursement rates were increased by 23% on average. As such, the increased funding provided through Appendix K represents an influx of billions of additional dollars into the HCBS IDD service system. While this funding was desperately needed during the pandemic, it also means that, since Appendix K is a temporary authority, after the public health emergency (PHE) is over, funding for HCBS for people with IDD will reduce dramatically. In fact, given rates in our study have already been decreasing since the second quarter of 2021, if these trends continue, increased funding may phase out before the pandemic is even over.

Post-pandemic HCBS will not look like pre-pandemic HCBS. Yet, it remains to be seen how the IDD service system will reconcile with returning to pre-pandemic reimbursement rates, especially as the HCBS IDD system was underfunded and fractured prior to the pandemic (ANCOR Foundation & United Cerebral Palsy, 2021). For example, as providers' operating costs are still higher than normal, lower reimbursement rates may lead to further provider instability and collapse (Avalere Health, 2020; Gathright, 2020). New advances of the pandemic, such as use of telehealth service delivery with people with IDD, may diminish as a result of reduced funding for these services. While increased wages and supplemental payments to DSPs were common during the pandemic, when these wages/payments go back to pre-pandemic rates, there is a risk DSP turnover will increase even further, both because their wages are often

inadequate, and because of the additional trauma and burnout DSPs' experienced during the pandemic (ANCOR Foundation & United Cerebral Palsy, 2021; Bogenschutz et al., 2014; Gathright, 2020; Keesler, 2016; Luterman, 2020). A further surge in DSP turnover threatens the health, safety, and quality of life of people with IDD as well as the stability of the HCBS service system (American Network of Community Options and Resources, 2014; Friedman, 2018, 2021; Venema et al., 2015).

Efforts must be made to expand HCBS and strengthen its infrastructure. To do so, states can amend their HCBS 1915(c) programs to implement changes permanently beyond the end of Appendix K, such as by increasing reimbursement rates. In fact, 10 states have indicated to CMS they are hoping to continue the emergency changes they made to their (not IDD specific) HCBS programs after the PHE ends (Centers for Medicare and Medicaid Services, 2022). In addition, federal efforts, such as the HCBS Access Act of 2021 (Dingell et al., 2021) and additional funding for HCBS in relief packages, would help not only improve HCBS infrastructure, but by extension, also improve people with IDD's quality of life.

Implications for Research

This study analyzed how states changed their rate structures and offered one-time supplemental payments in their HCBS programs for people with IDD. Despite the information about increased funding in IDD HCBS, these data do not indicate if or how this funding improved the quality of HCBS. Therefore, future research is needed to examine if increased funding in HCBS during the pandemic translated to increased stability of provider organizations – were human service organizations better able to provide services and maintain the quality of their services with the aid of this increased funding? Research should also explore the impact of this funding on the DSP workforce, including if this funding helped decrease DSP turnover as

intended, as well as if it helped reduce DSPs' workload, stress, and burnout. Finally, but most importantly, research should determine if this funding resulted in improved quality of life of people with IDD during the pandemic. This evidence-base is critical to help promote quality of life and quality of services as the pandemic continues and in future times of emergency.

Limitations

When interpreting this study's findings, a number of limitations should be noted. The aim of this study was to examine payment rates for IDD HCBS services via Appendix K. As such, HCBS waivers that combined populations (i.e., IDD with additional populations) were not included in this study as services for people with IDD or other populations cannot be differentiated. States are able to amend their Appendix K waivers multiple times. While our analysis was of the cumulous changes states made between the start of the pandemic and April 7, 2022, since the pandemic is ongoing, states may make further changes to their Appendix K waivers, including to increase reimbursement rates or roll back previous changes.

Conclusion

During the COVID-19 pandemic, states utilized Appendix K waivers to temporarily amend their HCBS programs in order to respond to this emergency. This study found the majority of states utilized Appendix K waivers to increase payment rates for IDD HCBS services and/or to offer one-time supplemental payments during the pandemic. While doing so likely helped stabilize the HCBS service system during this period of crisis, what remains to be seen is how the IDD service system will cope when this additional funding is discontinued. As such, forethought and planning are necessary to ensure the stability of HCBS infrastructure and to promote the health, safety, and quality of life of people with IDD during this ever-evolving pandemic and beyond.

Compliance with Ethical Standards

Disclosure of conflicts of interest: The author has no relevant financial or non-financial interests to disclose

Ethics approval: As this study involves publicly available policy documents, our IRB determined it was exempt from review.

Informed consent: Not applicable as no people were involved in this study.

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Table 1

Increased Reimbursement Rate by Service Category

	Services		Rate increase			
Category	*n*	*%*	*M*	*SD*	Min	Max
TOTAL	2,435	100.0%	23.3%	19.0%	3.5%	160.7%
Supports to live in one's own home	408	16.8%	23.7%	21.1%	4.9%	126.9%
Residential habilitation	405	16.6%	20.4%	14.9%	4.0%	75.0%
Health and professional services	322	13.2%	27.8%	25.9%	3.5%	123.7%
Clinical and therapeutic services	*184*	*7.6%*	*21.1%*	*24.0%*	*3.5%*	*123.7%*
Nursing and home health	*92*	*3.8%*	*42.6%*	*27.0%*	*5.0%*	*123.7%*
Crisis	*46*	*1.9%*	*29.0%*	*19.5%*	*4.9%*	*50.0%*
Dental	*10*	*0.4%*	*7.5%*	*1.3%*	*5.0%*	*8.2%*
Supported employment	320	13.1%	22.2%	16.8%	3.5%	111.4%
Day habilitation	286	11.7%	20.0%	12.0%	5.0%	50.4%
Respite	217	8.9%	31.5%	23.6%	3.5%	160.7%
Community transition supports	149	6.1%	26.1%	14.7%	3.5%	50.0%
Transportation	88	3.6%	19.7%	12.7%	3.5%	50.0%
Prevocational	75	3.1%	16.7%	11.8%	5.2%	50.4%
Specialized medical equipment and assistive technology	71	2.9%	20.2%	18.1%	4.9%	50.0%
Support coordination	33	1.4%	16.7%	14.5%	5.0%	50.0%
Adult day health	17	0.7%	17.7%	8.1%	6.4%	41.3%
Financial support services	2	0.08%	33.0%	0.0%	33.0%	33.0%
Self-advocacy training and mentorship	19	0.8%	12.1%	9.7%	8.0%	50.0%
Family services	12	0.5%	24.6%	19.5%	5.2%	50.0%
Individual goods and services	1	0.04%	n/a	n/a	n/a	n/a

Table 2
State Payment Changes

State	Rate increases		Offered supplemental payments
	n services increased	Average % increase	
Alabama	136	45.09%	No
Alaska	24	50.00%	No
Arkansas	0	0.00%	Yes
California	18	8.17%	No
Colorado	763	16.79%	Yes
Connecticut	64	6.88%	No
Delaware	3	5.00%	Yes
District of Columbia	43	60.36%	Yes
Florida	0	0.00%	No
Georgia	145	9.53%	No
Hawaii	20	17.86%	No
Idaho	2	29.81%	Yes
Illinois	3	28.33%	No
Indiana	40	14.00%	No
Iowa	0	0.00%	No
Kansas	0	0.00%	No
Kentucky	12	50.00%	No
Louisiana	9	25.49%	No
Maine	116	19.88%	Yes
Maryland	48	39.73%	No
Massachusetts	66	12.50%	No
Michigan	13	50.00%	No
Minnesota	4	5.85%	No
Mississippi	0	0.00%	No
Missouri	18	5.29%	No
Montana	0	0.00%	Yes
Nebraska	114	10.00%	No
Nevada	0	0.00%	Yes
New Hampshire	34	NS	No
New Jersey	0	0.00%	No
New Mexico	21	13.67%	No
New York	6	NS	No
North Dakota	1	50.00%	No
Ohio	0	0.00%	Yes
Oklahoma	88	20.00%	No
Oregon	22	5.95%	No
Pennsylvania	181	38.53%	Yes
South Carolina	18	17.91%	No
South Dakota	0	0.00%	Yes
Tennessee	129	26.84%	No
Texas	10	29.28%	No
Utah	1	50.00%	Yes
Virginia	109	12.50%	Yes
Washington	127	50.00%	No
West Virginia	27	38.21%	No

Note. NS = Increases offered but rates not specified in Appendix K.

Table 3
One-Time Supplemental Payments

		Supplemental payment		
Category	*n*	Flat rate (average)	% of claims (average)	*(n* amount not specified)
For all claims	4	n/a	8.0%	0
Service specific				
Residential habilitation	40	n/a	10.1%	21
Supports to live in one's own home	143	$802 per DSP	8.7%	74
Adult day health	3	n/a	16.0%	1
Community transition supports	5	n/a	5.0%	2
Day habilitation	27	n/a	9.9%	0
Financial support services	13	$110 per person with IDD served	10.0%	0
Support coordination	12	n/a	11.1%	0
Transportation	10	n/a	13.5%	0
Prevocational	13	n/a	14.0%	0
Supported employment	99	n/a	11.8%	1
Specialized medical equipment and assistive technology	6	n/a	33.1%	0
Health and professional services	57	n/a	9.3%	0
Clinical and Therapeutic Services	*50*	*n/a*	*8.6%*	*1*
Nursing and Home Health	*6*	*n/a*	*16.7%*	*1*
Crisis	*1*	*n/a*	*5.0%*	0
Respite	72	$604 per DSP	6.1%	1
Family services	7	n/a	5.0%	0
Other (not service specific)				
Services that contain direct care (general)	5	n/a	10.0%	0
Working with COVID+ people with IDD	4	$344 per DSP	n/a	0
DSP recruitment/retention	2	$1,000 per DSP	n/a	0
Staff training, credentialing, and business associates programs	3	Greater of $50,000 or 1% of annual revenue (per provider)		0
Purchase PPE	2	$250 per person with IDD served	n/a	0
Technology for HCBS providers	3	$20,000 per provider	n/a	0
Technology for support coordinators	3	Greater of $150,000 or 10% of annual revenue (per provider)		0

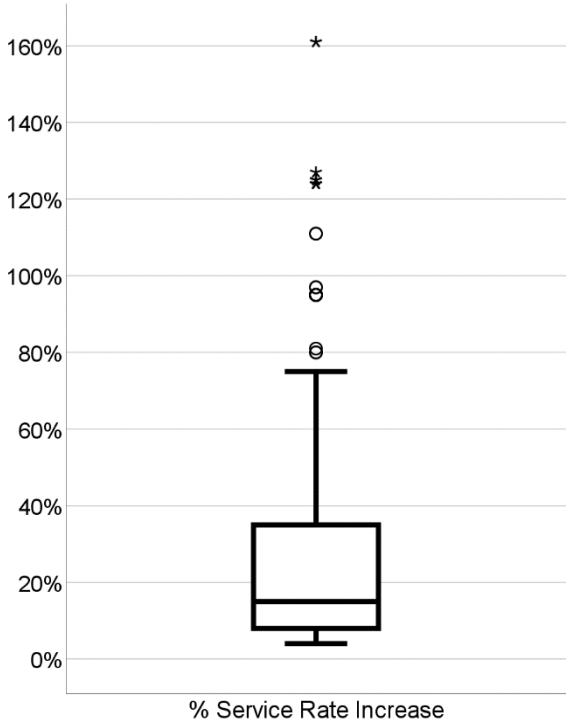

Figure 1. Reimbursement rates increases for services.

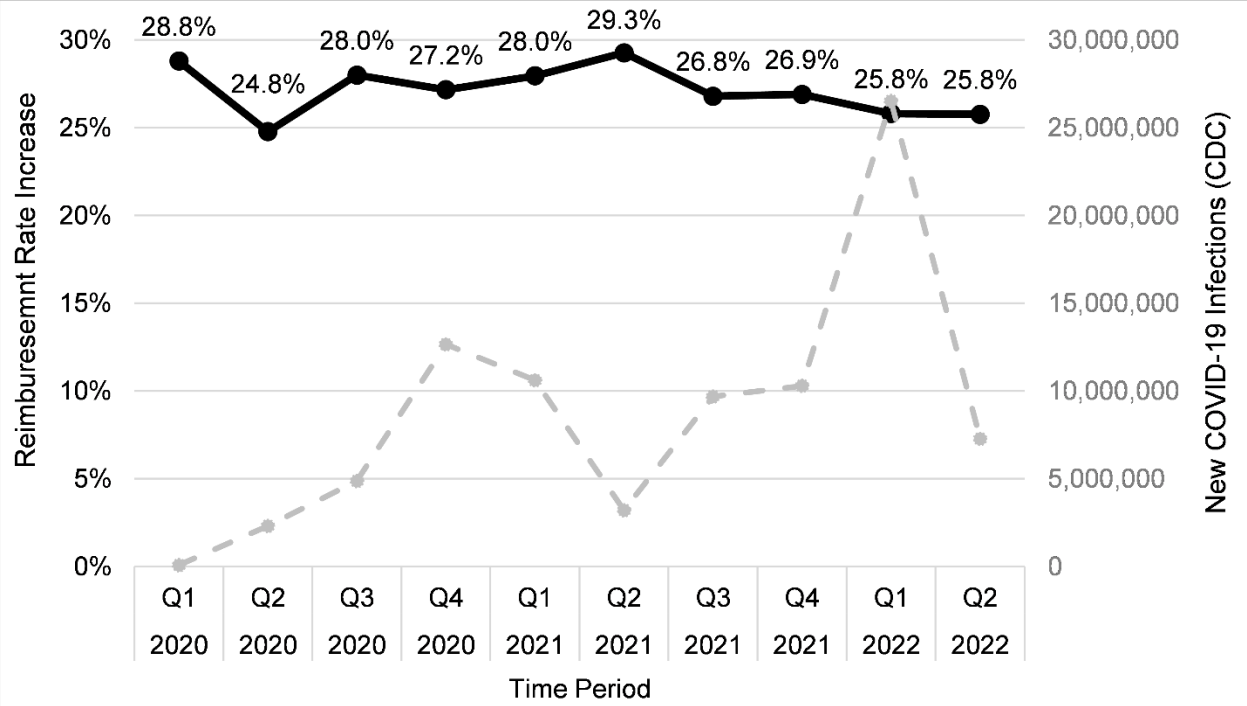

Figure 2. Change in reimbursement rate increase by quarter. Q = quarter.

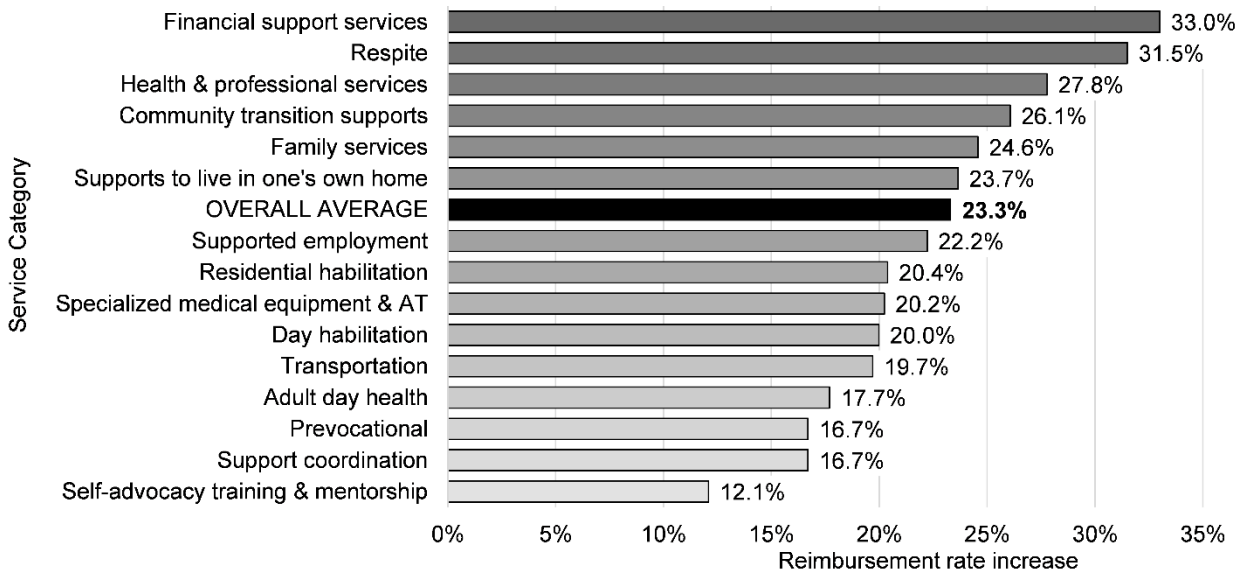

Figure 3. Reimbursement rate increase by service category. AT = assistive technology.