Research

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Abstract

Purpose. This study's aim was to examine the impact of pandemic emergency Home- and Community-Based Services (HCBS) payments on the continuity and security of people with intellectual and developmental disabilities (IDD).
Methods. Using a multilevel logistic regression, we analyzed secondary Personal Outcome Measures interviews from 738 people with IDD (March 2020 through April 2022), and state pandemic emergency HCBS payment data from 16 states.
Results. The odds of people with IDD experiencing continuity and security during the pandemic increased by 3% for every 1% states increased their payment rates, and by 398% when states offered retainer payments.
Conclusion. Increased reimbursement rates and retainer payments can help providers maintain operations and promote the continuity and security of people with IDD.

Keywords: Medicaid Home- and Community-Based Services (HCBS); COVID-19 pandemic; people with intellectual and developmental disabilities; reimbursement rates; personal outcomes

Continuity and security includes people's basic needs being met and people having the economy security to plan their lives and futures (security), and people having minimal negative change and disruption in their lives that is outside of their control (continuity; The Council on Quality and Leadership, 2017). People's continuity and security are often related as changes in people's lives may have economic consequences, among others; economy security can also help people prevent or recover from changes or disruption in their lives. In fact, while instability adversely impacts people with intellectual and developmental disabilities' (IDD's [including autism]) mental health, continuity and security positively impact people with IDD's mental and behavioral health, and quality of life (American Psychological Association, 2020; Centers for Disease Control and Prevention, 2020; Friedman, 2022b). While the COVID-19 pandemic impacted all peoples' lives, with most people feeling less secure as a result of the pandemic (American Psychological Association, 2020), people with IDD were particularly vulnerable. Not only were people with IDD more likely to contract and die of COVID-19 (Centers for Disease Control, 2022), they also have less economic security and are more likely to live in poverty than nondisabled people (Pinilla-Roncancio & Alkire, 2021).

In addition to being higher risk for infection and mortality, the pandemic had a wide ranging impact on the lives of people with IDD. People with IDD were more isolated during the pandemic as a result of sheltering-in-place and lockdown restrictions due to the threat COVID-19 represented to them and/or because they lived in congregate settings where COVID-19 spreads rapidly (ANCOR Foundation & United Cerebral Palsy, 2021; Bradley, 2020; Embregts et al., 2022; Lund et al., 2020; Lunsky et al., 2022; Pettinicchio et al., 2021; Scheffers et al., 2021). In addition to increased loneliness, people with IDD are more stressed, anxious, bored, and depressed during the pandemic (Desroches et al., 2021; Embregts et al., 2022; Hewitt et al.,

2020; Lund et al., 2020; Lunsky et al., 2022; Pettinicchio et al., 2021; Scheffers et al., 2021). In fact, given the high infection and mortality rates among this population, the pandemic was likely especially traumatic for people with IDD as they lost friends, housemates, and self-advocacy leaders to COVID-19 (Lund et al., 2020).

In addition to the negative impact on people with IDD's mental and physical health, the pandemic resulted in many people with IDD losing their jobs, having their work hours reduced, or having their day programs close (Bradley, 2020). Moreover, even when lockdown restrictions were lifted, many people with IDD had fewer opportunities to participate in their communities due to politices and practices that were not designed with their needs in mind (e.g., masking, vaccine prioritization, etc.), and staff shortages (Embregts et al., 2022). In fact, many people with IDD have experienced disrupted routines and services, rapid support staff turnover, a lack of support availability, and decreased quality of support during the pandemic (ANCOR Foundation & United Cerebral Palsy, 2021; Bradley, 2020; Embregts et al., 2022; Lund et al., 2020; Scheffers et al., 2021).

People with IDD's "dependence on [human service] organization[s] often links changes in people's lives to organizational changes" (The Council on Quality and Leadership, 2017, p. 25). The COVID-19 pandemic negatively impacted and disrupted the provision of Home- and Community-Based Services (HCBS), upon which many people with IDD depend as an alternative to institutional care (Centers for Medicare and Medicaid Services, 2020). HCBS provides wrap-around community-based services and supports to promote the community living of people with IDD. In addition to attending to acute care needs, such as health and safety, HCBS also often includes services that promote the continuity and security, quality of life, and

community integration of people with IDD, such as residential supports, assistive technology, and employment supports.

As a result of the pandemic, many HCBS service providers are struggling to function and adequately support people with IDD. For example, during the COVID-19 pandemic, direct support professional (DSP) turnover increased significant as a result of DSPs' fears of infection, increased workloads, and DSPs needing to take care of their own family members (ANCOR Foundation & United Cerebral Palsy, 2021; Luterman, 2020). Unfortunately, DSP turnover hinders HCBS provision and negatively impacts people with IDD's health, safety, and quality of life (Friedman, 2018a, 2021c). HCBS providers have been negatively impacted by increased DSP turnover and staff shortages, government orders closing some service lines/types (e.g., day services), and a lack of resources and funding (ANCOR Foundation & United Cerebral Palsy, 2021; Avalere Health, 2020). These difficulties intensified the struggles of a system that was already underfunded and fractured – prior to the pandemic, the average provider only had enough "cash on hand to maintain operations" for a single month (ANCOR Foundation & United Cerebral Palsy, 2021, p. 6). During the pandemic, 32% of IDD service providers lost revenue because of closing service lines due to government orders (Avalere Health, 2020); the result of which led some providers to total collapse (Avalere Health, 2020), thereby hindering the continuity and security of the people with IDD they supported. In fact, people with IDD were significantly less likely to experience continuity and security in 2020 than they were in 2019 (Friedman, 2021a).

Pandemic Changes to HCBS

Since the COVID-19 pandemic is a significant threat to the health and safety of people with IDD, and the stability of the HCBS service system at large, states began making emergency

changes to their HCBS programs to meet the needs of people with IDD during the pandemic. Given the increased expenditures and financial concerns of providers during the pandemic, many states temporarily increased the rates they paid providers for HCBS (Friedman, 2022a). In fact, 90% of states temporarily increased payment rates for IDD HCBS during the pandemic in order to expand providers' capacity to deliver services to people with IDD (Friedman, 2022a). Increasing reimbursement rates was aimed at compensating providers for emergency staffing needs, lost revenue due to changing service lines, additional service delivery and administrative costs. While on average states increased IDD HCBS service reimbursement by 23%, the rates for some service lines rates were increased up to 160%; states most frequently offered increased payments for residential supports services (Friedman, in press).

Another mechanism states used to promote stability of IDD HCBS was introducing retainer payments (Friedman, 2022a). Retainer payments allow providers to receive payments for services even when the person with IDD's is not able to participate in certain services, such as closed day services, or temporarily while a person is in the hospital (Centers for Medicare and Medicaid Services, n.d.). Retainer payments allow providers to continue their operations and maintain their workforce, while helping compensate for lost revenue and increased expenditures (Friedman, 2022a). During the pandemic, 78% of states offered retainer payments for IDD HCBS (Friedman, 2022a).

Emergency changes to HCBS, including increased payment rates and retainer payments, were aimed at improving the stability of the IDD service system, and, by extension, the continuity and security of people with IDD during the pandemic. For this reason, the aim of this study was to examine the impact of pandemic emergency HCBS payments – increased payment rates and retainer payments – on the continuity and security of people with IDD who received

HCBS. We had the following research question: did increased payment rates and retainer payments in HCBS improve the continuity and security of people with IDD? To explore this research question, we analyzed secondary data about the continuity and security of 738 people with IDD who received HCBS from Personal Outcome Measures® (POM) interviews (March 2020 through April 2022), and state pandemic emergency HCBS payment data from the 16 states in which they lived.

Methods

Data and Measures

Continuity and Security: Personal Outcome Measures® (Level 1: Individual)

Secondary data about the continuity and security of people with IDD who received HCBS came from the POM, a validated person-centered quality of life tool (Friedman, 2018b; The Council on Quality and Leadership, 2017). Developed in 1993 based on focus groups with people with disabilities, family members, and other stakeholders about what really mattered in people with disabilities' lives, the POM has been further refined over its 30 years of administration through pilot testing, expert reviews, a Delphi survey, feedback from advisory groups, and continued validity and reliability testing (Friedman, 2018b). In addition, interviewers are required to pass (85% or higher) interrater reliability tests with expert interviewers before being certified to conduct interviews.

POM administration occurs in three stages. In the first stage, the interviewer has an in-depth, open-ended guided conversations with the person with IDD about 21 different areas of quality of life, ranging from health and safety to rights to community integration. During the second stage, the interviewer speaks with someone who knows about the organizational supports the person with IDD receives and asks them about those supports. If needed, record reviews or

observations can also be conducted; otherwise, in the final stage the interviewer completes decision trees (see The Council on Quality and Leadership (2017) for decision-trees) using all of the data gathered to determine if each of the 21 quality of life areas are present (1) or not (0).

One quality of life outcome the POM measures is continuity and security. For people with IDD to have the continuity and security outcome present (1; not present [0]) all of the following conditions must be met: (1) the person with IDD must have economic resources to meet their basic needs; (2) their control over changes in their lives in the past two years must be similar to people not receiving services; (3) the changes in their lives in the past two years must be due to the person with IDD's informed personal choice; (4) changes in their lives in the past two years must not have had a negative impact on people with IDD's lives; and, (5) the changes in their lives in the past two years must have been planned in advanced to minimize the disruption (The Council on Quality and Leadership, 2017).

The POM data used in this study were originally collected between March 2020 and April 2022 from organizations that provide services to people with IDD, including: residential services; employment and other work/day services; family and individual supports; behavioral health care; service coordination; case management; non-traditional supports (micro-boards and co-ops); and human services systems. The data were de-identified and transferred to the research team. The data contained POM interviews for 1,001 people with IDD, 73.7% of which were Medicaid HCBS beneficiaries. People with IDD who were not Medicaid HCBS beneficiaries (n = 263) were removed from the sample. As a result, the final sample included a total of 738 people with IDD who received HCBS. The people with IDD in the sample lived in 16 states: Alabama; Colorado; Connecticut; Georgia; Illinois; Indiana; Iowa; Minnesota; Missouri; New Mexico; New York; North Carolina; North Dakota; Ohio; South Dakota; and Tennessee.

Emergency Pandemic HCBS Payments: Appendix K HCBS Amendments (Level 2: State)

Data about the emergency payments states made to their IDD HCBS programs came from Appendix K: Emergency Preparedness and Response HCBS amendments, as analyzed by Friedman (2022a, in press). States use Appendix Ks to document to the Centers for Medicare and Medicaid Services (CMS) how they will temporarily change each of their HCBS 1915(c) waiver programs during the COVID-19 pandemic (Centers for Medicare and Medicaid Services, n.d.). Between March 2020 and April 2022, states submitted 294 Appendix Ks to temporarily change their HCBS waiver programs for people with IDD.

Increased Payment Rates. Specifically, data about the 16 states' temporary increases to their payment rates for IDD HCBS came from Citation removed for review's (in press) analysis of increased pandemic payment rates in IDD HCBS. In that study, we analyzed the data states provided in section K-2-f of Appendix K waivers, to determine if each state increased payment rates for IDD HCBS waiver services, and, if so, how much they increased the payment rates (average percent increase). For this study, we used the increased payment rates (%) data from Friedman (in press) for each of the applicable 16 states as one of the independent variables.

Retainer Payments. Data about the 16 states' temporary retainer payments for IDD HCBS came from Citation removed for review's (2022a) analysis of emergency pandemic changes to IDD HCBS waivers. As part of that study, we analyzed the data states provided in section K-2-j of Appendix K waivers to determine if each state temporarily offered retainer payments. For this study, we used the retainer payment status (offered [1], did not offer [0]) data from Friedman (in press) for each of the 16 states as one of the independent variables.

Demographics

[Table 1 approximately here]

The average age of people with IDD who received HCBS (Level 1) was 47.4 years old (*SD* = 16.4; Table 1). Slightly more than half of people with IDD who received HCBS were men (58.7%). Most people with IDD who received HCBS were White (76.3%), communicated through verbal/spoken language (82.8%), and had some form of guardianship (72.4%). About one-fifth (20.2%) of people with IDD who received HCBS had complex medical support needs (12+ hours of skilled nursing care) and one-third (29.6%) had comprehensive behavior support needs (requiring 24-hour supervision due to risk of harm to self/others). People with IDD who received HCBS most commonly lived in provider owned/operated homes (e.g., group homes; 54.3%), their own homes (21.6%), or with family members (15.1%). The most common additional disabilities/diagnoses people with IDD had were: anxiety disorder (22.0%); mood disorder (21.1%); and 'behavior challenges' (14.4%).

Among the 16 states (Level 2), the average increase in HCBS IDD payment rates during the pandemic was 14.8% (*SD* = 16.1%), ranging from 0% (4 states) to 50.0%. The majority of states (68.8%) offered temporary retainer payments for HCBS IDD during the pandemic.

Analyses

We first analyzed descriptive statistics. Next, we explored the impact of pandemic emergency HCBS payments on the continuity and security of people with IDD who received HCBS. To do so, due to the nested structure of the data between individuals with IDD and states, we used a multilevel logistic regression. In the first model, we ran an intercept-only unconditional model with continuity and security from the POM as the primary outcome and the random intercept to examine the variation in continuity and security by state. In the second model, we entered all sociodemographic variables as fixed-effects. In the third model, we added state pandemic emergency HCBS payments – increased payment rates and retainer payments –

as fixed-effect variables. For all three models, we calculated intraclass correlation coefficients (ICCs) to indicate variance in continuity and security attributed to different states. We calculated ICC according to the following formula (Sommet & Morselli, 2017):

$$ICC = \frac{Residual\ variance}{Residual\ variance + (\pi^2/3)}$$

In addition to ICC, we calculated likelihood-ratio tests (LR χ^2 (1)) to determine if each model improved the goodness of fit; we calculated LR χ^2 (1) by subtracting the deviance of each model (Sommet & Morselli, 2017). Confidence intervals (CIs) for all odds ratios (ORs) were set at 95%.

Results

Between May 2020 and April 2022, 36.9% of people with IDD who received HCBS experienced continuity and security (n = 272), while 63.1% of people with IDD who received HCBS did not (n = 465).

Model 1: Unconditional

To explore if continuity and security differed depending on pandemic emergency HCBS payments, multilevel logistic models were utilized. In the first unconditional (null) model, which was calculated without any covariates, the ICC indicated 13.0% of the total variation in continuity and security was attributed to differences between states (Table 2).

[Table 2 approximately here]

Model 2: Individual Sociodemographics

Model 2 incorporated the individual-level sociodemographic characteristics. After adjusting for sociodemographic covariates, the variation in intercepts between states (ICC) was 19.4%. The addition of individual-level sociodemographics significantly improved the goodness of fit (LR χ^2 (1) = 461.84, $p < 0.001$). A number of sociodemographic covariates were

significant. Controlling for all other sociodemographic characteristics, for every one-year increase in age, the odds of people with IDD who received HCBS experiencing continuity and security increased by 1.4% (OR[CI] = 1.01 [1.00, 1.03]). Controlling for all other sociodemographic characteristics, people with IDD who received HCBS with independent decision-making were 2.02 times (CI [1.27, 3.21]) more likely to experience continuity and security than people with IDD who received HCBS with guardianship. Controlling for all other variables, people with IDD who received HCBS who lived with their families were 2.21 times (CI [1.15, 4.24]) more likely to experience continuity and security than people with IDD who received HCBS who lived in provider owned/operated homes. Controlling for all other variables, people with IDD who received HCBS who also had 'other psychiatric disability' were 2.56 times (OR[CI] = 0.39 [0.20, 0.76]) less likely to experience continuity and security than people with IDD who received HCBS who did not also have 'other psychiatric disability.'

Model 3: State Pandemic Emergency Payments

Model 3 incorporated state pandemic emergency payments – increased payment rates and retainer payments. After adjusting for state pandemic emergency payments in Model 3, the variation in intercepts between states (ICC) reduced to 4.4%, suggesting state pandemic emergency payments partly explain the variation in continuity and security of people with IDD who received HCBS. The addition of state pandemic emergency payments significantly improved the goodness of fit (LR χ^2 (1) = 714.23, $p < 0.001$).

The model indicated the more states increased their HCBS payment rates during the pandemic on average, the more likely people with IDD who received HCBS were to experience continuity and security during the pandemic. For every 1% increase in the average payment rates, the odds of people with IDD who received HCBS experiencing continuity and security

increased by 2.5% (OR[CI] = 1.02 [1.00, 1.05]; Figure 1). For example, controlling for all other variables, when a person with IDD who received HCBS lived in a state that had an average increased payment rate of 10.0%, the probability of the person experiencing continuity and security was 16.2%; in comparison, when a person with IDD who received HCBS lived in a state that had an average increased payment rate of 40.0%, the probability of the person experiencing continuity and security was 28.8%.

[Figure 1 approximately here]

In addition, the model indicated when states implemented retainer payments, people with IDD who received HCBS were significantly more likely to experience continuity and security during the pandemic. Controlling for all other variables, people with IDD who received HCBS who lived in states that offered retainer payments were 4.98 times (CI [2.25, 10.99]) more likely to experience continuity and security than people with IDD who received HCBS who lived in states that did not offer retainer payments (Figure 2).

[Figure 2 approximately here]

In addition to state emergency payments, several sociodemographic covariates were also significant in Model 3. Controlling for all other variables (including state payments), women with IDD who received HCBS were 1.79 times (OR[CI] = 0.56 [0.34, 0.91]) less likely to experience continuity and security than men with IDD who received HCBS. Controlling for all other variables, compared to people with IDD who received HCBS who lived in provider owned/operated homes, those who lived in family homes were 2.54 times (CI [1.23, 5.28]) more likely to experience continuity and security, and those who lived in 'other' residential settings 3.48 times (CI [1.02, 11.89]) more likely. Controlling for all other variables, people with 'other intellectual/developmental disability' who received HCBS were 2.78 times less likely (OR[CI] =

0.36 [0.15, 0.88]) to experience continuity and security compared to people with IDD without 'other intellectual/developmental disability' who received HCBS. Controlling for all other variables, people with IDD who received HCBS who also had 'other psychiatric disability' were 2.38 times (OR[CI] = 0.42 [0.20, 0.86]) less likely to experience continuity and security than people with IDD who received HCBS who did not also have 'other psychiatric disability.'

Discussion

During the COVID-19 pandemic, there was mass destabilization of the IDD HCBS system. States implemented emergency changes to their HCBS programs through Appendix K in hopes that doing so would promote the continuity and security of people with IDD; the aim of our study was to examine the impact of states doing so. We found that when states introduced emergency HCBS payments, people with IDD who received HCBS were significantly more likely to experience continuity and security during the pandemic. In fact, the odds of people with IDD experiencing continuity and security during the pandemic increased by 3% for every 1% states increased their payment rates on average, and by 398% when states offered retainer payments. Increased payment rates and retainer payments allow providers to continue their operations and maintain their workforce by helping providers compensate for lost revenue due to changing service lines, additional service delivery, and administrative costs, and pay for emergency staffing needs, such as hazard pay and overtime due to shortages (Edwards et al., 2020). Retainer payments in particular allow providers to maintain their staff, who would without pay need to seek other employment, and help prevent the costs – time, financial, and quality – involved in needing to find new employees and get them onboarded and trained (Edwards et al., 2020).

While increased reimbursement rates and retainer payments help providers maintain operations (Friedman, 2022a), they can also help promote the continuity and security of people with IDD, and, by extension, the health and quality of life of people with IDD. Continuity and security is a social determinant of health – "conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks" (United States Office of Disease Prevention and Health Promotion, n.d., n.p.). For example, when people with IDD experience continuity and security there is a 66% decrease in emergency department visits (Friedman, 2021d). In addition to helping promote the health and safety of people with IDD, continuity and security plays a key role in people with IDD's quality of life (Friedman, 2022b). For example, the odds of people with IDD exercising their rights increases by 503% when they experience continuity and security (Friedman, 2022b). In addition to the immediate impact continuity and security has on people with IDD's lives, provider instability can also hinder people with IDD's future quality of life; if providers go out of business, people with IDD will have fewer opportunities to thrive in their communities (ANCOR Foundation & United Cerebral Palsy, 2021). As such, by increasing payments during the pandemic, states were helping promote the continuity and security of people with IDD, both in the short-term and the long-term.

Sociodemographic Differences in Continuity and Security

There were also a number of sociodemographic characteristics which were correlated with people with IDD's likelihood of experiencing continuity and security, regardless of if their states made emergency changes to HCBS. For example, women with IDD were less likely to experience continuity and security during the pandemic than men with IDD; this finding parallels

previous research which has found similar disparities for women specific to continuity and security, and other areas of quality of life more broadly (Friedman, 2021a).

People with IDD with any form of guardianship were less likely to experience continuity and security than people with IDD with independent decision-making. Past research indicates people with IDD with guardianship frequently face disparities in quality of life outcomes compared to those without guardianship, including when it comes to the opportunity to make choices about the changes in their lives (Friedman, 2021b; Friedman & VanPuymbrouck, 2018). The lack of continuity and security people with IDD with guardianship experienced during the pandemic may in part be due to the fact that they often receive fewer organizational supports to facilitate their quality of life (Friedman, 2021b; Friedman & VanPuymbrouck, 2018). In addition, in the United States, guardianship is often applied to people with IDD in a broad sweeping manner, resulting in people having significantly less control over their lives, which may have particular implications when it comes to continuity and security (Salzman, 2011).

People with IDD who lived in provider homes were less likely to experience continuity and security than people with IDD who lived in family homes and ‘other’ settings, regardless of the changes their states made to HCBS payments. Research indicates people with IDD have the most favorable outcomes, including experiencing less DSP turnover, in individual settings, including living in their own homes and in family homes, compared to congregate settings, such as provider group homes (Friedman, 2018a, 2019, 2020; Hemp et al., 2014; Larson et al., 2013). In addition, people with IDD who live in congregate settings are more likely to experience a lack of continuity and security because they are often more dependent on the service system, having fewer choices about where and with whom they live (Friedman, 2020).

People with IDD with ‘other intellectual/developmental disability’ were less likely to experience continuity and security. As this is a large umbrella category, including a large list of disabilities, ranging from muscular dystrophy to Fragile X to Tourette’s syndrome, we believe more research is needed to examine differences in continuity and security between people with different types of IDD to explore not only if there are differences among those subgroups but also the factors contributing to those differences. People with IDD who also had ‘other psychiatric disability’ were significantly less likely to experience continuity and security during the pandemic. This finding is especially problematic given people with IDD who also have psychiatric disabilities, often called dual diagnosis, are at higher risk for re/institutionalization – the destabilizing effect of a lack of continuity and security may lead to a greater risk of people with dual diagnosis becoming institutionalized because of a lack of community infrastructure to support people with IDD in times of mental and behavioral crisis (Lulinski & Heller, 2021).

Limitations

When interpreting findings from this study, a number of limitations should be noted. As people with IDD volunteered to participate in POM interviews, there is a chance of self-selection bias. As this was an analysis of secondary data, we did not have the opportunity to ask follow-up questions or ask additional questions. For example, we had no way to determine what subgroups fell into the category ‘other intellectual/developmental disability.’ People’s pandemic experiences, especially related to continuity and security, likely changed significantly during different periods of the pandemic; yet, POM data only came from one point in time per person interviewed. In addition, as the people with IDD in the sample lived in 16 states, the data on state pandemic HCBS changes only came from 16 states. Also, states were able to amend their HCBS programs using Appendix K multiple times; our analysis was of the cumulus changes states

made between March 2020 and April 2022. Rate and retainer payment changes may have been added, amended, or removed throughout this period; in addition, while most states implemented Appendix K changes effective retroactively, providers may have received the increased rates or retainer payments after March 2020 due to a lag in reimbursement time.

Implications

While our findings suggest increased payment rates and retainer payments improved the continuity and security of people with IDD, it is important to recognize that the emergency changes states made to their HCBS programs were done through *temporary* authorities (Appendix K). When the public health emergency is declared over, these emergency HCBS changes will revert to pre-pandemic design, resulting in a decrease in payment rates and a loss of retainer payments. How this will impact the IDD HCBS system, which was underfunded and disjointed prior to the pandemic, remains to be seen (ANCOR Foundation & United Cerebral Palsy, 2021); however, it could lead to provider instability and collapse due to continued high operating costs and further DSP turnover due to burnout (ANCOR Foundation & United Cerebral Palsy, 2021; Avalere Health, 2020). To promote the continuity and security of people with IDD, the HCBS infrastructure must be strengthened, with permanent changes made beyond Appendix K. While 10 states across the nation have suggested they hope to continue increased rates for HCBS (not IDD specific) after the end of the public health emergency (Centers for Medicare and Medicaid Services, 2022), additional federal efforts to improve the HCBS infrastructure would be beneficial. Yet, to date, HCBS has not been prioritized in federal relief packages. For example, although funding for HCBS was originally included in the most recent federal relief package, the Inflation Reduction Act, funding for HCBS was completely removed prior to it becoming law (Autistic Self Advocacy Network, 2022).

Moreover, additional research would be beneficial to help ensure that policy and funding changes, including during the COVID-19 pandemic, flow downward to actually improve people with IDD's continuity and security, and quality of life. For example, while this study examined the impact of Appendix K rate changes and retainer payments on people with IDD's continuity and security, future research should explore the impact on quality of life more broadly. In addition, to determine best practices for future pandemics and times of emergency, it would be beneficial to explore if, and, how, other changes states made improved people with IDD's quality of life during the pandemic. For example, did adding services, expanding who could qualify for HCBS, or changing rules for service provision during the COVID-19 pandemic translate to improved outcomes? Examining provider differences that impacted people with IDD's continuity and security during the pandemic would also be fruitful for future research.

Conclusion

The COVID-19 pandemic significantly disrupted the lives of people with IDD, including those who received HCBS. Hoping to minimize this disruption, states made emergency changes to their HCBS programs, including by increasing reimbursement rates and introducing retainer payments. In this study, we found that people with IDD who lived in states that increased HCBS payment rates and offered HCBS retainer payments were more likely to experience continuity and security during the pandemic. Our findings suggest policy decisions not only directly impact people with IDD's lives, but also that HCBS spending can help increase the stability of the service system, including in times of crisis. Investing in HCBS is an investment in the quality of life of people with IDD.

References

American Psychological Association. (2020). *Stress in the time of COVID-19*. https://www.apa.org/news/press/releases/stress/2020/stress-in-america-covid.pdf

ANCOR Foundation, & United Cerebral Palsy. (2021). *The case for inclusion 2021: A special report on the sustainability of community disability services in America*. https://caseforinclusion.org/application/files/2416/1376/5849/Case_for_Inclusion_2021_Special_Report.pdf

Autistic Self Advocacy Network. (2022). *Congress leaves disability community priorities out of Inflation Reduction Act*. Retrieved August 16 from https://autisticadvocacy.org/2022/08/congress-leaves-disability-community-priorities-out-of-inflation-reduction-act/

Avalere Health. (2020). *Impact of COVID-19 on organizations serving individuals with intellectual and developmental disabilities*. American Network of Community Options and Resources (ANCOR). https://www.ancor.org/sites/default/files/impact_of_covid-19_on_organizations_serving_individuals_with_idd.pdf

Bradley, V. J. (2020). How COVID-19 may change the world of services to people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 58*(5), 355-360. https://doi.org/10.1352/1934-9556-58.5.355

Centers for Disease Control. (2022). *Brief summary of findings on the association between disabilities and severe COVID-19 outcomes*. https://www.cdc.gov/coronavirus/2019-ncov/downloads/clinical-care/C-Disability-Review.pdf

Centers for Disease Control and Prevention. (2020). Mental health, substance use, and suicidal ideation during the COVID-19 pandemic — United States, June 24–30, 2020. *Morbidity and Mortality Weekly Report, 69*(32), 1049-1057.

Centers for Medicare and Medicaid Services. (2020). *Long-Term Services and Supports rebalancing toolkit*. Author. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-toolkit.pdf

Centers for Medicare and Medicaid Services. (2022, May 11). *After the Public Health Emergency: Changes to Home and Community-Based Services and delivery methods [Webinar]* https://acl.gov/news-and-events/announcements/cms-webinar-changes-home-and-community-based-services-hcbs-and

Centers for Medicare and Medicaid Services. (n.d.). *1915(c) Home and Community-Based Services waiver instructions and technical guidance: Appendix K: Emergency preparedness and response*. https://www.medicaid.gov/state-resource-center/downloads/1915c-appendix-k-instructions.pdf

Desroches, M. L., Ailey, S., Fisher, K., & Stych, J. (2021). Impact of COVID-19: Nursing challenges to meeting the care needs of people with developmental disabilities. *Disability and health journal, 14*(1), 101015. https://doi.org/10.1016/j.dhjo.2020.101015

Edwards, E., Machledt, D., & Lav, J. (2020). Retaining Medicaid COVID-19 Changes to Support Community Living. *Saint Louis University Journal of Health Law & Policy, 14*(2), 391-428.

Embregts, P. J., van den Bogaard, K. J., Frielink, N., Voermans, M. A., Thalen, M., & Jahoda, A. (2022). A thematic analysis into the experiences of people with a mild intellectual disability during the COVID-19 lockdown period. *International Journal of*

Developmental Disabilities, 15(2), 168-196. https://doi.org/10.1080/20473869.2020.1827214

Friedman, C. (2018a). Direct support professionals and quality of life of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 56*(4), 234-250. https://doi.org/10.1352/1934-9556-56.5.234

Friedman, C. (2018b). The Personal Outcome Measures®. *Disability and health journal, 11*(3), 351–358. https://doi.org/10.1016/j.dhjo.2017.12.003

Friedman, C. (2019). The influence of residence type on personal outcomes. *Intellectual and Developmental Disabilities, 57*(2), 112-126. https://doi.org/10.1352/1934-9556-57.2.112

Friedman, C. (2020). *There's no place like home: A national study of how people with intellectual and/or developmental disabilities and their families choose where to live*. The Arc of the United States, & CQL | The Council on Quality and Leadership. https://futureplanning.thearc.org/assets/CFP_Housing_Survey_Technical_Report-80e6eb718c816d07a15a9972df06a6e73b1393d5b56ae145acc058fce243cd93.pdf

Friedman, C. (2021a). The COVID-19 pandemic and quality of life outcomes of people with intellectual and developmental disabilities. *Disability and Health, 14*(4), 101117. https://doi.org/10.1016/j.dhjo.2021.101117

Friedman, C. (2021b). Disparities in social determinants of health amongst people with disabilities. *International Journal of Disability, Development and Education*, Advanced online publication. https://doi.org/10.1080/1034912X.2021.2004299

Friedman, C. (2021c). The impact of direct support professional turnover on the health and safety of people with intellectual and developmental disabilities. *Inclusion, 9*(1), 63-73. https://doi.org/10.1352/2326-6988-9.1.63

Friedman, C. (2021d). Managed care and value-based payment: The relationship between quality of life outcomes and emergency room utilization. *Intellectual and Developmental Disabilities, 59*(1), 22-38. https://doi.org/10.1352/1934-9556-59.1.22

Friedman, C. (2022a). Emergency COVID-19 pandemic changes to Home- and Community-Based Services for people with intellectual and developmental disabilities. *Inclusion, Advanced online publication*. http://aaidd.org/publications/journals/articles-accepted-for-publication

Friedman, C. (2022b). The impact of continuity and security on quality of life. *Intellectual and Developmental Disabilities, 60*(2), 101-112. https://doi.org/10.1352/1934-9556-60.2.101

Friedman, C. (in press). Increased payment rates for HCBS for people with intellectual and developmental disabilities during the COVID-19 pandemic. *Journal of Developmental & Physical Disabilities*.

Friedman, C., & VanPuymbrouck, L. (2018). The impact of people with disabilities choosing their services on quality of life outcomes. *Disability and health journal, 12*(2), 187-194. https://doi.org/10.1016/j.dhjo.2018.11.011

Hemp, R., Braddock, D., & King, M. (2014). Community-based Medicaid funding for people with intellectual and developmental disabilities. *National Conference of State Legislatures LegisBrief, 22*, 1-2.

Hewitt, A., Pettingell, S., Kramme, J., Smith, J., Dean, K., & Kleist, B. (2020). *Results of The direct support workforce and COVID-19 national survey 2020*. Institute on Community Integration. https://publications.ici.umn.edu/community-living/covid19-survey/overview

Larson, S., Lakin, C., & Hill, S. (2013). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: U.S. studies

from 1977 to 2010. *Research and Practice for Persons with Severe Disabilities, 37*(4), 235-246. https://doi.org/10.2511/027494813805327287

Lulinski, A., & Heller, T. (2021). Community capacity to provide mental/behavioral health services for people with IDD transitioning from state-operated developmental centers. *Intellectual and Developmental Disabilities, 59*(3), 224-238. https://doi.org/10.1352/1934-9556-59.3.224

Lund, E. M., Forber-Pratt, A. J., Wilson, C., & Mona, L. R. (2020). The COVID-19 pandemic, stress, and trauma in the disability community: A call to action. *Rehabilitation Psychology, 65*(4), 313-322. https://doi.org/10.1037/rep0000368

Lunsky, Y., Jahoda, A., Navas, P., Campanella, S., & Havercamp, S. M. (2022). The mental health and well-being of adults with intellectual disability during the COVID-19 pandemic: A narrative review. *Journal of Policy and Practice in Intellectual Disabilities, 19*(1), 35-47. https://doi.org/10.1111/jppi.12412

Luterman, S. (2020). *The neglect of disability care*. The American Prospect. https://prospect.org/familycare/the-neglect-of-disability-care/

Pettinicchio, D., Maroto, M., Chai, L., & Lukk, M. (2021). Findings from an online survey on the mental health effects of COVID-19 on Canadians with disabilities and chronic health conditions. *Disability and health journal, 14*(3), 101085. https://doi.org/10.1016/j.dhjo.2021.101085

Pinilla-Roncancio, M., & Alkire, S. (2021). How poor are people with disabilities? Evidence based on the global multidimensional poverty index. *Journal of Disability Policy Studies, 31*(4), 206-216. https://doi.org/10.1177/1044207320919942

Salzman, L. (2011). Guardianship for persons with mental illness: A legal and appropriate alternative? *Saint Louis University Journal of Health Law & Policy, 4*, 279-330.

Scheffers, F., van Vugt, E., & Moonen, X. (2021). Assessing the quality of support and discovering sources of resilience during COVID-19 measures in people with intellectual disabilities by professional carers. *Research in Developmental Disabilities, 111*, 103889. https://doi.org/10.1016/j.ridd.2021.103889

Sommet, N., & Morselli, D. (2017). Keep calm and learn multilevel logistic modeling: A simplified three-step procedure using Stata, R, Mplus, and SPSS. *International Review of Social Psychology, 30*(1), 203-218. https://doi.org/10.5334/irsp.90

The Council on Quality and Leadership. (2017). *Personal Outcome Measures®: Measuring personal quality of life* (3rd ed.). Author.

United States Office of Disease Prevention and Health Promotion. (n.d.). *Social determinants of health*. Author. https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health

Figure Captions

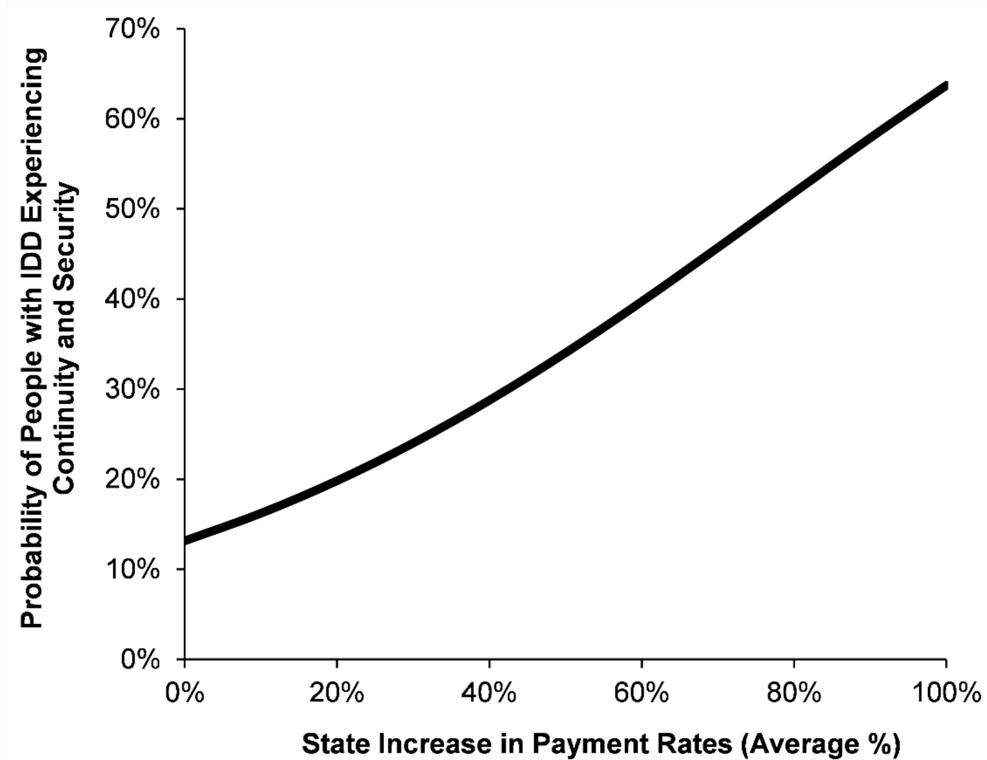

Fig. 1 The relationship between state increased payment rates and people with IDD experiencing continuity and security

Figure description: This graph shows that as the state increase in payment rates (average %) increases, so does the probability of people with IDD experiencing continuity and security.

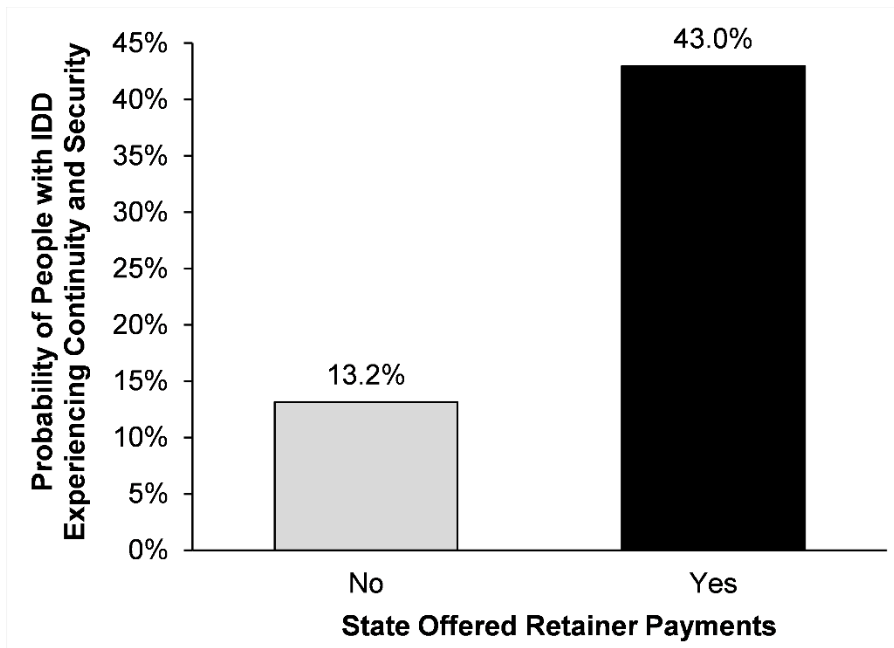

Fig. 2 The relationship between state retainer payments and people with IDD experiencing continuity and security

Figure description: This graph shows that when states do not offer retainer payments, the probability of people with IDD experiencing continuity and security is 13.2%. When states do offer retainer payments, the probability of people with IDD experiencing continuity and security is 43.0%.

Table 1
Demographics

Characteristic	*n*	%
Individuals (Level 1; *n* = 738)		
Age (M [SD])	47.4 (16.4)	
Gender (*n* = 728)		
Man	427	58.7%
Woman	301	41.3%
Race (*n* = 730)		
White only	557	76.3%
Black only	130	17.8%
Latinx only	25	3.4%
Other or multiracial	18	2.5%
Primary communication method (*n* = 726)		
Verbal/spoken language	601	82.8%
Other	125	17.2%
Decision-making authority (*n* = 735)		
Independent decision making	203	27.6%
Some form of guardianship	532	72.4%
Complex support needs (*n* = 682)		
None	418	61.3%
Complex medical support needs	138	20.2%
Comprehensive behavior support needs	202	29.6%
Residence type (*n* = 753)		
Provider owned/operated home	400	54.3%
Own home	159	21.6%
Family home	111	15.1%
Host family/family foster care	33	4.5%
Other	33	4.5%
Disabilities/diagnoses		
Anxiety disorder	162	22.0%
Autism	155	21.0%
Behavior challenges	106	14.4%
Cerebral palsy	86	11.7%
Down syndrome	35	4.7%
Hearing loss severe or profound/Deaf	20	2.7%
Impulse control disorder	80	10.8%
Limited or no vision/blind	23	3.1%
Mood disorder	156	21.1%
Personality/psychotic disorder	60	8.1%
Physical disability	54	7.3%
Seizure disorder	105	14.2%
Other intellectual/developmental disability	673	91.2%
Other psychiatric disability	81	11.0%
State pandemic changes to HCBS (Level 2; *n* = 16)		
Increase in payment rates (%; M [SD])	14.8% (16.1%)	

Offered retainer payments		
Yes	11	68.8%
No	5	31.3%

Note. People could have more than one complex support need and disability/diagnosis.

Table 2

Likelihood of People with IDD who Received Medicaid HCBS Experiencing Continuity and Security During the COVID-19 Pandemic

Variables	Model 1 (Null)	Model 2: Demographics (OR [CI])	Model 3: State HCBS (OR [CI])
Fixed effects			
Individuals (Level 1)			
Age		1.01 [1.00, 1.03]*	1.01 [0.99, 1.03]
Woman (ref: man)		0.72 [0.49, 1.06]	0.56 [0.34, 0.91]*
Race (ref: White only)			
Black only		1.21 [0.74, 1.99]	1.11 [0.63, 1.94]
Latinx only		1.32 [0.50, 3.52]	0.86 [0.20, 3.61]
Other or multiracial		0.41 [0.08, 1.98]	0.62 [0.12, 3.30]
Primary communication method: verbal/spoken (ref: other)		1.36 [0.79, 2.35]	1.55 [0.73, 3.30]
Independent decision making (ref: guardianship)		2.02 [1.27, 3.21]*	2.34 [1.34, 4.11]**
Complex medical support needs (ref: no)		1.02 [0.58, 1.79]	0.97 [0.50, 1.88]
Comprehensive behavior support needs (ref: no)		0.83 [0.52, 1.34]	1.20 [0.67, 2.16]
Residence type (ref: provider owned/operated home)			
Own home		1.12 [0.62, 2.02]	1.02 [0.54, 1.92]
Family home		2.21 [1.15, 4.24]*	2.54 [1.23, 5.28]*
Host family/family foster care		1.63 [0.64, 4.20]	1.28 [0.48, 3.42]
Other		3.07 [0.93, 10.21]	3.48 [1.02, 11.89]*
Disabilities/diagnoses			
Anxiety disorder		1.24 [0.76, 2.02]	1.12 [0.54, 2.29]
Autism		1.06 [0.62, 1.81]	0.82 [0.38, 1.74]
Behavior challenges		0.83 [0.47, 1.44]	0.49 [0.19, 1.27]
Cerebral palsy		0.94 [0.47, 1.87]	0.80 [0.35, 1.80]
Down syndrome		1.32 [0.52, 3.38]	0.82 [0.25, 2.62]
Hearing loss severe or profound/Deaf		1.59 [0.53, 4.74]	1.53 [0.38, 6.11]
Impulse control disorder		1.10 [0.59, 2.05]	0.87 [0.35, 2.16]
Limited or no vision/blind		2.36 [0.87, 6.39]	0.49 [0.05, 4.75]
Mood disorder		1.18 [0.74, 1.89]	0.79 [0.41, 1.55]
Personality/psychotic disorder		1.00 [0.49, 2.06]	0.91 [0.37, 2.23]

Physical disability		1.67 [0.79, 3.53]	0.85 [0.26, 2.79]
Seizure disorder		0.85 [0.49, 1.49]	1.15 [0.59, 2.26]
Other intellectual/developmental disability		0.64 [0.31, 1.35]	0.36 [0.15, 0.88]*
Other psychiatric disability		0.39 [0.20, 0.76]**	0.42 [0.20, 0.86]*
State pandemic changes to HCBS (Level 2)			
Increase in payment rates (average %)			1.02 [1.00, 1.05]*
Offered retainer payments (ref: no)			4.98 [2.25, 10.99]***
Random effects			
Deviance (Bayesian)	3,367.80	2,905.96	2,191.73
LR χ^2 (1)		461.84***	714.23***
Variance (residual)	0.49 [0.18, 1.36]	0.79 [0.26, 2.34]	0.15 [0.007, 3.11]
ICC	0.13 [0.02, 0.29]	0.19 [0.07, 0.42]	0.04 [0.002, 0.49]

*p<0.05. **p<0.01. **p<0.001