

Inclusion

Gaps Between Policy and Practice: Outcomes and Supports of People with Disabilities who Receive HCBS --Manuscript Draft--

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Abstract:	<p>The aim of this study was to examine the quality of life outcomes (personal outcomes) and person-centered supports of people with disabilities who receive Medicaid Home- and Community-Based Services (HCBS). We analyzed secondary Personal Outcome Measures® (POM) interview data from 5,869 people with disabilities who received Medicaid HCBS (2016-2024). People with disabilities who received HCBS had 48.4% of personal outcomes and 51.3% of person-centered organizational supports present, with indicators related to choice and control being the least present. Outcomes and supports were also less present after the HCBS Settings Rule implementation deadline. While the HCBS Settings Rule represents important values for choice and integration in theory, our findings suggest they are not frequently upheld and implemented on the ground.</p>

HCBS OUTCOMES AND SUPPORTS

Gaps Between Policy and Practice: Outcomes and Supports of People with Disabilities who Receive HCBS

Abstract

The aim of this study was to examine the quality of life outcomes (personal outcomes) and person-centered supports of people with disabilities who receive Medicaid Home- and Community-Based Services (HCBS). We analyzed secondary Personal Outcome Measures[®] (POM) interview data from 5,869 people with disabilities who received Medicaid HCBS (2016-2024). People with disabilities who received HCBS had 48.4% of personal outcomes and 51.3% of person-centered organizational supports present, with indicators related to choice and control being the least present. Outcomes and supports were also less present after the HCBS Settings Rule implementation deadline. While the HCBS Settings Rule represents important values for choice and integration in theory, our findings suggest they are not frequently upheld and implemented on the ground.

Keywords: Home- and Community-Based Services (HCBS); personal outcomes; quality of life; people with disabilities; person-centered practices.

Long-Term Services and Supports (LTSS) are facility (institutional) or community-based services for people who need assistance caring for themselves because of age, functional limitations, and/or disability. Medicaid LTSS were originally exclusively available in institutions, including intermediate care facilities and nursing homes. However, in 1981, Medicaid Home- and Community-Based Services (HCBS) were introduced, waiving key provisions of the Social Security Act to allow states to create LTSS for people who need institutional care but want to live in their own homes and communities. Through HCBS, most often 1915(c), states create customized plans for specific populations, featuring a wide range of wrap-around services that often address social determinants of health (U.S. Department of Health and Human Services, 2000). For example, in addition to health care services like occupational and physical therapy, many states provide personal care services, assistive technology, employment and day services, and community integration supports. Today, HCBS is the largest funding source for LTSS, with \$124.6 billion spent on HCBS for 4.2 million people as of fiscal year 2020 (Mohamed et al., 2023; Murray et al., 2023). While HCBS has facilitated more people with disabilities physically living in the community, many people with disabilities, especially people with intellectual and developmental disabilities (IDD), still remain socially isolated and are not meaningfully included in their communities (Friedman, 2020; Havercamp & Scott, 2015; World Health Organization, 2022).

The Centers for Medicare and Medicaid Services (CMS) note that HCBS has the potential to help lower costs, prevent institutionalization, improve people's outcomes, expand self-determination, and promote community integration (Lynch, 2020; Robbins et al., 2013). Not only do integrated community-based services result in better outcomes than segregated services and settings, including for people with higher support needs, but people also have the right to the

least restrictive setting according to the *Olmstead* decision (Beadle-Brown et al., 2016; Friedman, 2019; Hemp et al., 2014; Lakin et al., 2011; Larson et al., 2013; Mansell & Beadle-Brown, 2004; Mirenda, 2014; "Olmstead v. LC," 1999; Young, 2006).

To increase outcomes and the quality of HCBS, in 2014 CMS introduced the HCBS Settings Rule (CMS 2249-F/2296-F), which aims to promote *meaningful* community integration and choice. The HCBS Settings Rule aims to move “away from defining home and community-based settings by ‘what they are not,’ and toward defining them by the nature and quality of participants’ experiences” by emphasizing person-centered quality of life outcomes (e.g., community integration, health, safety, rights, relationships), rather than process measures (Medicaid Program, 2014). Person-centered is when people’s services, supports, and goals are driven by what the person wants and values. For example, rather than making assumptions about what people with IDD want, person-centered services should learn what they want and customize services accordingly. Research indicates when people with IDD play an active role in deciding what services they want and directing these services, they not only have increased satisfaction, but also better outcomes (DeCarlo et al., 2019; Friedman & VanPuymbrouck, 2018).

In addition to defining which settings are community-based, the Settings Rule introduced and reinforced many civil rights for people receiving HCBS which providers must honor. For example, it specified that people receiving HCBS must be able to choose where they live and work, have keys to their homes, be allowed to have visitors at any time, have access to food in their homes, etc. There is a particular emphasis on person-centered planning, and people’s services being driven by their wants, needs, preferences, and goals.

While many of these requirements may seem straightforward, given the legacy of institutionalization on service culture and structure, especially in the IDD service system

(Friedman & VanPuymbrouck, 2019; Spagnuolo, 2016), many complex changes were needed to implement the Settings Rule. In fact, many of the changes undertaken by providers, such as shifting from segregated day programs to integrated ones or reducing congregate home size, requires significant financial resources, despite no additional funding being associated with the Settings Rule (Neidorf et al., 2024). As a result of the scale of the necessary changes, as well as the disruptions to the service system caused by the COVID-19 pandemic, the final HCBS Settings Rule implementation deadline was delayed multiple times, from 2019 to 2022 to 2023 (Lynch, 2020; Neale, 2017). However, despite the final deadline having passed, many states have not fully implemented the HCBS Settings Rule requirements (Mohamed et al., 2023). Moreover, many state IDD agency directors and staff, while supportive of the cultural changes the Settings Rule represents, believe the HCBS Settings Rule has been watered down and weakened from the initial intent – it is lacking “teeth” (Neidorf et al., 2024, p. 7).

HCBS, including the tenants of the Settings Rule, is vitally important for people with disabilities, especially people with IDD who primarily rely on HCBS for their LTSS (Larson et al., 2022). Yet, implementation has been uneven, with many states still working on corrective action plans to align with the Rule, and progress is still needed, with many states still working on fully implementing the Settings Rule (Mohamed et al., 2023; Neidorf et al., 2024). For these reasons, the aim of this study was to examine the person-centered quality of life outcomes (i.e., personal outcomes) of people with disabilities who receive Medicaid HCBS. The secondary aim was to examine the presence of person-centered supports to facilitate people with disabilities who receive HCBS’ personal outcomes. We had the following research questions:

1. What are the most and least common personal outcomes present among people with disabilities who receive HCBS?

2. How have outcomes changed after the Settings Rule implementation deadline?
3. What are the most and least common person-centered supports in place among people with disabilities who receive HCBS?
4. How have supports changed after the Settings Rule implementation deadline?

To examine these research questions, we analyzed secondary Personal Outcome Measures[®] (POM) interview data from 5,869 people with disabilities who receive Medicaid HCBS.

Methods

Data and Participants

This study's secondary data (determined exempt by our Institutional Review Board) were originally collected between January 1, 2016 and May 10, 2024. Originally, the data were collected by human service organizations providing services to people with disabilities (e.g., residential services, mental and behavioral health, employment/day services, support coordination, etc.) and local and state governments as part of their person-centered planning or their quality improvement initiatives. Prior to being transferred to the research team, identifiers were removed. The sample included a total of 5,869 people with disabilities who received HCBS (any type of HCBS [e.g., 1915(c), 1915(i), etc.]). In total, 679 interviews were from 2016, 918 from 2017, 1,274 from 2018, 932 from 2019, 458 from 2020, 523 from 2021, 414 from 2022, 490 from 2023, and 181 from 2024 (through May 10). The data came from 34 states, with an average of 172.6 people per state.

Age was relatively evenly distributed, although fewer participants (13.3%) were older than 65 (Table 1). Most participants were men (55.9%), white (74.3%), and primarily communicated through verbal/spoken language (82.7%). 'Other intellectual/developmental disability' (85.5%), anxiety disorder (18.0%), mood disorder (16.9%), and autism (16.7%) were

the most common disabilities. The most common form of decision-making authority (i.e., guardianship) was full/plenary guardianship (40.3%). In terms of average hours of support people received a day, the most frequent was 24/7 around the clock (59.9%). In terms of support needs, 16.3% had complex medical support needs (i.e., 12+ hours of nursing care) and 24.9% had comprehensive behavior support needs (i.e., 24-hour supervision for risk of harm to self/others). The most common residence type was provider-owned/operated home (e.g., group home; 55.9%) and people lived with an average of 3.9 housemates. In terms of work/day activities, 61.7% of people participated in community-based day programs, 52.0% in segregated day programs, and fewer in other types of work/day activities. In addition to receiving Medicaid HCBS, 5.3% of participants also received Medicare (i.e., were dual eligible). About one-third of POM interviews (35.2%) were conducted prior to the COVID-19 pandemic (2016-2019). The majority of interviews (90.4%) were collected prior to the HCBS Settings Rule Implementation deadline of March 17, 2023, while 9.6% were collected after the deadline (March 18, 2023 – May 10, 2024).

Measure and Variables

Data from this study came from the POM, a validated, person-centered quality of life measure used to examine the personal outcomes of people with disabilities and older adults (Friedman, 2018b; The Council on Quality and Leadership, 2017). In the 1990s, the POM was developed based on focus groups with people with disabilities and their families about what mattered in their lives; it has since been revised based on pilot testing, Delphi surveys, literature reviews, reviews by content experts, feedback from advisory groups, and revalidations. To be certified as reliable, interviewers need to attend a week long workshop about the POM and its implementation, participate in coaching and practice interviews with an expert from the Council

on Quality and Leadership, and pass an interrater reliability test with a score of at least 85% with the expert. The POM is included in CMS' HCBS Quality Measure Set, the set of quality measures for HCBS aimed to promote national quality standards (Tsai, 2024).

The current version of the POM includes 21 areas of quality of life, called indicators: people are safe; people are free from abuse and neglect; people have the best possible health; people experience continuity and security; people exercise rights; people are treated fairly (i.e., due process); people are respected; people use their environments; people live in integrated environments; people interact with other members of the community; people participate in community life; people remain connected to natural support networks; people have friends; people have intimate relationships; people decide when to share personal information; people perform social roles; people choose where and with whom to live; people choose where to work; people choose services; people choose personal goals; and, people realize personal goals. The POM examines both if the person has each of the 21 outcome areas present, and if they are receiving person-centered organizational supports to promote each of the 21 outcome areas. While they differ by indicator, individualized person-centered organizational supports (henceforth referred to as “person-centered supports” for brevity) are supports (services) provided by human service organizations to facilitate outcomes; these supports must be individualized and person-centered in that they are based on the wants and needs of the person receiving the services. For example, an organization choosing what activity a person participates in in the community is not person-centered supports – they must find out what the person is interested in, ask them what they want to do, and support them to participate in the activity of their choosing.

There are three stages for POM administration. A certified reliable interviewer speaks with the person with disabilities, following open-ended, guided prompts about each of the 21 indicators. Proxies are not used; instead, there are particular methods that can be used with people with higher support needs, such as visual cues, preference testing, augmentative alternative communication, gestures, observations, etc. for accessibility (Overpeck, 2019). Then the interviewer speaks with someone who knows the person with disabilities well and who knows about the person-centered supports they receive, most often a direct support professional (DSP), support staff supervisor, or service coordinator, and asks about service provision to help understand what the organization knows about people's wants and needs for supports. If more information is needed the interviewer may observe the person in their environments or conduct record reviews. Otherwise, the interviewer uses all of the information gathered to complete decision-trees (see The Council on Quality and Leadership (2017) for decision-trees) to determine if each of the 21 outcomes are present (1; not present [0]) and if each of the 21 person-centered supports are in place (1; not in place [0]). The 21 outcomes are aggregated to represent a person's total personal outcomes, and the 21 person-centered supports are aggregated to represent how many total person-centered supports the person has in place. The total outcomes and total person-centered supports, as well as each of the individual indicators were used as variables in this study.

Melda and Smith (2014) mapped how the POM indicators align with the HCBS Settings Rule rules and regulations. The following 11 POM indicators align with HCBS Settings Rule regulations: people are free from abuse and neglect; people exercise rights; people are respected; people use their environments; people live in integrated environments; people interact with other members of the community; people participate in the life of the community; people choose

where and with whom to live; people choose where to work; people choose services; and people choose personal goals. These indicators were used as variables both individually and aggregated to represent HCBS Settings Rule related outcomes and person-centered supports. Cronbach's alpha was 0.77 for HCBS Settings Rule outcomes and 0.80 for HCBS Settings Rule person-centered supports. The remaining 10 POM indicators also served as variables in this study (see below).

Analyses

To examine our first research question (What are the most and least common personal outcomes present among people with disabilities who receive HCBS?), we utilized descriptive statistics. For our second research question (How have outcomes changed after the Settings Rule implementation deadline?), after running descriptive statistics, we used a linear regression model with Settings Rule deadline serving as the IV and total HCBS Settings Rule outcomes (out of 11) as the DV; to control for their impact, participants' sociodemographics served as covariates (CVs). For our third research question (What are the most and least common person-centered supports in place among people with disabilities who receive HCBS?), we used descriptive statistics of the total and individual person-centered supports. For our final research question (How have person-centered supports changed after the Settings Rule implementation deadline?), after running descriptive statistics, we used a linear regression model with Settings Rule deadline (IV) and total HCBS Settings Rule person-centered supports (out of 11) as the DV; participants' sociodemographics served as CVs. Significance (p) was set at < 0.05 (unadjusted). All confidence intervals (CIs) were set at 95%. All assumptions were met for the regression models.

Results

Outcomes

People with disabilities who received HCBS had an average of 10.15 out of 21 total personal outcomes present (48.4%). The most frequently present outcomes were: people are safe (78.0%); people have the best possible health (66.0%); and people use their environments (65.0%; Table 2). In contrast, the outcomes least frequently present were: people choose where and with whom to live (28.7%); people choose services (31.0%); and people perform different social roles (34.8%).

HCBS Settings Rule-Related Outcomes

People with disabilities who received HCBS had an average of 5.06 out of 11 HCBS Settings Rule-related outcomes present (46.1%; Table 2). The HCBS Settings Rule-related outcomes most frequently present were people use their environments (65.0%), people are free from abuse and neglect (55.1%), and people are respected (52.8%), while the least present were people choose where and with whom to live (28.7%), people choose services (31.0%), and people choose where to work (35.6%).

According to a linear regression model, total HCBS Settings Rule-related outcomes significantly differed after the implementation deadline, even when sociodemographics were controlled, $F(63, 4005) = 13.69, p < 0.001, R^2 = 0.18$. HCBS implementation deadline was a significant variable ($B = -0.43 [-0.75, -0.11], t = -2.65, p = 0.008$). According to the model, controlling for all sociodemographics, including the COVID-19 pandemic, people with disabilities who received HCBS had an average of 6.05 out of 11 HCBS Settings Rule-related outcomes present prior to the deadline (55.0%), while people with disabilities who received HCBS had an average of 5.05 HCBS Settings Rule-related outcomes present after the implementation deadline (45.9%).

Person-Centered Supports

People with disabilities who received HCBS had an average of 10.77 out of 21 total person-centered supports in place (51.3%; Table 3). The person-centered supports most in place were: people are safe (81.5%); people use their environments (66.6%); and people have the best possible health (65.9%). The person-centered supports least in place were: people choose where and with whom to live (29.9%); people choose services (32.1%); and people perform different social roles (32.2%).

HCBS Settings Rule-Related Person-Centered Supports

People with disabilities who received HCBS had an average of 5.34 out of 11 HCBS Settings Rule-related person-centered supports present (48.5%). The HCBS Settings Rule-related person-centered supports most frequently present were people use their environments (66.6%), people are free from abuse and neglect (63.0%), and people are respected (58.0%), while the least present were people choose where and with whom to live (29.9%), people choose services (32.1%), and people choose where to work (37.3%).

According to a linear regression model, total HCBS Settings Rule-related person-centered supports significantly differed after the implementation deadline, even when sociodemographics were controlled, $F(63, 3994) = 8.69, p < 0.001, R^2 = 0.12$. HCBS implementation deadline was a significant variable ($B = -1.26 [-1.61, -0.91], t = -7.06, p < 0.001$). According to the model, controlling for all sociodemographics, including the pandemic, people with disabilities who received HCBS had an average of 6.31 out of 11 HCBS Settings Rule-related person-centered supports present prior to the deadline (57.4%), while people with disabilities who received HCBS had an average of 5.05 HCBS Settings Rule-related outcomes present after the implementation deadline (45.9%).

Discussion

Not only were people with disabilities who received HCBS lacking in a lot of outcomes in our study, especially those directly related to the HCBS Settings Rule, but it also appears that outcomes worsened after the implementation deadline. While the Settings Rule represents important values for choice and integration, our findings suggest they may not frequently be upheld and implemented on the ground. And yet, our findings also indicate a significant need to promote the very same areas of people's lives that the Settings Rule aims to support, such as choice.

Unfortunately, a lack of person-centered services significantly hinders doing so. While there may be some factors outside of human service providers' control that negatively impact people's outcomes, such as systemic inequities and discrimination, human service organizations do have full control over the person-centered supports they provide. As such, each of the 21 person-centered supports should be significantly more present, especially for HCBS Settings Rule-related indicators. Yet, people with disabilities receiving HCBS in our study had fewer than half of these Settings Rule-related person-centered supports present on average, with indicators related to person-centered planning and choice being among the least frequently present, despite being a central focus of the Setting Rule. In fact, in the year after the Settings Rule implementation deadline (March 18, 2024 to May 10, 2024), less than 15% of people with disabilities who received HCBS in our study were supported to choose their services.

Given our findings about the lack of outcomes and person-centered supports among people with disabilities who receive HCBS, we believe a significant influx of individualized, person-centered supports is necessary, especially to facilitate choice, relationships, and community integration as those outcomes and person-centered supports were less frequently present, especially compared to health and safety. In fact, when people with disabilities have

greater control over their lives and services, they have better outcomes (DeCarlo et al., 2019; Friedman, 2021a, 2023; Friedman & VanPuymbrouck, 2018; Kim, 2019). Our findings suggest further cultural change is needed so that HCBS provision on the ground focuses on self-determination and dignity of risk, rather than operating under the traditional custodial model of care, which aim to ‘protect’ people above all else (Perske, 1972).

The new HCBS Access Rule (CMS 2249-F/2296-F) introduced in April 2024 aims to promote personal outcomes, through the implementation of state quality measurement and eventual benchmarking. Given the disparities found in this study, we believe doing is not only extremely needed but hopefully will also be extremely beneficial. The HCBS Access Rule also aims to help address the DSP workforce crisis, through instituting thresholds regarding what percent (80%) of reimbursement rates must be passed direct to DSPs. It has been suggested this can be a useful strategy to help with the DSP crisis (Wright, 2009). Given DSPs play a critical role in promoting the health, safety, and quality of life of people with disabilities, and the quality of supports they receive (Friedman, 2018a, 2021b), this change will hopefully translate to improved outcomes among HCBS recipients. However, given the Access Rule is new, it remains to be seen if the passthrough requirement will result in increased payment rates for DSPs; in addition, these payment requirements are only for homemaker services, home health aide services, and personal care services, which does not capture all the other types of services DSPs provide to people who receive HCBS. As such, future research should examine the impact of this passthrough requirement, both on DSPs working conditions and wages, and on people with disabilities who receive HCBS’ outcomes.

Limitations

When interpreting this study's findings, several limitations should be considered. This was a secondary dataset, and, as such, we did not have the ability to ask follow-up questions or collect additional data. In addition, it was not a random or representative sample, therefore generalizability should not be assumed. For example, most people in the sample had IDD, people with other disabilities may have different support needs or access to HCBS than people with IDD. About two-thirds of the sample were white and cultural differences may impact outcomes and the person-centered supports people receive. In addition, states' compliance with the HCBS Settings Rule was significantly impacted by the COVID-19 pandemic; although we attempted to control for the pandemic's impact in our analyses, given the prevalence of its influence, it is likely not completely possible to do so. Moreover, due to this study being conducted only a year after the deadline, more interviews were collected prior to the final Settings Rule deadline than after it; future research should be conducted over longer post-deadline periods to see if the trends remain.

Conclusions

HCBS and the HCBS Settings Rule has the potential to completely transform and improve the lives of HCBS recipients. Unfortunately, the findings of this study suggest, for many people with disabilities who receive HCBS, the Settings Rule is still a *potential* and not a *reality*. We found people with disabilities who received HCBS had less than half of the outcomes present that the Settings Rule aims to directly target. In addition, our findings suggest, many people with disabilities who receive HCBS are still not receiving high quality, person-centered services and person-centered supports. Much more work appears to be necessary to ensure the Settings Rule's vision of choice and integration is met. This necessitates truly listening to people who receive services about what they want and need.

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Table 1
Sociodemographics (n = 5,869)

Characteristic	Total (% [n])	Year (% [n])								
		2016	2017	2018	2019	2020	2021	2022	2023	2024
Age (n = 5,494)										
18 to 24	8.7% (476)	8.5% (54)	6.1% (53)	10.5% (126)	12.2% (107)	7.3% (32)	7.5% (36)	7.5% (29)	6.2% (28)	6.9% (11)
25 to 34	22.9% (1259)	21.9% (139)	21.2% (184)	24.5% (295)	24.3% (212)	20.4% (89)	23.5% (112)	19.6% (76)	22.6% (102)	31.4% (50)
35 to 44	19.1% (1049)	16.5% (105)	19.1% (166)	20.0% (241)	18.9% (165)	15.3% (67)	18.9% (90)	19.8% (77)	23.7% (107)	19.5% (31)
45 to 54	17.7% (970)	20.2% (128)	19.2% (167)	16.8% (202)	17.6% (154)	22.0% (96)	14.9% (71)	16.0% (62)	14.6% (66)	15.1% (24)
55 to 64	18.4% (1009)	20.3% (129)	19.0% (165)	17.7% (213)	16.2% (142)	19.9% (87)	20.1% (96)	20.6% (80)	16.9% (76)	13.2% (21)
65 to 74	9.7% (535)	9.0% (57)	11.2% (97)	7.5% (90)	9.0% (79)	10.3% (45)	10.9% (52)	11.1% (43)	12.0% (54)	11.3% (18)
75+	3.6% (196)	3.6% (23)	4.3% (37)	3.1% (37)	1.7% (15)	4.8% (21)	4.2% (20)	5.4% (21)	4.0% (18)	2.5% (4)
Gender (n = 5,773)										
Man	55.9% (3228)	53.0% (357)	51.7% (471)	57.0% (707)	59.1% (538)	55.2% (250)	57.0% (292)	59.5% (244)	57.2% (277)	51.4% (92)
Woman	44.1% (2545)	47.0% (316)	48.3% (440)	43.0% (534)	40.9% (372)	44.8% (203)	43.0% (220)	40.5% (166)	42.8% (207)	48.6% (87)
Race (n = 5,755)										
White only	74.3% (4278)	77.0% (520)	81.2% (732)	70.6% (870)	69.4% (631)	80.3% (359)	73.8% (381)	78.9% (321)	70.3% (341)	68.0% (123)
Black only	18.3% (1054)	11.3% (76)	12.1% (109)	22.1% (273)	23.3% (212)	15.7% (70)	17.2% (89)	15.7% (64)	23.5% (114)	26.0% (47)
Latiné only	3.3% (188)	3.0% (20)	2.1% (19)	3.5% (43)	4.1% (37)	2.0% (9)	5.6% (29)	2.7% (11)	3.1% (15)	2.8% (5)
Indigenous only	1.9% (109)	5.9% (40)	2.9% (26)	1.7% (21)	0.9% (8)	0.4% (2)	0.6% (3)	0.7% (3)	1.0% (5)	0.6% (1)
Asian only	0.8% (44)	1.0% (7)	0.4% (4)	0.4% (5)	1.1% (10)	0.4% (2)	1.0% (5)	0.7% (3)	1.0% (5)	1.7% (3)
Other	0.6% (32)	0.6% (4)	1.0% (9)	0.6% (7)	0.4% (4)	0% (0)	0.8% (4)	0% (0)	0.6% (3)	0.6% (1)
Multiracial	0.9% (50)	1.2% (8)	0.3% (3)	1.1% (14)	0.8% (7)	1.1% (5)	1.2% (5)	0.4% (2)	0.4% (2)	0.6% (1)
Disabilities/diagnoses*										
Other intellectual/developmental disability	85.5% (4897)	89.5% (599)	86.8% (785)	88.5% (1088)	83.9% (760)	83.7% (376)	84.5% (344)	84.5% (344)	81.7% (388)	75.0% (132)
Anxiety disorder	18.0% (1028)	17.0% (114)	16.8% (152)	15.9% (196)	16.3% (148)	25.2% (113)	18.2% (93)	18.9% (77)	18.9% (90)	25.6% (45)
Mood disorder	16.9% (968)	14.6% (98)	21.5% (194)	15.4% (189)	12.9% (117)	18.3% (82)	22.1% (113)	13.5% (55)	17.3% (82)	21.6% (38)
Autism	16.7% (959)	11.8% (79)	13.4% (121)	16.1% (198)	20.0% (181)	18.3% (82)	18.0% (82)	19.9% (81)	17.7% (84)	23.3% (41)
Seizure disorder/neurological problems	16.4% (938)	18.8% (126)	19.8% (179)	18.2% (224)	15.3% (139)	15.1% (68)	13.3% (68)	14.0% (57)	11.8% (56)	11.9% (21)
Behavior challenges	13.4% (766)	17.2% (115)	15.3% (138)	12.7% (156)	11.1% (101)	14.7% (66)	12.1% (62)	13.3% (54)	11.8% (56)	10.2% (18)
Other psychiatric disability	13.0% (743)	13.0% (87)	14.2% (128)	11.8% (145)	12.9% (58)	13.9% (71)	14.0% (57)	14.0% (57)	12.2% (58)	12.5% (22)
Cerebral palsy	12.0% (687)	13.2% (88)	12.4% (112)	14.2% (174)	13.1% (119)	11.8% (53)	8.4% (43)	11.3% (46)	7.8% (37)	8.5% (15)
Impulse-control disorder	8.2% (469)	8.1% (54)	10.1% (91)	7.1% (87)	6.6% (60)	11.6% (52)	9.0% (46)	6.6% (27)	8.6% (41)	6.3% (11)
Personality/psychotic disorder	8.1% (464)	9.3% (62)	10.0% (90)	7.6% (94)	60% (54)	7.8% (35)	9.4% (48)	7.6% (31)	7.4% (35)	8.5% (15)
Physical disability	6.3% (360)	5.8% (39)	5.2% (47)	6.7% (82)	6.2% (56)	9.1% (41)	6.3% (32)	8.1% (33)	4.8% (23)	4.0% (7)
Obesity	6.2% (353)	7.8% (52)	6.3% (57)	5.0% (61)	5.3% (48)	5.3% (24)	8.0% (41)	6.6% (27)	6.3% (30)	7.4% (13)
Down syndrome	5.5% (317)	6.4% (43)	6.3% (57)	6.7% (82)	5.4% (49)	5.3% (24)	4.3% (22)	4.2% (17)	4.0% (19)	2.3% (4)
Limited or no vision: legally blind	3.7% (212)	3.7% (25)	4.4% (40)	4.1% (50)	3.4% (31)	4.0% (18)	2.9% (15)	3.4% (14)	2.9% (14)	2.8% (5)

Hearing loss: severe or profound	2.8% (161)	2.4% (16)	3.4% (31)	2.6% (32)	2.9% (26)	3.6% (16)	2.1% (11)	2.7% (11)	3.2% (15)	1.7% (3)
Brain injury	2.0% (116)	3.0% (20)	2.5% (23)	1.6% (20)	1.3% (12)	2.4% (11)	2.1% (11)	1.0% (4)	1.9% (9)	3.4% (6)
Alzheimer's disease or other dementia	1.6% (93)	2.4% (16)	2.8% (25)	1.4% (17)	1.0% (9)	2.2% (10)	0.8% (4)	1.0% (4)	1.7% (8)	0% (0)
Substance use disorder	0.9% (53)	0.7% (5)	0.7% (6)	0.9% (11)	1.0% (9)	1.1% (5)	1.6% (8)	1.0% (4)	0.2% (1)	2.3% (4)
Eating disorder	0.6% (34)	0.7% (5)	0.7% (6)	0.04% (5)	1.0% (9)	0.7% (3)	0.2% (1)	1.0% (4)	0% (0)	0.6% (1)
Primary communication method (<i>n</i> = 5,801)										
Verbal/spoken language	82.7% (4800)	85.0% (574)	81.4% (738)	77.3% (974)	93.5% (767)	83.8% (379)	86.4% (444)	84.6% (346)	88.9% (431)	81.7% (147)
Facial/body expression	13.7% (792)	11.7% (79)	15.0% (136)	19.3% (243)	13.4% (123)	10.8% (46)	9.7% (50)	11.2% (46)	8.9% (43)	12.8% (23)
Sign language	1.2% (67)	0.4% (3)	1.3% (12)	0.9% (11)	1.7% (16)	2.9% (13)	1.2% (6)	0.5% (2)	0.4% (2)	1.1% (2)
Communication device	0.8% (49)	1.3% (9)	1.1% (10)	0.3% (4)	0.5% (5)	1.3% (6)	1.2% (6)	0.5% (2)	0.6% (3)	2.2% (4)
Other	1.6% (93)	1.5% (10)	1.2% (11)	2.2% (28)	0.9% (8)	1.1% (5)	1.6% (8)	3.2% (13)	1.2% (6)	2.2% (4)
Decision-making authority (<i>n</i> = 5,748)										
Independent decision-making	29.9% (1721)	32.7% (219)	30.5% (276)	22.4% (279)	25.9% (231)	25.1% (114)	35.0% (179)	34.5% (140)	36.7% (177)	58.9% (106)
Assisted decision-making	27.7% (1595)	29.3% (196)	28.1% (255)	30.8% (383)	30.0% (268)	29.2% (133)	23.3% (119)	27.1% (110)	20.5% (99)	17.8% (32)
Full/plenary guardianship	40.3% (2319)	35.5% (238)	29.2% (355)	44.9% (559)	42.4% (379)	45.1% (205)	40.3% (206)	37.7% (153)	38.4% (185)	21.7% (39)
Other	2.0% (113)	2.5% (17)	2.2% (20)	1.9% (24)	1.9% (24)	1.7% (15)	0.7% (3)	1.4% (7)	0.7% (3)	4.4% (21)
Average hours of support (<i>n</i> = 5,693)										
On call (supports as needed)	2.2% (125)	1.1% (7)	1.1% (10)	1.0% (13)	2.2% (20)	2.5% (11)	3.0% (15)	3.5% (14)	4.8% (22)	7.2% (13)
0-3 hours/day	6.3% (358)	6.4% (42)	4.7% (42)	9.3% (117)	5.9% (54)	5.3% (23)	7.0% (35)	3.5% (14)	5.0% (23)	4.4% (8)
3-6 hours/day	9.0% (515)	9.3% (61)	9.2% (82)	7.4% (93)	10.3% (97)	8.3% (36)	11.2% (56)	6.0% (24)	8.4% (39)	15.0% (27)
6-12 hours/day	10.9% (620)	7.9% (52)	10.6% (94)	13.2% (166)	12.5% (115)	7.4% (32)	9.0% (45)	10.5% (42)	11.3% (52)	12.2% (22)
12-23 hours/day	8.5% (484)	5.5% (36)	8.0% (71)	10.3% (129)	10.6% (97)	6.0% (26)	9.2% (46)	8.5% (34)	7.4% (34)	6.1% (11)
24/7 (around the clock)	59.9% (3411)	67.1% (440)	64.6% (573)	55.5% (697)	55.3% (508)	68.0% (295)	58.0% (290)	66.4% (265)	54.3% (251)	51.1% (92)
Other	3.2% (180)	2.7% (18)	1.7% (15)	3.3% (41)	3.0% (28)	2.5% (11)	2.6% (13)	1.5% (6)	8.9% (41)	3.9% (7)
Complex medical support needs (<i>n</i> = 5,415)										
No	83.7% (4530)	86.7% (555)	85.7% (738)	86.1% (1044)	86.4% (758)	76.9% (320)	82.2% (393)	76.9% (267)	80.8% (333)	70.9% (122)
Yes	16.3% (885)	13.3% (85)	14.3% (123)	13.9% (168)	13.6% (119)	23.1% (96)	17.8% (85)	23.1% (80)	19.2% (79)	29.1% (50)
Comprehensive behavior support needs (<i>n</i> = 5,415)										
No	75.1% (4066)	75.3% (482)	76.3% (657)	76.5% (927)	81.2% (712)	69.2% (288)	69.7% (333)	73.5% (255)	68.4% (282)	75.6% (130)
Yes	24.9% (1349)	24.7% (158)	23.7% (204)	23.5% (285)	18.8% (165)	30.8% (128)	30.3% (145)	26.5% (92)	31.6% (130)	24.4% (42)
Residence type (<i>n</i> = 5,788)										
Provider owned/operated home	55.9% (3234)	64.5% (434)	55.1% (499)	55.1% (696)	51.1% (470)	54.8% (251)	57.8% (297)	55.5% (227)	57.9% (268)	50.8% (92)
Family home	18.3% (1057)	12.6% (85)	15.7% (142)	21.9% (277)	26.3% (242)	14.2% (65)	15.2% (78)	11.2% (46)	16.2% (75)	26.0% (47)
Own home	17.8% (1031)	17.5% (118)	22.2% (201)	15.7% (198)	13.2% (121)	22.5% (103)	19.3% (99)	17.6% (72)	19.0% (88)	17.1% (31)
Host family / family foster care	3.6% (209)	0.9% (6)	2.8% (25)	3.9% (49)	3.5% (32)	3.9% (18)	5.4% (28)	5.1% (21)	5.0% (23)	3.9% (7)
State HCBS group home	1.6% (94)	3.0% (20)	2.1% (19)	1.9% (24)	1.7% (16)	1.3% (6)	0.8% (4)	0.5% (2)	0.6% (3)	0% (0)
Other	2.8% (163)	1.5% (10)	2.2% (20)	1.6% (20)	4.2% (39)	3.3% (15)	1.6% (8)	10.0% (41)	1.3% (6)	2.2% (4)
Total housemates (<i>M</i> [<i>SD</i>]; 5,609)	3.9 (2.7)	5.0 (3.4)	4.3 (3.1)	4.0 (2.6)	3.6 (2.3)	3.4 (2.1)	3.6 (2.1)	3.5 (2.5)	3.3 (2.0)	3.3 (2.3)

Work/day activities* (n = 4,878)										
Community day program	61.7% (2997)	51.1% (296)	62.5% (480)	62.8% (689)	63.3% (467)	67.9% (262)	64.6% (285)	66.3% (193)	60.4% (235)	52.6% (90)
Segregated day program	52.0% (2522)	60.8% (359)	54.4% (414)	53.4% (577)	50.7% (373)	51.4% (198)	42.8% (188)	49.2% (145)	49.5% (195)	43.5% (73)
Supported community employment	13.2% (638)	15.3% (88)	11.6% (88)	10.4% (112)	14.6% (108)	13.5% (52)	15.6% (69)	17.8% (53)	11.3% (44)	14.4% (24)
Competitive employment	11.6% (560)	11.5% (66)	10.6% (81)	9.3% (101)	10.2% (76)	11.1% (43)	15.3% (67)	11.9% (35)	16.3% (63)	16.5% (28)
Sheltered work	11.5% (552)	23.6% (135)	19.6% (148)	10.9% (117)	9.6% (70)	5.7% (22)	4.5% (20)	6.5% (19)	4.6% (18)	1.8% (3)
Education	6.6% (320)	3.5% (20)	4.3% (33)	7.7% (85)	9.1% (68)	8.5% (33)	6.5% (29)	5.7% (17)	7.9% (31)	2.3% (4)
Enclave work	4.7% (224)	8.6% (49)	6.5% (49)	3.7% (40)	4.0% (29)	4.7% (18)	5.9% (26)	2.4% (7)	1.5% (6)	0% (0)
Receives Medicare (in addition to HCBS)										
No	94.7% (5557)	91.1% (624)	92.9% (853)	95.7% (1219)	95.9% (894)	91.9% (421)	95.2% (498)	94.9% (393)	97.6% (478)	97.8% (177)
Yes	5.3% (312)	8.1% (55)	7.1% (65)	4.3% (55)	4.1% (38)	8.1% (37)	4.8% (25)	5.1% (21)	2.4% (12)	2.2% (4)
Interview during COVID-19 pandemic										
No	64.8% (3803)	100% (679)	100% (918)	100% (1274)	100% (932)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)
Yes	35.2% (2066)	0% (0)	0% (0)	0% (0)	0% (0)	100% (458)	100% (523)	100% (414)	100% (490)	100% (181)
Interview timing related to HCBS Deadline										
Prior to deadline	90.4% (5306)	100% (679)	100% (918)	100% (1274)	100% (932)	100% (458)	100% (523)	100% (414)	22.2% (108)	0% (0)
After deadline	9.6% (563)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)	78.0% (382)	100% (181)

Note. * = could fall into more than one subcategory.

Table 2
Quality of Life Outcomes: Descriptive Statistics

Indicator	Across years	Year								
		2016	2017	2018	2019	2020	2021	2022	2023	2024
HCBS Settings Rule-related indicators										
People are free from abuse and neglect	55.1%	63.6%	59.0%	56.4%	58.5%	55.0%	48.2%	49.4%	46.3%	32.8%
People exercise rights	47.4%	45.3%	43.5%	53.5%	55.4%	46.8%	45.5%	40.0%	41.4%	31.7%
People are respected	52.8%	54.4%	49.5%	55.4%	58.3%	54.3%	46.1%	52.4%	53.3%	32.2%
People use their environments	65.0%	65.4%	69.9%	67.2%	64.2%	61.3%	63.4%	57.1%	65.5%	58.6%
People live in integrated environments	45.7%	31.2%	41.6%	50.1%	50.4%	42.0%	45.1%	49.2%	53.2%	49.2%
People interact with other members of the community	52.2%	57.1%	59.1%	57.9%	57.5%	36.8%	38.7%	45.0%	48.6%	37.0%
People participate in the life of the community	40.2%	48.4%	42.6%	46.3%	47.1%	24.3%	24.5%	30.8%	37.6%	32.2%
People choose where and with whom to live	28.7%	26.5%	23.1%	28.8%	37.3%	27.1%	28.7%	28.3%	30.0%	20.6%
People choose where to work	35.6%	32.6%	30.7%	33.9%	42.6%	30.0%	37.9%	35.4%	41.4%	38.3%
People choose services	31.0%	34.4%	29.6%	37.9%	36.9%	23.9%	27.2%	25.2%	23.7%	9.4%
People choose personal goals	51.9%	45.0%	46.3%	48.7%	54.1%	63.2%	57.7%	56.7%	59.0%	42.8%
Other quality of life indicators										
People are safe	78.0%	77.3%	78.9%	81.4%	79.7%	82.8%	76.5%	70.7%	75.7%	58.3%
People have the best possible health	66.0%	72.3%	67.2%	70.1%	67.5%	65.4%	65.8%	61.0%	54.9%	43.9%
People experience continuity and security	46.2%	47.9%	47.6%	50.7%	51.5%	41.1%	37.7%	34.1%	46.5%	37.2%
People are treated fairly	53.6%	54.4%	51.1%	59.0%	60.3%	54.7%	49.5%	46.5%	46.9%	33.3%
People are connected to natural support networks	43.3%	47.9%	47.6%	43.6%	46.5%	33.9%	35.4%	42.5%	42.2%	37.0%
People have friends	35.8%	43.9%	36.9%	34.5%	39.1%	33.7%	28.1%	32.7%	34.9%	30.4%
People have intimate relationships	39.3%	44.2%	39.2%	42.6%	42.1%	33.5%	33.1%	37.0%	36.9%	28.7%
People decide when to share personal information	49.3%	50.8%	48.1%	57.5%	53.4%	48.4%	45.7%	44.6%	38.4%	25.4%
People perform different social roles	34.8%	37.0%	33.6%	37.0%	39.2%	33.5%	29.7%	28.1%	34.3%	28.7%
People realize personal goals	61.5%	62.5%	54.3%	61.5%	64.8%	64.1%	56.7%	64.1%	67.3%	61.1%

Table 3
Individualized Supports: Descriptive Statistics

Indicator	Across years	Year								
		2016	2017	2018	2019	2020	2021	2022	2023	2024
HCBS Settings Rule-related indicators										
People are free from abuse and neglect	63.0%	71.2%	63.9%	63.5%	68.5%	65.9%	61.2%	57.1%	52.4%	35.4%
People exercise rights	48.4%	50.0%	44.2%	51.8%	58.0%	52.1%	47.0%	42.3%	37.8%	26.4%
People are respected	58.0%	60.1%	54.1%	60.4%	63.8%	58.9%	54.7%	57.5%	55.7%	38.2%
People use their environments	66.6%	67.2%	70.6%	67.6%	66.7%	67.8%	68.1%	62.6%	62.2%	50.3%
People live in integrated environments	44.4%	34.9%	43.4%	47.2%	48.5%	43.8%	47.6%	46.1%	44.3%	31.8%
People interact with other members of the community	55.4%	59.9%	60.0%	60.8%	59.2%	49.0%	50.7%	44.0%	48.5%	31.3%
People participate in the life of the community	50.4%	55.4%	50.9%	58.3%	54.2%	44.6%	45.3%	36.5%	43.3%	33.1%
People choose where and with whom to live	29.9%	32.6%	25.3%	29.0%	38.7%	29.3%	31.9%	25.2%	27.4%	18.5%
People choose where to work	37.3%	34.9%	35.9%	36.1%	41.8%	30.6%	43.8%	34.8%	39.8%	35.4%
People choose services	32.1%	36.8%	28.6%	39.4%	40.1%	26.7%	27.6%	25.8%	21.7%	7.9%
People choose personal goals	47.9%	44.3%	43.7%	41.9%	48.8%	58.4%	57.7%	50.4%	54.3%	41.0%
Other quality of life indicators										
People are safe	81.5%	81.3%	81.0%	83.2%	83.7%	84.7%	83.0%	74.6%	80.6%	66.3%
People have the best possible health	65.9%	70.4%	64.6%	68.6%	68.6%	68.7%	70.0%	61.8%	55.9%	39.3%
People experience continuity and security	61.1%	60.0%	61.5%	64.3%	67.4%	61.8%	56.8%	47.9%	58.2%	57.3%
People are treated fairly	53.5%	58.7%	50.4%	57.2%	60.6%	55.4%	51.6%	46.5%	43.7%	30.9%
People are connected to natural support networks	61.7%	65.6%	65.0%	60.4%	64.8%	61.3%	63.8%	63.0%	53.9%	38.0%
People have friends	41.6%	48.6%	41.8%	39.0%	43.0%	46.8%	43.2%	38.4%	34.9%	31.3%
People have intimate relationships	38.0%	46.9%	40.3%	38.6%	38.7%	41.6%	37.1%	34.8%	27.6%	15.1%
People decide when to share personal information	54.3%	52.5%	49.6%	60.6%	62.1%	55.6%	52.4%	47.6%	47.8%	34.1%
People perform different social roles	32.2%	34.3%	31.7%	32.4%	36.6%	33.9%	33.3%	25.1%	28.8%	20.1%
People realize personal goals	51.7%	54.2%	51.0%	48.7%	53.0%	58.2%	49.4%	51.2%	53.7%	46.1%