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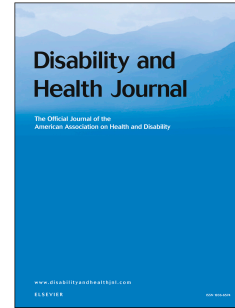

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Niveda Tennety, Bridgette M. Schram, PhD, Jacqueline Kish, PhD, Tonie Sadler, PhD, Ross Kaine, Katie Kaufman, Steve Lutzky, PhD, Allen Heinemann, PhD

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Systemic Barriers Hinder Person-Centered Home and Community Based Services (HCBS): Perspectives of Service Users and Professionals

Niveda Tennety[1]; Bridgette M Schram, PhD[1]; Jacqueline Kish, PhD[1]; Tonie Sadler, PhD[1,2]; Ross Kaine[1], Katie Kaufman[1]; Steve Lutzky, PhD[4]; Allen Heinemann, PhD[1,3] (ORCID 0000-0003-2782-7326)

[1]Center for Rehabilitation Outcomes Research, Shirley Ryan AbilityLab, 355 E. Erie St, Chicago, IL 60611

[2]American Institute of Research, Riverside Plaza, Suite 600. Chicago, IL 60606

[3]Department of Physical Medicine and Rehabilitation, Feinberg School of Medicine, Northwestern University, Chicago, IL 60611

[4]HCBS Strategies, 222 Ridgewood Rd, Baltimore, MD 21210

Corresponding Author: Bridgette M Schram

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1 **Abstract**

2 **Background.** In response to the 2014 Final Settings Rule issued by the Centers for Medicaid and
3 Medicare Services, home-and-community based services (HCBS) provider organizations strengthened
4 person-centered (PC) planning for HCBS to improve participants' choice and control over their services.
5 Despite the call for widespread adoption of PC services, systemic barriers influence service users' and
6 professionals' experiences in receiving and delivering PC services.

7 **Objective.** This study describes the perspectives of HCBS professionals and users on systemic barriers
8 that affect PC HCBS delivery.

9 **Methods.** Semi-structured interviews with 20 HCBS users and 22 HCBS professionals explored
10 perspectives on providing and receiving PC HCBS as well as higher level systems challenges to providing
11 PC services. Qualitative analysis focused on participants' perspectives of system-level issues.

12 **Results.** Qualitative analysis generated three themes: (1) Workforce considerations; (2) Resources and
13 service access; and (3) Infrastructure for feedback. High direct service provider turnover rates, service-
14 eligibility determination procedures, and waitlists affected service delivery. Participants highlighted a
15 need for increased direct service provider compensation, access to higher-quality training, improved
16 financial resources, and effective feedback infrastructures. Waiver flexibility due to the Covid-19 public
17 health emergency allowed expanded service access and improved quality.

18 **Conclusion.** Organizational and system-level issues hinder delivery of PC services. Increased flexibility
19 and resource allocation for service provision, as demonstrated in the Covid-19 public health emergency
20 response, should be sustained. HCBS users' suggestions for service-delivery improvements are consistent
21 with recent state and organizational initiatives. HCBS improvements benefit from user-identified
22 solutions in program development and implementation.

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23 **Abbreviations**

24 CMS Centers for Medicare and Medicaid Services

25 DSP Direct service provider

26 HCBS Home- and community-based services

27 NCAPPS National Center on Advancing Person-Centered Practices and Systems

28 NQF National Quality Forum

29 PC Person-centered

30 PCP Person-centered planning

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Introduction

Home and community-based services (HCBS) are long-term services and supports designed to support individuals with disabilities to live in the community rather than institutional settings.[1] Services can include personal care (e.g., cleaning, meals, errands), daily tasks (e.g., dressing, bathing, eating), and home health services (e.g., physical, occupational, and speech therapy). The Centers for Medicare and Medicaid Services (CMS) funds HCBS alongside state contributions, with most services accessed through and managed by individual states with Medicaid waivers.[2] States adapt waivers to their needs, such as populations served, eligibility criteria, and enrollment caps.[3] There are currently over 257 different waiver types offered across states, creating large variations in populations served, services offered, and access to HCBS.[4] These variations have led to a complex system that generates implementation challenges affecting states, providers, the direct workforce supporting HCBS, and the individuals served. The Covid-19 public health emergency magnified the challenges in this complex system; however, the flexibility offered to states through a public health emergency Appendix K authority demonstrated how federal HCBS policies may unintentionally impede access and quality care.[5-7]

Community living can lead to positive outcomes for people with disabilities, including improved quality of life, greater self-determination, enlarged social networks, and enhanced choice and control.[8,9] Community living is the preference of most people with disabilities.[9,10] The 1999 Supreme Court Olmstead decision propelled a systemic shift towards prioritizing community living rather than nursing homes and long-term care facilities.[11,12] Over half of funding designated for Long Term Services and Supports is now allocated to HCBS settings, double the amount at the time of Olmstead decision and halving the amount spent on institutional settings.[13] Despite this decision and increased funding, people with disabilities still struggle for meaningful community inclusion.[9]

CMS sought to maximize choice and control for people supported by HCBS by implementing person-centered (PC) approaches. CMS defined PC planning in its 2014 HCBS Final Settings Rule, stating

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55 that individuals should inform the services they receive.[14,15] The policy, effective March 2023, aims to
56 improve the integration of people with disabilities into the community using a PC approach. It includes
57 provisions to strengthen the implementation of the PC planning process, improving choice and control
58 for HCBS users in their living arrangements, employment, and services received. In April 2023, CMS
59 released a proposed Access Rule focused on improving quality measurement and reporting within
60 HCBS.[16,17] It included improved transparency of quality data, waitlists, and pay rates of direct service
61 providers (DSP). The Access Rule recognizes the need to support PC planning with systems-level
62 mandates.

63 The Final Settings Rule initiated an industry-wide emphasis on providing person-centered
64 practices (PCP) in HCBS.[1,15] PCP place the person at the center of their services, ensuring that services
65 are individualized to their needs and focus on choice and community integration.[18] Positive, albeit
66 moderate, effects of PCP on outcomes have been facilitated with improved training for DSPs and
67 resource development for those providing direct care.[15,19-21] The Administration for Community Living
68 funded the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) to assist in
69 implementing PC planning. NCAPPS developed a framework of five competency domains to implement
70 PC planning.[22] Relatedly, the National Quality Forum (NQF) developed a set of core competencies for
71 facilitating PC planning.[23] Longstanding accreditation standards developed by the Council on Quality and
72 Leadership[24] and CARF International[25] further support PC planning. These efforts help providers improve
73 PC planning and extend the focus to the practices and systems that support PC planning. Despite these
74 efforts in improving PCP, 19 states report only partial implementation of Settings Rule requirements for
75 PCP and providers struggle in delivering person-centered services.[4]

76 Despite the mandates for PCP, much remains unknown about the implementation of PCP in
77 HCBS, including challenges and barriers experienced by providers. This study sought the perspectives
78 and experiences of HCBS professionals and users on PC competency domains as well as the

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79 organizational and system-level characteristics impeding PC service delivery from professionals' and
80 users' perspectives. Therefore, the aim of this study is to describe perspectives of HCBS professionals
81 and users on organizational and system-level characteristics that influence the delivery of PCP.

82 Methods

83 Sample and Recruitment

84 HCBS professionals were eligible if they were an HCBS provider, service coordinator, quality
85 measurement expert, or payer. HCBS users were eligible if they had received or were receiving Medicaid-
86 funded HCBS, demonstrated understanding of study consent, and could describe their HCBS experience.
87 All participants lived within the United States, were at least 18 years old, and had internet or telephone
88 access.

89 We used purposive sampling to ensure representation by disability type, service setting, and
90 race/ethnicity. We contacted state-level HCBS personnel, provider agencies, disability advocacy
91 organizations, project advisory councils, and collaborator networks, then sent emails with IRB-approved
92 flyers with study information. We sought representation across disability type
93 (intellectual/developmental disability, mental health-related disability, age-related disability and physical
94 disability), setting (residential, day program, and home care), and states. We adjusted recruitment efforts
95 when gaps in program representation became evident. We used snowball sampling to solicit additional
96 participants at the conclusion of interviews. Participants received $40.

97 Data Collection

98 A PhD-level project manager, post-doctoral fellow, and two project coordinators conducted
99 interviews which lasted approximately 60 minutes and were recorded using Zoom. Occasionally, support
100 people were present during the interviews upon participant request. Participants provided consent after
101 being informed of the study aims, their rights, and compensation with easy-read text and teach-back
102 procedures. The semi-structured interview guides (Table 3) asked users and professionals to share their

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experiences related to competencies for PC planning, organizational characteristics, training practices, and service-delivery during the public health emergency. NCAPPS' five competency domains for PC planning informed development of the guide.[22] We encouraged participants to discuss organizational and system-level characteristics impeding PC service delivery. We assured feasibility, accessibility and comprehensiveness by pilot testing with an HCBS user. This study was approved by Northwestern University's Institutional Review Board.

Data Analysis

Four research team members completed the data analysis. A post-doctoral fellow and one project coordinator reviewed users' transcripts while a project manager and second project coordinator reviewed professionals' transcripts. We used a deductive then inductive approach in developing a thematic codebook. The NCAPPS' service delivery competencies framework informed the initial deductive codes, followed by inductive coding focused on systems-level factors. This report presents themes distilled from the inductive codes.[26] All four researchers participated in coding of all interviews. Coders achieved consensus via initial and ongoing discussions of code definitions and coding processes, verifying agreement throughout the analysis, and reconciling disagreements. They achieved intercoder reliability across five transcripts with reconciliation across all researchers at 80%+ agreement.[27] They coded the remaining transcripts independently using NVivo (Version 11) software.[28] We addressed dependability by creating audit trails which included emerging themes.[26] A larger team of all researchers, including the principal investigator, two post-doctoral fellows, two project managers, two project coordinators, and a research intern, took part in theme refinement.

Research Team and Reflexivity

The study team included individuals with backgrounds in rehabilitation psychology, disability studies, public health, social work, occupational therapy and kinesiology. One researcher identifies as a man and the rest as women; all members identify as nondisabled. The team sought feedback from

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127 advisory councils comprised of people with disabilities and industry representatives. The team reflected
128 on their biases and subjectivity during data analysis through group discussion.

129 Results

130 Forty-two individuals participated in interviews during the spring and summer of 2022, including
131 HCBS users (n=20) and professionals (n=22). Professionals included state waiver personnel, managers,
132 and DSPs. Table 1 provides demographic characteristics of the participants; Table 2 provides information
133 about the professionals.

134 Researchers identified 13 codes then refined them using pattern coding into six inductive codes:
135 DSP workforce crisis, service quality, service access, training, the Covid-19 public health emergency,
136 resources and funding, and service utilization. The research team reviewed these codes and collapsed
137 them into three final themes with exemplar quotes: (1) Workforce Considerations, (2) Resources and
138 Service Access, and (3) Infrastructure for Feedback. Table 4 lists the themes, definitions, and sample
139 quotes related to each theme.

140 Theme 1: Workforce Considerations

141 This theme characterized workforce shortages and instability in the direct service workforce.
142 HCBS users detailed their relationships with DSPs, the effects of workforce issues on their daily lives, and
143 their experiences receiving services. Two subthemes emerged: (a) workforce shortage and instability; (b)
144 PCP training.

145 (a) Workforce Shortage and Instability

146 All participants cited challenging work, high caseloads, and burnout as reasons for the high rates
147 of DSP turnover. During the Covid-19 public health emergency, many services closed, exacerbating the
148 shortage of DSPs and high turnover rates. Respondents spoke about structural barriers DSPs face, such as
149 lack of access to health insurance, poor pay and long hours, and reimbursement structures that
150 perpetuate low wages: "[T]he reimbursement rate from the regional center is very low…[We] can't

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151 afford to [increase pay] because we're not getting paid more from the state… [I]t's a statewide crisis right
152 now" (Program director).

153 Instability in the DSP workforce affects HCBS users' quality of life and services as reflected in
154 variable standards of services and difficulty building trust. An HCBS user detailed difficulty doing valued
155 activities, such as visiting their mother's gravesite, after the case manager accepted another job. Users'
156 fear of not finding another DSP led them to settle for a DSP who did not meet their needs: "[I]n the back
157 of your mind, you always know that you could be out of help if you decided that [DSP] wasn't a good
158 match" (HCBS user).

159 Self-directing as well as non-self-directing participants reported workforce challenges. Some
160 users on self-direction waivers reported hiring people who were not qualified because of pandemic
161 disruptions.

162 HCBS users appreciated their DSPs' struggles and needs. For example, one user acknowledged
163 that while DSPs may care deeply, many have multiple jobs. Other users witnessed DSPs struggling to pay
164 bills, coping with high caseloads, and experiencing burnout.

165 Both professionals and users discussed potential supports for DSPs including better pay and
166 consistent raises, high-quality training, union membership, and advocacy led by HCBS users. At the state
167 level, recommendations included flexible DSP eligibility requirements, using funds from various sources
168 to bolster compensation, market surveys to assure competitive pay, and bolstering non-wage benefits.
169 DSPs and leaders cited a lack of non-wage benefits such as health and dental insurance, paid holidays,
170 and bonuses as factors contributing to high turnover rates. While some professionals shared examples of
171 non-wage benefits provided by their organizations, many stated that adequate benefits were not
172 available.

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173 HCBS leaders reflected on the variation of the workforce shortage by location, with more severe
174 shortages in rural than urban areas. Innovative solutions in one state waiver program included
175 recruitment of DSPs from sources like churches, shelters, and food banks in rural areas.

176 (b) PCP Training

177 Interviewees discussed experiences with training and limitations in training practices, offering
178 recommendations to improve training. HCBS personnel described training for DSPs, including job roles,
179 cultural competency, PCP, topics relevant to waiver populations, compliance training, communication
180 skills, user rights, and trauma-informed services. Leaders described training for case managers, including
181 training on implementing PCP, trauma-informed care, motivational interviewing to facilitate support
182 planning, and ethics. Beyond required training and competencies, organizations often developed their
183 own curriculum or hired consultants. Providers' training practices included employing self-advocates,
184 offering peer support as part of the training, co-creating curricula with community members, and
185 creating opportunities to develop specific skills.

186 Participants highlighted issues with widespread implementation of PCP training. Several
187 interviewees said that mandatory training for DSPs did not adequately cover topics relevant to PCP but
188 instead focused on infection control, first aid training, and documentation procedures: "The initial
189 training is 40 hours…I would say maybe around 2 hours of that 40 hours [is dedicated towards training in
190 PC supports]" (HCBS provider).

191 A trainer reflected that federal mandates coupled with funding may help or hinder organizations
192 implementing PCP.

193 *"If an organization has a good culture and they understand what their expectations are, then*
194 *they're going to want their staff who are in planning roles to get trained in being person*
195 *centered...If an organization is struggling to survive and they don't have enough staff...you have*

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196 *those complex problems laying on top of each other; they're not going to do the person-centered*
197 *thinking and planning training." (HCBS trainer)*

198 Inadequate training affected both professionals and users. One user shared that a personal
199 assistant wanted training, but the training was not meaningful. HCBS professionals recommended
200 improving the quality and accessibility of training in PCP. Improvements for DSPs included
201 accommodating DSPs' learning styles and integrating HCBS users and DSPs into training development.
202 Training recommendations for both DSPs and case managers included virtual training at flexible times
203 and dedicating full-time staff at states and providers to facilitate training.

204 **Theme 2: Resources and Service Access**

205 HCBS professionals and users described factors that impede and expand users' access to high
206 quality services. Two subthemes were: (a) service access barriers and (b) service access facilitators.

207 (a) Service Access Barriers

208 Respondents discussed the role of resources, resource allocation, organizational procedures,
209 state eligibility determination criteria, and other barriers that shaped the experiences of professionals
210 and users.

211 Resource issues identified by state waiver personnel and providers were insufficient state
212 budgets and Medicaid reimbursement rates that did not align with users' needs. Waiver program
213 employees described being unable to serve people due to a shortage of resources and extensive
214 waitlists.

215 *"And I think we had 7,000 people on the waiting list. When we closed that list [for the 1915C*
216 *waiver], the name was changed to 'referrals', and that was rolled over to the 1115 [waiver].*
217 *Since then…I have no idea [how many people are currently on the waiting list to receive*
218 *services]" (HCBS state waiver employee).*

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219 Other waiver program employees shared unsuccessful experiences advocating for funding to
220 expand the number of people served by a waiver program and having to turn away clients in crises
221 because of capacity limits.

222 Many cited service eligibility determination procedures as barriers to accessing services. Users
223 described the nature of eligibility determination as "medicalized" and "arbitrary." "If you're somebody
224 whose IQ is at times like 71… even at one point, they can deny you. Let's [change the policy] toward
225 function [rather than IQ]" (HCBS user).

226 Eligibility determination procedures did not allow choice and control over services. "I wanted
227 more hours for my aides, and they said no, and that I can't get them because it wouldn't serve a
228 purpose. So, I'm screwed when I have my surgery…I know my body" (HCBS user).

229 Interviewees identified a lack of information about the HCBS service system, the workforce
230 shortage, administrative burden from required documentation, and racial and ethnic disparities in
231 service access as service barriers.

232 (b) Service Access Facilitators

233 Interviewees identified facilitators related to expanding HCBS users' access to services,
234 responsive service-eligibility determination procedures, organizational flexibility in service provision, and
235 targeted resource allocation. They described specific Covid-19 pandemic changes as positive.

236 Several interviewees discussed improvements to eligibility determination procedures that
237 include regular reassessment of support needs and lowering functional limitation thresholds to allow
238 more individuals to qualify for services. Users emphasized times that staff members recognized their
239 support needs and ensured that they remain eligible during eligibility redetermination. "So [case
240 manager] was asking me all these weird questions…Like, do you need help plugging your phone?…And
241 that added like 15 minutes to my [hours]" (HCBS user).

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242 Telehealth emerged to expand service access. Participants indicated that flexibility in service
243 provision helped meet clients' needs better. Two state employees described procedures that enabled
244 clients to choose services to help them achieve goals, which allow greater choice over services. "We, as
245 an agency, keep a provider directory…so that clients can choose from…a number of different providers"
246 (HCBS state waiver employee).

247 Other strategies for improving states' waiver programs included supplementing state funding
248 with other sources, purchasing assistive technology, supplementing HCBS with community resources,
249 and developing complementary services like nutrition and rent assistance programs.

250 Providers and states adapted to maintain service access during the public health emergency.
251 Providers expanded telehealth to enable clients to check-in with case managers and staff. Providers sent
252 assistive technology to users to facilitate telehealth and ensure that people with limited technology
253 access could participate in HCBS.

254 Several professionals shared that CMS' emergency waiver provisions allowed under Appendix K[5]
255 enabled providers to launch home-delivered meals, provide personal protection equipment to staff, and
256 maintain funds to continue services. HCBS professionals mentioned that Appendix K provisions allowed
257 some users to self-direct services better. This flexibility allowed users to hire and fire caregivers, and
258 many users chose to hire family members during the pandemic.

259 *"Appendix K...allowed the option for a family member within the home to be able to act as the*
260 *attendant. I think that really helped limit exposure but also created a really person-centered*
261 *environment. Historically we have not done that across our waivers." (HCBS state waiver*
262 *employee)*

263 Some respondents shared that expanded flexibility was also beneficial for DSPs, allowing them
264 to use virtual peer support spaces and benefit from remote work opportunities.

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265 **Theme 3: Infrastructure for Feedback**

266 HCBS waiver and provider personnel shared mechanisms to obtain user feedback, which are
267 required by CMS as part of most waivers. HCBS users shared positive and negative experiences providing
268 feedback and had suggestions for improving feedback infrastructure.

269 HCBS professionals described several ways that states and providers obtain feedback from users.
270 One example was a feedback loop between users, providers, and the state: When a user mentions an
271 issue regarding a provider to a state employee, the state employee contacts the provider to resolve the
272 issue; they may move the client to a different provider if a resolution is not reached.

273 *"I like to, in the training, make sure the staff are aware of how in control our clients are, how*
274 *much oversight there is in this program, and make them aware that they're working for that*
275 *individual...We try to, right from day one with the staff, emphasize how person-centered this is*
276 *and that it's really the client's choice. It's the client's life." (HCBS state waiver employee)*

277 Other practices included focus groups of users, work groups to inform program development
278 and interventions, and annual user surveys to assess satisfaction and concerns.

279 HCBS users expressed the value of providing feedback to service providers. They cited
280 collaborative procedures and leadership as key factors in feeling heard. A few said that they can suggest
281 changes to their services and providers. Explicit feedback procedures made providing feedback easier
282 through readily available contact information and multiple avenues to provide feedback.

283 While some HCBS users had positive experiences providing feedback, others experienced
284 challenges. Several shared that they did not experience any meaningful change after providing feedback
285 and filed numerous appeals before hearing from their providers. Sometimes, these appeals were
286 overruled. "I filed many appeals in order to force them…[I had to] force them to provide me with person-
287 centered services…[T]hey tried to do various things that didn't comply with my lifestyle" (HCBS user).

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288 Changing parts of service plans was complicated because obtaining agency approval was
289 difficult. Two participants shared that they were effective because of personal relationships with staff.
290 Some mentioned the fragmented nature of their states' quality measurement systems, which caused
291 challenges in understanding how well services work.

292 Users shared recommendations for improving feedback systems to improve service quality.
293 Some emphasized the importance of states and providers developing multiple avenues for user feedback
294 like email, text, phone, and accessible websites. Others emphasized the need for input from self-
295 advocates in policy and program development, and that providers should routinely seek input from
296 diverse stakeholders to ensure that services support all people.

297 **Discussion**

298 This report describes HCBS professionals' and users' perspectives on organizational and system-
299 level barriers experienced when providing or receiving HCBS. Interviews focused on NCAPPS competency
300 domains to elicit information on service-delivery competencies for PCP; however, participants discussed
301 systems and organizational level issues affecting the delivery of PCP throughout the interviews. While
302 PCP focuses on enabling individuals to live the lives they want, this study demonstrates that PCP is
303 influenced by processes and structures at the organization, state, and federal level. Especially important
304 to address is resource allocation related to workforce issues, reduction of administrative barriers, and
305 understanding the benefits resulting from the flexibility allowed by CMS in response to the Covid-19
306 public health emergency.

307 Implementation of PCP is mandated at the federal level via CMS' Final Settings Rule, including
308 compliance requirements for states and provider organizations. This study reveals how policies and
309 processes at the systems level inhibit implementation of PCP and adherence to waiver requirements.
310 Investigators have identified numerous challenges in the HCBS system, including resource allocation in
311 the direct workforce[29,30] and administrative barriers impacting service access, delivery, and quality

312 control. [31-33] The HCBS leaders and users in this study voiced the same concerns. Policy reform that
313 addresses PCP implementation within systems, is needed to enhance PCP and improve HCBS users'
314 quality of life. Results of this study suggest practical changes across policy and systems that would allow
315 HCBS providers to improve PCP.

316 Participants in this study identified challenges and solutions reflective of DSP workforce issues
317 including high turnover and training.[34-36] DSPs are motivated to remain in the workforce because of
318 positive experiences working with people they support and the desire to make a difference;[37] but, they
319 described difficult working conditions that result in workforce instability. DSP's quality of life and ability
320 to provide optimal services are limited by low pay, insufficient training, challenging work, and high
321 caseloads, leading to high turnover and poor-quality services.[34-36] DSP continuity greatly affects quality of
322 life and ability to engage in valued activities for people with disabilities in terms of security, community,
323 relationships, choice, and goals.[38]

324 DSP compensation is a critical factor in improving continuity, as wages are a critical factor in staff
325 retention.[36] Both users and DSPs suggest increasing wages and access to health insurance as a resolution
326 to HCBS workforce issues. Initiatives to improve DSP compensation have been addressed by states
327 including permanent wage increases, temporary wage increases or limited bonus payments, and, in a
328 few states enhancing non-wage benefits for DSPs.[6] States that have adopted wage pass through
329 programs have been able to increase DSP compensation as much as 12%. However, there is limited
330 evidence of the effectiveness of compensation initiatives and non-wage benefits in reducing turnover
331 rates.

332 PCP training can result in positive work experiences, including increased knowledge, job
333 satisfaction, confidence and preparedness, and career resilience;[19,39] however, system-level barriers can
334 prevent access to and quality of training. While PCP training was available to many, the costs associated
335 with training and satisfaction with training resources varied across participants. Both case managers and

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336 DSPs expressed a need for more flexibility in training delivery and resource allocation to solicit and be
337 responsive to employees' needs and priorities. HCBS users and DSPs emphasized that training is often
338 focused on administrative duties and documentation, lacking content that helps them apply PCP and
339 understand how to provide individualized services. Our findings indicate that while there is an urgent
340 need to improve the relevance, quality, and access of PCP training, organizations struggle to prioritize
341 training given their resource constraints. Established high quality PC resources like NCAPPS, training
342 consultants such as Support Development Associates, and accreditation entities like CARF International
343 and the Council on Leadership and Quality provide high quality PC training.[19] Integrating HCBS users,
344 DSPs, and case managers into training could improve the relevance of the curriculum, using their
345 experience to ensure that content applies to the demands of service-delivery and provide opportunities
346 for practical application of competencies. Future studies should explore DSPs' and users' perceptions of
347 the quality and utility of competency-based training requirements as well as alternative models that
348 support improved PCP. State waiver programs and other stakeholders should endeavor to deliver the
349 resources and supports HCBS provider organizations need to implement high-quality training.

350 Administrative barriers to PCP include challenges across care coordination, assessment
351 procedures, and the complexity of the HCBS system.[40] The perspectives of HCBS users and professionals
352 about barriers in service plan processes differed; however, they both discussed major challenges
353 associated with financial assets (reimbursement, DSP pay, programmatic capacity, wait lists), compliance
354 requirements (documentation, limited quality measurement), and operational challenges (feedback
355 structures, confusing eligibility criteria). Leadership and executive commitment are an important factor
356 in addressing these challenges through feedback mechanisms that solicit and implement user
357 engagement.[41] Users recommended multiple avenues for feedback, such as steering committees for
358 inclusion in PC quality monitoring and program development. Future studies should expand our
359 understanding of how these barriers restrict access to and provision of PC HCBS.

360 The public health emergency initiated during the Covid-19 pandemic provided opportunities to
361 redesign HCBS around new safety measures, and in turn, has allowed flexibility that benefits users and
362 professionals.[5] State waiver program employees and provider organization personnel discussed tangible
363 benefits resulting from Appendix K of CMS' Emergency Preparedness waivers on service expansion,
364 provider payment increases, DCW training, and expanding technology access. Appendix K allowed HCBS
365 providers to modify waiver programs, allowing expanded access and innovative approaches to service
366 delivery and DSP supports. Expanded self-directed services also improved choice and control and
367 reduced unmet needs. ADvancing States analyzed states' plans for spending funds authorized by the Act
368 and categorized states' initiatives into topical areas, including service expansion; eligibility and
369 enrollment activities, provider payment increases; direct care worker recruitment, retention, and
370 training; technology for providers and state agencies; capital and structural Improvements; quality
371 initiatives; and strengthening state administration.[6] For example, Nevada aligned its rates to minimum
372 wage standards, Mississippi developed a strategy and plan focused on recruitment and retention of
373 direct support staff, and Oregon provided seed funding toward a new healthcare trust for long-term care
374 workers. These initiatives help sustain funding and flexibility beyond temporary measures to enhance
375 HCBS quality and the delivery of PC services.

376 Recent legislation allows HCBS programs to retain some pandemic-era flexibility through the
377 2023 Consolidated Appropriations Act and rules issued by CMS.[42] This legislation provided more than
378 $1.7 trillion to fund federal agencies, including an extension of telehealth waivers and the Acute Hospital
379 Care at Home individual waiver. Participants cited expansion of telehealth services as a key factor in
380 programs ensuring safety and service continuity during the pandemic and allowing more participants in
381 rural areas to access services. Given the benefits experienced by participants, legislation that allows
382 waiver programs and organizations to expand service access should be sustained. Additionally, a better

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383 understanding of mechanisms employed during the pandemic-era flexibility is needed to determine
384 what mechanisms best support people in living the lives they want.

385 Study Limitations

386 This study represented varied waiver programs and states across a modest sample. However, we
387 did not achieve comprehensive nor equal representation across disability types, settings, states, and
388 other characteristics. The majority of HCBS users identified as having either intellectual and/or
389 developmental disabilities or physical disabilities, with mental health and age-related disabilities having
390 less representation. While participants came from 10 states and represented all regions of the US, the
391 majority were from Illinois. Therefore, findings may not reflect all variations in HCBS across service
392 provision specific to disability population and across states. Despite these limitations, participants
393 provided rich details about their experiences resulting in good information power.[43]

394 **Future Research Directions**

395 This study explored the organizational and system level challenges in PC service delivery and
396 effects on individuals receiving HCBS. Future studies will benefit from the use of social ecological models
397 and implementation science methods. NCAPPS' Nine Elements of a Person-Centered System provides a
398 framework to build on this work.[22] Future studies should explore administrative barriers in HCBS,
399 including state eligibility determination criteria and waitlists, and their influence on service access and
400 the implementation of PCP. This study highlights the complexity of delivering high quality PC HCBS;
401 future studies could explore how assets and supports within systems and organizations help users to live
402 the lives they want. Policy research should focus on the public health emergency flexibility and changes
403 that enhanced HCBS delivery, as well as issues that are common across and specific to disability
404 populations, waiver programs, and service types.

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405 **Conclusion**

406 HCBS professionals and users discussed workforce considerations, resources and service access,
407 and infrastructure characteristics that affect PCP. Key issues that require research for service delivery
408 improvement include DSP compensation, implementation of PC training, systems-level barrier
409 resolution, and strategies for user engagement and feedback. CMS' public health emergency-related
410 flexibility to states in administering Medicaid waivers provides examples of program innovation that
411 enhanced PCP.

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Tables Legend

Table 1. Demographic Characteristics of Study Participants

Table 2. Demographic Descriptive Statistics for HCBS Professionals

Table 3. Example Questions from Interview Guides by Competency Domain for HCBS Users and Professionals

Table 4. Results: Themes, Subthemes, and Quotes

Appendix. COREQ Reporting Guidelines

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Table 1

Demographic Characteristics of Study Participants (n=42)

Variable		HCBS Interview Group		
		Users 20 (47.6)	Professionals 22 (52.4)	Total (n=40)
Gender Identity				
Female	n (%)	10 (50.0)	17 (85.0)+	27 (67.5)
Male	n (%)	6 (30.0)	3 (15.0)+	9 (22.5.0)
Non-binary	n (%)	4 (20.0)	0 (0.0)+	4 (20.0)
*Race				
White	n (%)	16 (80.0)	13 (65.0)+	29 (72.5)
Native Hawaiian/Pacific Islander	n (%)	1 (5.0)	0 (0.0)+	1 (2.5)
Black or African American	n (%)	2 (10.0)	3 (15.0)+	5 (12.5)
Asian	n (%)	1 (5.0)	2 (10.0)+	3 (7.5)
American Indian/Alaska Native	n (%)	2 (10.0)	0 (0.0)+	2 (5.0)
Prefer not to say	n (%)	1 (5.0)	1 (5.0)+	2 (5.0)
Hispanic or Latino				
No	n (%)	15 (75.0)	17 (85.0)+	33 (82.5)
Yes	n (%)	3 (15.0)	3 (15.0)+	6 (15.0)
Prefer not to answer	n (%)	2 (10.0)	0 (0.0)+	2 (5.0)
Highest educational level				
Less than high school	n (%)	1 (5.0)	0 (0.0)+	1 (0.0)
High school diploma/GED	n (%)	9 (45.0)	2 (10.0)+	11 (27.5)
Bachelor's degree	n (%)	5 (25.0)	10 (50.0)+	15 (37.5)
Masters	n (%)	1 (5.0)	5 (25.0)+	7 (17.5)
Doctorate	n (%)	2 (10.0)	2 (10.0)+	4 (10.0)
Other	n (%)	2 (10.0)	1 (5.0)+	3 (7.5)
*Disability Population				
Intellectual & Developmental	n (%)	13 (65.0)		
Physical	n (%)	14 (70.0)		
Mental Health	n (%)	5 (25.0)		
Age-Related	n (%)	1 (5.0)		

Note.
*Participants could select more than one option; therefore totals are larger than sample size.
+Two HCBS Professionals did not provide demographic information; therefore, percentages reflect n=20.

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Table 2

Demographic Descriptive Statistics for HCBS Professionals (n=22)+

Variable	Description		
Job Position			
	State-level employees	n (%)	6 (30.0)
	Case managers/ DSPs	n (%)	4 (20.0)
	Other HCBS organizational and training personnel	n (%)	8 (40.0)
	Managed care organization representatives	n (%)	4 (20.0)
*Service Type(s) Provided			
	Case management	n (%)	10 (50.0)
	Transportation	n (%)	4 (20.0)
	Home Health Care	n (%)	2 (10.0)
	Personal Care	n (%)	3 (15.0)
	Day Center	n (%)	2 (10.0)
	Residential	n (%)	3 (15.0)
	Vocational	n (%)	3 (15.0)
	Therapy	n (%)	1 (5.0)
	Behavorial Management	n (%)	4 (18.2)
	Other	n (%)	5 (20.0)
	No response	n (%)	7 (35.0)
*Disability Type(s) Served			
	Intellectual and Developmental	n (%)	11 (55.0)
	Physical	n (%)	8 (40.0)
	Aging/Age-Related	n (%)	6(30.0)
	Mental Health	n (%)	13 (65.0)
	Other	n (%)	3 (15.0)
	No response	n (%)	7 (35.0)

Note. *Participants could select more than one, therefore totals are larger than sample size. +Two HCBS Professionals did not provide demographic information, therefore all percentages reported reflect n=20.

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Table 3.

Example Questions from Interview Guides by Competency Domain for HCBS Users and Professionals

Strengths-based, culturally informed, and whole person-focused	
HCBS User	How are meaningful activities incorporated into your day?
HCBS Professional	How do you identify the strengths of the individuals you provide direct services to?
Rights, choice, and control	
HCBS User	In what ways do the people providing your services support your decisions?
HCBS Professional	What does choice and control mean in person-centered supports for people receiving your services? How do you assist individuals in advocating for their needs?
Partnership, teamwork, facilitation, and communication	
HCBS User	In what ways is your voice heard and responded to by the people providing your services?
HCBS Professional	How do you instill a culture of teamwork at your agency?
Person-Centered Planning included in Documentation, Implementation, and Monitoring	
HCBS User	Do you have the opportunity to provide feedback about the services you receive? If so, can you talk a little more about what that looks like?
HCBS Professional	How do you gather feedback from the people receiving services?
Cultivating connections inside the system and out	
HCBS User	What are some challenges or successes you've experienced when the people who provide your services partner with other companies or organizations to provide your services?
HCBS Professional	How are you involved with others outside of your system?

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Table 4

Results: Themes, Subthemes, and Quotes

Subtheme	HCBS User Quote	HCBS Professional Quote
Theme 1: Workforce Considerations		
Workforce shortage and instability Contributing factors to the shortage and turnover of the direct support workforce and user perspectives on the impact it has on their daily lives and experiences receiving services	"[My worker's] health care is awful... [Their employer doesn't] provide health care for [her]... she's doing over 40 hours a week with me, and so she does not qualify for [Medicaid]." (HCBS user) "[My DSP got fired because she cared about her clients. The] people that really wanted to listen and make changes were often really easily replaced out of the system. They burned out." (HCBS user)	"I'm constantly getting feedback... about how it's been so difficult to try to staff [so many] cases. [W]e have a lot of clients right now that are not getting the amount of service that... they need." (HCBS state waiver program employee)
PCP training Training experiences for the direct support workforce and recommendations for training practices and development	"I think [most DSPs] are well-intended... but nobody tells them what it is they're supposed to do, how to do it, or where to find out how to do it." (HCBS user) "[The disabled community has given the advice] to look for someone who does not consider themselves well-trained or an expert... those people are more adaptable." (HCBS user)	"I wouldn't say that anybody could go through [mandatory] training and then just be ready to go [work]… [They need to be shown how to] work with a specific person. [P]eople develop the skills over time" (HCBS leader and DSP) "You can see [during trainings] that people who are in the IDD sector have much more familiarity with the tools and the language because they've been focusing on being person-centered for a lot longer

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Subtheme	HCBS User Quote	HCBS Professional Quote
		...All the other sectors are just hearing it for the first time." (PCP instructor)
Theme 2: Resources and Service Access		
Service access barriers Factors (i.e., policies, procedures, allocation of resources, practices) that impede HCBS participants' access to services and/or person-centered supports	"[W]hen I have a job, I don't know really how much I can earn... I would lose a benefit." (HCBS user) "[My case manager] asks the question on the form and fills out the numbers and says, 'ok you get... fifteen minutes a day of this and a half an hour a day of this and an hour a week of this.' It has nothing to do with real life." (HCBS user)	"Five years ago, the [state waiver program] approached the legislature about increasing the cap. It was denied due to budget reasons... in April, we started our new five-year period for the mental health waiver. [W]e were not allowed to increase our census." (HCBS state waiver program employee) "There is no distinction [in our state] for different levels of support need... [in one of our locations], we have a lot more people that have higher levels of personal care support needs... but the billing rate is exactly the same. There's an ability to get one-to-one funding [in our state] but the process to get it is incredibly convoluted and impossible." (Manager at adult day program)
Service access facilitators Factors (i.e., policies, procedures, allocation of resources, practices) that expand HCBS participants' access to services and/or person-centered supports	"My [current case manager is] more understanding that having homemaker services is not going to be adequate... [so she told me] 'although we don't normally do this, we are going to allow you to have PAs and homemakers at the	"We actually lowered the [score on an assessment that measures functional limitations] so that we could encompass more individuals, provide the most services [downstream to] hopefully prevent escalation." (HCBS state

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Subtheme	HCBS User Quote	HCBS Professional Quote
	same time.'" (HCBS user)	waiver program employee) "A lot of state-funded programs are looking to build supportive services for people... [and provide] earlier intervention so that people don't have to be so sick before they qualify for our services." (HCBS state waiver program employee)
Theme 3: Infrastructure for Feedback		
Descriptions of current feedback acquisition practices; users' experiences providing feedback; and recommendations for improving state and provider infrastructure to solicit feedback from users	"[I]t's important for policymakers to understand that in order to implement something that is going to meaningfully address issues experienced by [HCBS participants], you need to include [them] in your planning work." (HCBS user) "Every month or so, field workers come to your house and ask you questions... 'how are you' and 'how are you and your homemaker getting along'... I didn't see any kind of meaningful change... not at all." (HCBS user)	"We [the state] realized that we need... to have oversight... to ensure that the people are actually getting the services they're supposed to be getting." (HCBS state waiver program employee)

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