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Experiences of individuals self-directing Medicaid Home and Community-Based Services during COVID-19

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ABSTRACT

Background: In response to COVID-19, many state Medicaid Home and Community-Based Services (HCBS) programs increased flexibilities and options for self-direction.
Objective: Our study sought to investigate the experiences of individuals self-directing during COVID-19. In particular we explored the following areas: 1) How have individuals maintained access to HCBS and workers?; 2) how have individuals maintained safety against COVID-19?; and 3) how have individuals maintained their health and well-being?
Methods: We partnered with community-based and national disability organizations for recruitment. We used a semi-structured interview guide to conduct remote interviews with 36 individuals from eleven states. The sample was diverse with regard to age, race/ethnicity, gender, and disability type.
Results: Three main themes emerged related to maintaining access to HCBS and direct care workers: 1) Benefits of authority to hire and fire; 2) benefits of ability to hire family members; and 3) fluctuations in needs and availability of workers. Two themes emerged related to maintaining safety against COVID-19: 1) Strategies for staying safe with workers; and 2) barriers in public health and service system response. Three themes emerged related to maintaining health and well-being: 1) Barriers to basic needs; 2) delaying needed care; and 3) use of telehealth and technology.
Conclusions: This study was among the first to examine the experiences of individuals self-directing their HCBS during COVID-19. The flexibility of the model provided many benefits, which have implications for future policy and practice. Findings also highlight barriers in maintaining health and well-being during COVID-19, illustrating the importance of planning for future public health emergencies.

Approximately 12 million Americans need long-term services and supports.[1] LTSS include a wide range of services and supports that assist older adults and individuals with disabilities with self-care and tasks of everyday living. Medicaid is the primary payer of formal LTSS, financing approximately 62% of LTSScosts.[2] Most individuals needing LTSS desire to receive supports at home.[3] The US Supreme Court's *Olmstead* decision[4] and federal programs over the past decade have contributed to significant progress in shifting from services in nursing homes and other institutional settings to home and community-based services (HCBS). Nationally, over 56% of total Medicaid LTSS spending is now devoted to HCBS.[5] Approximately 3.5 million individuals receive Medicaid HCBS.[6]

We know very little about the impact of COVID-19 on individuals receiving Medicaid HCBS. While Congress mandated data collection and reporting on nursing homes, the Centers for Medicare and Medicaid Services (CMS) has not reported COVID-related data for HCBS beneficiaries. An emerging body of work has shown, however, that HCBS recipients have struggled to maintain access to workers during the pandemic and obtain access to personal protective equipment (PPE) for themselves and workers.[7]

HCBS beneficiaries are low-income individuals with disabilities and older adults who have high rates of secondary chronic health conditions that place them at risks for COVID-19.[8,9] HCBS recipients typically rely on in-home supports delivered by personal care attendants and direct care workers, and thus have substantial rates of exposure. Some HCBS beneficiaries also receive supports within congregate settings, such as group homes for individuals with intellectual and developmental disabilities (IDD), and congregate adult day and habilitation settings. Findings from states have indicated individuals with IDD receiving HCBS have experienced higher rates of contracting COVID-19 and mortality than the general population.[10,11] While states vary considerably in the design of

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their Medicaid HCBS programs, one model of service delivery that has grown over the last several decades is self-direction. Self-direction provides individuals receiving HCBS greater flexibility and control of services. Generally, there are two forms of self-direction: 1) Individuals have control over hiring and supervising their personal care attendants and direct care workers (employer authority); and 2) individuals have control over an individualized budget and decide what services and supports are purchased (budget authority). An extensive body of literature, including evaluations of the Cash and Counseling demonstrations, has highlighted the benefits of this model for individuals with disabilities and family caregivers.[12,13] The last inventory of self-directed programs identified 265 programs nationally (66% funded by Medicaid) with over 1.2 million participants enroled.[14]

In response to COVID-19, many state Medicaid programs have increased options for self-direction and flexibilities within existing programs, such as greater ability to hire relatives.[15] Greater flexibility, choice and control, appear to be particular advantages of this model during the COVID-19 pandemic. However, we currently know very little about the experiences of individuals in such programs during the COVID-19 pandemic. Our study sought to explore the following questions: 1) How have individuals maintained access to HCBS and workers?; 2) how have individuals maintained safety against COVID-19?; and 3) how have individuals maintained health and wellbeing?

Methods

We initially partnered with community-based disability organizations in five states (Massachusetts, Texas, Illinois, Kansas, and California) to conduct recruitment of participants. State selection was based on the following factors: extent of self-direction within the state, racial/ethnic minority representation, rates of COVID-19 hospitalizations and deaths in the state during the study period, and our access to community-based organizations to assist with recruitment. While we initially focused on specific states that were heavily impacted by COVID-19, we engaged in national outreach as the pandemic spread to virtually every community across the country. Recruitment was subsequently conducted via distribution of information about the study through newsletters and listservs of organizations with a national reach, including the Administration for Community Living, Association of University Centers on Disabilities, Applied Self-Direction, and the American Association on Health and Disability. Eligibility criteria included: being at least eighteen years of age, receiving Medicaid-funded home, and community-based services, and self-directing those services.

The final sample consisted of 36 individuals receiving Medicaid HCBS in self-directed programs. These individuals live in the following states: Texas (n = 3), Kansas (n = 4), Massachusetts (n = 11), California (n = 5), New Jersey (n = 1), Alaska (n = 1), Ohio (n = 2), North Carolina (n = 1), New York (n = 2), Illinois (n = 5), and Florida (n = 1). We purposefully recruited to obtain a diverse sample based on age, race/ethnicity, gender, and disability type.[16] More specifically, we screened individuals who expressed interest in the study for demographic information and selected individuals to achieve desired diversity. Participants reported that they had several different types of disabilities, including cerebral palsy, physical disabilities, traumatic brain injury, heart disease, obesity, cancer, depression, anxiety, autism, multiple sclerosis, and others. See Table 1 (below) for additional information about study participants.

Table 1
Participant demographic information.

	N (%)
Race	
White	20 (55.6%)
Black	9 (25%)
Hispanic/Latino	5 (13.9%)
Asian/Pacific Islander	3 (8.3%)
Gender	
Male	16 (44.4%)
Female	18 (50%)
Transgender/non-binary	2 (5.6%)
Employment Status	
Employed (full or part time)	13 (36.1%)
Unemployed or retired	23 (63.9%)
Residence	
Lives alone or with roommates	18 (50%)
Lives with family	12 (33.3%)
Lives with personal care assistant	3 (8.3%)
Missing	3 (8.3%)
Age	
18–39	14 (38.9%)
40–59	9 (25%)
60+	13 (36.1%)

We developed a preliminary, semi-structured interview guide with input from HCBS policy experts and individuals with disabilities that serve as advisors to the Community Living Policy Center at Brandeis University. The interview guide contained 9 open-ended questions concerning maintaining access to HCBS and direct care workers, access to personal protective equipment, impacts on health and well-being, and use of remote technology and strategies to stay socially connected. Interview guide and informed consent processes were approved by the university Institutional Review Board.

Interviews were conducted via telephone and video conferencing during a six-month period of the COVID-19 pandemic from October 2020 to April 2021. Interviews were conducted by three research staff, including one staff who is a researcher with disabilities who uses Medicaid HCBS and self-directs. Accommodations were provided upon request, including options for interviews in Spanish and American Sign Language. Interviews lasted approximately one hour and individuals received a stipend ($50 gift card) for their participation.

Interviews were professionally transcribed. Notes were also taken during interviews and used in data analysis. We used qualitative software, ATLAS.ti, to assist with coding data. Constant comparative analysis was used to develop a coding system and identify major themes, guided by grounded theory.[17] These processes were driven by our specific research questions. Coding was conducted by two research staff who also conducted interviews with participants. Initial coding was conducted separately on a subset of interviews. Following this initial coding, the research team convened to discuss discrepancies and further refine the coding scheme. The research team continued to meet regularly and discuss emerging themes and subthemes. As a member check, we shared preliminary findings with study participants to determine if our analyses aligned with their experiences.[18]

Results

Maintaining access to HCBS and workers

Three main themes emerged related to maintaining access to HCBS and direct care workers: 1) Benefits of authority to hire and fire; 2) benefits of ability to hire family members; and 3) fluctuations in needs and availability of workers.

Benefits of authority to hire and fire

Several participants noted that their decision-making authority with regards to hiring and firing enabled them to (a) select workers according to workers' exposure levels, and (b) enforce guidelines for acceptable exposure. As one participant illustrated:

> Oh, I had to get rid of somebody because they wouldn't go along with the mask and the hand washing and all that. They didn't think it was real, they thought it was just blown out of proportion. So, I had to dismiss that person which was a bummer.

Thus, this person was able to independently determine acceptable levels of risk, and fire (or hire) accordingly, thus avoiding being forced to hire someone who put him in danger. Similarly, another person shared the following:

> We had to be able to say, ‘If you don't do what we want you to do, we're going to have to fire you. We can't have you socializing in parties and stuff.’ And because they're Filipino, and having parties with family and friends is part of their culture, so we knew it was really hard on them. But yeah, it's important that we could say that to them.

Fortunately, this person did not need to fire his workers, because they adhered to his rules. However, because this person had the authority to fire them if he needed to, he was able to enforce his own safety standards.

Benefits of ability to hire family members

Several participants also expressed benefits associated with hiring family members, states have flexibility to dictate which family members may be hired within self-directed programs. Most Medicaid HCBS authorities (except for state plan personal care services) allow for services to be provided by family members, including “legally responsible individuals,” such as spouses or parents of minor children under specific circumstances.[19] Some states have waived those restrictions also allowing them to be hired under some circumstances. In our study, benefits associated with hiring family members included (a) the prevention of service gaps, (b) increased trust that the worker was invested in the participants' safety, and (c) enhanced social connectedness for the participant. Being able to hire family members prevented services gaps for many individuals during the COVID-19 pandemic, as one individual stated:

> Well, I have been able to keep the one that I have, and the only reason I've been able to keep her is because she's related to me. Had she not been related to me, she would have been out the door and on about her business, I'm pretty sure.

Another individual expressed the level of intimacy and trust they had with family members:

> And you know, I've known her for years. Really, she's related to me. And she takes very, very good care of me. Very good care. Even with the pandemic she has her gloves on, she has her mask on. When she takes me to the store, she makes sure that I'm masked up and my gloves on and she's masked up. I mean she's good. I don't want nobody to come in my house and take her place. Nobody can come in and take her place.

This person clearly expressed a high level of trust for her worker and the care that she provides. She alludes that this trust is at least partially due to their longstanding relationship (they are family members), and thus her ability to hire family members contributed to the sense of safety that she feels with her workers.

Fluctuations in needs and availability of workers

COVID-19 contributed to a lot of fluctuation on needs and availability of workers. Some individuals did experience service gaps due to lack of available workers. It was challenging to find new workers during COVID-19, as one participant stated:

> Well, the biggest challenge is finding attendants. I think, well, if there's a lot of people unemployed, but I don't think they want to work in a situation like this or… I don't know. It's been probably twice the difficulty of finding a good PCA.

Participants also experienced gaps in services when their workers became sick or there was concern about potential exposure. Most often, there was no emergency back-up plan. So most often individuals went without assistance. Others consciously chose not to bring in new workers, even in instances where they were allotted more hours, due to potential exposure risks.

Another subtheme was the increased responsibilities of staff during this time due to new COVID-related needs. As one participant illustrated:

> The CDC started saying, “You know, you got to clean up these places, you got to keep the countertops clean, you got to wipe down the doorknobs, you got to wipe the lights.” So, we started zooming in on, “Before you leave, make sure you wipe down that countertop with these disinfectant wipes and make sure the doorknobs are cleaned off and the telephones are wiped down, and all that,” which took time away from what I normally had them working on.

Maintaining safety against COVID-19

Two main themes emerged from discussions with participants about maintaining safety against COVID-19: 1) Strategies for staying safe with workers, and 2) barriers in public health and service system response.

Strategies for staying safe with workers

Participants described several strategies and considerations related to maintaining safety in the context of the COVID-19 pandemic. Participants described protocols that they developed with their workers to reduce the likelihood of passing COVID-19 between the consumer and their workers. These strategies included absences (i.e., “and even if she wakes up with a sniffle, she doesn't come in to work”) and workday routines. One participant described his routine with his workers as follows:

> Every time they come in, that's part of the routine they have to do is to make sure those wipes come out and everything gets wiped down, and they have their gloves on, and they wash their hands all the time, and they have their masks on and all that stuff's in place. And it took a little while to implement that because it wasn't a habit, it wasn't a habit for some of these people—and it wasn't a habit for me always. So, yeah, it took some readjusting, but now we do it, we do it because we have to.

In some cases, participants reported that service agencies they were connected to provided guidelines for how to maintain safety with workers. However, in most cases, consumers and their workers developed their own routines.

Barriers in public health and service system response

Participants viewed access to PPE, testing, and vaccination for themselves and their workers as critical, and they had diverse experiences with regard to ease of access. As one participant stated:

> Because at the beginning of the pandemic, there wasn't really easy way to access masks, and that's why we had to improvise in my mom making masks for us.

Another person shared that while she was easily able to access testing, it was more complicated for her workers to get routinely tested.

Data collection occurred during the early roll out of the vaccine, and many participants expressed frustration, ambiguities, and barriers in access for them and their workers. One person said:

> And I'm now worried about am I going to get the shot? I called my doctor's office. They keep saying they don't have the shot. I don't have a computer, so I can't go on and find out stuff.

Another person said,

> Everything was just sort of set in stone for older people—which is fine—but I just feel young people with disabilities get forgotten; and for some people that aren't born with a disability, they don't realize that young people with disabilities exist, so then we just sort of have to—we get swept under the rug.

While some participants reported that agencies were helpful in providing access to information and resources, many expressed that agencies could have been more helpful in this regard. One person said,

> It was more recently, like in the middle, kind of towards the beginning/middle. It just came. They didn't say it was coming. It just came, and then I got on the website and I saw everybody else was thanking them for the packages and stuff like that. So, I thought that was really neat because it was a lot of necessities that we really needed.

Maintaining health and well-being

Three main themes emerged from discussion about maintaining health and well-being: 1) Barriers to basic needs; 2) delaying needed care; and 3) Use of telehealth and technology.

Barriers to basic needs

COVID-19 changed the ways basic needs could be met including food and other items that were made essential during the pandemic. Most individuals had to pay out-of-pocket for personal protective equipment, hand sanitizer, and other items. These expenses comprised a significant financial burden and jeopardized other basic needs. As one participant shared:

> So, even out of what little income I have—which, for me, is just social security—I was buying better quality medical gloves on Amazon.

Another participant shared.

> Ever since the pandemic, my income has gone down because I recently lost jobs … I've dealt with, well still dealing with food insecurity right now, and then a lot of it is just trying to make ends meet when it comes to paying for just certain things.

The COVID-19 pandemic also contributed to individuals experiencing rationing due to scare resources. One participant shared experiencing scarcity in accessing essential medical equipment that was also being used to treat people with COVID-19 in hospitals,

> I've run into other issues, vent supplies. They've been rationing our vent supplies since the beginning. I knew this was going to happen the first week of March… I'm getting one vent circuit a month when I used to get one a week. So I've been getting constant, major airway infections ending up on IV antibiotics on a monthly basis.

Delaying needed care

Several participants spoke about the challenges and decisions that needed to be weighed when considering routine health care. One participant stated:

> I was supposed to go for a repeat scan on my breast back in March and because of the pandemic I put off the appointment, and I kept putting it off, but I should not have done that. I was just diagnosed this week with breast cancer.

Another participant mentioned similar decisions of avoiding routine check-ups for both the direct care worker and themselves:

> We both need dental work and we didn't do it at all because we were so afraid we'd get COVID if we went—because we have to have our dental work done in the hospital setting … so we haven't done that and we haven't seen a doctor for an actual physical where they're right there with you now for over a year.

Many expressed fears of being hospitalized due to COVID and treatment of individuals with disabilities in such settings. Some participants expressed considerable fears about ending up in nursing facilities. As one individual shared:

> Well, I had COVID in April. I was pretty sick, but because of some incredible support from a few of my aides at risk for themselves, I was able to stay at home. I'm pretty sure—and others agree with me—that although for my health, I mean I would have been better in some ways in the hospital, but I really don't think I would come out alive had I been in a hospital or any facility.

Many participants also shared stories of the impact of COVID on their mental well-being. One participant shared:

> It's been very stressful—very stressful—and very isolating. I feel very isolated because I've just basically had to stay inside, stay away from the population. And I'm at very high risk for COVID—and I just didn't know what else to do but to stay at home and stay away from most of my family.

For some participants, the direct care worker they hired helped to strategize ways to support mental health and well-being,

> So, the pandemic kind of made us housebound for a while and very, very boring and just depressing at times. But my worker, we found ways around it, just the two of us … But we had to be very selective on where we went, and that really bothered me because we used to be able to jump in the vehicle … But the pandemic slowed that down for a while, my depression set in really bad, not being able to do a lot. But like I said, my

> worker found ways to help deal with that part and keep me going, and we found new ways to venture out without venturing out.

Use of technology and telehealth

Notably, telehealth access and the increased access to virtual ways of connection was a welcomed change for many participants. As one individual stated:

> I've been really grateful for telehealth mental health services. You know, I see my therapist once a week over Zoom and that's really kept me together. I think I would've fallen apart a while ago if I didn't have her and if I didn't have the ability to have that face-to-face contact.

Some individuals noted the benefits of telehealth for individuals with disabilities and hoped it would continue to be available following the pandemic.

> I have telehealth appointments with the doctors and I do therapy that way; and in all honesty, that is the best way for my, period. Because, for me, traveling is very difficult; I have a lot of health issues that make it really hard to get in and out of the van and wait out in the cold and whatever the elements are.

Many participants raised the ways technology added to their social connectedness while still being able to conduct daily-living activities such as running errands,

> I'm a very social person. And staying home has been really hard, you know. I can order what I need and what I want off of Amazon but it's not the same as like going to target, you know, and being able to peruse the aisles."

Beyond the ease of accessing medical care, the increased use of online communication to foster social networks was an additional experience that participants commented on:

> I'm a member of a church and so everything went online. Everybody's Zooming and things. So now I can tune into the coffee hour and different things like that which I didn't really do before because it was too early in the morning, I had to get it all together and get down. So that's been a real positive thing.

Discussion

This study was among the first to examine the experiences of individuals self-directing their HCBS during COVID-19. The inherent flexibility of the model provided many benefits. While some individuals experienced gaps in services and difficulty finding workers during COVID-19, for most, the ability to hire, particularly close friends and family members, seemed to assist individuals in maintaining supports during COVID-19. The use of family members seemed to be particularly prevalent among individuals from racial and ethnic minority backgrounds in our sample. Previous research has suggested greater interest in self-direction among some racial and ethnic minority groups;[20] there may be opportunities for self-direction to support health equity through the provision of culturally competent supports.[21] Control over hiring and managing workers also allowed individuals to adopt person-centered strategies to manage safety for themselves and workers and individualized decisions to limit potential exposure to COVID-19.

Findings also highlight barriers which could help inform planning for future public health emergencies. Most individuals faced significant challenges in accessing to PPE, COVID-19 testing and vaccination, and other resources. Many felt they did not receive adequate resources and supports from the public health and formal service system. Individuals self-directing their services and supports may have fewer ties to formal agencies. Some individuals are in agency with choice models, where an agency is the primary employer and the individual is the managing employer. One strategy some states took during the COVID pandemic was distributing information and resources such as PPE through fiscal management services (FMS) agencies. While these entities primarily provide payroll assistance and accounting, they could serve as a key point of contact in reaching individuals and workers during emergencies. Some states expanded budget authorities and flexibilities to allow individuals to purchase PPE, additional supplies and equipment, such as computers and other technology, to meet changing needs.[22] While some individuals did not feel safe allowing new staff into their homes, emergency back up plans, and systems are also critical for planning for unexpected gaps in staff and workers.[23]

This study also has limitations which are important to note. Our recruitment approach, initially through local disability organization and later through national outreach, resulted in overrepresentation of participants from some states, particularly Massachusetts. Approximately one third of the participants in the sample were age 60 or older, while the majority of self-direction programs serve adults age 65 and older. Thus, while this research explores the experience of a diverse group of adults who self-direct their Medicaid-funded HCBS, it is not representative of the population of adults in self-directed Medicaid-funded HCBS programs.[24]

A second limitation pertains to our ability to assess whether participants were recruited from budget or employer authority self-direction programs. While the interview guide included related probes (i.e., "Do you recruit, hire, train and supervise your workers? Do you have a budget and decide how to spend the money on services and supports?"), participants' responses did not explicitly indicate specific program types. Responses to the question about budget authority were unclear, perhaps due to unfamiliarity with this model or the way the question was asked. Based on the information we obtained and additional follow up with participants we were able to determine that at least 23 of the participants (64%) were in employer authority models. Individuals within budget authority models have authority to set wages of individuals. In some states, they may also have the ability to purchase items, equipment, and supports to meet their needs. However, participants in our study primarily focused on their experiences hiring and manage staff and did not share experiences using budget authority for purchasing additional items and supports. Additional research is needed to understand how states and individuals in self-directed programs with budget authority may have used this model during the pandemic to maintain workers or purchase items such as PPE.

Additionally, data were collected prior to the vaccine rollout, and also during the initial phases of the rollout. Thus future research is needed in order to investigate how experiences were impacted by worker and consumer eligibility for vaccines. Finally, while we did ask about if and how services and supports changed during the pandemic, most participants discussed workers and related safety issues. We do not know if participants enroled in self-directed programs prior to or during the pandemic. It will be important for future research to investigate how changes in program enrolments and policies persist in the post-COVID context. Despite these limitations, this study provides critical information about the experiences of adults with disabilities during the COVID-19 pandemic.

Conclusion

Most expansions of self-direction and additional flexibilities to hire family members made during COVID-19 are temporary and tied to the end of the public health emergency. As states plan beyond COVID-19, policymakers should consider long-term changes in HCBS programs. Moreover, Congress provided $12.7 billion in enhanced federal funding for HCBS through the American Rescue Plan enacted in January 2021 and the Biden Administration has proposed providing significant federal investment in HCBS.[25] These investments provide significant opportunities for states to improve access to self-directed HCBS and infrastructure to support self-direction.

While not directly tied to self-direction, findings from this study highlight many barriers in maintaining health and well-being during COVID-19. For example, individuals indicated barriers to meeting basic needs such as food security, delaying needed care, stresses, and impacts on mental health. In some cases, access to telehealth and technology facilitated access for participants. However, an important limitation of our study was that our methods limited participation to individuals who had access to technology and were also more likely connected to advocacy organizations. Data collection also occurred prior to the full roll out of the vaccine. Continued research is needed to more fully understand the broad-based and ongoing impacts of COVID-19 on the health and well-being of individuals with disabilities.

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Disclaimer

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Conflicts of interest

The authors have no financial conflicts of interest to disclose.

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