

Intellectual and Developmental Disabilities

Understanding the Impacts of COVID Policy Changes on Access to Needed Supports

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Abstract:	<p>The COVID-19 pandemic necessitated rapid policy changes to address new demands on disability service systems. A statewide survey of families of people who received Medicaid funded HCBS LTSS in one Midwestern state was conducted to understand (1) utilization of services allowed under the policy change, (2) family's experiences if their family member with a disability accessed the services, and (3) family's perspectives on the need for ongoing changes in the future. Overall, the results suggest that a subset of families took advantage of flexibilities introduced into service delivery models during the pandemic, and the changes – when accessed - addressed important needs that a large majority of families that accessed the services hoped would be sustained in the future.</p>

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Abstract

The COVID-19 pandemic necessitated rapid policy changes to address new demands on disability service systems. A statewide survey of families of people who received Medicaid funded home- and community-based (HCBS), long-term services and supports (LTSS) in one Midwestern state was conducted to understand (1) utilization of services allowed under the policy change, (2) family's experiences if their family member with a disability accessed the services, and (3) family's perspectives on the need for ongoing changes in the future. Overall, the results suggest that a subset of families took advantage of flexibilities introduced into service delivery models during the pandemic, and the changes – when accessed - addressed important needs that a large majority of families that accessed the services hoped would be sustained in the future.

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Understanding the Impacts of COVID Policy Changes on Access to Needed Supports for Families with Children Receiving Medicaid HCBS Waiver Services

The Coronavirus Disease 2019 (COVID-19) pandemic introduced unprecedented challenges and necessitated rapid deployment of solutions that were not previously available in disability service systems (Sabatello et al., 2020). For families that included a child or adult receiving Medicaid-funded home and community-based services (HCBS), waiver services authorized under section 1915(c) of the Social Security Act, there were specific and unique issues and challenges that emerged. The Centers for Medicaid Services (CMS) allowed states to make changes to service delivery and Medicaid billing to ensure that people with disabilities could access long-term supports and services (LTSS) without risking their, their families, or their provider's health and safety (Musumeci et al., 2020). Understanding perceptions of these changes and their impact are important not only to plan for future public health crises, but to also explore what was learned and how it can inform ongoing changes and improvements to service delivery beyond the pandemic (Bradley, 2020).

Even before the pandemic, there were long-standing issues for people with disabilities to access needed supports and services. The COVID-19 pandemic exacerbated these issues and introduced the need for unimagined changes (Nygren & Lulinski, 2020). For example, there was an immediate need for greater access to telehealth as health and safety protocols necessitated reduction of in-person interactions. While telehealth was a solution that had been used prior to the pandemic, systemic policy and practice barriers limited its use (Friedman, 2022; Friedman & VanPuymbrouck, 2020). Specialized medical care and personal care attendant services were also still needed during the pandemic, and telehealth was not an option for many of these supports and services. Even prior to the pandemic there were long-standing issues with the direct support

workforce and accessing high quality staff for specialized medical and personal care services at home and in the community (Laws & Hewitt, 2020). Systems of care encountered even more extensive workforce shortages and a need for a closer network of service providers, as many people with disabilities were unable to receive services delivered by people outside of the home because of health and safety risks during certain phases of the pandemic.

Aligned with CMS policies and allowances, multiple states enacted specific changes to their Medicaid policies to ensure HCBS waiver recipients had access to services and supports needed during the COVID-19 pandemic. This study focuses on family perceptions of the impact of policy changes in a Midwestern state with a focus on immediate experiences and perceived longer-term impacts and needs. This state focused on: (1) providing reimbursement for medical appointments to be held through telehealth; (2) allowing family members to bill for provision of specialized medical care; (3) allowing family members to bill for provision of personal care services, and (4) allowing a greater number of hours for in-home services. To better understand the impacts of these changes, both positive and negative, from the perspective of families, the state conducted a survey of families with a family member (children and adults) on the HCBS waivers impacted by the policy change. The findings provide not only insight into the impact of changes that occurred during the COVID-19 pandemic, but also highlight potential avenues to consider on an ongoing basis for enhancing Medicaid funded HCBS LTSS services and supports.

Methods

Participants

From August to October of 2021, the state department with oversight of the Title V Maternal and Child Health Programs, in partnership with the Medicaid HCBS Director, disseminated a survey online through various channels to reach families that included children

and adults receiving Medicaid HCBS waiver services. Specifically, the survey was disseminated through multiple social media outlets as well as to partner organizations to disseminate to families they worked with that had family members who received HCBS waiver services. Thus, the exact numbers of families who received the survey is unknown. Through these recruitment channels, 481 family members engaged with the survey, with 410 providing responses to more than one item and meeting eligibility criteria (i.e., receiving HCBS waiver services). When the survey was disseminated slightly over 30,000 people in the state received HCBS waiver services.

Of the 410 respondents, the most commonly represented waiver program was the Intellectual and Developmental Disability Waiver (n = 246) followed by the Technology Assisted Waiver (i.e., children who are chronically ill or medically fragile and dependent on a ventilator or medical device, n = 78), the Physical Disability Waiver (n = 16) and the Autism Waiver (n = 16). The remainder of the sample accessed multiple waivers, or other less frequently represented waivers including the Traumatic Brain Injury Waiver, the Serious Emotional Disturbance Waiver or the Frail Elderly Waiver. No other demographic information was collected.

Survey

The goal of surveying families of people with disabilities and special health care needs was to explore the impact of changes made to HCBS policies in the state in response to the pandemic in four areas: utilization of telehealth; paid caregivers or family members providing specialized medical care; paid caregivers or family members providing personal care services, and access to additional hours of personal care services. For each of these four areas, survey respondents were first asked to indicate if they had received this service during the pandemic (yes/no). If they had accessed the service, families were asked to rate how important it was to them during the pandemic (1-10 scale; not important to very important). Additionally, if

families accessed the service, they were asked to provide open-ended responses to two additional questions: (1) What accessing the service meant to their family during the pandemic and (2) What were they most concerned about if service went away when the pandemic was over. There were also additional, specific questions for some of the service areas based on specifics of the policy changes. For telehealth services, families were also asked to list which medical providers they had seen over telehealth. For paid personal care services, families were asked if they had utilized a sibling between the ages of 16-18 to provide services, as this was allowed under the changes. Finally, for additional hours of personal care, families were also asked if they planned to keep children in a learning environment other than in-person school (e.g., online school, remote classroom, home schooling).

Analysis

For the yes/no questions (i.e., did you access the service) and ratings of the importance of the services, descriptive statistics were calculated. Open ended responses to questions about each of the services were analyzed using content analyses to gain a deeper understanding of families' experiences of these services. Due to an overlap of the responses to the questions about what the service meant and concerns if it were to stop, responses to each question were analyzed together, within each service area. A postdoctoral researcher, who identifies as a person with a disability led the coding. Coding was organized within each of the four service areas, to identify key themes related to each service area. Additional coders were: A family member of a transition-age youth with a disability who has extensive knowledge of disability policy in Kansas and two researchers focused on HCBS waiver services and experiences of people with intellectual disabilities during COVID-19, one of whom experiences disability. These team members engaged in an iterative coding process, with the initial codebook developed by the

postdoctoral researcher and refined based on input and ongoing coding from the project team. The iterative process focused on identifying agreements and resolving disagreements with two to three meetings per service area to refine and apply codes (a total of 8-12 meetings). Agreements on initial codes ranged from 87-96% across service areas. Disagreements were discussed until agreement on codes was reached. Once codes were agreed upon, the research team then collapsed codes into themes for each service area, identified the frequency of each code and theme, and identified representative quotes illustrating each theme.

Results

We present results organized by the four areas where policy changes were made: telehealth services, paid caregiver or family member specialized medical services, paid caregiver or family member providing personal care services, and additional personal care services. [Table 1 provides information on the number of families that accessed each service and families' ratings of the importance of these services, as calculated by the state.](#)

Telehealth Services

Receiving medical services via telehealth was the most frequently accessed service, with 50.5% of families accessing medical services through telehealth during the pandemic (see Table 1). According to family reports, the most accessed type of provider was primary care, followed by neurology, mental health, and gastroenterology. More than 50% of families that accessed telehealth during the pandemic reported seeing more than one provider via telehealth prior to the survey being distributed. The average rating of importance of telehealth by families that accessed these services was 5.96, slightly above the middle of the range.

Families were asked to identify what telehealth services meant to them during the pandemic and their concerns for if these services ended after the pandemic was over. While some

families (n = 10; 5% of families that accessed telehealth) identified that they did not value telehealth and did not want it to continue, a more common theme was that telehealth was important during the pandemic because it reduced exposure. Over 50% of families communicated the importance of reducing risk to COVID-19 exposure at the time they were surveyed. As one family stated, “I have 3 high risk children, 2 are moved out, but having the option to go virtual is so important to us because of the ever-increasing cases of Covid. I like the fact that we are still able to meet and discuss our concerns with the doctors without coming into close contact with others who maybe sick.”

Families also noted that this reduced exposure had potential benefits beyond the pandemic, and they would be concerned if it went away. “The pandemic forecast is unknown and leaves already fragile persons with mental and physical disabilities exposure to all kinds of bacterial infections, viruses, (chronic/acute) illness. Telehealth, and homebound services, are essential to preventative care. I am concerned that if these community resources are taken away our loved ones will become more sickly, hospitalized more frequently, or placed in long-term care facilities.”

Another common theme was that families perceived telehealth as more convenient and flexible than in-person and for these reasons, did not want it to go fully away. For example, noting the convenience of telehealth, one family commented, “Did not have a 4-hour drive, loading and unloading child, transferring equipment and supplies. Much easier on us as a family because we did not have to find someone to stay with our children that did not have an appt. Loved it all around!!” Families also noted that, “If the pandemic is over, it won’t be so crucial – however, it’s a great convenience – especially the out-of-town appointments.” Other families noted fewer scheduling difficulties. Additionally, families reported that there were mental health

benefits, “Our son has extreme anxiety at the doctor. Telehealth has helped us get medical advice without causing our son significant distress.” One family noted being concerned about having to “sit and wait for an appointment well past our appointment times causing meltdowns if they went back to in-person appointments.” Families also described financial benefits, reduction in travel time to appointments, monetary savings because of the elimination of travel particularly from rural areas and needing to take less time off work. For example, “Our doctors are two hours away and being able to do telehealth for follow-up appointments has been amazing! We are missing less work and school.”

Paid Caregiver or Family Member Providing Specialized Medical Services

A smaller number, but still almost a quarter (23.9%) of the surveyed families, reported having family members provide and bill for providing specialized medical services during the pandemic. This was rated very high in terms of its importance (9.08). Families consistently noted that the lack of ability to find providers to come into the home as well as their concerns about exposure made being able to provide and bill for specialized medical care extremely meaningful for their family. Families highlighted that the difficulty in finding providers was a problem before the pandemic and they were concerned it could be even more of a problem in the future if family members could no longer provide paid specialized medical services.

Two broad and intertwined themes emerged that were expressed by a majority of families that accessed this service because of policy changes. The first was the essential need for specialized medical care to ensure health and wellbeing of people with disabilities in the home before, during, and after the pandemic. The second was the benefits of additional income to support the person and family needs. For example, one family noted, “We could not find providers willing to provide the care. It is always challenging with three sons on the spectrum,

all with different behaviors and challenges, but now even more so. Because of the lack of workers, my husband and I took time away from work. The payments helped with gas to travel, groceries, and house utilities (gas, electric, etc.)...It has truly been a blessing for us.”

Also showing the intertwined nature of these themes, another family noted, “It has been so nice since we lost our day nurse during the pandemic. Our day nurse travels from house to house and I was very uncomfortable with her being in the homes of others and potentially putting my daughter at risk coming to our house. It has allowed me to be paid since I can’t do much work outside the home due to caring for my daughter.” Similarly, another family described their situation. “Even before the pandemic, we were never fully staffed, and the nurses we had were unreliable and often exposed my son to additional illnesses. I was never able to keep a job due to unreliable help, and our financial resources were often strained. As it stands now, I have been able to receive an income while working for him and limiting his exposures to keep him healthier. I have a wonderful nurse that helps 1-2 evenings a week, but she is part time because her other job pays her \$7 more per hour. We have been trying to get nursing help to go with him to school through 2 agencies, but there are no nurses available. I currently stay with him through the school day. I can't imagine with the pay discrepancy that there will be any more help available in the near future, so if I lose this benefit, I will be out of work while still caring for my son nearly 24/7.”

A related theme that was reflected by a smaller number of families was the life and death consequences of not being able to access care and how family members being paid for specialized medical care enabled families to support their family member to remain at home and not be institutionalized. “In our specific circumstances, our child would expire. Without a replacement for outside employment, our child would be forced into a nursing home or similar.”

A final theme centered on concerns for the future and the potential impacts on family financial and emotional wellbeing if this option went away. “It would be completely devastating to our family. There's no dependable help from family or nursing for me to be able to work somewhere else and I'm the breadwinner of the family.” Another family member said, “I have spent 8 years struggling to keep my employers happy with me when I am constantly having to leave early or call in from work because my son is frequently ill and can't go to school or feels unwell and has to come home early from school. It has been an amazing weight of stress off my shoulders for the first time in 8 years to not have to worry about a phone call requiring me to leave every single day I go to work. Not having to constantly apologize and beg for forgiveness for my unreliability to my employer has been unimaginably life changing to me, my family, and all of my kids.”

Another family shared, “Before we were able to be a paid caregiver, we were on government assisted programs like WIC and SSI. If this option goes away, we will be forced to go back on government assistance. Again, being a paid caregiver has stabilized our home financially. That is only GOOD for Kansas families and for our medically complex children. Our children are assigned a certain amount of hours because the need is there. This is verified every 6 months. Let us care for our children. Do not force us to bring a stranger into our home to care for our child, then leave when a better paying job comes along.”

Paid Caregiver or Family Member Providing Personal Care Services

Almost 40% of families reported having a family member provide paid personal care services during the pandemic. Of the 155 families that utilized this service, 18 (11.6%) reported having a sibling between the ages of 16 and 18 provide these services. Families also rated this as very important (9.03; see Table 1). Four key themes emerged from family member's open-

ended responses. There was some overlap with themes reflected in the specialized medical services area.

The most common theme, noted by 37.8% of families, was the impact of having additional funds to provide care and support for the family member with a disability during the pandemic. For example, one family said, “It's been extremely important. There have been months where I am not working and at home in order to provide the personal care services my son needs. The pay for the services allowed for income during this time to provide him with what he needed and keeping him safe first, which is why I had to stop working.” Another family described that, “One of my daughter's caregivers quit and finding another caregiver has been impossible right now. By allowing me to work with her for pay, I have been able to maintain her routine of integrating in the community with volunteer work and other things.” Another family said, “My child was still able to work on his goals, skills and future plans.”

Families also noted benefits for the entire family, “The extra income helps us keep afloat of course but the bonding and respect for each other has become much stronger. You each can interact more effectively and a better understanding of each other.” One family member said, in expressing concerns about this option going away, “Families (including ours) can't help their situation because one income isn't enough when you have kids with multiple diagnoses like we do. We can't work more hours in a day. We're exhausted as it is. We don't get the breaks in care that normal families get. And eventually, we will also become ill with our own health issues if we don't keep this financial relief that has happened during the pandemic. With this extra income, a huge amount of financial burden has been lifted. I'm fearful it will all come back should this new income go away.” Similarly, another family noted: “When I was not working last year but was home with the kids, it helped immensely to be able to pay bills. Many times, I

have to take off work to do things for my child and that is lost income. I'm a single parent and any lost income is detrimental to us.”

Families also noted less need for additional, external financial supports, “This has allowed our family the financial independence to get off state help. It has allowed us to provide the needed equipment for my daughters care that Medicaid has denied. It has allowed us to have a reliable and trustworthy care provider (as in past we have had many issues with unreliable and abusive nurses and PCAs).”

Another related theme identified by over a quarter of families was the increased access to needed supports when family members could be paid. As one family said, “My son’s care is complicated and finding someone willing to work for state provided wages is difficult. Being able to include family members in the search helps a lot.” Another mother said, “My Mom is an attendant for my son while I work. I'm a single Mom (no child support) -- and I have to work for insurance and income -- so it's very nice to be able to hire my Mom/Grandma to watch my son -- because she knows him so well and takes excellent care of him.” Another family highlighted how losing these supports is raising concerns. One family said they were “concerned about how difficult it will be to get helpers and caregivers. It was difficult enough before. Now even more so, and they have to be vaccinated too? More hurdles.”

The pervasive issues related to finding personal care services were noted by a large number of families, before, during, and – as these families highlighted – potentially after the pandemic. As one family member described, “I have had a very difficult time finding workers to cover shifts even before Covid. During Covid it would have been impossible. The amount and level of coordination it has taken to schedule my workers, keep up on workers, etc. is incredible even in the best of times. The level of stress and anxiety not knowing if you have a care shift

covered during working hours is another layer of stress on the family. On top of that, the last-minute cancellations that come with home caregivers and unreliability make stable 8-5 employment without a flexible boss not feasible. The up and down health of my child also makes managing employment difficult.”

A smaller number of families noted impacts and concerns around health and safety, particularly around COVID-19 exposure. As one family described it, “It kept strangers out of our home. It let us keep a safe bubble and security in knowing we are safe.” Another family member said, “We have been able to keep our son safe and don't have to worry about someone coming into our home and getting him sick.”

Finally, several families noted the importance of being allowed to be paid during this time because of new and different financial demands, saying, “More purchases had to be made for food, entertainment and home activities and this has assisted in the budget.” Another family, noting that multiple family members lost their job during the pandemic, stated, “This allowed our family to survive and stay safe. Our main care providers decided to not work during the pandemic due to their own health complications. We could not risk hiring new staff and jeopardizing getting exposed to Covid. Our son was able to receive the best care while staying safe, and our family was able to survive.”

It is important to note a very small number of families did report that they wanted to transition back to paid external supports and services. One family said, “I'm not concerned about it (paid family caregiver support) going [away] after the pandemic is OVER. At that point we can have workers back in our home.” Another described that, “I would prefer to have outside help rather than my husband providing services because of the physical, mental and emotional demands it places on us 24/7. It is exhausting enough to take care of our son when we do have

help for most or all of our hours. We usually have about 50 hours a week of paid help through day services and in-home services, but my husband is only allowed to use 40 hours even when we don't have staff to cover any hours. So, we are providing for the needs 24/7 and that is not what we want for us or our son. We much prefer to have paid staff working with him directly instead of family providing the paid support.”

Additional Personal Care Services Hours

Close to 20% of families reported seeking out additional personal care services hours, and of the 77 families that did, 16 of them identified that their family member was remaining in a different learning environment (e.g., online school, remote classroom, home schooling) during the pandemic. Some families, due to the waiver they were on, reported not being eligible for additional hours. Families that were able to access additional hours, rated it as an 8.18 in terms of importance. Three main themes emerged in families’ responses to the open-ended questions.

First, the responses reflected how these additional hours filled a critical need for respite services that were otherwise unavailable, especially during the pandemic. One family describe it as, this “provides much needed respite for parents, especially at night.” Another described it as, this “allows me to be human – shower, run errands, care for my older son.” Another commonly identified theme was that it allowed for “filling in” of additional support needs introduced by the demands of the pandemic. One family described how being home, together 24-hours a day without school or other supports necessitated “more time and effort to keep him active and learning.” As another family described it as, “We had to find personal care providers to facilitate her online learning and keep her busy so we could continue working. Without this support, one of us would have had to quit our job to stay home with her.” Another family said, “Unlimited hours allowed us to pay for full-time teaching/school hours during the school day

while my child was remote. It allowed for evening and weekend care (as needed.) My spouse is a health professional so the majority of family tasks fell on my plate and could only be done outside of my full-time job hours.” As one mother summed it up, “I went from a mom of an autistic child to also a special ed teacher, a speech therapist, occupational therapist, physical therapist and a autism worker all in one day! Of course, that is a huge learning curve and I needed much more time to figure out how to do these services and how to do them successfully at best. As I'm not versed on any of these positions.”

Additionally, family members noted how their career demands changed during the pandemic necessitating more support hours. “My husband and I are in the medical field as well and have had to work additional hours because of the pandemic so this has allowed us to have care extended.” Finally, families noted how accessing additional hours filled in gaps in supports and services that were always present but were exacerbated during the pandemic. One family said, “Our daughter has seizures at night. It has been beneficial to increase our hours to cover nighttime help to keep her safe. It was also helpful when my daughter was doing remote learning.” Another family member said, in relation to concerns about this service going away, “I just can’t do this on my own anymore and give them everything they need. Someone would need to be placed. That not fair to me or them. They have a loving home.” Another family elaborated, “I would be most concerned with having enough hours to cover the school day, especially since him being homeschooled has nothing to do with COVID.” Families also noted concerns with summer supports. As one family said, they feared “the 12 hours a day limit being reinstated. We struggle each summer to cover the workday and baseball games. Our child on a waiver does not like watching his brother play and would prefer to stay home. Having some flexibility has been so appreciated.” Relatedly another family noted, “We really don't want to expose our

daughter to the activities of our older children we have to attend. It is wonderful to be able to leave her at home in a safe environment.”

One family shared their significant concerns about the future, “The need for stable, consistent care is not going to go away. It’s only going to become more exasperated due to everyone losing their paid caregiver status. Government assistance programs will be flooded with applications again. Parents will be forced to find work that takes them away from the critical caretaking of their children. Children will be left without care. They’ll miss appointments, therapies and eventually regress, resulting in more appointments and therapies. The cycle will only continue.”

Discussion

This study sought to understand family perspective on policy changes impacting Medicaid funded HCBS LTSS for people with intellectual and developmental disabilities enacted during the COVID-19 pandemic. A survey distributed to families sought to understand (1) utilization of services allowed under the policy change, (2) family’s experiences if their family member with a disability accessed the services, and (3) family’s perspectives on the need for ongoing changes in the future. Four main service areas were explored: reimbursing for telehealth, allowing families to bill for providing specialized medical care, allowing families to bill for providing personal care services, and increasing available hours for in-home services. Overall, the results from the survey suggest that a subset of families took advantage of flexibilities introduced into service delivery models during the pandemic, and the changes – when accessed - addressed important needs. Further, families wanted these flexibilities to continue beyond the pandemic to address ongoing challenges in existing systems of care for people with disabilities living in their communities (Hewitt & Nye-Lengerman, 2019).

Half of families (50.5%) reported accessing telehealth services, with half of these families reporting seeing more than one provider via telehealth. Families rated this as average (5.96) in importance, on a 10-point scale. This was the lowest rating of the importance of any of the service flexibilities (see Table 1). Approximately 50% of families whose family member with a disability utilized telehealth said that this was important to reduce exposure, particularly for high-risk family members. Smaller numbers of families suggested that telehealth addressed important issues that would extend beyond the pandemic, including supporting family members with disabilities who struggled with transitioning to physician's offices, dealing with delays at medical appointments, as well as transportation/driving demands of appointments, particularly from rural areas. This relatively low rating of importance may reflect some families not preferring telehealth or wanting options for in-person visits or procedures that were not available during the most restrictive periods of the pandemic. [Overall, however, the findings suggest the importance of providing options and choices regarding telehealth in the future aligned with family preferences considering the type of appointment and the travel / transportation demands as having this option appeared to be beneficial for families that utilized it.](#)

It is important to note, however, that 49.5% of families did not report accessing telehealth for medical appointments. [Ongoing research is needed to better understand the characteristics of families and family members with disabilities who reported benefiting from telehealth to further tailor ongoing access options. Additionally, ongoing research should explore families that did not report utilizing these services.](#) For example, were there no medical needs during this time for the person with a disability? One family noted, "While we did not have a reason to need to utilize telehealth services, knowing we had the option was comforting." Or, was care delayed because of a range of factors, including lack of comfort with telehealth, lack of knowledge of

telehealth options, or lack of access to technology to engage in telehealth? While these numbers are consistent with other research on telehealth utilization in other disability populations during the pandemic (Friedman & VanPuymbrouck, 2021), ongoing research is needed to examine both the impacts of the pandemic on access to care as well as ways to ensure equitable access to telehealth, if this remains an option moving forward [as many families that utilized the service reported benefits of having flexible options](#). Other researchers have suggested there may be systemic barriers that limit access to and engagement with telehealth in some populations, including people with disabilities and people from marginalized backgrounds (Friedman & VanPuymbrouck, 2020). For telehealth to be a viable option to promote health and address health disparities, a specific and targeted focus must be placed on addressing equity through structural reform, reducing not exacerbating existing health and access disparities for people with disabilities and from racially and ethnically marginalized backgrounds (Anaya et al., 2022; Sabatello et al., 2020).

A smaller number of families reported accessing the additional flexibilities offered during the pandemic, including accessing additional personal care services (18.8%) and family members providing paid specialized medical services (23.9%). When accessed, these were rated as highly important by families, 8.18 and 9.08 on a 10-point scale, respectively. A larger number of families had a family member provide paid personal care services (37.8%), including a sibling aged 16-18 provide this service (11.6%), and also rated this flexibility as highly important (9.03). While it is widely acknowledged that supports in the home were critical during the pandemic for all families (Bradley, 2020; Neece et al., 2020; Nygren & Lulinski, 2020), only 19 and 38% of families reported accessing these additional flexibilities for those services in this survey. [Again, ongoing research is needed on the characteristics of families that utilized these flexibilities and](#)

the reasons they chose to access these services. Ongoing research is needed to explore the reasons some families did not access these services. Was it not relevant to their family's life during the pandemic or was it a lack of information and awareness of the flexibilities? For example, one family member wrote in response to an open-ended question about having a sibling between 16-18 provide paid personal care services, "I didn't know it was available to have a child between 16-18 sign up. No one told me that." Ongoing research is needed to better understand what influences use of these flexibilities, and if there are systemic barriers that create inequities in accessing these services that must be addressed if these options continue in the future. However, the current data does suggest that it was helpful for a subset of families to have this benefit, and that having this as an option in waiver services should be considered in the future.

Of families that did access additional service-related flexibilities, the overwhelming majority wanted these flexibilities to continue, in some form. It is important to note, a small number of families did describe wanting to go back to having paid supports from outside the family so that they could maintain their employment and roles as family members, not paid staff. This reflects the importance of having options for services and service delivery modalities in waiver services. Families noted the difficulties with accessing and retaining high-quality direct support and specialized medical care staff before, during, and, they anticipated, as we continue to move through the pandemic and into the future. The direct support crisis is well known (Laws & Hewitt, 2020); the perspectives shared by families highlight how the lack of options for families to provide these services has real consequences both for the person with a disability and the larger family structure they are embedded in. Families described how without having family members provide paid specialized medical and personal care services, their family members with

disabilities were at risk for needing institutional or nursing home care because of shortages and health or behavioral needs. The lack of access to external, paid supports often limited family members ability to work, maintain employment or grow their career, as has been found in other research (Banda et al., 2022). While the pandemic exacerbated this, families communicated this fear and a “teetering on the edge” of being able to maintain community living, despite ongoing policy changes such as the HCBS Settings rule that seeks to ensure access to community-based services and supports. The relationship of these stresses to supporting a meaningful quality of life for the family was clearly expressed and consistent with past research (Boehm & Carter, 2019). Families noted how, financially, extra resources introduced by family members being paid for providing services impacted their financial security, particularly given that the frequent difficulty with finding and retaining paid supports. However, without being able to consistently plan for outside supports of a level of quality that they trust, many families would prefer to organize their own services and pay themselves, consistent with the work they are doing and to supplement income to meet family needs. Families’ responses suggest they wanted to be trusted to do what is best for their family member and to also have access to supports that they can trust.

Overall, the findings suggest the policy changes implemented in the state to address pandemic-related needs were effective in supporting families that included a family member with a disability, although more research is needed on the characteristics of families that access these services and promote equitable access to the supports needed for community living for people with intellectual and developmental disabilities across the lifespan. The findings also make clear that the needs and challenges are not going to go away as we move through the pandemic and in fact many families worry that they could become even worse with the lack of available staff to support community living and participation. This highlights the ongoing importance of

[providing access to flexibilities as we continue to move through the pandemic and the public health emergency ends.](#) [There is an ongoing need to advance economic justice for people with disabilities and their families; families' stories about difficult choices between maintaining employment, caring for a family member, and meeting basic needs reinforce the need to address economic justice in the disability community and to consider how to do this in partnership with family support providers and people with disabilities \(Suarez- Balcazar et al., 2022\).](#)

Limitations and Future Directions

Like all research, there are limitations that must be considered in interpreting the findings and implications. [Data were collected by a state agency in one state, meaning the broad range of policy and practice changes across states during the pandemic could not be examined. Further, the survey was disseminated through social media and through requests to partner organizations to disseminate to families they supported. The survey was not directly emailed to all HCBS waiver recipients in the state. Thus, the total number of families that received the survey is unknown and the number of respondents reflects a low number in comparison to all HCBS waiver recipients in the state. It is also possible given the focus on family members completing the survey that more families that included children under the age of 18 accessed the survey. Various factors shape engagement in research, particularly in marginalized communities, and more work is needed to implement participatory approaches that engage people with disabilities and their families at all stages of research \(McDonald & Stack, 2016; Shogren, in press\). More targeted dissemination and recruitment efforts could be adopted in future research to ensure that all HCBS waiver recipients and their families or support teams are provided access and the opportunity to provide input through surveys, providing a more robust and representative perspective.](#)

However, even with these limitations, the numbers of families who reported their family member with a disability accessed these flexibilities in services was relatively low, suggesting that there was possible overall low up-take of service flexibilities in the state. More research is needed to examine what contributes to decision making about service utilization particularly as demographic data was not available to explore factors related to racial/ethnic marginalization or geographic locations of families. Additionally, the survey was only distributed electronically, potentially creating issues with access or engagement in the survey for some families. Given these issues, there is an ongoing need for more in-depth, mixed-methods research on the impacts of current and future policies and policy changes on families and family quality of life.

Finally, this research was intended to capture the voices and experiences of families of people with special health care needs, complex medical needs, or disabilities. However, people with intellectual and developmental disabilities within those families hold their own beliefs about their services and supports and critical areas of importance during the pandemic and in the future. Other researchers have found that people with disabilities hold unique insight into their experiences during the pandemic (Toste et al., 2021). Ongoing research is needed that explores and centers the experiences of people with intellectual and developmental disabilities both during public health crises (Sabatello et al., 2020) as well as in broader research seeking to understand supports and services, engagement, and participation in communities (Shogren, in press). An ongoing focus on advancing equity through policy changes that meaningfully address the crisis in community-based supports for people with intellectual and developmental disabilities is essential to enhancing health, wellbeing, and self-determination during and beyond public health emergencies (Bradley, 2020).

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Table 1*Families that Accessed Services and Ratings of Importance*

Service Area	Number (%) of Families that Accessed Service (<u>N = 410</u>)	Of Families that Accessed, Ratings of Importance (out of 10)
Telehealth	207 (50.5%)	5.96
Paid caregiver (i.e., family member) specialized medical services	98 (23.9%)	9.08
Paid caregiver (i.e., family member) paid personal care services	155 (37.8%)	9.03
Additional personal care services	77 (18.8%)	8.18