

The Case for Inclusion 2021



**A Special Report
on the Sustainability
of Community
Disability Services
in America**

caseforinclusion.org



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FOREWORD: A YEAR LIKE NO OTHER

In a word, 2020 was a year of chaos. In just days, COVID-19, which had hardly entered our national vocabulary by the start of the year, turned our economy, health care, education and political systems upside down.

On an emotional level, the pandemic has left people in a fragile state, triggering feelings of anxiety and isolation. For those of us who have watched loved ones suffer from or succumb to COVID-19, the chaos of 2020 has done irreparable damage to our psyches.

The trauma of the past year will continue to live on for all of us, but for people with intellectual and developmental disabilities (IDD), the effects of the pandemic are especially pronounced. The pandemic has left people with IDD more isolated than ever, struggling to understand why the world feels so fractured, so unfamiliar. Routines have shattered. Connections with loved ones have severed. Access to important places has been embargoed.

Meanwhile, the professionals who support our family members, friends, colleagues and neighbors with IDD are exhausted. They're exhausted by constant worrying. They're exhausted by the added steps necessary to ensure the people they support remain isolated from the virus but not from their communities. In some places, they're exhausted by the constant need to calculate the number of days they'll have to reuse their personal protective equipment (PPE) before they run out. And in nearly every corner of the country, they're exhausted by thinking things are getting better—only to see case rates, hospitalizations and deaths soar again.

As the ANCOR Foundation and United Cerebral Palsy began planning for the *Case for Inclusion 2021* in the midst of this chaos, we knew that atypical times demanded an atypical strategy. Since 2006, we have prided the *Case for Inclusion* on being an effective advocacy tool, and that doesn't change with this year's edition. But releasing a compendium of data that don't reflect the situation wrought by the pandemic simply would not be helpful to advocates calling for deeper investments in disability services.

Therefore, this year's *Case for Inclusion* departs from what long-time readers are used to. Whereas previous reports looked back at how well state programs supported people with IDD, this year's report instead takes a look ahead at what's next. It starts with an examination of where we've been over the past year and how it has changed our understanding of the cracks that long existed in our system. It then lays out our blueprint for how lawmakers at all levels of government can seize on this critical moment to both transition to a post-pandemic world and build from the lessons of COVID-19 to invest in structural changes that usher in long-term sustainability for community-based disability supports.

In all, this *Case for Inclusion 2021* Special Report seeks to capture the experiences, lessons and opportunities needed to bring an ambitious vision to fruition. While the past year has taught us never to be too confident about what the future holds, we anticipate publishing a *Case for Inclusion* that looks more like past editions come 2022, when data will begin accounting for the impact of the pandemic on community supports. In the meantime, we are grateful for the opportunity to engage with advocates like you to herald a new system for a more inclusive society.

The COVID-19 pandemic has amplified crises that have long plagued the Medicaid-funded system of community-based disability supports and services. That, along with the fact that extant data do not account for the impact of the pandemic on the Medicaid system and the people it supports, led UCP and the ANCOR Foundation to envision the *Case for Inclusion 2021* as a blueprint for a fundamentally transformed system of community-based disability supports.

The fundamentally transformed system we envision:

- Delivers higher-quality outcomes to more people.
- Supports people with IDD in the community and in the places where they choose to live, work and play.
- Prioritizes long-term sustainability by taking seriously the need for deeper investments in community-based providers and the direct support professionals (DSPs) they employ.
- Deemphasizes cost savings in favor of meeting people's unique needs, regardless of the severity of their disability or the complexity of their support plans.

The reforms needed to make this vision a reality generally support one of three broad objectives:

- 1 Resources for addressing providers' needs triggered by the pandemic
- 2 Resources and innovations for supercharging the direct support workforce
- 3 Innovations for empowering providers to improve quality outcomes

At the state level, this means making permanent the regulatory flexibilities established in response to the pandemic, such as retainer payments, payment of family caregivers, and flexibility to deliver telehealth services and virtual supports. Additionally, state governments should take steps to strengthen the direct support workforce, including by (1) expanding eligibility criteria to attract a larger pool of qualified DSPs, and (2) pilot testing the viability of value-based payment models.

At the federal level, both Congress and the Biden administration can take meaningful steps to ensure the sustainability of community services. These steps are outlined in the table below.

The Biden Administration Should...	The 117 th Congress Should...
<ul style="list-style-type: none"> • Incentivize states to develop and implement a plan for addressing each component of the direct support workforce crisis. • Require CMS to include Home and Community Based Services (HCBS) under the equal access rule. • Target DSPs with the incentives established by the 100,000 Caregivers proposal. • Direct HHS to fund alternative payment model pilot programs. 	<ul style="list-style-type: none"> • Appropriate additional funding for the CARES Act Provider Relief Fund. • Ensure community providers have sufficient access to staffing, PPE and technology. • Compel the Bureau of Labor Statistics to establish a Standard Occupational Classification for DSPs. • Provide funding to incentivize the development of DSP pipeline programs. • Pass the HCBS Infrastructure Act.

THE CRACKS IN OUR SYSTEM

For most of America, it was March 2020 when it became clear that we could not prevent COVID-19 from reaching pandemic status. While we may not have fully understood the depths of what such a crisis would bring, we knew that even the most immediate challenges would trigger significant distress.

For community-based providers of long-term supports and services for people with IDD, the beginning of the pandemic meant putting out fires left and right, discerning how to support people in their homes—with limited resources and where social distancing is virtually impossible.

First, consider the public health challenge confronting providers. To isolate the people they support from the coronavirus, providers found themselves scrambling to adopt safety precautions—despite a lack of clear guidance about which practices were most effective. To isolate their employees from the coronavirus, providers needed PPE, but significant shortages and inadequate resources made it hard to compete against other buyers in the marketplace. As a result, adequate PPE became the second-most-often cited concern among nearly 700 providers surveyed in the early days of the pandemic.¹

If PPE was the number-two concern, then staffing was number one. As day and employment programs closed to comply with states' lockdown orders, providers found themselves supporting people in their homes 24 hours a day—a proposition that continues to be extremely labor-intensive. Fanning these flames was the fact that many direct support professionals (DSPs) were compelled to leave the workforce—to care for a loved one who became ill, to care for children whose schools were closed, or out of fear of contracting the virus themselves.

Out of necessity, providers began incurring unthinkable overtime costs. According to the aforementioned survey, more than half (52%) of



Individuals supported by UCP of Long Island in New York.

respondents reported overtime expenses that far outpaced typical overtime costs, amounting to an annualized average cost increase of \$930,172. Payroll costs were further inflated when providers, realizing it was the right thing to do, began offering enhanced pay and more flexible scheduling to better support their essential workers. However, they did all of this without knowing if or when they would have the money to do so.

To say the least, these financial challenges continue to threaten the long-term viability of provider organizations. As of April 2020, more than two-thirds (68%) of providers reported having to discontinue one or more services, resulting in an average revenue loss of 32%. A follow-up survey of 191 provider organizations conducted in July 2020 found that 77% of respondents had discontinued at least one service, and among those, 16% anticipated the closures would be permanent, largely because of preexisting financial instability.² In fact, when the pandemic struck, the average provider had only enough cash on hand to maintain operations for a single month in the event of a significant loss of revenue.

Of course, these fires weren't new—they were just newly uncontained.

The IDD services system was long suffering the effects of a vicious cycle of inadequate staffing and resources long before 2020; the pandemic simply helped to fan the flames. The direct support workforce crisis was making recruitment and retention seemingly impossible tasks before COVID-19; as we reported in the *Case for Inclusion 2020*, states' average turnover rates exceeded 50%, in large part due to a median hourly wage for DSPs of just \$12.09.³

To put this in perspective, imagine yourself in the shoes of the typical DSP in America. You work 40 hours every week. You're highly skilled. You're drawn to the field not because it's lucrative, but because you believe in the power of inclusion for all. But you earn just barely above \$25,000 annually, and that's *before* taxes. Your best shot at earning something closer to a livable wage is to pick up several shifts of overtime each week, but working all those hours doesn't necessarily help you advance in your career.

And then...the pandemic hits. Suddenly, you realize that every hour at work is another hour to potentially be exposed to a deadly virus. Meanwhile, your son or daughter's school is closed and someone needs to be home with them to facilitate their online learning. You love working with the people you support, but *why not* leave the field? Is the money really worth the potential cost to your health and your children's education?

Let's say you decide to stay in your job. In that case, your new pandemic life involves the things you always did—helping people with activities of daily living, empowering them to connect with family members and friends, ensuring they have the medications they need and rides to their medical appointments when they need them, and so much more. But on top of that, you have a whole host of new job responsibilities. It is now your job to go out to procure groceries and essential supplies so the people you support aren't directly exposed to COVID-19. It is now your job to tell the family members of the people you support that to keep the virus from spreading, they aren't allowed to visit their son or daughter, their sister or brother.

THE HUMAN IMPACT OF THE DIRECT SUPPORT WORKFORCE CRISIS

Not long before the pandemic was declared, ANCOR surveyed its membership to identify the more personal ways in which the direct support workforce crisis was impacting providers' operations and the people they support. Here's how one Indiana-based respondent described it:

"Our organization can't move forward with new or innovative programs. Quality supports are sacrificed. We often provide the bare minimum because we don't have the resources to do any more. We have to say no to people who want our services because we don't have staff to provide the service. Coaching and supervision don't happen as they should because the individuals hired to do [management] jobs are spending half their work week doing direct support work. [...] All of this contributes to burnout, lack of quality and retention issues, and puts people at risk of abuse and neglect."

Now imagine that—despite all the hurdles you’ve cleared—you now need to defend the essential nature of your work to public health officials. Imagine hearing that despite being funded by Medicaid to deliver a wide range of supports to people in their homes where social distancing is not possible, the fact that your occupation isn’t recognized by the federal government means you may or may not be eligible for priority access to PPE, testing and, later on down the road, vaccination.

This scenario isn’t imaginary—it has confronted the 1 million workers who comprise the DSP workforce on a daily basis since the pandemic began. More importantly, this reality reveals that in addition to the short-term crisis facing providers, new challenges wrought by COVID-19 are exacerbating pre-existing cracks in the system that threaten the long-term viability of community-based disability services. In turn, the ability of people with IDD to be included in the community is in jeopardy—if providers go out of business, the people they support will have fewer options and resources to live, work and thrive in the community of their choosing. In that scenario, institutionalization may be the only option.

Troublingly, the increased vulnerability of these essential lifeline services comes at a time of already substantial unmet need among people with IDD. The Kaiser Family Foundation reports that at the end of 2018, there were nearly 590,000 people with IDD on states’ waiting lists for Home and Community Based Services (HCBS).⁴ As we discussed in the *Case for Inclusion 2020*, we know that although the Kaiser Family Foundation provides the best available data on states’ waiting lists, these estimates are conservative—they do not account for families that don’t opt into waiting lists, or for disparities in states’ methodologies for calculating and reporting unmet need.

Furthermore, those who were receiving services have experienced significant disruptions. In the most general sense, most community-based disability services are either residential services (i.e., those delivered in people’s homes) or day services (i.e., those that enable people to work or engage in activities in the community during the day). This latter category was hardest hit by the pandemic.

Because people were required by their states to stay home, day program facilities closed, and many who were previously engaged in supported employment saw their workplaces close as well. In turn, providers of day services were no longer able to deliver these essential programs, which meant they couldn’t receive reimbursement from the state, causing revenues to plummet. The revenue impact was felt by all providers of day services, but was especially devastating for those that only provide day services; with no revenue from residential services on which to rely, these providers faced the potential of going out of business permanently.

The disappearance of these services, whether temporary or permanent, continues to have a potentially calamitous impact on people with IDD. These services foster skill development, social interaction, community engagement and vocational training. In turn, they serve as a bridge to community building and a sense of belonging, knowing the value of an honest day’s work and, in some cases, financial security. These services are also vital for people who can live independently, as well as for family caregivers who rely on the respite these services provide.

In all, disability services are at a crossroads. The pandemic has cultivated new challenges, but it has also amplified cracks in the system that existed long before anyone had heard of COVID-19.



Three individuals supported by Cedar Lake, a Kentucky-based provider, at an event hosted by the agency (from left: Bethany, Jennie, Warren)

And, despite the resilience of providers—perhaps demonstrated more clearly in the past year than ever before—those cracks were becoming larger and deeper. Absent some significant intervention, the entire system was due to shatter.

In some ways, the pandemic may have been that intervention. Despite the darkness it brought for everyone in our country and across the globe, there have been some positive outcomes from the pandemic as well. Within the provider community, perhaps the most obvious silver lining was the range of legislative and regulatory changes that proved what's possible when community-based services can operate with the flexibility they need to succeed. Those flexibilities—as well as the precarious situation in which providers will find themselves if flexibilities are discontinued—are discussed in detail in the next section.

STORIES OF IMPACT: THANKS TO UCP OF STANISLAUS COUNTY, PEOPLE WITH DISABILITIES DON'T LET DAY PROGRAM CLOSURES STOP THEM FROM CONNECTING TO THEIR COMMUNITIES

Although all of us experienced the immense challenges that came in mid-March of 2020 when our lives were turned upside-down by the coronavirus, many people with IDD were disproportionately impacted, as the closure of day programs left them unable to connect with their friends, neighbors and others in their communities.

Fortunately, the most isolating impacts of the pandemic have been avoided by people leveraging the support of UCP of Stanislaus County (UCPSC). Following California's stay-at-home orders early in the pandemic, UCPSC secured a grant that ensured every person they supported had a device that would enable them to participate in day programs remotely. "Technology became our best friend," the agency's leadership proclaims.

The ability to receive supports via Zoom was a game-changer for people like Andrew, one of the participants in UCPSC's Turlock day program. "I enjoy visits with [direct support professional] Nicael because she helps me calm down, work on my goals and I have someone to talk to," said Andrew. Andrew's mother, Susan, reaffirmed Andrew's enthusiasm. "Andrew was emotionally falling apart at the beginning of COVID. I can say that he would not have survived COVID without Zoom classes and [the support of UCPSC]."

UCPSC was fortunate to have received grant funding to transition its services to online formats. However, it will be essential for the thousands of other providers in the country to have access to funding, training and technology so that supports can continue to be delivered remotely, both as the pandemic persists and beyond.

A HOUSE OF CARDS REVEALED

The resilience of providers during the COVID-19 pandemic has been perhaps the biggest boost and the greatest threat to the future of the community-based disability services system.

Since the darkest days of the pandemic, we have heard story after story of providers and DSPs going above and beyond. We heard about Family Residences & Essential Enterprises, the Long Island provider that set up its own grocery delivery service to ensure that more than 80 group homes had what they needed while minimizing the number of people having to go out in public. We heard about the direct support professional at UCP of Georgia who taught a man she supports, Quanzi, to sew; with his new-found skill, Quanzi made masks for more than 60 of his agency's employees. We heard about the direct support professional at UCP of Georgia who taught a man she supports, Quanzi, to sew; with his new-found skill.



Quanzi, a man supported by UCP of Georgia, sewing masks with Annette, one of UCP of Georgia's Community Access Mentors

As a result, people with IDD in every corner of the country have been remarkably isolated from the worst effects of the pandemic. Every week, it seems that there's another breaking news story about how people with IDD are more vulnerable than the general population to the worst effects of COVID-19.⁵ But data from eight states representing about one-third of the U.S. population found that people with IDD who leveraged community-based services were no more likely than members of the general population to contract the coronavirus.⁶

This is perhaps the best news to be born of the pandemic. But the situations that have demanded providers prove their resilience have had an unintended consequence as well: they have revealed the fragility of the disability services system. Like a house of cards, providers have found themselves one minor crisis away from collapse.

Ironically, the fragility of the system has been amplified by several actions taken by state and federal governments that were designed to relieve the strain on providers. To be sure, many provider organizations have received financial relief, though that relief came neither quickly nor easily. Moreover, much of the effort to relieve the strain on provider organizations has come in the form of regulatory flexibilities which—though a godsend for many providers—were designed to be temporary. If suddenly taken away, providers face the possibility of falling harder and faster than they would have without these flexibilities.

In the remainder of this section, we take stock of the financial and regulatory relief issued by state and federal governments, noting that despite their overwhelmingly positive impact, they run the risk of collapsing this fragile house of cards if discontinued.



Eric and Sally, two people supported by Kentucky-based Cedar Lake, at an event hosted by the agency.

Economic Relief in Response to COVID-19

On March 27, 2020, then-President Donald Trump signed into law the Coronavirus Aid, Relief and Economic Security Act, better known as the CARES Act. At the time, the sweeping, \$2.2 trillion legislation was the largest economic stimulus package ever passed, and it authorized an array of relief spending. Among these programs were two that proved especially vital for Medicaid providers: the Paycheck Protection Program (PPP) and the Provider Relief Fund (PRF).

Although not specifically designed to aid Medicaid providers, PPP was established to furnish forgivable loans to businesses with fewer than 500 employees so workers could continue to be paid while businesses were closed. Essentially an effort to reduce strain on states' unemployment rolls, PPP helped many smaller Medicaid providers continue paying their employees. However, many providers were ineligible to apply because they employ more than 500 employees.

The second program, PRF, offered emergency relief tailored specifically to providers of an array of health care and health care-adjacent services, including Medicaid providers.⁷ Although the funding distributed through the PRF has been an essential lifeline, the rollout of the program was wrought with challenges. Before it could be implemented, states had to first furnish a curated list of providers in "good standing" to the U.S. Department of Health & Human Services (HHS).

FROM THE FIELD: MAINE PROVIDER FORCED TO MAKE IMPOSSIBLE CHOICES DESPITE FEDERAL RELIEF

Between March and July of 2020, John F. Murphy Homes in Auburn, Maine, lost an estimated \$5 million in revenue and incurred more than \$500,000 in additional expenses related to the pandemic. Because John F. Murphy Homes has more than 500 employees, it did not qualify for Paycheck Protection Program relief. However, as of August 2020, the organization had received \$924,000 from the CARES Act Provider Relief Fund.

Todd Goodwin, CEO for John F. Murphy Homes, noted that he was immensely grateful for the PRF resources his organization received, but they were far from adequate in preventing some impossible sacrifices. Some of the toughest choices Goodwin made included furloughing more than 300 employees, halting all employee raises despite the incredible work his staff was doing, instituting a hiring freeze, and delaying several initiatives designed to improve service delivery.

Fortunately, John F. Murphy Homes has been resilient, but countless other providers have faced similar choices—without the financial stability John F. Murphy Homes enjoyed prior to the pandemic. Whereas Goodwin's agency has managed to stay afloat, far too many others will not.

This may partly explain why it took 90 days from the authorization of the funding by Congress to the opening of the application portal by HHS. It's worth noting that the application portal itself was the source of many challenges as well, as it required complex information for providers, especially those with unique funding situations.

Together, PPP and PRF come nowhere close to making providers whole again following the devastating economic effects on community disability services. Nevertheless, these CARES Act programs have played an important role in sustaining provider organizations' operations.⁸

Regulatory Flexibility in Response to COVID-19

The effectiveness of the economic relief described above was maximized by several regulatory flexibilities authorized by the federal government. With remarkable speed, the Centers for Medicare & Medicaid Services (CMS) authorized states to request emergency waivers that unlocked a range of important flexibilities, including retainer payments to replace lost revenues, the ability to deliver telehealth services and more.

States took advantage of said flexibilities by activating two special waivers: Section 1135 and Appendix K of Section 1915(c). Section 1135 waivers primarily define flexibilities in the administration of states' Medicaid programs and included specific items such as suspending the requirement for prior authorizations, amending timelines on Fair Hearing Requests, and allowing out-of-state providers to deliver services. Appendix K waivers, on the other hand, more specifically apply to a state's 1915(c) waiver, which is a key vehicle for the delivery of the HCBS program. Some of the flexibilities granted to states by CMS through the approval of Appendix K waivers included the ability to temporarily increase service limits, the ability to modify person-centered plans using electronic signatures, and permission for providers to bill Medicaid for services delivered during the short-term hospitalization of a person receiving HCBS.

Although it was up to CMS to review and approve states' Section 1135 and Appendix K waiver requests, states played a key role in helping providers adapt to the pandemic. In preparing Section 1135 and Appendix K waiver requests, states made important choices regarding which flexibilities to pursue. Once these requests were approved by CMS, states maintained the power to decide if and how to implement the approved flexibilities. The significant differences by state in the experiences of providers as they manage through the crisis speaks to the important but uneven roles state governments have played.

CHECKLIST: KEY PREDICTORS OF PROVIDER SUCCESS

Providers operating in states that offered more of the following flexibilities have tended to fare better than their counterparts in states that offered fewer flexibilities:

- ✓ Retainer Payments
- ✓ Utilization of Telehealth Services
- ✓ Utilization of Virtual Supports
- ✓ Electronic Signatures
- ✓ Payment of Family Caregivers

The list of flexibilities states had the choice to pursue is too numerous to list here. Therefore, we focus specifically on regulatory flexibilities in two areas: those that have enabled providers to operate more efficiently given the capacity lost to the pandemic, and those that have been so essential that they demand to be made permanent. Regarding the latter category, providers have been forced into such a precarious situation that although these flexibilities were designed to be temporary, some of them risk jeopardizing the ability of providers to stay in business if discontinued.

Retainer Payments. For providers that had to suddenly discontinue or significantly reduce lines of service (e.g., day programs closed to adhere to states' stay-at-home orders), revenue plummeted. This sudden destabilization created significant uncertainty as to whether shuttered services would later re-open. By expanding "bed hold" provisions—those which dictate the payments providers can continue receiving during temporary disruptions in service delivery—retainer payments facilitated providers' ability to stay afloat while stay-at-home orders forced day services onto hiatus.

Utilization of Telehealth Services. For years, telehealth has been improving access to health care for traditionally disconnected populations, such as elderly patients, those living in rural areas, and those with lack of access to transportation. However, access to telehealth was previously limited for people with IDD as regulation failed to keep pace with innovation. The ability to utilize telehealth during the pandemic improved access to specialized health care, whether for COVID-19-related concerns or routine medical needs that posed greater threats when hospitals and health care facilities began treating COVID-19 patients.

FROM THE FIELD: ALASKA PROVIDERS LEVERAGE BENEFITS OF TELEHEALTH FLEXIBILITY

Clara Sanderson is the Senior Public Relations Officer for The Arc of Anchorage in Alaska. Sanderson's organization has been grateful for the variety of state and federal actions taken to support organizations like hers through the pandemic, but The Arc of Anchorage has especially appreciated the ability to deliver remote supports. "Our Behavioral Health team has benefitted from the State of Alaska's [regulatory flexibility] for therapy services to be available over the phone or video/internet so they could continue to support individuals through telemedicine access with our in-house medical provider for medications."

Despite the immense value of this regulatory flexibility, advocates in Alaska report that the state's waiver renewal application will reflect previous regulations, which did not allow telehealth and virtual supports. "The ability to take full advantage of these flexibilities has been a gamechanger," says Lizette Stiehr, Executive Director of the Alaska Association on Developmental Disabilities. "But while the state supports the goals of these flexibilities, Alaska is under immense pressure due to the pandemic, and officials have offered to consider adding certain flexibilities as an amendment after the waiver renewal submission."

Utilization of Virtual Supports. Shifting services such as community, day and employment supports from in-person to virtual (or a hybrid of the two) allowed people to stay home but continue to receive supports. Like just about everything else in 2020, disability supports shifted to video conferencing platforms, enabling providers to deliver creative programming and connect people to community events. It should be noted that the transition from in-person to virtual supports serves as a perfect example of how flexibility and diversity in services can improve outcomes for people with IDD. For some, in-person supports elicit the best outcomes; for others, virtual supports help people thrive. This flexibility has revealed a world of possibility for a future in which access to services is less dependent on things like transportation, weather, and individual comfort levels.

Electronic Signatures. A small provision with big impact was the flexibility to use electronic signatures on individuals' support plans. Previously, providers would spend hours chasing down signatures of meeting participants, sending documents by mail, and having to repeat the process when the postal service was hampered by delays. The long-desired flexibility to sign documents electronically created efficiencies in service delivery, thereby allowing case managers to keep up with the rapid changes in plans and services wrought by the pandemic. The new system has also allowed case management to be more accessible to people with IDD, enhancing their ability to more fully participate in the development and monitoring of their own plans.

Payment of Family Caregivers. Family caregivers are an important but overlooked piece of the support system puzzle. Even when augmented by paid caregivers, it is often the free labor of family caregivers that allows people with IDD to remain in their homes and communities. With the pandemic further constricting the direct support workforce, the flexibility to pay family caregivers became a lifeline for many.⁹ Paying family caregivers is a strategy for filling in many of the cracks in the Medicaid system that existed well before the pandemic; this strategy can help alleviate the direct support workforce crisis, enable people to choose from a wider variety of residential settings (e.g., host homes), and mitigate states' ever-growing waiting lists for HCBS services.



Tiante (left) and Michael (right), two men supported by Ohio-based provider Koinonia, with Mina Nardi (center), Koinonia Direct Support Professional and 2018 Ohio DSP of the Year



Deb, a woman supported by Maine-based provider Uplift, Inc. (at right), with Uplift Executive Director Heidi Mansir

In all, regulatory action at the federal and state levels has helped people with IDD and the providers on which they rely avoid the worst impacts of the COVID-19 pandemic. But as we look toward a post-pandemic world, providers now see a more precarious situation than the one they navigated before. Because of the capacity providers have lost to the pandemic, they cannot simply return to the way things once were. However, that is the precise burden being placed at their feet if the regulatory flexibilities described in this section are permitted to expire.

As we discuss in the next and final section, the permanent extension of these initially temporary flexibilities, along with a series of structural reforms, will be essential for providers as they transition away from pandemic-era operations, as well as for the long-term sustainability of the service delivery system.

FROM THE FIELD: IN LIGHT OF PANDEMIC, COLORADO LEAPS INTO ACTION

Although providers in Colorado aren't operating without challenges, the state's network of community-based services for people with IDD is faring well compared to its counterparts in many other states. In large part, this can be attributed to the swift and decisive actions taken by the state early in the pandemic. Among other steps the state took, Colorado:

- ✓ Authorized 100% retainer payments for Day Habilitation, Supported Employment and Prevocational services in March, and continued these payments until they were mandated to end by the federal government.
- ✓ Authorized temporary reimbursement rate enhancements for residential (which includes a family caregiver model), personal care and homemaker services to cover increased expenses related to staffing and PPE.
- ✓ Pursued Appendix K amendments to its HCBS waivers to include telehealth/remote services, flexibilities which preserved access to key services while helping to reduce potential for exposure to the virus among both staff and people supported.

According to Josh Rael, Executive Director of Alliance, these moves, as well as additional assistance the state is working on, continue to help providers minimize layoffs, furloughs, program reductions and closures, all while ensuring the highest-quality supports continue to be delivered.

A BLUEPRINT FOR A BRIGHTER FUTURE

A system of community-based supports that can meet the immediate needs necessitated by the pandemic and the transition to a post-pandemic world, *and* achieve long-term sustainability for the inclusion of people with IDD, requires resources that:

- 1 Address providers' immediate needs as the COVID-19 pandemic persists.
- 2 Supercharge the direct support workforce.
- 3 Cultivate innovations that empower providers to improve quality outcomes.

This section offers policy proposals within these areas that will enhance the long-term sustainability of community supports.

Note to the reader: In the remainder of this section, the use of the lightbulb emoji 💡 indicates a specific policy proposal that we believe should be adopted by state governments, the Biden administration, the 117th Congress or some combination of the three.

First and foremost, state Medicaid agencies should work with CMS to make permanent the following regulatory flexibilities, which were initially established in response to the pandemic and designed to be temporary.

💡 **Retainer Payments:** States should maintain expanded "bed hold" requirements to ensure that providers can continue to receive funding during temporary disruptions to service delivery.

💡 **Utilization of Telehealth Services:** States should continue to actively encourage the use of telehealth services so people with IDD can access routine medical care without having to travel to a health care facility.



Coco (left), who is supported by Ashley (right), a Direct Support Professional at Kentucky-based Cedar Lake

💡 **Utilization of Virtual Supports:** States should continue to encourage the delivery of virtual supports, such as the delivery of day programming using video conferencing technology, to expand the available choices, especially for people unable to participate in in-person programs.

💡 **Electronic Signatures:** States should continue to allow individuals' supports plans to be signed electronically.

💡 **Payment of Family Caregivers:** States should continue to allow people who provide support services to a family member with IDD to be paid for their time, to alleviate the burdens on both currently unpaid family caregivers and the overstretched direct support workforce.

The extension of these regulatory flexibilities is not only key to achieving each of the three objectives outlined at the beginning of this section—they're essential to ensuring that community supports don't go careening off the cliff. At the same time, these are far from the only reforms needed to ensure that system is situated on solid ground. There is an array of opportunities for state and federal governments to strengthen the service delivery system, each of which is outlined in the remainder of this section.

Addressing Providers' Immediate Needs During the Pandemic

Given how long the pandemic has persisted, the steps taken by state and federal governments to put providers on surer financial footing have been crucial but inadequate. Additional financial resources are needed, and Congress has the ability to authorize such resources.

💡 Therefore, the 117th Congress should ensure that community service providers have sufficient staffing, PPE, and equipment and training for telehealth by adopting legislation similar to Section 30103 of the *HEROES Act* (H.R. 6800; introduced by the House during the 116th Congress). Such legislation would create a dedicated increase in the Federal Medical Assistance Percentage (FMAP) rate for the HCBS program.

💡 The 117th Congress should also appropriate supplemental funding for the CARES Act Provider Relief Fund. This new spending should be automatically disbursed to providers for the express purposes of (1) increasing base wages for DSPs, and (2) endowing a pool of resources from which providers can draw to capitalize “hero pay” during this and subsequent emergencies.

Supercharging the Direct Support Workforce

The COVID-19 pandemic has only amplified the detrimental effects of a longstanding direct support workforce crisis. Efforts to strengthen this essential workforce should consider the immediate challenges of the pandemic, as well as the longer-term challenges confronting the provider community.

Fortunately, state and federal governments can partner together to advance these dual purposes.

💡 At the state level, Medicaid programs should consider expanding eligibility criteria for professionals entering the field of direct support, as doing so would broaden the pool of professionals to fill direct support roles. In doing so, it will be of utmost importance that states ensure that the workforce maintains its high standards for qualification. For example, such an expansion might include retirees seeking a second career, college students preparing for careers in human services, and family caregivers newly eligible to be paid for their labor thanks to expanded regulatory flexibilities.

At the federal level, the Biden administration should:

💡 Direct CMS to incentivize states to develop and implement a plan that addresses each individual driver of the crisis, including low wages, low reimbursement rates, high turnover and inadequate training.

💡 Require CMS to include HCBS under the equal access rule, which requires rates to be set to ensure equal access to services.

💡 Direct the Administration for Community Living (ACL) within HHS to work with states and stakeholders to develop strategies that address severe workforce shortages in Medicaid HCBS programs. One promising strategy is to specify DSPs as among the types of caregivers targeted by the incentives enumerated in the Biden-Harris “100,000 Caregivers” proposal.¹⁰

There are also meaningful steps Congress should take to improve recruitment and retention within the direct support workforce. 💡 In particular, the 117th Congress should compel the U.S. Bureau of Labor Statistics to establish a Standard Occupational Classification (SOC) for DSPs by adopting legislation similar to the bipartisan *Recognizing the Role of Direct Support Professionals Act* (H.R. 6045/S. 3369, introduced in the 116th Congress). Currently, DSPs are considered part of the same pool of workers as home health aides and personal care attendants, despite performing different and often more complex duties. Establishing a SOC would be the first step toward collecting data about the DSP workforce, which would support longer-term efforts to professionalize the workforce and inform policymaking.

💡 The 117th Congress should also establish pipeline programs for DSPs by furnishing enhanced administrative match funding and/or grant funding to states and/or providers. Such funding would support pipeline initiatives that recruit, train and retain DSPs, and the establishment of these programs would improve retention and decrease turnover.

Supporting Innovation to Improve Outcomes

A key strategy for significantly improving the financial sustainability of the Medicaid disability services system involves piloting alternative payment models that compensate providers for the achievement of outcomes, as opposed to the traditional fee-for-service model which instead pays for the delivery of services in time increments. While some jurisdictions slowly transition to managed care through contracts with third-party managed care organizations (MCO), incentivizing providers directly would eliminate MCO administrative costs and create an opportunity

to redeploy resources into expanded services and improved compensation for DSPs.

Payment reform represents an opportunity for state and federal governments to work together, as the federal government can provide funding that states can use to test various options. 💡 Therefore, the Biden administration should direct HHS to provide dedicated funding for such pilots. In doing so, states should focus on alternative payment models that meet the range of criteria outlined in the 2019 publication, *Advancing Value & Quality in Medicaid Service Delivery*.¹¹

Beyond investing in the development and testing of alternative payment models, there have been multiple legislative efforts at the federal level to inspire innovation. 💡 For example, the 117th Congress should reintroduce and pass the HCBS Infrastructure Act (S. 3277). Initially introduced in 2019, the Act included several key provisions that would make structural improvements in the HCBS program by investing in funding to (1) assist states to comply with the HCBS Settings Rule, (2) implement quality measurement, (3) expand employment opportunities, (4) supercharge workforce development efforts, (5) promote employment for people with disabilities, (6) improve case management, (7) assist states in developing community housing, and (8) address necessary changes to HCBS to address COVID-19 risk.

Mobilizing an Engaged Constituency

There's one other element of our blueprint that will be critical to our ability to transform our system based on the vision described in this document: an energized and engaged constituency of advocates who are ready for a society defined by inclusion.

We know that ushering in this new system is both the right thing to do and the smart thing to do. But we also know the reforms described here won't happen overnight. We know that there will be those who resist change, just as they always have. They'll insist that change isn't possible, or that it'll cost too much, or that the system isn't that broken.

But *not that broken* isn't good enough when it comes to ensuring every person in our country—regardless of their ability—can live life without limits. If we are to take seriously the need to foster person-centered services supported by a robust direct support workforce, our future system must be built on policies that support flexibility. Such a system must be developed in partnership with the people it is designed to serve, in concert with their families and providers. It must reflect the values and needs of the people for whom the absence of such a system could make the difference between community inclusion or forced isolation.

A new system will require a variety of diverse efforts, but uniting these efforts will be a shared commitment to a fundamental culture shift—one that prioritizes the needs of people and communities over the push to deliver services at the lowest possible cost.

And although we're still reeling from the pandemic, the time to invest in this culture shift is now. For all the difficulties thrust upon the system by COVID-19, providers have proven their resilience. They've proven the lengths to which they'll go under the most overwhelming circumstances to ensure the people in their care are safe and healthy. Now it is

our turn to prove that their own resilience isn't the only thing providers have to fall back on.

Change can feel scary, especially when the status quo starts to feel comfortable. We become accustomed to longstanding processes. We get used to standard ways of working. We like the comforts of business as usual. But in this moment, hardly any of us can remember what business as usual looked like. Overnight, we were forced to evaluate what is most important and pivot each day to rise to unimaginable occasions. We've been calling the plays without any discernable playbook, and in the process, we have revealed the fragility of our system—but also the resilience of those who make it work.

Just imagine a system in which everyone can live where they want to live, in settings with fewer people, which we know are less likely to facilitate the spread of infectious disease.

Just imagine a system in which everyone can work in a job that is fulfilling and meaningful to them, with the support they need to thrive.

Just imagine a system in which states do not have hundreds or thousands of people waiting for services because providers have the qualified professionals necessary to support everyone in need.

This world need not be confined to our imaginations, and investing now will pay off in spades down the road. Just like managing through the COVID-19 pandemic has required previously unprecedented federal spending, so too will a functional, sustainable service delivery system require meaningful investment. And just like with COVID-19, we know that better outcomes make these investments well worth their while.

Ready to Join Us?

Above all, the *Case for Inclusion* is designed to be a tool for advocates who believe in the power of our vision. If you believe that this vision should be the blueprint for the service delivery system of the future, then we need you to be involved—you are an essential builder of a brighter future. If you're ready join us, here are three ways to take action today:

- 1 Visit the *Case for Inclusion 2021* website at **caseforinclusion.org** to access stories, data and other resources beyond this report that can aid in your advocacy.
- 2 Use the ANCOR Amplifier at **amplifier.ancor.org** to lend your voice to calls on our elected officials to take meaningful action in service of this shared vision.
- 3 Connect with a UCP Affiliate in your community at **[UCP.org](https://ucp.org)** to see how you can get involved at a local level.



**For all you do to
build more inclusive
communities for
people with IDD,
thank you.
We can't do it
without you.**

¹ *Impact of COVID-19 on Organizations Serving Individuals with Intellectual and Developmental Disabilities* (Alexandria, VA: ANCOR, 2020, May 1).

² *COVID-19-Related Losses and Increased Expenses: July 2020 Data on the Fiscal Impact of COVID-19* (Alexandria, VA: ANCOR, 2020, August 18).

³ *The Case for Inclusion 2020 Key Findings Report* (Washington, DC: United Cerebral Palsy & the ANCOR Foundation, 2020, February 6), 10-11.

⁴ "Waiting List Enrollment for Medicaid Section 1915(C) Home and Community-Based Services Waivers," Kaiser Family Foundation, accessed December 28, 2020.

⁵ See, for example, Alistair MacDonald and Caitlin Ostroff, "COVID-19 is Deadlier for People with Autism, Down Syndrome. Now Families are Pushing Hard for Vaccines," *Wall Street Journal*, 2020, December 23; Michelle Diamant, "COVID-19 Risk Varies Among Those with IDD, Study Finds," *Disability Scoop*, 2020, December 14.

⁶ Scott Spreat, Ryan Cox and Mark Davis, *COVID-19 Case & Mortality Report: Intellectual or Developmental Disabilities* (Harrisburg: Pennsylvania Resources for Autism and Intellectual Disabilities & New York Alliance for Inclusion & Innovation, 2020, October 27).

⁷ Eligible providers were initially compensated in the amount of 2% of their total "patient revenue" from the most recent fiscal year for which data were available (e.g., a provider whose total patient revenue in Fiscal Year 2018 was \$10 million received a \$200,000 direct deposit), and more recently, opportunities to apply for additional funds have been made available by HHS.

⁸ Profiles of providers that leveraged these CARES Act-authorized programs to weather the financial storm spurred by the COVID-19 pandemic can be found in *Racing Against the Clock: Preserving Disability Supports During the COVID-19 Pandemic* (Alexandria, VA: ANCOR, 2020, October 26).

⁹ Some states already allowed for the payment of family caregivers prior to the flexibilities established in response to the COVID-19 pandemic.

¹⁰ "The Biden Plan for Mobilizing American Talent and Heart to Create a 21st Century Caregiving and Education Workforce," Biden for President, accessed December 14, 2020.

¹¹ *Advancing Value & Quality in Medicaid Service Delivery for Individuals with Intellectual & Developmental Disabilities* (Alexandria, VA: ANCOR, 2019, January 16).

APPENDIX:

Regulatory Flexibility Authorization By State

The chart below offers an at-a-glance view of which states received authorization for the key regulatory flexibilities identified in this report and made possible through the federal Medicaid program's emergency waiver allowances.

	REGULATORY FLEXIBILITIES ADOPTED**				
STATE	RETAINER PAYMENTS	TELEHEALTH SERVICES	VIRTUAL SUPPORTS	ELECTRONIC SIGNATURES	PAID FAMILY CAREGIVERS
Alabama	✓	✓	✓	✓	✓
Alaska	✓	✓		✓	✓
Arizona	✓	✓	✓	✓	✓
Arkansas		✓	✓	✓	
California	✓	✓	✓	✓	✓
Colorado	✓	✓	✓		✓
Connecticut	✓	✓	✓	✓	✓
Delaware	✓	✓	✓	✓	✓
District of Columbia	✓	✓	✓	✓	✓
Florida	✓	✓	✓	✓	✓
Georgia	✓	✓	✓	✓	✓
Hawaii	✓	✓	✓	✓	✓
Idaho		✓	✓	✓	✓
Illinois	✓	✓	✓	✓	✓
Indiana		✓	✓	✓	✓
Iowa	✓	✓	✓	✓	
Kansas	✓	✓	✓	✓	✓
Kentucky	✓	✓	✓	✓	
Louisiana	✓	✓	✓	✓	✓
Maine		✓			✓
Maryland	✓	✓	✓	✓	✓
Massachusetts	✓	✓	✓	✓	
Michigan		✓	✓	✓	
Minnesota		✓	✓		✓
Mississippi		✓	✓	✓	✓
Missouri		✓	✓	✓	✓

APPENDIX: Regulatory Flexibility Authorization By State

	REGULATORY FLEXIBILITIES ADOPTED**				
STATE	RETAINER PAYMENTS	TELEHEALTH SERVICES	VIRTUAL SUPPORTS	ELECTRONIC SIGNATURES	PAID FAMILY CAREGIVERS
Montana	✓	✓	✓	✓	✓
Nebraska	✓	✓	✓	✓	
Nevada	✓	✓	✓	✓	
New Hampshire	✓	✓	✓	✓	✓
New Jersey	✓	✓	✓	✓	✓
New Mexico	✓	✓	✓	✓	✓
New York	✓	✓	✓	✓	
North Carolina	✓	✓			✓
North Dakota	✓	✓	✓	✓	✓
Ohio		✓	✓	✓	✓
Oklahoma	✓	✓	✓	✓	✓
Oregon	✓	✓		✓	
Pennsylvania	✓	✓	✓	✓	✓
Rhode Island	✓	✓	✓	✓	✓
South Carolina	✓	✓	✓	✓	✓
South Dakota	✓	✓	✓	✓	✓
Tennessee	✓	✓	✓	✓	
Texas		✓	✓	✓	
Utah	✓	✓	✓	✓	✓
Vermont		✓	✓	✓	✓
Virginia	✓	✓	✓	✓	✓
Washington	✓	✓	✓		
West Virginia	✓	✓	✓	✓	✓
Wisconsin	✓	✓	✓	✓	✓
Wyoming		✓	✓	✓	

Source: "Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19," Kaiser Family Foundation, accessed February 8, 2021

****NOTE:** Most states received authorization for multiple Appendix K waivers. In some cases, the regulatory flexibilities authorized may apply to some but not all of the state's approved Appendix K waivers.

About United Cerebral Palsy

United Cerebral Palsy (UCP) is an international charitable nonprofit organization.

Since 1949, UCP has promoted the independence, productivity and full citizenship of people with cerebral palsy, intellectual and developmental disabilities, and other conditions. Its mission is to be the indispensable resource for individuals with cerebral palsy and other disabilities, their families and their communities.

Through its 58 Affiliates in the US and Canada, UCP serves as a trusted leader, advocate and resource in the disability community by working to open doors to homeownership, health care reform, inclusive education, competitive employment, therapies, research and assistive technology.

To learn more, visit UCP.org.



About the ANCOR Foundation

For more than 50 years, the American Network of Community Options and Resources (ANCOR) has been a leading advocate for the critical role service providers play in enriching the lives of people with intellectual and developmental disabilities.

As the 501(c)3 charitable arm of ANCOR, the ANCOR Foundation exists to expand the commitment and capacity of providers and communities dedicated to improving quality of life for people with disabilities.

Learn more at ANCORFoundation.org.

