

ADVANCING DISABILITY EQUITY AND ACCESS IN TANF AND SNAP FOR PEOPLE WITH LONG COVID



Ashley Burnside, Elizabeth Lower-Basch, Teon Dolby, Parker Gilkesson, and Lisa McCorkell October 2022

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INTRODUCTION

People need health care, food, housing, and money to live, work, and thrive. The United States has public programs that help people meet these basic needs when income from work or other sources is not enough. But several of these programs come with work reporting requirements that deny assistance to people who cannot prove that they are working or participating in another countable activity for a specified number of hours each week. Programs with such rules include cash assistance under the Temporary Assistance for Needy Families (TANF) block grant and food assistance under the Supplemental Nutrition Assistance Program (SNAP, also known as food stamps).

These requirements are grounded in racist, classist stereotypes that assume that people will not work unless forced to do so. They are also based on an outdated understanding of disability that treats people as either completely unable to work due to disability or "able-bodied" with no work limitations.^{1,2}

One group that is particularly burdened by work requirements is disabled people. (Throughout this paper, we will use person-first and identity-first language interchangeably to reflect the varied preferences and identities of the disability community.) Due to the COVID-19 pandemic, more people nationwide now experience some form of disability. As of August 2022, **one in 13** of all adults in the United States report currently having Long COVID. This condition involves symptoms lasting three or more months following COVID infection that they didn't have previously.³

Long COVID can impede a person's ability to hold a job and restrict what work is available to them; this loss of income, in addition to increased medical costs, can cause economic precarity.

TANF and SNAP should be available to help people with Long COVID and other disabilities to avoid hunger and hardship. And yet, disabled people consistently face barriers in accessing these programs. Further, systemic inequities in being denied benefits, or losing them, most harm disabled people of color, individuals with low incomes, and those with marginalized identities. Federal, state, and local policymakers and administrators must make focused efforts to address the challenges that disabled people face in accessing and keeping TANF and SNAP.

This report recommends concrete actions policymakers and program administrators can take to improve accessibility of public programs for people with Long COVID and other disabilities. Throughout the report, we include quotes collected during interviews with people who have Long COVID about their experiences accessing public benefit programs and health care.

This report reviews the following topics:

- 1. An overview of disabilities and workplace barriers;
- 2. Processes that people with low incomes experience when applying for help under TANF and SNAP and what they must do to keep those benefits;
- 3. How disabilities in general and Long COVID in particular interact with the expectations of the public benefit system; and
- 4. Policy and program recommendations for federal, state, and local leaders.

BACKGROUND

Conditioning access to core basic needs programs on participation in work or work activities for a set number of hours a week – and on submitting documentation -- frequently results in undue stress and denial of benefits for people experiencing high levels of need.⁴ Other forms of administrative burden, such as excessive paperwork, frequent demands for medical documentation of exemptions, mandatory in-person meetings, and long hold times for phone assistance also result in the same outcomes.

Many people lose benefits when programs impose work requirements. This happens for a variety of reasons: unemployment; discrimination; caregiving responsibilities; lack of medical documentation; work hours that fluctuate depending on employer needs; or people failing to keep up with reporting requirements. Disabled people are especially burdened by these requirements.

In theory, people who have disabilities that either limit their ability to work, or find work, are supposed to be exempt from work requirements. But state implementation of these exemptions varies widely and can be very limited. Agencies do not always tell applicants about the availability of exemptions, and even those who know to ask may be denied. People who have a disability but who have not been approved for disability benefits and social insurance programs (such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), or Veterans' disability) often struggle to receive exemptions. People who experience health issues that are not externally visible and do not have a clear diagnostic test or timeframe for recovery are particularly at risk of being denied exemptions.

While these issues have existed for decades, we are now in the midst of a mass disabling event.⁶ One in five U.S. adults who get COVID develop Long COVID.⁷ Long COVID often stems from initially mild or asymptomatic infections. People of all ages, genders, races/ethnicities, and prior health statuses develop it. Younger people, transgender and bisexual people women, Hispanic/Latinx people, and American Indian or Alaskan Native people report Long COVID more often.^{8,9}

There are over 200 documented symptoms of Long COVID, including cognitive dysfunction (or "brain fog"), menstrual changes, post-exertional malaise, fatigue, changes to taste and smell, and tachycardia. While there is variation in the severity and duration of Long COVID symptoms, the disease often limits people's ability to work and/or the jobs that they have access to. One study conducted by the Patient-Led Research Collaborative found that two-thirds of respondents with Long COVID who had previously been working had to reduce their hours or could not work at all. ¹⁰ A survey conducted by the COVID-19 Longhauler Advocacy Project found that 44 percent of respondents have been out of work completely (67 percent of these for over a year) and 51 percent had to reduce their work to part time (63 percent for over a year). ¹¹ This, plus the increased medical costs of receiving adequate care, has had critical economic consequences for them and their families.

Over time, more people with Long COVID may need public assistance to meet their financial needs as well as the needs of their family. The COVID-19 Longhauler Advocacy Project's survey found that 41 percent of those whose employment had been limited by Long COVID reported that they either had applied for disability benefits or expected to do so soon. ¹² While some will eventually qualify for disability benefits, others will not, and many will need other financial support during the long period of waiting for their application to be reviewed.

Without critical policy and programmatic changes, people experiencing Long COVID are likely to fall through the cracks in the public benefits system and be denied basic cash and food assistance. Long haulers who have other marginalized identities – such as people of color, those with limited English proficiency, and those without prior relationships with a health care provider – are particularly at risk of being denied benefits.

LACK OF ADEQUATE WORKPLACE ACCOMMODATIONS RESULTS IN BARRIERS FOR PEOPLE WITH DISABILITIES

An individual with a disability is defined under the Americans with Disabilities Act (ADA) as a person who has a physical or mental impairment that substantially limits one or more major life activities; a person who has a history or record of such an impairment; or a person who is perceived by others as having such an impairment. This is the broadest legal definition of disability, while benefit programs use more narrow definitions. The lived experience of being disabled is unique to each person.

It's important to emphasize that just because someone has a disability does not mean they are unable to work. Many people with disabilities work full-time jobs and successfully complete the required tasks, especially when reasonable accommodations are provided to them. Under the ADA, workplaces are legally obligated to provide reasonable accommodations, but there is a lack of enforcement of the law and ways to track enforcement.

Workers also face challenges getting the necessary paperwork to receive needed workplace accommodations. Because of this lack of enforcement and challenges for getting accommodations approved, workplaces often do not provide any or enough accommodations for disabled people, and employers often have ableist expectations. As a result, some people with disabilities face discrimination through demotions, being fired, or needing to stop working for their own health. Until a variety of accommodations (e.g. telework, flexible schedules, reclining chairs, etc.) become more commonplace in work settings, and until we remove the ableist assumptions and narratives from workplace expectations, many disabled people will continue to be left out from engaging in employment opportunities, even when they want or are able to work.

Defining Ableism and How it Shows Up in the Workplace

Ableism is the discrimination and prejudice against disabled people. The phrase also is used to summarize the systemic barriers in place for people with disabilities that make it harder for them to achieve equity and access. One example of an ableist expectation in the workplace is an employer requiring all cashiers at a grocery store to stand up while working their shift, despite someone being able to complete the task just as efficiently while sitting down. This requirement to stand while serving customers doesn't consider the burden it places on people who have a disability that makes it harder for them to stand for periods of time. This is just one example of the ableist expectations that employers may carry that can cause workplaces to be less accommodating to disabled people. Making workplaces accessible for disabled people requires us to evaluate the ableist biases individuals may hold, and the systemic barriers in place.

COMPLEX DISABILITIES LIKE LONG COVID SHOULD NOT LIMIT ACCESS TO BENEFITS

All disabilities look different and impact individuals in different ways. This complexity, and the lack of flexibility in public benefit programs, can make it harder for people with disabilities to receive the supports that they need. The same disability or diagnosis may impact two people very differently.

The ways that disabilities impact people can change depending on the day and their environment. For example, someone who experiences chronic pain due to their disability may be able to work steadily and do an entire day's worth of work in one day. But on another day, they may be unable to walk for more than 20 minutes at a time due to muscle spasms. This person could meet a work requirement on some days but not others.

Some people with Long COVID experience post-exertional malaise, a condition where modest amounts of activity lead to an exacerbation of symptoms lasting for days or weeks, sometimes

described as "crashes." ¹³ If caseworkers don't understand how to accommodate a wide range of disabilities, they may fail to recognize that an individual qualifies for a work exemption.

The millions of people with Long COVID experience this firsthand. Long COVID is not well known publicly, and it is an illness that does not yet have a specific biomarker or diagnostic test identified. Its symptoms and severity can fluctuate frequently. This makes it difficult for a caseworker to understand what barriers a person with the illness faces and whether they can obtain and maintain employment. Lessons can be learned from other post-viral illnesses being diagnosed in people with Long COVID, such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and dysautonomia, but caseworkers may not be familiar with these illnesses either.

"X-rays, MRIs, certain blood tests all come back within a normal range, so they're [doctors] kind of at a loss, and say, 'well, we don't know what to attribute your symptoms to.'" – Lauren

MULTIPLE HURDLES CAN BLOCK NEEDED SUPPORT

Having Long COVID or another disability may mean an individual needs to attend more medical appointments. This also infringes on their ability to work full time, especially if they cannot find a job that offers generous sick leave policies or accommodations like flextime. Driving may be difficult or impossible, meaning they would require reliable and accessible public transportation to get to and from their work or medical appointments. This is hard to find, especially in rural communities. If their community doesn't provide such transportation services, this could be another factor preventing them from working or obtaining needed medical documentation.

Even if public transportation is provided, the travel itself can present challenges. Public transit trips may include standing, walking, climbing stairs, and unpredictable movement, which can be difficult for people who have fatigue, post-exertional malaise, and symptoms triggered by movement. But the disability determination process for public benefit programs does not always take these factors into account when assessing if someone can work.

According to polling of over 400 people experiencing Long COVID from the COVID-19 Longhauler Advocacy Project, 23 percent of those surveyed who are working requested workplace accommodations. Over half of those respondents (58 percent) were denied those accommodations.¹⁴

The changing nature of a disability can interfere with a disabled person's ability to work a certain number of hours per week consistently. The same is true of a lack of accommodations and ableist requirements of their workplace. Regardless of the barrier, people with disabilities should not lose access to critical public benefit supports like SNAP and TANF. Unfortunately, our nation has a long history of this happening, especially to disabled people who are not receiving disability benefits. Our interviews confirm that people with Long COVID who seek help from these programs frequently run into these longstanding barriers, and into new ones.

WHAT IS NEEDED TO GET HELP FROM TANF AND SNAP

TANF CASH ASSISTANCE

Cash assistance under TANF is limited to families with children who have very low incomes. Federal law mandates that TANF monthly basic assistance go toward "needy families," but each state gets to determine what that threshold is. In a little more than half the states, a family of three with earnings at half of the federal poverty level earns too much to qualify for cash assistance under TANF. Many states also deny benefits to families who have more than a minimal amount of savings or other assets.

States get to make other choices about eligibility criteria for TANF, such as the details of the work reporting requirements, the penalties for non-compliance, and how long a family can receive benefits. States can also add additional requirements, such as drug testing, child support enforcement, school attendance requirements, or immunization requirements.

APPLYING FOR TANF

Typically, TANF applicants need to complete an application either online, over the phone, or inperson at a benefit administering agency office. The application may require numerous forms to verify one's identity, residency, immigration status, income, assets, and other factors. This is often done via several appointments or phone calls. ¹⁶ Some states require that parents participate in a "job readiness workshop" or apply to a certain number of jobs before they can be approved to receive TANF. ¹⁷

Once the application has been processed, the applicant will typically be required to attend an orientation program that reviews program requirements and/or meet with a TANF caseworker before being approved to get monthly benefits. Some states use a private provider to administer the TANF work requirements. This means that TANF applicants may have to work with multiple agencies throughout the application process. ¹⁸

"I also want to flag the amount of stress and zigzags and the maze that chronically ill patients have to go through to try and navigate how they're able to access these benefits." – Karyn During the COVID-19 public health crisis, some states eased the burdens of applying for TANF. For example, some states temporarily removed in-person interview requirements ¹⁹ or made it possible to apply online for the first time. Some states also extended recertifications, so recipients didn't have to recertify as frequently to maintain access to their monthly benefits. These temporary policies made the program less burdensome to access for applicants and recipients. But overall, TANF reaches only a small share of the families who are struggling to afford their basic needs. ²⁰ According to the U.S. Department of Health and Human Services, just more than 1 in 5 – 21.3 percent – of families who are eligible for benefits received cash assistance in 2019. ²¹

To qualify for TANF, parents must generally work a certain number of hours per week or meet a work requirement through engaging in other qualifying activities. ²² Depending on the state, people who fail to meet this requirement—or who fail to submit the required documentation of their participation—can lose benefits. They may be dropped from just the adult's portion of a TANF benefit, or from the entire grant, including the portion allocated to children. During portions of the pandemic, many states suspended the work requirements and sanction policies and granted broad good cause exemptions for people receiving benefits. ²³

States have the authority to decide what activities count toward their work requirements. They can also decide whether to exempt disabled people, or people with caregiving responsibilities for an ill or incapacitated person, from the requirements. Nearly all states offer the possibility of such an exemption, or of a modification of the work requirements. However, states vary in how broad the exemption is and what documentation is required. (See Appendix Table A.)

Moreover, states with up-front job search requirements or orientation requirements frequently do not assess people for exemptions until after they have made their way through the application process.²⁴

"I had already submitted three doctors' letters recommending I didn't work. Their doctor reviewed my medical information and deemed I could work.... They really didn't care that I was sick." – Sara

OUTDATED MEASURES LIKE THE WORK PARTICIPATION RATE HURT STATES AND DISABLED PEOPLE

One of the reasons that states tend to provide extremely limited exemptions from work activities for people with disabilities is that individuals who are granted exemptions are not removed from the "work participation rate" (WPR). This measure is used by the federal government to make sure that states are engaging TANF recipients in work-related activities.

This rate measures the share of families receiving assistance who participate in a specific list of countable work activities for at least 30 hours a week (or 20 hours a week for single parents with one or more children under age 6). States that fail to meet this target face financial penalties.²⁵

An overwhelming majority of states currently far exceed their required targets. However, most states have not revisited their TANF policies in decades and continue to limit exemptions. Instead of implementing flexible and innovative policies to help families achieve economic mobility, most states still enforce outdated and restrictive requirements.

The WPR also makes it challenging for states to receive credit for providing appropriate activities to individuals with disabilities and to people who have other barriers to full participation. States do not receive partial credit when engaging recipients for less than the minimum required hours, even if they have modified the participation requirement as part of an accommodation required under the ADA.

Barrier removal activities such as mental health services and substance abuse treatment are only countable toward the work participation rate as part of "job search/job readiness," which is only countable for a few weeks per year. These requirements hurt people who can't work due to discrimination; lack of opportunity and workplace accommodations; disability; or caregiving responsibilities.

SNAP

Nutrition assistance under SNAP is available to a much broader range of people with low incomes. It is available at all stages of life; is not limited to families with children; and reaches people with incomes somewhat above the poverty level. In 2021, SNAP reached an average of over 41 million people a month, including children, students, disabled people, caregivers, seniors, and workers paid low wages. ²⁶ Benefits are set at a national level, and states are not allowed to add eligibility requirements. However, even SNAP has restrictions and requirements that act as barriers to access.

APPLYING FOR SNAP

As with TANF, the first step to receiving benefits is completing an application (which, depending on the state, may be combined with the application for TANF or other benefits). This application may be completed online, in person, or by phone. During this process, the applicant is asked multiple questions to determine their eligibility and may be required to submit verifications to prove their income and various expenses.

Applicants must also complete an interview in person or by phone with a caseworker. In some cases, this is combined with the initial application process. In other cases, the applicant must wait for a letter informing them of the time and date of their interview and then be available to answer the phone at that time. People applying for SNAP frequently cite problems in the application

process, such as receiving these notices after the time of their interview, not being called during the specified period, or facing long waits to speak with a caseworker.

Mandatory Education and Training Programs

States have the option to require certain individuals who receive SNAP to participate in employment and training activities.

Individuals are exempt from these requirements if they are:

- Under 16 or over 60;
- "Unfit for employment" due to mental or physical disability;
- Receiving unemployment insurance or TANF benefits and complying with the job search or work requirements of the program;
- Parents with dependents who are age six or younger or responsible for the care of a dependent who is "incapacitated;"
- Participating in a drug or alcohol treatment program;
- Employed or self-employed for at least 30 hours; or
- Enrolled at least half time in school, training, or another institution of higher education. (As discussed below, college students who do not meet another exemption are required to work 20 hours per week in addition to attending school.)

There is not a federal definition for "unfit for employment." Federal regulations require states to set their own definitions and procedures for verification but prohibit states from being less restrictive than the comparable definitions for TANF.

There is limited federal guidance about how state agencies should verify disability status and employment requirements. ²⁷ Usually, states require diagnoses from a medical professional, however, the documentation needed varies according to the state. In general, individuals approved for other disability benefits such as SSI are automatically exempt from work requirements.

State agencies typically use either documentation from the applicant or their own assessment to determine whether an applicant is 'unfit for employment.' Caseworkers face challenges in classifying whether an applicant meets this standard, especially in instances where there are fewer face-to-face meetings. Even when doing face-to-face meetings, caseworkers will still face challenges in classifying individuals with invisible or episodic disabilities.

In FY 2022, most states operated voluntary SNAP Employment and Training programs. They provided employment and training, as well as related supportive services to individuals receiving

SNAP benefits who chose to participate. Utah operated only a mandatory program, meaning that individuals could lose their food benefits for not participating. **Florida, Idaho, Mississippi, New York, North Dakota, Ohio,** and **Texas** ran both mandatory and voluntary programs for different groups of SNAP recipients. (Even in states that operate only voluntary programs, non-exempt recipients must register as looking for work, typically with the state SNAP agency or employment services. They must also accept a suitable job if offered one.)

Able Bodied Adults without Dependents (ABAWDs)

A smaller group of SNAP recipients are subject to an additional restriction that limits them to just three months of SNAP benefits in a 36-month period unless they are working or otherwise exempt. This population is between 18 and 49 years old; does not live in a household with a minor child (or is pregnant); and are deemed mentally and physically able to work. They are sometimes referred to as "able-bodied adults without dependents" or ABAWDs. Most workingage adults without minor children are subject to this time limit, unless they have a disability, or they report at least 20 hours of work or related activities each week. Federal regulatory language on the "unfit for work" provision specifies that states must exempt people who receive public or private disability benefits, whose unfitness is obvious to the State agency, or who have documentation from a medical professional. (See Appendix B for the SNAP regulatory language about ABAWD's time limit exemptions.) The differing exemption policies under the time limit rules and the general work requirements are a source of confusion for both applicants/recipients and caseworkers.

TIME LIMITS AND WORK REPORTING RULES HURT PEOPLE MOST IN NEED

This time limit has been temporarily suspended since March 2020. At the beginning of the COVID-19 public health crisis, Congress prohibited states from cutting people off SNAP due to the program's time limits unless they refused an employment and training opportunity offered through SNAP.²⁹ The time limit suspensions will end one month after the public health emergency (PHE) is lifted.

When in effect, this policy cuts off hundreds of thousands of unemployed people from food assistance when they need it most. ³⁰ Unlike work reporting requirements in most public assistance programs, SNAP time limit rules do not require states to offer options for meeting these requirements before cutting people off benefits. Historically, most states have chosen not to help people subject to the time limit find qualifying work or training activities. ³¹ Many individuals will lose SNAP if they cannot find a qualifying activity – which does not include job search – on their own.

People subject to the time limit can face a variety of challenges with keeping stable employment. During an Ohio Association of Foodbanks pilot period, work experience assessment specialists were able to complete evaluations of people referred to their work experience program because of the time limit. They found many participants faced barriers such as a lack of reliable

transportation; unstable housing arrangements; engagement with the carceral system; unstable work histories; or undiagnosed physical or mental disabilities. This is true even though such disabilities should have exempted them from the time limit in the first place.³² In particular, people in states that have not expanded Medicaid are likely to have trouble getting access to a doctor to document their disability.

States must carefully screen for exemptions from the time limit and connect recipients to necessary resources and information before ending benefits.³³ This should include exempting people experiencing Long COVID or who are at high risk of COVID complications from the time limits.

The work requirement policy stems from false assumptions that people receiving SNAP will only work when it is mandated. In reality, people who are receiving benefits want to work but may face significant systemic or individual barriers to employment. A much better focus for public policy is to invest in strategies that support people in having stable housing and affordable access to health care and other necessities. Such investments can help people develop skills and access training that prepares them for jobs that pay living wages. They can also foster an economy that creates more quality jobs with fair wages.

"I remember that on the phone call [with the SNAP interview], I had to verify my eligibility. They said that I was disqualified because I was a student.

And they asked me ... do I receive a certain kind of grant funding for school or was I qualifying for certain kinds of assistance for school, and because I didn't qualify for that they just said, 'You don't qualify for SNAP, sorry.'"

– Lauren

SNAP College Student Restrictions

SNAP imposes additional requirements on college students who seek food assistance. If students are attending school at least half–time and meet the standard SNAP eligibility rules, they may get SNAP benefits if they:

- Are employed at least 20 hours per week; or
- Meet other exemption criteria such as caring for a young child; or participate in a qualifying education and training program as part of their educational experience.³⁴

One of the qualifying criteria for an exemption is that they are "physically or mentally unfit" for work. As with the general work requirements, the rules for what qualifies a student for an exemption due to a disability, illness, or other health reason are set at the state level.

Documentation from a medical provider may be required if the unfitness is not evident to the State agency.³⁵

As a result, the U.S. Government Accountability Office has estimated that less than 40 percent of college students who are likely eligible for SNAP benefits actually receive them.³⁶ This estimate predates the COVID-19 pandemic and the temporary expansion of exemption criteria.

PUBLIC BENEFIT WORK REQUIREMENTS CAUSE BARRIERS FOR PEOPLE WITH DISABILITIES

Due to systemic and structural barriers, having a disability can have significant implications for whether a person can work or obtain work, whether they will be paid a living wage, and whether they will be able to achieve economic stability. Disabled people can be left out of our nation's public benefit programs due to their stringent work requirement policies.

Accessibility barriers and stigma among program staff and caseworkers are other common barriers for people with disabilities when they are trying to access basic needs programs. As a result, many disabled people are left without financial assistance for food and other essentials.

BENEFIT PROGRAMS DON'T ACCOUNT FOR REALITIES OF GETTING MEDICAL DOCUMENTATION

"Patients will have to keep up with when their waivers expire to ensure they're getting their medical appointments for that waiver on time, and by on time, I mean probably give your doctor's office at least two to three weeks because they have a form to fill out in addition to your appointment with the doctor." – Karyn

People seeking assistance through TANF and SNAP can address those programs' work requirements by providing documentation of their disability status to a caseworker. The documentation must prove that working a certain number of hours per week is not feasible for them due to their disability. This allows them to receive an exemption from the program's work requirement. (In some instances, recipients may qualify for a work requirement exemption for another reason, such as caring for a young child.) But the disability determination requirements to qualify for an exemption can be very narrow, typically requiring the receipt of government disability benefits.

In some instances, recipients must prove their qualifying disability exemption again after a certain number of months during recertification periods to maintain access to their benefits. The process can be cumbersome to navigate and expensive if insurance doesn't cover such appointments. This prevents many people with disabilities from easily proving their qualifying status.

The limited number of medical providers with expertise in Long COVID creates additional barriers, on top of those experienced by other people with disabilities. Some specialists are booked for 6 to 18 months out, yet benefit forms need to be completed every 3 to 6 months. Other specialists may not be covered by insurance, may be out of network, or may not accept Medicaid, which creates out-of-pocket costs for each appointment. These providers may charge more than the maximum TANF monthly benefit.

RACIST AND ABLEIST HISTORY OF WORK REQUIREMENTS

The inclusion of work requirements in TANF stems from the racist stereotypes that lawmakers and the public have about so-called "welfare" recipients.³⁷ In 1996, when lawmakers replaced Aid to Families with Dependent Children (AFDC) with TANF, President Clinton promised to "end welfare as we know it." One key change made to the program was implementing a work reporting requirement for people receiving cash assistance, as well as the work participation rate for states.

Work requirements are racist, classist, and ableist, rooted in the assumption that people receiving public benefits must be forced to work. It also stems from the false narrative of who is 'deserving' or 'undeserving' to receive financial support. Work requirements make public benefit programs less accessible and more burdensome for people in need of help and caseworkers administering the program. These false narratives about work requirements burden disabled people who may already face barriers in completing required paperwork, applying for programs, and working.



ACCESSING DISABILITY BENEFITS IS COMPLICATED AND TIME-CONSUMING

States largely get to choose what qualifies a person as being "disabled enough" to qualify for an exemption from the work reporting requirements in public benefit programs like SNAP and TANF. In many states, these programs only qualify people who receive SSI or SSDI as being eligible for the disability work requirement exemption. But SSI and SSDI have extreme qualification requirements that will ultimately leave out many people with disabilities who still face difficulty working a certain number of hours per week within current work structures.

For both SSDI and SSI, individuals are considered eligible for benefits if the symptoms of their medical condition(s) make them unable to engage in any "substantial gainful activity." This is a much more restrictive definition of disability than under the ADA and many other federal disability laws. Under this definition, individuals must not be able to engage in work they previously did, or do any other kind of work due to the symptoms of their disability. Their physical and/or mental symptoms also must be expected to last for at least 12 months or result in their death.

KNOWLEDGE GAPS OF EMERGING ILLNESS COMPOUND CHALLENGES OF EXTREME RULES

Because of these requirements, people with Long COVID have had difficulties being approved for SSI and SSDI. Due to a lack of provider education on post-viral illness, few providers know what tests need to be conducted to adequately document objective evidence of Long COVID and other post-viral illnesses. Providers often stick to basic tests that come back normal, despite the presence of debilitating symptoms. In post-viral illnesses like Long COVID, the correct tests being performed would likely show abnormal results.³⁸

This knowledge gap makes it difficult to provide documentation of disability. Overlapping illnesses like ME/CFS and dysautonomia are known to have a small recovery rate. However, judges and medical providers are often not willing to admit that a person's Long COVID may not resolve within 12 months.

SEVERE APPLICATION BACKLOG FURTHER HINDERS ACCESS TO BENEFITS

Even for those who will eventually be approved, the application process for disability benefits is time-consuming and onerous. Applicants wait an average of over six months for a decision of whether they are eligible for benefits, but many people who apply face much longer waits.³⁹ And the average processing time for disability benefits increased even more during the COVID-19 pandemic, rising by 46 percent.⁴⁰ As a result of the COVID-19 pandemic and Long COVID, there is an influx of individuals and families qualifying for disability benefits--but not the resources and staff available to meet the increasing demand. Nearly half of calls to the Social Security Administration (SSA) office go unanswered, making it harder for people to get status updates and support for their disability benefit applications.⁴¹ SSA also has a nationwide shortage of staff to process applications.⁴² The SSI application process is extremely backlogged, with over 1 million

disability claims pending.43

The Social Security Administration estimates that the average wait time for approval of the initial application of disability benefits is 3-5 months. But this doesn't include the time required to appeal a denial of benefits, which many applicants ultimately must do before being approved.⁴⁴

When someone appeals a denial, it can take days. After that, the next step is a hearing with an Administrative Law Judge, which is scheduled an average of a year later⁴⁵ Only about one-quarter of SSI applicants are accepted for benefits upon their first time applying for the program, and fewer than 4 in 10 ultimately end up receiving benefits.⁴⁶

Similarly, most SSDI applicants are denied due to the strict eligibility criteria.⁴⁷ SSDI applicants often must secure legal aid to help them navigate the process of receiving the benefit. And once SSDI benefits are approved, recipients must wait five months before getting their benefits (with exceptions made for people who have amyotrophic lateral sclerosis (ALS.)⁴⁸

Such a burdensome application process means many people will be deterred from applying for SSI and SSDI. People who have cognitive dysfunction, fatigue, and post-exertional malaise will have an especially challenging time jumping through the many hurdles required to apply for and receive benefits.

TANF and SNAP applicants, therefore, face many barriers in states that require SSDI or SSI receipt to qualify for a disability exemption given the many backlogs and hurdles to access either benefit.

STIGMA AND MISUNDERSTANDING ABOUT DISABILITIES ARE ANOTHER BARRIER

PEOPLE WITH INVISIBLE DISABILITIES, INCLUDING LONG COVID, FACE HARMFUL BIAS

Unfortunately, many people do not understand disabilities and how they can impact a person. For individuals who have invisible disabilities, which often include Long COVID, being perceived as disabled by a public benefit caseworker can be even more complicated. Some disabilities are not visible to a stranger in the same way as using a wheelchair or having a service dog. But invisible disabilities can still be extremely limiting to someone's ability to work, warranting workplace accommodations. They may result in physical pain that debilitates a person's ability to work. Despite this—and due to misconceptions and stereotypes about ability status—people with invisible disabilities are too often assumed to be non-disabled and not in need of accommodations.

Having an invisible condition can make a disability harder to 'prove' to caseworkers and medical professionals. For example, if someone self-discloses a disability that isn't physically visible to other people, a caseworker may not believe that they are impacted by their disability as much as they are. Securing medical forms from a doctor or specialist to prove the severity of the disability is cumbersome, expensive, and time-consuming. Medical professionals and program caseworkers may carry additional biases about COVID-19 and Long COVID, making the process even more

complicated for people with Long COVID.

DISABLED PEOPLE ALSO EXPERIENCE OTHER FORMS OF STRUCTURAL DISCRIMINATION

Whether a caseworker believes that a person is disabled and needs support is also rooted in that person's other identities. Someone's race, gender, and/or sexual orientation will have significant impacts on how people perceive them. It will affect whether other people believe the self-attestation of their medical background and pain levels.

For example, research has found that medical professionals falsely believe Black people have biological differences compared to white people that impact their pain tolerance. ⁴⁹ Research has also found that medical professionals are likelier to prescribe less pain medication and provide less aggressive treatment to Black patients when compared to white patients with the same injuries. ⁵⁰ These same biases could cause a caseworker to distrust or minimize a Black person who says they are disabled and in chronic pain, when compared to a white person saying the same thing.

Women also face gender bias from medical professionals when experiencing pain or other medical emergencies. One study found that women receive less aggressive treatment when in emergency rooms compared to men, even when experiencing the same levels of pain. ⁵¹ Women may be taken less seriously by medical professionals and caseworkers when describing chronic pain, fatigue, and other ailments when compared to men. Transgender individuals also face high rates of discrimination in healthcare settings and by healthcare providers. ⁵²

Long COVID is more likely to occur among women, transgender people, and people of color.

Many of these biases and dismissals will be present as they seek care, diagnoses, and benefits.⁵³

People with disabilities also face the complexity of needing to identify as disabled in order to access benefits. People who need accommodations and disability exemptions may not identify as being disabled, despite having physical, learning, or mental limitations that increase their difficulty engaging in activities of daily living and operating the daily requirements of a job. The identity of being disabled comes with stigma, stereotypes, and fear. Due to this stigma and ableism, some people are resistant to identifying as disabled. They may not know to talk to their caseworker about how their health, external physical barriers, or other people's biases limit their ability to work.

INFORMATION GAPS SERVE AS AN OBSTACLE TO BENEFITS

"I don't recall being asked about a disability [during my SNAP application interview], but if I had been asked, I don't know that I would have thought to say that I was disabled at that point. One: because I was still trying to work ten hours a week at least, and two: because I was still going through all of these doctors' appointments for testing, and it hadn't been officially classified as Long COVID at that point. So, it wasn't reflected in any of my medical records yet." – Lauren

Lack of knowledge and stigma are also barriers to applying and receiving benefits. To apply for public benefit programs, people need to know about the assistance programs they may be eligible for. Yet many people, especially newly disabled people, are not aware. This causes an additional barrier for those who aren't steeped in knowledge about the anti-poverty programs available to help people meet their basic needs. Further, public benefit programs have historically been stigmatized. This characterization causes another obstacle people must overcome to get the support they need and are entitled to. Cultural barriers and fear of immigration consequences are also factors that affect people's willingness to apply for help.

The disability determination process in public benefit programs relies on self-advocacy from disabled people. If someone doesn't know how to advocate for themselves and they don't have a lawyer or advocate with them, they may not receive the accommodations they need. And even if the person advocates for themselves, their disability may not be validated by others if it is invisible or if the caseworker doesn't believe them due to their own biases and stereotypes.

"You shouldn't have to fight to get your benefits when you're struggling to get out of bed every day, because you're so sick." – Sara

POLICY RECOMMENDATIONS

State and federal agencies and Congress could implement many practices to improve access to public benefits for people with disabilities, including those who have Long COVID.

STATE AND LOCAL BENEFIT ADMINISTERING AGENCIES:

LIFT BARRIERS AND IMPROVE POLICIES FOR DISABLED PEOPLE RECEIVING BENEFITS

- Accept medical documentation verifying a medical condition from a wider range of
 medical providers to reduce the need for applicants to reach out to specialty clinics for
 diagnoses. This reduces their administrative burden and need to wait months for
 appointments with these specialists to receive care and diagnostics. Do not require
 people who have medical documentation from their own providers to see a provider from
 an agency list—or to get the same information on a different form. Accept documentation
 from other professionals, such as social workers or homeless service providers.
- State agencies should expand disability evaluations to take into account structural barriers and ableist biases, like lack of workplace accommodations and access to/ability to take public transportation, in determining if an individual is unable to feasibly substantially work to meet program requirements.

- For lifelong disabilities, remove the recertification requirements for individuals to reprove disability at different increments to remain eligible for benefits like SNAP and TANF.
- Create guidance for public benefit programs about pandemics and endemics that
 takes into account people who are immuno-compromised or high risk and provide
 accommodations to help those individuals meet requirements such as tele-meetings or
 work requirement waivers.

STRENGTHEN ACCESSIBILITY IN APPLICATION TECHNOLOGY AND INTAKE PROCESSES

- **Create a single application** that can be shared by multiple public benefit programs to reduce application burdens.
- **Provide phone, in-person, and online options to apply for benefits** and for recertifications so that people can select the option that works best for them.
- Improve websites for accessing public benefits to ensure they are more streamlined, easier to use, and include simplified language in program applications. While this is helpful for everyone, it is particularly important for people experiencing fatigue, post-exertional malaise, and cognitive dysfunction.
 - Ensure there is an option for applicants to save their progress and come back to their application at a later time. Include progress bars in the applications so people can see how much further they have to go.
 - o Provide options to upload required verifications directly to the application.
 - Test and regularly retest websites to ensure they are screen reader accessible.

EXPAND OUTREACH EFFORTS TO MULTI-MARGINALIZED GROUPS

- **Expand outreach efforts**, particularly to multi-marginalized groups, so people with Long COVID who meet the income and work requirements will know that these programs exist, that they may be eligible, and how they can apply.
- **Expand and increase funding** for programs like SSI/SSDI Outreach, Access, and Recovery (SOAR) to employ navigators who can help guide applicants through the application and recertification process for multiple public benefit programs.

IMPROVE TRAINING TO BETTER SERVE PEOPLE WITH DISABILITIES

- **Provide caseworkers and navigators with competency and anti-bias training** on disabilities including content about Long COVID. Caseworkers and navigators should also be trained in trauma-informed support and cultural competency.
- **Train caseworkers** to ensure that they understand all program details including work requirement exemptions and that college students who are "unfit to work" are not subject

to SNAP's 20 hours per week work requirement. Caseworkers should be given clear desk references that guide them to ask questions about people's potential eligibility for exemptions.

THE U.S. DEPARTMENTS OF HEALTH AND HUMAN SERVICES (HHS) AND OF AGRICULTURE (USDA):

ENCOURAGE STATES TO IMPROVE BENEFIT PROGRAMS FOR PEOPLE WITH DISABILITIES

- The USDA and HHS should write guidance targeted at state agencies with
 recommendations to add Long COVID into the qualifying circumstances as a qualifying
 disability that can exempt public benefit recipients from working. In this guidance, the
 agency should clarify that states are allowed to make this exemption. Caring for a
 dependent child who has Long COVID should also be a recommended qualifying
 circumstance.
- **HHS should encourage states** to acknowledge their adjusted work participation rate when implementing TANF work requirement policies.

IMPROVE TRAINING TO BETTER SERVE PEOPLE WITH DISABILITIES

• Improve training. Mandate that local and state agencies provide caseworkers with cultural competency and anti-bias trainings on disabilities – including content about Long COVID.

OTHER FEDERAL AGENCIES, INCLUDING THE U.S. CENSUS BUREAU:

• **Strengthen data collection.** To assess the impact of Long COVID on the labor market and how best to accommodate workers, the Census Bureau and other agencies should collect data about how Long COVID has impacted people's ability to work. This should include disaggregated data based on race, gender, economic status, and sexual orientation.

CONGRESS:

- **Abolish program work requirements** and time limits for TANF and SNAP.
- **Remove asset caps** for TANF, SNAP, Medicaid, SSI, and SSDI to allow people with disabilities to build up savings.
- Remove the requirement of Continuing Disability Reviews (CDRs) every seven years for people enrolled in SSI in instances where individuals have severe medical cases with no opportunities for significant improvement.

• **Increase funding** for local and state navigators who can help guide applicants through the various public benefit programs' application and recertification processes.

"A judge whose education background is in law, not the human body, should not be the one to decide if you are 'truly' disabled." – Whitney

Model Disability Screening Questions for Caseworkers and Public Benefit Programs to Use:

Below are some model screening questions that caseworkers could consider using to evaluate disability/illness status among people applying to benefit programs.

Caseworker guidance/manuals and application forms for public benefit programs should include multiple questions to screen whether applicants/recipients have a qualifying disability that impacts their ability to meet program work requirements. Providing multiple questions accommodates the nuanced experiences of having a qualifying medical condition and results in a more comprehensive screening tool.

Below are some model questions that could be included in such screeners:

- 1. Do you have a disability?
- 2. Do you have a medical condition(s) or health issues that interfere with your ability to work? (For example, such medical conditions could result in chronic pain, fatigue, or memory loss, among other symptoms.) Note that these health issue(s) could be physical, mental, or emotional and may come and go.
- 3. Do you need accommodations from your employer to work due to a medical condition or health issues?

CONCLUSION

Public benefit programs like TANF and SNAP are critical to help people meet their basic needs when they cannot keep or find employment. This is especially true for disabled people, who have barriers to employment including discrimination and a lack of accommodations. Across the United States, more working-age adults are increasingly facing disabling conditions from Long COVID. While it may have varied symptoms, this emerging disability can severely limit a person's capacity to work, especially when employers fail to provide accommodations.

However, work reporting requirements and time limits push critical assistance out of reach of people with Long COVID and other disabilities. These policies fall hardest on disabled people of color, people with low incomes, and those with other marginalized identities. Obstacles from work requirement policies can also be compounded by other hurdles, which take many forms.

Policymakers and administrators at the local, state, and federal levels can move these benefit programs toward equity. Several solutions exist to ensure TANF and SNAP better serve people with Long COVID and other disabilities. Leaders can require program staff to become culturally competent, for example, and take steps to streamline and enhance accessibility of administrative processes. Changing harmful state and federal policies are also among other effective strategies to improve these systems.

In our nation's COVID-19 pandemic reality, a significant population will continue to face post-viral illness. As its debilitating symptoms put people out of work, they may seek assistance from TANF and SNAP to make ends meet. By adopting the recommendations included in this report, decision-makers can help such public benefit programs better meet the needs of disabled people, whether from Long COVID or other conditions.

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APPENDIX A:

State Policies: Whether Incapacitated Individual and Family Member is Exempt from TANF Work Requirement

Requirement			
State	Whether an Incapacitated Person is Exempt	Whether Family Member Caring for Incapacitated Person is Exempt	
Alabama	Yes ¹	Yes	
Alaska	Yes ²	Yes ³	
Arizona	Yes	Yes	
Arkansas	Yes⁴	Yes⁴	
California	Yes⁵	Yes	
Colorado	No ^{5,6}	No ⁶	
Connecticut	Yes	Yes	
Delaware	Yes ⁷	Yes ⁷	
D.C.	Yes ⁷	Yes	
Florida	No ⁶	Yes	
Georgia	No	Yes ⁸	
Hawaii	No ^{9, 10}	Yes ¹¹	
Idaho	No	No	
Illinois	Yes ²	Yes ²	
Indiana	Yes	Yes	
lowa	No	No	
Kansas	No	Yes	
Kentucky	No	Yes	
Louisiana ¹³	Yes	Yes	
Maine	Yes ¹⁴	Yes 4, 15	
Maryland	Yes ¹⁶	Yes	
Massachusetts	No	No	
Michigan	Yes ⁹	Yes ⁸	
Minnesota	No ⁹	No ⁹	
Mississippi	Yes ¹⁷	Yes	
Missouri	Yes ^{14, 21}	Yes ¹¹	
Montana	Yes	Yes ^{8,11}	
Nebraska	Yes ⁷	Yes ⁷	
Nevada	No	Yes	
New Hampshire	Yes ^{8, 16}	Yes	
New Jersey	Yes	Yes	
New Mexico ¹⁸	No	No	
New York	Yes ⁸	Yes ^{8,11,12}	

North Carolina ⁶	No ¹⁹	Yes ^{8, 12}
North Dakota	No ⁶	No ⁶
Ohio	No	Yes ^{11, 12}
Oklahoma	Yes	Yes
Oregon	No	Yes
Pennsylvania	Yes	Yes ^{11, 12}
Rhode Island	Yes ¹⁴	Yes
South Carolina	Yes ²⁰	Yes ⁸
South Dakota	No ⁶	No ⁶
Tennessee	Yes	Yes
Texas	Yes ¹	Yes
Utah ⁹	No	Yes ^{1, 11, 12}
Vermont	Yes ⁸	Yes
Virginia	Yes ⁸	Yes ⁸
Washington	Yes	Yes
West Virginia	Yes	Yes
Wisconsin	No ⁶	No
Wyoming ⁶	No	No

 $\textit{Reference: Welfare Rules Database, Urban Institute, AE_ILLPS and AE_ILLCT.}$

https://wrd.urban.org/wrd/query/query.cfm

Please note that the footnotes below are a condensed version of the notes included in the Welfare Rules Database. Additional details about the state policies can be found in the Welfare Rules Database.

¹ An individual is exempt if the injury or illness is expected to last a certain number of days.

² The state requires the incapacitated individual to complete a self-sufficiency plan outlining their self-sufficiency activities they will participate in. Some states may still sanction clients for non-compliance.

³ If the disabled person is an adult, the caretaker is exempt only if they are related to the person and providing 24-hour care.

⁴ A review of the exemptions occurs at least every 6 months.

⁵Does not apply statewide – only applicable to a particular county in the state.

⁶The state does not consider these groups technically exempt, but they may meet the state's criteria for good cause for noncompliance or deferral.

⁷ A recipient meeting this exemption criteria will be placed in a non-time limited assistance benefit group.

⁸ Client must provide medical verification or documentation for this exemption. In some states, this must be reassessed after so many months.

- ⁹ The amount of participation required from each recipient is determined on a case-by-case basis, typically through a review done by a medical board or a medical review team.
- ¹⁰The recipient is subject to sanctions for noncompliance with required activities that are described in their rehabilitation or treatment plan.
- ¹¹ To qualify for this exemption, the disabled individual must live in the same household.
- ¹² To qualify for this exemption, the disabled individual must be a direct relative, such as a child or spouse.
- ¹³ A good cause determination may be granted to a work-eligible recipient for no more than 6 months to temporarily excuse the recipient from participation in assigned work activities, if conditions exist that warrant approval of good cause by a supervisor. Good cause is granted when the work-eligible recipient is temporarily incapacitated, ill, or disabled, as documented by a medical professional, and for other qualifying conditions.
- ¹⁴To be exempt, an ill or incapacitated person must receive SSI. Some states allow receipt of SSDI or other disability benefits, or a pending application for these programs. Or, in some states, the head of household must be caring for a spouse who is receiving SSI.
- ¹⁵ The recipient is not considered to be personally providing care if the individual is a full-time student.
- ¹⁶Exemptions are limited to a certain number of months unless the individual has applied for SSI (or, in some states, SSDI) and the application is approved, pending, or in appeal.
- ¹⁷ If determined eligible for vocational rehabilitation, ill and incapacitated clients can be assigned to a work program activity.
- ¹⁸A participant may request a limited work participation status, as determined by the department. Individuals who demonstrate extraordinary circumstances may be granted zero hour limited work participations status.
- ¹⁹ A healthcare provider may limit the activities and participation hours for a disabled individual to less than 30 per week.
- ²⁰ Individuals with incapacities expected to last longer than 90 days are referred to the C.A.R.E.S. program. The medical incapacity is subject to reevaluation at intervals that are specific to each recipient's circumstances, at a minimum, annually.
- ²¹ In addition to exemptions due to pending applications or receipt of disability benefits, a recipient can also receive the exemption if the Medical Review Team determines the individual will be disabled for 12 months or more.

APPENDIX B:

7 CFR § 273.24 – Time limit for able-bodied adults.¹

7 CFR § 273.24 - Time limit for able-bodied adults.

- (c) Exceptions. The time limit does not apply to an individual if he or she is:
- (2) Determined by the State agency to be medically certified as physically or mentally unfit for employment. An individual is medically certified as physically or mentally unfit for employment if he or she:
- (i) Is receiving temporary or permanent disability benefits issued by governmental or private sources;
- (ii) Is obviously mentally or physically unfit for employment as determined by the State agency; or
- (iii) If the unfitness is not obvious, provides a statement from a physician, physician's assistant, nurse, nurse practitioner, designated representative of the physician's office, a licensed or certified psychologist, a social worker, or any other medical personnel the State agency determines appropriate, that he or she is physically or mentally unfit for employment.

¹ https://www.law.cornell.edu/cfr/text/7/273.24

ENDNOTES

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<sup>2</sup> Elisa Minoff, The Racist Roots of Work Requirements, Center for the Study of Social Policy, 2020, https://cssp.org/wp-content/uploads/2020/02/Racist-Roots-of-Work-Requirements-CSSP-1.pdf.

<sup>3</sup> "Long COVID: Household Pulse Survey," Center for Disease Control and Prevention, National Center for Health Statistics, updated August 2022, https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm.

The survey text states, "Long term symptoms may include: tiredness or fatigue, difficulty thinking, concentrating, forgetfulness, or memory problems (sometimes referred to as "brain fog"), difficulty breathing or shortness of breath, joint or muscle pain, fast-beating or pounding heart (also known as heart palpitations), chest pain, dizziness on standing, menstrual changes, changes to taste/smell, or inability to exercise."

<sup>4</sup> Sharon Parrott, The New TANF Requirements and Individuals with Disabilities: State Comments to the TANF Regulations Illustrate Problems Posed by Inflexible Federal Requirements, Center on Budget and Policy Priorities, 2007, https://www.cbpp.org/research/the-new-tanf-requirements-and-individuals-with-disabilities.

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time and responsible for a dependent child who is 12 years old or younger; (7) they participate in a state or federally funded work-study program; (8) they participate in an on-the-job training program; (9) they are in school through a state or federally approved employment and training program; or (10) they are "physically or mentally unfit" for work.

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