



NOVEMBER 2022

Access Is Equity

Addressing the Crisis in Access to
Social Security Disability Benefits

PREPARED BY: COMMUNITY LEGAL SERVICES OF PHILADELPHIA



Introduction

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are critical lifelines for millions of people with disabilities. However, more than a decade of underfunding has made it extraordinarily difficult for people to access the vital benefits they need to survive. Applicants and beneficiaries must navigate woefully inadequate interpretation services, an outdated phone system, complex eligibility requirements, and other barriers in the application process. As a result of these longstanding issues and office closures during the pandemic, the Social Security Administration (SSA) issued over half a million fewer SSI awards than if awards had continued at pre-pandemic levels. This sharp decline has disproportionately impacted Black and Brown people. Nowhere have SSI recipients been hit harder than Pennsylvania, which saw the largest percentage decline of all 50 states, with SSI awards falling over 26% from 2019 to 2020.

Now that local Social Security Offices have reopened, SSA must immediately prioritize its resources so that it can implement policies, training, and consistent oversight to provide access for all. In April 2022, SSA released an Equity Action Plan in an attempt to reduce barriers and ensure that everyone has access to its services. Unfortunately, this plan does not come close to addressing the critical issues that deny access and create inequities in Social Security disability benefits. Indeed, the Equity Action Plan does not propose any real improvements to accessibility for hard-to-reach communities, nor does it acknowledge barriers to language access or propose solutions to address those barriers.

SSA's inability to appropriately serve disabled people with intersectionally marginalized identities represents a crisis in equitable access to disability benefits. In this report, Community Legal Services of Philadelphia (CLS) calls on SSA to address the barriers that prevent people from accessing life-sustaining Social Security disability benefits.

Addressing SSA's Crisis in Access to Disability Benefits

On June 28, 2022, CLS convened a roundtable discussion with our community partners and the offices of Congressman Dwight Evans, Congresswoman Mary Gay Scanlon, and Senator Bob Casey. Together, we discussed ideas to make Social Security programs more accessible and equitable. Additionally, participants with intersectionally marginalized identities described inequities that they face at SSA.

In this report, using vital feedback from our partners, CLS calls on SSA to seek adequate Congressional funding and prioritize existing resources to address the following barriers:

- People with limited English proficiency cannot meaningfully access benefits and services.
- SSA perpetuates a cycle of trauma, poverty, and incarceration when it prevents returning citizens from accessing SSI benefits even when their disabilities have not changed.
- Claimants and advocates cannot readily reach SSA for help.
- SSA staff erroneously tell disabled people that their immigration status disqualifies them from receiving SSI.
- Reporting income to SSA is unnecessarily difficult, especially for children involved in the child welfare system and families with inconsistent income.
- SSI's low resource limit traps disabled people and families in poverty.
- Without adequate training, SSA staff wrongfully deny people with psychiatric and intellectual disabilities, and this delay in benefits can lead to crisis.
- Altogether, these barriers force disabled people to give up and walk away from life-essential income they are entitled to.

Roundtable Participants

AIDS Law Project

Cambodian Association of Greater Philadelphia

Childrens Hospital of Philadelphia

Community Behavioral Health

Community Treatment Teams

HIAS PA

Homeless Advocacy Project

JEVS Human Services/Coalition on Adult Basic Education

Liberty Resources

Nationalities Service Center

Pennsylvania School for the Deaf

Philadelphia Reentry Coalition

SEAMAAC

SSA fails to provide meaningful access to benefits and services to people with limited English proficiency.

People with limited English proficiency have a right to meaningfully access benefits in their primary languages. Although SSA advertises that it has interpreters available, this is not always true in practice. Sometimes, finding an interpreter can take a very long time. Additionally, it can be very difficult for deaf people to get ASL interpretation, especially when they go in-person to the Field Office. This delay sometimes forces people to miss SSA's deadlines and lose access to critical income due to no fault of their own. Moreover, poor explanations and inaccessible language can prevent people from fully participating in their cases, especially for people with learning and intellectual disabilities. Lack of access to technology and digital literacy can also be a barrier.

Roundtable participants shared the following observations about language access at SSA:

- It is difficult to get interpreters for less common languages.
- Delays getting interpreters force clients to wait hours for help and cause delays in cases that already take a very long time to resolve.
- It is difficult to get ASL interpreters. SSA staff often pass notes to communicate, but English may not be the person's first language.
- Sometimes SSA is unable to provide an interpreter and then will not permit the person to choose someone they know and trust to interpret.
- Notices and required forms are only available in English with limited exceptions for Spanish. If people cannot understand what is being asked of them, they cannot meet deadlines or provide important information for their disability application.
- SSA uses complex language that is difficult for many people to understand, including people with cognitive or other disabilities that affect their ability to comprehend information.
- Moving things online will not help people who lack digital literacy and face additional barriers, including many SSI applicants who cannot afford or are otherwise unable to use technology.

Here's how SSA can improve language access:

- **Make it easier to obtain interpreters for all languages, including providing more than one vendor for telephonic interpretation**
- **Require employees to have an interpreter on the line before reaching an applicant. The Children's Hospital of Philadelphia has a good model for this: <https://www.chop.edu/services/language-services>**
- **Provide staff with a refresher training on how to work with interpreters**
- **Provide required disability forms and notices in languages other than English and in plain language, so that individuals can understand and fill them out**
- **Utilize captions for all video**
- **Include information about deaf interpreter services on signage**

SSA perpetuates a cycle of trauma, poverty, and incarceration when it prevents returning citizens from accessing SSI benefits.

People returning from incarceration disproportionately suffer from mental illness and have the compounded trauma of having been incarcerated. Many beneficiaries who received SSI due to mental illness prior to incarceration must start over and reapply because of SSI-specific termination rules. Additionally, returning citizens lack support in navigating the benefit eligibility process while incarcerated and must rely on prison staff to access limited-to-no medical records or treatment behind bars. As a result, roadblocks navigating Social Security eligibility lead many people to give up and resort to other ways to survive.

Roundtable participants shared the following observations about issues impacting people returning from incarceration:

- Most people released from incarceration are suffering from some sort of trauma and mental illness. To re-establish eligibility for SSI, they must overcome endless paperwork, confusing requirements, starting an application, and getting evidence to prove disability.
- People who are incarcerated for over a year are automatically terminated from SSI. When they return home, they must start the SSI process all over again, even if their disabilities have not changed or have worsened in confinement. For many, it took months or years to get on SSI before they were incarcerated, and now they must do it all again. SSI is often the only income that a person has. Without it, they may end up homeless, reincarcerated, or in worse health.
- There is little to no support for people to reapply for benefits or to get the documentation they need while they are still incarcerated. After being released, it often takes months or years to receive benefits again, and many claimants are initially denied.
- In Pennsylvania, far more people with disabilities have been incarcerated than are receiving Supplemental Security income. This demonstrates that SSA is underserving many marginalized people who are eligible for benefits.

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- Advocates report that people who are incarcerated lose benefits for an entire month even when they are not incarcerated for an entire month. Additionally, it is difficult to get benefits taken out of suspension after incarceration.
- Staff of carceral facilities are charged with submitting medical records and incarceration documents, so there is a power dynamic that puts potential benefits in the hands of people who hold power over the person seeking SSI.

Here's how SSA can support people involved in the criminal legal system:

- **Create a specialized team at SSA that deals specifically with returning citizens**
- **When released from incarceration, previous recipients should automatically be entitled to those benefits again. If benefits are not automatically reinstated, resources should be provided to incarcerated people so they can begin the application process for SSI prior to release, and six months of benefits should be provided upon release until their claim is adjudicated.**
- **Reduce reliance on incarceration institutions for people to get back on SSI benefits post-incarceration**
- **The SSI forfeit during detention should reflect the time spent detained, rather than counting an entire month if someone is incarcerated for any time that month.**
- **Prevent people awaiting trial from having their benefits suspended (The current average wait time in Philadelphia is more than 180 days.)**

Claimants and advocates cannot readily reach SSA for help.

Due to years of underfunding, SSA simply does not have the resources to provide adequate customer services. People must contact SSA multiple times before finally connecting with a representative. Even when people speak with a representative at SSA, they are not able to resolve the problem and must call repeatedly to reexplain the issue to a new person. If there is a specific person someone can contact for help, it is rare or impossible to connect with them, prolonging an already lengthy process. This lapse in communication forces people into precarious situations, such as moving back in with an abusive partner to avoid homelessness.

Participants shared the following observations about communicating with staff at Field Offices:

- People must call and talk to several people at Field Offices to resolve issues. It is discouraging to explain the problem to one person and then have to do it all over again with someone else.
- It is rare but helpful when the Field Office designates a specific person from SSA to work on an issue with a claimant. However, they often get assigned too late, and there is not a good way to reach them without having to navigate prompts, wait on hold to get transferred, or leave endless voice messages. This process strains community groups and is stressful for people whose disabilities make it difficult to meet repeatedly, who face trouble navigating the city, or who have limited funds.

Forced Back to Laos

A Laotian disabled woman needed help applying for SSI. It took two weeks for the case manager and the claimant to speak to someone at SSA. The claimant was in a precarious living situation involving suspected domestic violence. She was forced to move back in with her husband because she did not have any income. When she was approved for SSI, she was only getting \$41 because SSA counted her husband's income. After her husband lost his job, he sent her to live with a very poor family in Laos, where she does not have access to her diabetes medication.

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- Very few community groups have a special SSA representative assigned to assist them with SSI issues. More organizations should have access to this type of support.
- For people with disabilities and low-income families that have limited or interrupted phone access, the requirement to wait on hold or repeatedly call back can be impossible.
- Often documents are faxed or mailed to SSA but do not show up in the system for weeks or months.
- The notes from past issues are not always documented and shared to keep staff informed when an issue isn't resolved in one phone call. Beneficiaries then must explain their story and complete steps repeatedly.

Here's how SSA can improve communication with claimants and advocates:

- **Create systems that allow advocates who are representatives to speak directly with a specially assigned person without having to wait on hold, leave multiple voice messages, and repeatedly call back**
- **Reduce the number of times people need to contact SSA to receive benefits by shortening the SSI application, simplifying income eligibility rules (especially in-kind support and maintenance) and combining SSA forms**
- **Shorten the amount of time it takes the Field Offices to resolve issues with claimants and beneficiaries**
- **Improve information sharing across Field Offices and regional locations**

SSA staff erroneously tell disabled people that their immigration status disqualifies them from receiving SSI.

Many non-citizen immigrants can qualify for SSI, but SSA employees do not always seem to be aware of this. Advocates spend a lot of time explaining to SSA that their client has an immigration status that allows them to qualify for SSI. When clients are repeatedly told that they do not qualify when they know that they are eligible to receive benefits, this is demoralizing and prolongs the application process further.

A Year Later and No Results

A woman from Angola was granted asylum in February 2021 and began applying for SSI in April 2021. She has severe epilepsy that requires in-home care. Now, more than a year later, she is still in the application process because the SSA office has repeatedly misunderstood the qualifications of her legal status. Each time she called, an SSA representative would tell her they updated her file to indicate eligibility, but then SSA would call her back a month later, telling her there was no note of that. She is living with her elderly mother and has poor health with no income.

Participants shared the following observations about confusion about immigration status:

- Community groups encounter confusion among SSA staff about qualifying immigration statuses, which leads to wrongful denials and long delays for the issue to be corrected. As a result, case managers must spend time and resources to educate SSA staff instead of helping other people.
- There are many complicated rules for people who receive SSI that are not communicated to non-English speaking beneficiaries. The lack of translated materials for immigrant, non-English speaking people puts these groups at a disadvantage because of trouble understanding or completing documents.

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- The SSI qualifications regarding immigration statuses are very confusing and create long delays in accessing benefits. For example, one person who was approved for asylum faced significant delays in getting their application processed solely because SSA was confused about their immigration status.

"A family was evacuated from Afghanistan in August 2021. The SSA Field Office representative wrongfully told the family that they could not apply for SSI for their disabled child because their immigration status disqualified them. Even the denial notice that SSA sent was outdated, as it excluded Afghan parolees from the list of qualifying immigration statuses. Despite their desperate need for income to support their disabled child, the family now feels discouraged from moving forward after receiving such an immediate denial."

Here's how SSA can ensure that eligible non-citizens receive benefits:

- **Create a unit with several key employees who are trained on the complexity of immigration statuses eligible for SSI benefits and dedicate this unit to processing all of the local agencies' SSI applications involving immigrant statuses**
- **Designate a direct point of contact for community groups that work with refugee or immigrant claimants**
- **Require training and regular refreshing for relevant SSA employees on what immigration statuses qualify and what documentation applicants can supply to show a qualifying immigration status**
- **Translate notices and disability paperwork into multiple languages so that immigrants who are limited English proficient claimants can understand what is being asked of them**

Reporting income to SSA is unnecessarily difficult, especially for children involved in the child welfare system and families with inconsistent income.

Income reporting is required, but the options for doing so are difficult, especially for youth who have been involved in the child welfare system. Although people may report their income via phone, fax, mail, or an app, each of these options has its challenges. Beneficiaries must wait on the phone for hours, rely on unreliable mail or fax systems, or use an app that is difficult to set up. Additionally, the electronic portal for the app will sometimes lock out children who have been involved in the child welfare system due to having too many addresses. Furthermore, families with inconsistent income levels have trouble keeping up with reporting income to SSA and often receive overpayment notices to pay Social Security back.

One family had varying income levels because of health issues that led to an inconsistent work schedule. They received overpayment notices and were asked to pay back benefits twice. They won on appeal both times, but it was a stressful process.

Here's how SSA can improve income reporting for claimants:

- **Ensure that the systems SSA created to report income are user-friendly and designed to accommodate people with disabilities**
- **Provide a phone number to speak with a representative who can walk the beneficiary through steps**
- **SSA should not penalize people who were unable to report income because of technical difficulties or errors with the reporting system in place**
- **Raise the administrative waiver level and apply it automatically to eliminate minor overpayment created by small or one-off windfalls**

SSA's low resource limit traps people in poverty.

To qualify for SSI, low-income disabled people must own less than \$2,000 in resources, and couples must have less than \$3,000. This unreasonable resource limit traps people in poverty and does not allow them to save for emergencies or even enough for their own funeral expenses. In addition, the cap per person is even lower when disabled recipients marry, and this essentially penalizes people on SSI for getting married.

Here's how SSA could support more reasonable limits for SSI recipients:

- **Advocate for Congress to pass the SSI Savings Penalty Elimination Act or otherwise raise the resource limit**
- **Raise the burial fund exclusion beyond \$1,500, as most funerals cost more than this amount**
- **Advocate for Congress to eliminate SSI's marriage penalties for the benefit amount and resource limit**

Without adequate training, SSA staff wrongfully deny people with psychiatric and intellectual disabilities, and this delay in benefits can lead to crisis.

Some staff have trouble working with applicants with psychiatric and intellectual disabilities or do not fully understand complex rules, such as immigrant eligibility. This often leads to delays, and the consequences are dire. Many people become homeless, experience worsening medical conditions, and even die while waiting for their applications to be approved.

Participants shared the following observations about inadequate staff training:

- People with psychiatric disabilities and housing insecurity apply four, five, or six times. They also have problems collecting their medical history and keeping track of their appointments.
- Many people with psychiatric disabilities have negative interactions with staff. They often cannot reach representatives for help, get hung up on, or are sent somewhere else. Sometimes, staff put applicants on hold for hours.
- SSA employees do not adequately explain things, or they use inaccessible language when working with people with intellectual disabilities.
- The Disability Determination Service sometimes makes obvious mistakes, like failing to consider the listings of impairments, which forces people to go through a lengthy appeal process until an Administrative Law Judge approves their benefits.

A person diagnosed with PML, a neurological condition included in the listings, was denied initially and again when she appealed for reconsideration. Ultimately, she was approved based on the same medical information. During the unnecessary and lengthy appeal process, she lost her housing and was in poor health.

Here's how SSA can help applicants with psychiatric and intellectual disabilities:

- **Train staff to work more effectively with people with psychiatric and intellectual disabilities**
- **Increase targeted denial reviews so that staff know their decision to deny benefits will be reviewed just as often as their decision to grant benefits**

Altogether, these barriers force disabled people to give up and walk away from life-essential income.

Cumulatively, these barriers can make the application process repetitive, frustrating, and lengthy. For some, especially people with mental illnesses or a history of trauma, the size and number of barriers forces them to give up on their application. Even for those who eventually get benefits, the long delays mean they must spend time living with no income. When SSI is the only income people have, delays can push them into homelessness or other dangerous living situations.

Pushed into Homelessness

It took three years for a severely disabled man to get on benefits, even with significant support. He survived multiple strokes and experienced weakness, vision loss, and memory loss. He was also diagnosed with bipolar disorder. With all of those conditions and never having learned to read, it was extremely difficult for him to navigate the system. He was terminated for confusing reasons, fell into homelessness, and became the victim of robbery. At the time, he had nowhere to bathe or care for his wounds. If his claim had been approved sooner, he would have been able to rent a room, have a home health aide, and have the support to get the medical care he needed. The delays caused him undue stress and deteriorated his health.

Participants shared the following observations about how demoralizing it is to apply for benefits:

- It is common for transient and homeless populations to get denied for technical reasons— for example, based on their inability to timely submit a form or their lack of consistent access to a phone.
- When people are wrongfully told they are not eligible, stress and shame lead people to give up on their application. For people with mental illness and mood instability, representatives often get frustrated and hang up on them, rather than work to understand the disabled person's concern.

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- People navigate these processes while facing incredibly stressful situations (such as their child undergoing cancer treatment or a young person aging out of foster care) that often limit their capacity to handle such a complex process.
- The length of wait time for getting SSI is a huge problem for people who are homeless and living on the street. A two-year waiting period means two years of living on the street and not having access to basic necessities.
- People experiencing homelessness or psychiatric disabilities often apply for SSI without representation four to five times. Each time it takes four to six months for the medical claim to be reviewed. It is nearly an impossible feat without a lawyer or social worker. It should not be a prerequisite to have a lawyer to access income for your most basic needs.
- It takes too much time to resolve problems, including those related to existing benefits. People are told that they cannot meet with someone in the office to appeal negative decisions.
- Many people have their benefits cut off due to a missed letter and then they also miss the opportunity to appeal the decision because of the short deadlines. For people experiencing homelessness and sporadic or no access to mail, inflexible deadlines create further barriers.

A 22-year-old young woman with intellectual and cognitive disabilities due to full-body radiation treatment for leukemia was so overwhelmed by the bureaucratic barriers and unempathetic interviewers during the application process that she gave up on her application. She felt embarrassed, overwhelmed, and as if she was doing something wrong, even though she clearly qualified for disability benefits.

Here's how SSA can ensure that disabled people can quickly and successfully apply for disability income:

- **Have someone – such as a community navigator – who can sit with applicants in person, work with them on different steps, and communicate so that they don't have to be put on hold for hours over the phone**
- **Require empathy training for SSA staff because applicants feel ashamed, embarrassed, or defeated just by getting on the phone to try to access benefits they are entitled to**
- **Increase training about trauma and mental health to improve accessibility for people with mental illness, who have difficulty expressing what they need and regulating their emotions**
- **Increase walk-in appointment availability for initial and ongoing claims for people who do not have a phone or who have difficulty communicating over the phone**
- **Have onsite application and claims issues assistance, specifically for SSI**
- **Increase in-person assistance for appeals and continuing disability reviews**
- **Simplify the application and continuing disability review process, as the amount and complexity of paperwork is too challenging to navigate alone or even with an advocate**
- **Seek and allocate funding that will increase staffing to address the long wait times for claims to be processed**
- **Create more flexibility with deadlines, especially for mailed paperwork**

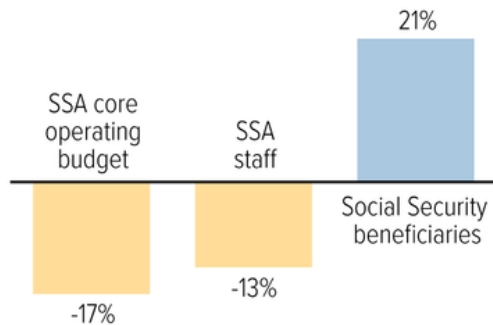
Congress must play a role in solving Social Security's service crisis.

SSA's ability to prioritize service to hard-to-reach communities will be unacceptably limited unless and until Congress boosts Social Security's operating budget in the 2022-23 Fiscal Year.

Long before the COVID-19 pandemic, SSA faced a funding and service shortfall due to Congress's failure to adequately fund operations. Over the last decade, SSA's operating budget fell 13% while beneficiaries increased by 21%. At the same time, SSA staffing is now at its lowest level in 25 years. As a result of underfunding and understaffing, the average wait for an initial disability decision hit an all-time high of 198 days in August 2022.

Social Security Administration Faces Increased Workload With Fewer Resources

Percent change from 2010 to 2022 (funding adjusted for inflation)



Note: For beneficiaries, figures reflect fiscal year 2010 to Apr 2022; for staff, figures reflect full-time equivalent staff (FTEs) between fiscal years 2010 and 2021.

Source: CBPP analysis based on Social Security Administration and Office of Management and Budget

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People with disabilities need Congress to act quickly to fund Social Security's field offices.

SSA's ability to prioritize existing resources is limited by inadequate funding. Meanwhile, thousands of people fall into deep poverty, file for bankruptcy, or even lose their lives while waiting for disability benefits. In fact, the Government Accountability Office found that more than 100,000 people died waiting to be approved for SSI or SSDI between 2008 and 2019. At Community Legal Services, we have seen firsthand the obstacles to benefits access. Our clients call local offices and can't get through to file an appeal for a denial of benefits. When someone with SSA tells them they need to fill out a form, it never arrives in the mail, or the paperwork arrives after the response deadline. Nationally, nearly half of calls to SSA go unanswered.

As Social Security's service infrastructure deteriorates, Congress has the power to solve the crisis. SSA's Acting Commissioner, Kilolo Kijakazi, estimates that the agency needs an additional \$2.3 billion to start to reduce wait times and backlogs. People with disabilities deserve a Social Security system that works. When Congress works on a 2022-23 Fiscal Year budget at the end of 2022, SSA operations must be a key budgetary priority.

Conclusion

This report summarized and highlighted the key findings from CLS's roundtable discussion with our community partners and the offices of Congressman Dwight Evans, Congresswoman Mary Gay Scanlon, and Senator Bob Casey. These advocates have deep expertise in helping disabled people with intersectionally marginalized identities overcome barriers that prevent them from accessing the vital Social Security disability income they need to survive. Their experiences tell the story of a system designed to keep families trapped in poverty and jeopardize their health.

SSA's persistent inability to make its programs accessible and equitable to disabled people represents a national crisis in access. When immigrants and refugees, returning citizens, people with intellectual and psychiatric disabilities, and other claimants apply for benefits, they often cannot reach SSA for help and consistently encounter staff who do not have adequate training or customer service skills. These experiences not only delay life-essential benefits but also exacerbate the disabilities that bring people to SSA in the first place. Although SSA's Equity Action Plan attempted to address these issues, it falls far short of what disabled people deserve.

Ultimately, SSA needs adequate funding to ensure that everyone has access to its services. Congress has an obligation to correct its underfunding for the nation's most critical income security system that lifts more people out of poverty than any other program. CLS looks forward to working with our community partners, SSA, and members of Congress to solve this crisis once and for all.

Acknowledgements

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- Claire Grandison, Supervising Attorney, SSI Unit and the Youth Justice Project
- Sara Lynch, former Staff Attorney, SSI Unit
- Chi-Ser Tran, Supervising Attorney, SSI Unit and the Language Access Project

We would also like to thank the following for contributing to this report:

- Jennifer Burdick, Supervising Attorney/Duffy Fellow, SSI Unit
- Kristen Dama, Managing Attorney, SSI Unit
- Zakya Hall, Communications and Content Manager
- Caitlin Nagel, Director of Advancement and Communications
- Summer law interns Charlotte Edelstein, Steven Jessen-Howard, and Zihui Ye



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