

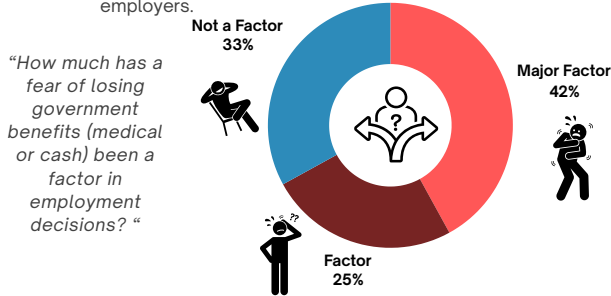
KEY INSIGHTS

FEAR OF LOSING SSA BENEFITS IS DETERING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES FROM WORKING. THEIR FEARS ARE JUSTIFIED.

In July 2023, the Orange County Local Partnership Agreement (OCLPA) Benefits Committee, in conjunction with the California State Council for Developmental Disabilities conducted a survey to determine the impact of SSI and Title II Benefits on those wanting to earn a living through employment. The survey was shared by ARCA with other Regional Centers for distribution. There were 605 responses from Individuals with Developmental Disabilities (IDD) who reside in California representing 43 of the 58 counties. 52% have Autism, 29% have Intellectual Disabilities, and 7% have Cerebral Palsy. 86% of the respondents were parents and representative payees. 21% of the IDD were currently working with 19% having previously worked.

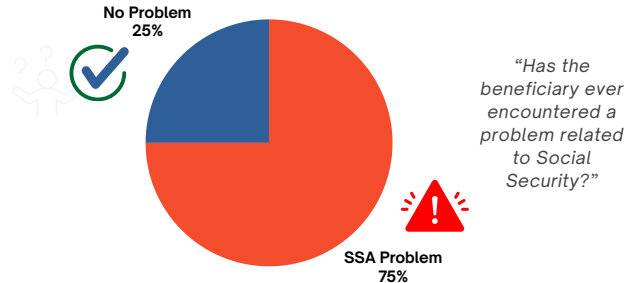
67% SAY THAT FEAR OF LOSING THEIR SOCIAL SECURITY BENEFITS IS A FACTOR IN THEIR DECISION TO WORK

Many individuals with developmental disabilities depend on Social Security as a major source of income. In addition, they rely on MediCal and/or Medicare for their health insurance. These adults often choose not to work or to work fewer hours to reduce the risk of triggering a problem with SSA. They typically have problems finding work, and the constraints of working fewer hours makes them less attractive to employers.



75% OF IDD WHO HAVE WORKED HAVE ENCOUNTERED A SOCIAL SECURITY PROBLEM

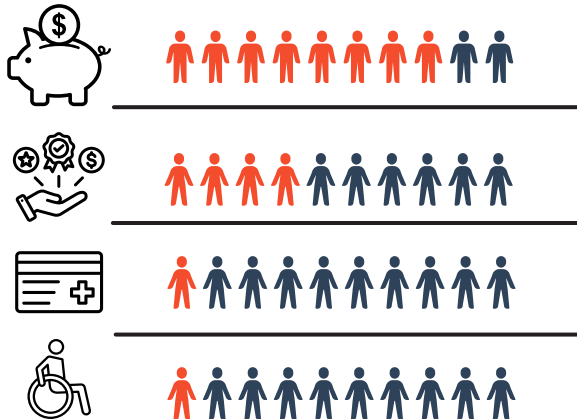
It is no wonder that people are fearful, as 3/4 of those who either previously worked or are currently working have encountered a problem with Social Security. Dealing with SSA means long waits on the phone, 50% indicating that it takes months to years to address, with 54% of the respondents indicating they have yet been unable to resolve their problem.



OVERPAYMENTS IS THE LEADING ISSUE ENCOUNTERED. WITH 76% FACING NOTICES INDICATING THE NEED TO REPAY THOUSANDS OF DOLLARS.

These SSA problems cause those with IDD and their families...

- **Financial Strain:** Overpayments and benefit issues often lead to significant financial strain, affecting beneficiaries' ability to pay for necessities such as rent or medical care.
- **Emotional and Psychological Impact:** The ongoing stress of dealing with SSA errors, long wait times, and ineffective communication takes a toll on beneficiaries and their families.



76% OVERPAYMENT NOTICES

39% BENEFITS TERMINATED

15% LOST MEDICAL INSURANCE

11% CHANGED DISABILITY STATUS

THE IDD STORIES SHOW THESE FUNDAMENTAL SSA PROBLEMS

1. Overpayment Issues

- **Inaccuracy and Delay:** Many individuals report receiving overpayment letters due to inaccuracies or delays in the SSA's accounting processes. This includes situations where benefits were calculated incorrectly, resulting in excessive deductions from payments.
- **Reporting Errors:** Overpayments often stem from errors in wage reporting or the misinterpretation of reported income, sometimes due to outdated or incorrect wage data being used.

2. Communication Difficulties

- **Long Wait Times:** Difficulty contacting SSA representatives is a common issue, with long wait times on the phone or in-person at SSA offices.
- **Ineffective Help:** Even when contact is made, individuals often encounter unhelpful or unknowledgeable staff who provide conflicting advice or fail to address the issues adequately.

3. Processing and Administrative Errors

- **Lost Paperwork:** There are numerous instances of lost or misplaced documents, such as pay stubs or medical review paperwork, which contribute to delays and errors in benefit processing.
- **Incorrect Documentation Handling:** Issues such as paperwork not being properly transferred between offices, or forms being incorrectly processed, are frequently mentioned.

4. Benefit Termination and Suspension

- **Unfair Termination:** Some beneficiaries experience termination or suspension of benefits, sometimes due to misunderstandings about income limits or eligibility requirements.
- **Appeals and Reinstatements:** The process for appealing wrongful terminations or suspensions is often slow and frustrating, with many individuals waiting long periods for resolution.

5. Inconsistent and Unclear Guidelines

- **Conflicting Information:** Beneficiaries frequently receive conflicting or unclear information about their benefits, which complicates understanding and compliance with SSA requirements.
- **Program Misunderstandings:** Misunderstandings about benefit programs, eligibility, and income reporting requirements are common, leading to frustration and errors.

RECOMMENDATIONS

SUGGESTIONS FOR FIXING THE IDD EXPERIENCE WITH SOCIAL SECURITY THEREBY REMOVING THE FEAR OF LOSING BENEFITS WHEN EMPLOYED

The Orange County Local Partnership Agreement Benefits Committee reviewed the problems experienced by IDD with Social Security benefits when attempting to work considering the following six areas of improvements

- **Legislative Change:** These resolutions require enactment of new or amending existing laws.
- **SSA Procedural Change:** These resolutions require process change by the Social Security Administration.
- **Family Training:** These matters can be addressed with highly available and informative training.
- **Staffing and Training:** Implementation of these resolutions can be addressed with staffing and training of SSA Staff and Service Providers.
- **New Forms:** These resolutions can be addressed by modifying existing or creating new forms.
- **Software and Technology:** Some resolutions are best addressed with modifying existing software or implementing new technology.

Below is our top nine recommendations. For a complete list of the 64 recommendations, please visit the OCLPA Transition Website, Work Teams (Benefits Planning and Management). <https://transitionca.org/oclpaworkteams/>



ENHANCE MYSOCIALSECURITY WEBSITE* TO ALLOW FOR REPORTING OF WORK INCENTIVES / EMPLOYMENT SUPPORTS

Making employment and work incentive data available on My Social Security will increase accuracy and transparency; remove problems associated with lost data, and ensure that SSA has all the correct information prior to starting any type of CDR or Overpayment proceedings. This is a cost savings reducing workload, improving turn-around, lowering unnecessary hearings.

*<https://www.ssa.gov/myaccount>



LIMIT OVERPAYMENT TO ONE YEAR

Limit overpayment to one year of benefits, if the delay is not due to IDD and/or Representative Payee failure to report. The size of the Overpayment Burden is directly related to SSA delays caused by untimely file reviews. Faster notification means that the IDD can address the problem. But if they are unaware of the problem, the Overpayment Burden can increase significantly. (Similar to not hearing about an overdue book from the library for 20 years.) Minor cost increase to SSA – but reduces financial burden on individuals with IDD who lack financial means.



RESET TIMEFRAMES FOR CONTINUING DISABILITY REVIEW OF IDD TO TEN YEARS

Reset timeframes for IDD Continuing Disability Review to ten years using Blue Book classifications to identify those with more severe/significant disabilities that are unlikely to substantially improve over time. This will reduce the burden on SSA to implement CDRs and will reduce stress on families.



GUARANTEE IMMEDIATE REINSTATEMENT FOR IDD UPON LOSS OF EMPLOYMENT

Allow IDD to resume SSI/SSDI based on need, guaranteeing immediate reinstatement upon loss of employment. This one action will reduce fear of losing benefits and thereby increase the likelihood that IDD will attempt employment. As a result, the IDD community will work more hours and generate more tax revenue. Many may achieve financial independence and better quality of life.



PROVIDE ADDITIONAL ASSISTANCE TO IDD WHEN GOING THROUGH AN APPEALS PROCESS

Provide additional assistance when going through an appeals process, expanding the role of the benefits planner, WIPA, CWIC, or WIPS to include representation for helping persons with IDD/families navigate the appeals process. Slightly higher cost but will help individuals who lack means but need to navigate the appeals process.



STOP CONFUSING ABILITY TO WORK WITH BEING DISABLED

Stop confusing ability to work with still being disabled; Do not link disability designation with ability to earn a living. Will increase costs to SSA.



MAKE TITLE II TRIAL PERIOD NINE CONSECUTIVE MONTHS VERSUS NONCONSECUTIVE MONTHS

Modify Title II Trial Period by making the nine-month trial work period consecutive versus nonconsecutive earnings. Prevent triggering success that has not been achieved.



IMPLEMENT CASE MANAGEMENT TRACKING SYSTEM

Implement Case Management Tracking System, that tracks open issues and timelines (case number) with guaranteed response time. Improve beneficiary satisfaction. Lower costs by streamlining problem resolution. Provide better data for managing escalations.



ESTABLISH IDD HOT LINE

Establish Hot Line for help with IDD. Improve beneficiary satisfaction. Reduce problems by having more timely responses to questions.

FOR MORE INFORMATION

For more information, visit the OCLPA Transition Website, Work Teams (Benefits Planning and Management).

<https://transitionca.org/oclpaworkteams/>

