



IMPROVING EMPLOYMENT OUTCOMES FOR SELF- SUFFICIENCY BY INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD) WITHIN THE SOCIAL SECURITY ADMINISTRATION (SSA) SYSTEM



ABSTRACT

The Social Security Administration (SSA) provides essential income for some individuals with intellectual and developmental disabilities (IDD) either through Supplemental Security Income (SSI) and/or Title II benefits (Social Security Disability Insurance or Childhood Disability Benefits). Although significant effort is being focused on helping those with IDD to become self-sufficient and employed to their full capacity, the current implementation of SSI/Title II Benefits and the associated SSA Work Incentive System are ineffective for many, complicated, and can disincentivize those with IDD who wish to work to their maximum capacity. The purpose of this whitepaper is to outline elements of the SSI and Title II programs that are ineffective when attempting to secure employment, expand hours, and plan for promotional opportunities to become self-sufficient. This white paper looks at the programs, the work incentives, and the problem resolution procedures.

Benefits Planning Committee of the Orange County
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Introduction

Project Summary

The Social Security Administration (SSA) provides essential income for some individuals with intellectual and developmental disabilities (IDD) either through Supplemental Security Income (SSI) and/or Title II benefits (Social Security Disability Insurance or Childhood Disability Benefits). The overall intent of SSA is to support individuals to navigate rehabilitation or training so that they may become gainfully employed and reduce their dependence on SSA benefits.

Although significant effort is being focused on helping those with IDD to become self-sufficient and employed to their full capacity, the current implementation of SSI/Title II Benefits and the associated SSA Work Incentive System are ineffective for many, complicated, and can disincentivize those with IDD who wish to work to their maximum capacity. Due to the extensive application process, time and challenges in applying for SSA disability benefits, the result is that persons with IDD are often being “misinformed” that they should work fewer hours to keep their benefits or simply not work at all. (An indicator that the system is broken from the self-advocate, agency, families, individuals, and supporting counselors/service staff perspective.)

The problems associated with work and SSA benefits has intensified driven by:

- Cost of living increases, especially housing costs, while Substantial Gainful Activity (SGA) has only marginally increased. This is making it difficult for persons with IDD to be self-supporting. Note that SGA is not the only measure used by the government to determine poverty level. In 2022:
 - In 2023, SGA for non-blind is \$1470/month and for blind individuals, SGA is \$2460/month.
 - The United States Department of Housing and Urban Development Income Limits used by the Orange County Housing Authority for administration of rental assistance shows \$2350/month for *extremely low* and \$3954.17/month as *very low*.ⁱ
 - [Individualized 1619b Threshold Amounts, set locally](#) and determining qualification for medical insurance is \$4,507/month.
- Confusion over how to utilize and apply for work incentive programs, especially with the new paid work experiences such as apprenticeships and internships offered through education/service agencies.
- The interaction between the individual and Social Security system is complicated by real/perceived procedures, deadlines, and forms, making it extremely difficult to navigate the process. Additionally, a movement towards using applications and websites to manage the processes can be difficult for some members of the community served.ⁱⁱ
- Increases in the minimum wage to \$15.50+/hour (CA), accelerates persons with IDD’s ability to meet SGA with fewer hours of employment. This gives a false impression that the person is “gainfully employed” meeting SSA’s SGA standards, when in reality, they are only working 21 hours/week and that is often with various subsidies and special conditions. The results is that they are being encouraged and perhaps “misinformed” that they should work fewer hours to keep their benefits or simply not work at all. This can make them less attractive to potential employers.

- Frequent changes in the economy and changes in disability-related needs (such as mental and/or physical health) of persons with IDD can result in periods of unemployment. Unfortunately, those who have already lost their benefits because of achieving SGA during a period of employment, may find it confusing if not impossible to reinstate their Social Security benefits.
- Problems with access to Social Security Administration (SSA) and Office of Hearing Operations (OHO) creates delays for resolution of benefit disputes.

The purpose of this document is to outline elements of the SSI and Title II programs that are ineffective when attempting to secure employment, expand hours, and plan for promotional opportunities to become self-sufficient. This white paper looks at the programs, the work incentives, and the problem resolution procedures.

This white paper focuses on the problems associated with employment in California, although many ideas could be extended nationally. This team met weekly for nearly a year to develop this document.

Note: It should be pointed out that the Spotlights 2022 Editions are an excellent source of relevant information. Effort should be given to expand on the available Spotlights and educate persons with IDD and their families about their existence and use. (For access to Spotlights visit - <https://www.ssa.gov/ssi/links-to-spotlights.htm>)

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Journey of Persons with IDD and Their Families

For a family dealing with IDD, the journey is painful, expensive, complicated, and never ending. It starts with getting a diagnosis. For many disabilities this may take expensive trips to different professionals with inconsistent assessments. Once a diagnosis is achieved the next challenge is finding the proper support. This can include application to agencies and researching potential treatments.

After years of treatment, that can be expensive and sometimes ineffective, and a life of isolation and challenges, the child may then reach age eighteen. If not eligible prior to age 18, at this point, families may apply for Social Security support. The process can take a year is lengthy and often is met with rejection. Some families may need to hire attorneys and advocates to assist. If they are lucky enough to get approved, they treasure having their loved one covered by medical insurance and some source of income.

Many individuals and families are anxious to have the person with IDD find employment. This is challenging because employers are not anxious to hire individuals with IDD. Many families are concerned over the potential of disrupting their SSA benefits. Those who are aware may seek the advice of a counselor, benefits planner, or Work Incentives Planning and Assistance (WIPA). The complicated rules regarding loss of benefit for money earned and the risk of losing the benefits if they earn too much creates anxiety and concern.

Following the advice of some benefit specialists, persons with IDD will let the potential employers know that that they can only work a restricted number of hours, making them less attractive as a job candidate. Some who qualify and find a knowledgeable advisor may apply for some of the known work incentives. Those who either are unaware of the potential for loss of the benefit may start working and not realize that their benefit may be in jeopardy.

While SSA explains employment reporting requirements for beneficiaries and those serving as representative payees, persons with IDD and more commonly, their parents helping them, are already barraged with remembering each and every single agency's reporting requirement, applications, rules, and policies, because each agency has different rules and requirements. It is not uncommon for the person with IDD and/or their parent to not report due to simply trying to manage day to day affairs and not remembering.

Once working, wages must be reported. Any kind of accommodations and job supports must be tracked. However, the processes of matching up the accommodations to the earned income are confusing and unclear to the representative payees and persons with IDD.

The law requires SSA to perform a medical Continuing Disability Review (CDR) at least once every three years, however, if the individual has a medical condition that is not expected to improve, SSA will still review the case, once every five to seven years. Some report that they did not realize that the CDR was in process. Many families do not realize that this happening. For those who are aware of the process, they have 10 days to respond. If they do not file the right paperwork or do so incorrectly, they may be notified that they are no longer eligible as they have been redetermined as no longer being disabled. During the CDR, SSA often also conducts a "redetermination" to ensure that the beneficiary continue to meet the non-medical program requirements (income, resources, living arrangements).

Loss of Employment

At some point, many people with IDD lose their jobs. This can either occur due to:

- Staffing reductions
- Elimination of the specific job
- Business closure
- Ineffective implementation of needed accommodation
- Disability-related setback
- Changes in management
- Changes in job descriptions

After layoff or termination, the process for reinstatement of the Social Security benefit is unclear and can be problematic to the person with IDD and/or their parent, job coach, employment specialist.

The above is a simplification of the experience of most families and persons with IDD. It is the rule, not the exception. It is with that in mind, that this work has been undertaken.

Document Organization

The next section of this white paper analyzes the specific problems and proposed resolutions to better assist those persons with IDD who are receiving SSI or Title II benefits and are attempting to achieve competitive integrated employment for a life-sustaining wage. Recommendations on policy, procedure, staffing, and software changes are included.

We have organized them into six subject areas:

1. [Employment](#) (E X)
2. [Work Incentives](#) (WI X)
3. [Continuing Disability Review](#) (CD X)
4. [Medical Insurance](#) (MI X)
5. [Problem Resolution and the Appeals Process](#) (PR X)
6. [Expedited Reinstatement](#) (ER X)

Within each subject area, we have enumerated the recommendation with a code containing an alpha abbreviation of the subject area and a number. This coding is used in [Appendix A](#) which contains a set of tables analyzing the subject areas by the type of reform required. Note that endnotes are provided at the end of this paper.

Employment

The key to achieving self-sufficiency is employment. Individuals with IDD receiving SSI or Title II benefits face many challenges and concerns:

1. As individuals with disability, they have a hard time competing for employment.
2. They are overwhelmed with the complexity of reporting wages when employed.
3. They are anxious that they may lose important benefits.
4. They are concerned that if they become unemployed and are unable to find work that they will not have their benefits to fall back on.

It should be noted that we are aware of the Work Incentives and Employment Supports available; however, we have found that these can be complicated and insufficient to address individuals needs. This is covered in the [Work Incentives](#) section.

Problems	Recommendations
<ul style="list-style-type: none"> ▪ Difficult to report wages and employment supports/accommodations/work incentives to Social Security when doing wage reporting (mySocial Security) ▪ Persons with IDD are advised to provide this information via certified mail or face-to-face at SSA office, requesting a receipt. 	<ul style="list-style-type: none"> ▪ Integrate the input of Work Incentives / Employment Supports with wage reporting (mySocialSecurity Application) (E1)
<p>Lack of Social Security Expertise and Availability</p> <ul style="list-style-type: none"> ▪ Lack of Staffing at Social Security staff on the phone. ▪ Lack of assigned case manager for persons with IDD. ▪ Limited access to Social Security staffing in person at the local office. ▪ Lack of expertise at Social Security Offices or on the Phone regarding primary benefits for Individuals Intellectual/Complex Disabilities. ▪ Area Work Incentive Coordinator (AWIC) staff reduction and expanded responsibilities, has made them less available. OC does not have an SSA Area Work Incentive Coordinator. 	<ul style="list-style-type: none"> ▪ Increase knowledge of local SSA office staff with regards to SSI and SSDI for persons with IDD. (Make people aware of supplemental information, such as Spotlight Information Sheets. Address gaps in topics.) (E2) ▪ Provide Technical Expert Team to SSA staff, in addition to the Area Work Incentive Coordinator (AWIC). (E3) ▪ Expand AWICs. (Hire in OC) (E4) ▪ Unclear unknown potential utilization of the Work incentive Liaison (WIL) (E5) ▪ Implement a HOT-LINE for people for people with developmental disabilities and their families perhaps you can leverage the Title II and SSI Specialists at Social Security. (E6)

Work Incentives

The Social Security Agency offers a myriad of work incentives that were originally designed to encourage those receiving SSI or Title II benefits to seek employment. These work incentives, although well intentioned, are problematic:

1. They are complex and the procedure for applying for incentives is unclear.
2. IDD and their loved ones have difficulties finding the consistent and clear advice.
3. Movement to My SSA and other applications have not fully integrated how to specify which incentives are in play.
4. Incentives have not kept up with the person-centered approach to individuals with disability.
5. The incentives have not kept up with the cost of living and place individuals with disabilities below the poverty level.
6. Reinstatement if the individual should become employed is difficult, thereby motivating those with IDD to not hit salary plateaus to avoid losing benefits.

Problems	Recommendations
<p>System Encourages Persons with IDD to Remain in Poverty Status</p> <ul style="list-style-type: none"> ▪ The cost of living for individuals with disabilities far exceeds the maximum monthly SSI benefit for individuals. (Especially in California) The maximum benefit for persons with IDD (not blind in CA) is \$1,041.21/month for someone in independent living status. ▪ SSI: Reduction in cash benefits is a disincentive to employment (Loss of 50 cents per dollar earned After disregarding the first \$85 (general income exclusion [if no other unearned income] and earned income exclusion)) ▪ SSI Recipients can lose their ENTIRE cash benefits if they earn \$2,165.42 Gross (breakeven point) – problematic given new minimum wage <p><i>Persons with IDD are often advised to work a limited number of hours (less than they are capable/and potentially unemployable) to reduce risk/fear of losing benefits</i></p>	<ul style="list-style-type: none"> ▪ The goal is to provide ample income to stay out of poverty and not have loss of \$ benefit be a concern for why not to seek or be fully employed. Below are some alternatives to be considered: ▪ Reduce the loss of benefit from 50 cents per dollar earned to 25 cents per dollar earned. ⁱ (WI 1) ▪ And/or increase the earned income exclusion from \$65 to poverty level. (For discussion is whether we should use SGA, 1619b Threshold amount, or HUD local income levels) (WI 2) ▪ Increase the CA state supplement so that when SSI calculations are done, the person will be able to retain more of their SSI benefit in addition to their work wages. This is a very CA specific change that would not impact other states/federal given the higher cost to live here. (WI 3)

Problems	Recommendations
<p>The SSDI System and Work Incentives/Employment Supports are complicated and insufficient to address (See Work Incentives/Employment Supports for additional details.)</p> <ul style="list-style-type: none"> ▪ It is Difficult to Manage Benefits when self-employed (such as Gig and Microenterprises) ▪ Difficult to report employment supports/work incentives to Social Security when doing wage reporting (my Social Security Application) ▪ Social Security office staff do not provide aid or referrals related to work incentives. 	<ul style="list-style-type: none"> ▪ Fix Work Incentives / Employment Supports (See Other Section). (WI 4) ▪ Ensure that all persons with IDD have access to benefits planners who are trained to act as a guide to the work incentives/employment support (WI 5) ▪ Work Incentives / Employment Supports (See Other Section) (WI 6) ▪ Additional AWIC support is needed to address technical concerns regarding Work Incentives, overpayments, and other benefit-related issues. Note OC AWIC has not been replaced. (WI 7)
<p>(SSI Only) Earned Income Exclusions – Provides that SSA does not count the first \$65 of income from employment and \$20 general income exclusion before reducing benefits by \$1 for each \$2 earned.</p> <ul style="list-style-type: none"> ▪ \$65 for Earned Income Exclusion set too low. This keeps beneficiary in poverty. ▪ Disincentive to work 	<ul style="list-style-type: none"> ▪ Reduce the loss of benefits from one dollar for every two dollars (50% of wages) earned to 50 cents per two dollars earned (25% of wages).ⁱ (WI 8) ▪ Increase the CA state supplement so that when SSI calculations are done, the person will be able to retain more of their SSI benefit in addition to their work wages. This is a very CA specific change that would not impact other states/federal given the higher cost to live here. (WI 9) ▪ And/or increase the earnings exemption from \$65 to poverty level. (For discussion is whether we should use SGA, 1619b Threshold amount, or HUD local income levels) (WI 10)

Problems	Recommendations
<p>(SSI Only) Student Earned Income Exclusion (SEIE) – Allows a student under the age of 22 to exclude income as long as they are earning student credits of 12 hours per week. Although there is a provision that allows for fewer units less time than 12 hours per week for reasons beyond the student's control, such as illness. There are also exceptions for those immunocompromised and receiving education from home; those with IDD or their loved-ones may not be aware of those exceptions or the process of securing them.</p> <ul style="list-style-type: none"> ▪ Age 22 is too young. Many Intellectual and Developmental Disabilities (IDD) will be in college till age 35 or more. ▪ Educators, students, and family are not aware of this exclusion. 	<p>Let an Individual's Person-Centered Plan within the ITP/ IEP, IPP, or IPE, created by an appropriate agency/school in conjunction with the student/family determine requirements for Student Earned Income Exclusion and allow increase in age to 35 years old. (WI 11)</p> <p>Status should be shown on <i>mySocialSecurity</i>. (WI 12)</p>
<p>(SSI & Title II both) Impairment Related Work Expense (IRWE) – Deduction of the cost of certain impairment-related items and services needed to work from gross earnings when we decide if your work is substantial gainful activity (SGA).¹</p> <ul style="list-style-type: none"> ▪ Families are unclear about what is included IRWE ▪ Reporting procedures for IRWE are unclear. 	<ul style="list-style-type: none"> ▪ Modify <i>mySocial Security</i> to ensure IRWE is reported when earnings are reported. (WI 13)

¹ There are lots of examples of IRWE's from SSA. There is one spotlight, but there are so many others that actually list potential IRWE's. However, lots of IDD connected with RC or DOR don't use IRWE's since most of their impairment related work expenses are paid by others and not out of pocket.

[https://choosework.ssa.gov/library/2018-11-28-faq-impairment-related-work-expenses#:~:text=Impairment%2DRelated%20Work%20Expenses%20\(IRWE,for%20Social%20Security%20disability%20benefits](https://choosework.ssa.gov/library/2018-11-28-faq-impairment-related-work-expenses#:~:text=Impairment%2DRelated%20Work%20Expenses%20(IRWE,for%20Social%20Security%20disability%20benefits)

<https://www.ssa.gov/ssi/spotlights/spot-work-expenses.htm>

<https://secure.ssa.gov/poms.nsf/lnx/0410520000>

Problems	Recommendations
<p>(SSI only) 1619A - receive Supplemental Security Income (SSI) cash payments even when your earned income (gross wages and/or net earnings from self-employment) is at the substantial gainful activity (SGA) level. This provision eliminates the need for the trial work period or extended period of eligibility under SSI.</p>	<p>Create an 1619A SSA Spotlight Information Sheet to better define this benefit and how to implement it. (WI 14)</p>
<p>(SSI & Title II both) Section 301 - Appropriate vocational rehabilitation (VR) or similar services, that allow benefits to continue until participation in the program ends.</p> <ul style="list-style-type: none"> ▪ Confusing how to implement Section 301 ▪ Permanent Removal may be an unrealistic goal – as individuals mental and physical states change over time. ▪ “We review” puts determination of the value in the hands of SSA who are likely to be unfamiliar with the program and the individual’s disability status. ▪ Programs like RC Paid Internship Program should be included. 	<p>Let an Individual’s Person-Centered Plan (e.g. IEP/IPP) created by an appropriate agency/school in conjunction with the student/family determine requirements for 301 benefit versus Social Security. (WI 15)</p>

Problems	Recommendations
<p>Title II Trial Work Period Process: Keeps people at poverty levels.</p> <ul style="list-style-type: none"> ▪ The trial work period allows testing of ability to work for at least nine non-consecutive months in a 60-month rolling period. The problem is that if the months are non-consecutive they really do not demonstrate a person’s ability to earn a living wage. ▪ Risk of losing cash benefits is a disincentive to employment. (All or nothing for Title II) ▪ In 2022, a trial work month is any month your total earnings are over \$970. During the trial work period, there are no limits on your earnings. During the 36-month extended period of eligibility, you usually can make no more than \$1,350 (\$2,260 if you are blind) a month in 2022 or your benefits will stop. These amounts are known as Substantial Gainful Activity (SGA). Both SGA and trial work month amounts are below poverty levels.ⁱⁱⁱ ▪ Self-supporting and independent earning levels are inconsistent and below poverty (\$940, \$1310) ▪ Advocates and services providers recommend working reduced hours to avoid benefit issues (Disincentive to work) ▪ These limitations contribute to a disincentive for employers to hire persons with Intellectual and Developmental Disabilities (IDD) 	<ul style="list-style-type: none"> ▪ Modify Title II Trial Period/Extended Period of Eligibility Frameworks by making the nine-month trial work period consecutive versus nonconsecutive earnings. (WI 16) ▪ Raise income levels to the amount set for Individualized 1619b Threshold Amounts not at poverty level. Note SGA is \$16,200 (\$1350/month) (This is \$5.17/hour working 40 hours). Individualized 1619b Threshold Amounts is \$4,507 per month. (WI 17)

Continuing Disability Review

The law requires Social Security Administration (SSA) perform a medical Continuing Disability Review (CDR) at least once every three years, however, if the individual has a medical condition that is not expected to improve, SSA will review the case, once every five to seven years. The purpose of the periodic review is to determine if the person continues to have a disabling condition that impacts their ability to be gainfully employed. During this time, SSA will also review the individual's income, resources, and living arrangements to ensure that they continue to meet the non-medical program requirements in addition to the medical requirements.

Problems	Recommendations
<ul style="list-style-type: none"> ▪ CDR happens sometimes without the person with IDD/Family input, in spite of the fact that SSA requires the person with the disability (and/or their representative) to complete the SSA-454 (Continuing Disability Review Report) or SSA-455 (Disability Update Report) form. ▪ Note: Ability to meet self-support and independent earning levels and existence of disability are combined, when they are two separate measures of need 	<ul style="list-style-type: none"> ▪ Notification of plans for medical evaluation/redetermination should be sent certified mail to the person with IDD and loved one, and Rep Payee, with adequate time to provide appropriate documentation. (CD 1) ▪ Do not link disability designation with ability to earn a living (Problem with Redetermination). (CD 2) ▪ If someone is going to lose their benefit, a next step plan must be put in place at least 3 months prior to the loss of the benefit (Plan should be agreed to by an approved agency, loved-one, person with IDD) (CD 3)
<p>Ability to earn SGA as part of the CDR should take into account Subsidies and Special Conditions which are not easily reported.</p> <ul style="list-style-type: none"> ▪ Social Security is supposed to consider the existence of subsidies and/or special conditions (e.g. Job Coaching, Subsidized Wages, etc.) when they make a substantial gainful activity (SGA) decision. However, these are not easily reported and do not include all types of Subsidies and Special Conditions. 	<ul style="list-style-type: none"> ▪ Reporting of income MUST provide the option to specify Subsidies and Special Conditions relative to success employment (job coaching, paid training programs, job modifications made to support the person with IDD). This should be a feature of the My Social Security website/mobile app. (CD 4)

Problems	Recommendations
<p>The Continuing Disability Review (CDR) is being implemented without appropriate notice–</p> <ul style="list-style-type: none"> ▪ Continuing Disability Review can happen randomly and often create a significant burden on the Rep Payee and persons with Intellectual and Developmental Disabilities (IDD) ▪ This procedure (we believe) can be delegated to out of state agencies, that can add incremental confusion. ▪ SSA notification process does not guarantee receipt by the person with IDD and by the Rep Payee. ▪ Continuing Disability Review can be initiated without comprehensive medical, psychological, and work information –leading to incorrect” disability has ceased” designation and loss of benefits 	<ul style="list-style-type: none"> ▪ Use Blue Book (https://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm) to identify those with more severe/significant disabilities where the condition is unlikely to substantially improve to warrant CDR. Alternatively, perhaps it can be a standard timeframe of ten years and if a person keeps classification for 2 CDR then no future CDR will be initiated. (CD 5) ▪ Revise the Blue Book to indicate when a disability is considered permanent. (CD 6) ▪ Written notification needs to be sent certified mail to both the person with IDD and Rep Payee. Provide formal process to demonstrate receipt and acknowledgement. (CD 7) ▪ My Social Security shall also be updated with email sent to person with IDD and Rep Payee for original notification and all phases and requests. (CD 8)

Problems	Recommendations
<p>Medical Redetermination is being tied to ability to meet SGA requirement (Page 10 of Redbook)</p> <ul style="list-style-type: none"> ▪ Title II: Medical Improvement and meeting SGA are TWO separate designations. It should not be assumed that there is a medical improvement simply because an individual achieves SGA. ▪ Medical Improvements (mental health) can be temporary with high potential for decline (Many persons with IDD typically never fully RECOVER – they may achieve and ability to meet SSA – but this situation can change based on loss of employment (For details refer to Loss of Employment in this paper), loss of supports, or a mental health episode. 	<ul style="list-style-type: none"> ▪ Title II/SSI: Medical Improvement must have input from Rep Payee and person with IDD. While SSA is supposed to send the authorized representative or beneficiary the SSA-454 or SSA-455, it does not always happen. Designation of medical improvement shall not be determined without a similar vetting as the original determination of the disability. (CD 9)

Medical Insurance

Health Insurance is a necessary need. Especially to those persons with IDD, who have little chance of obtaining health insurance through employment or have the financial means to pay for their own health insurance. Health insurance is typically linked to SSI and Title II benefits. Specifically, those receiving SSI are also provided with Medi-Cal (in California). Those receiving Title II benefits may be eligible for Medicare after a two-year waiting period. If in financial need, those receiving Medicare may also be provided with Medi-Cal, often called Medi-Medi.

Medi-Cal and Medicare are two separate and distinct programs,

As a Medicaid program, Medi-Cal (based in California) serves as a health care safety net, paying the medical expenses for beneficiaries who have low incomes. This can include individuals, families, children, those who are pregnant, as well as seniors and people who have **disabilities**. With Medi-Cal, you have to meet certain income requirements, a condition not required by Medicare.

Medicare, by contrast, is a federal program that operates on a nationwide basis, providing health care coverage to more than 63 million seniors and **disabled** beneficiaries under the age of 65.

The SSA does periodic reviews to determine persons with IDD continuing medical eligibility for benefits. Those who make more than the SGA are often classified by SSA as no longer being disabled which is not the case for most individuals with IDD

An individual may be enrolled in both programs where Medi-Cal and Medicare are to work together in coordinating and providing care. With this type of arrangement, Medi-Cal wraps around Medicare coverage, helping to pay for Medicare premiums, copayments and deductibles.

Problems	Recommendations
<p>(SSI only) 1619B - After returning to work, Medicaid coverage can continue, even if earnings become too high for a Supplemental Security Income (SSI) cash payment. The “threshold amount” is the measure that is used to decide whether your earnings are high enough to replace your SSI and Medicaid benefits.</p> <ul style="list-style-type: none"> ▪ Can be confusing due to notices from county. ▪ What is confusing is the letters from the county social services agency that determine Medi-Cal eligibility and DHCS if on 250% Working Disabled. The letters alone from the various agencies are confusing. 	<ul style="list-style-type: none"> ▪ Should happen automatically, not clear that it does. (MI 1) ▪ Need a “how to guide” for navigating medical benefits timelines. (MI 2)

Problem Resolution and Appeals Process

You can appeal most SSA determinations and decisions. SSA has established appeals procedures for individuals who disagree with the determination(s) or decision(s) made by SSA. The determination(s) or decision(s) that can be appealed are called "initial determinations". The levels of appeal are:

- Reconsideration
- Hearing by an administrative law judge
- Appeals Council Review; and
- Federal Court

All of these SSA processes have an associated timeline which must be followed. The persons with IDD may not have to go through all the appeal levels. To initiate an appeal individuals must contact SSA to reconsider a decision made. The challenges for the persons with IDD is understanding the requests of SSA and the timeline can be excessive and often has a huge impact on their life. Additionally, it can be difficult to identify someone to assist with challenging the SSA decision.

Problems	Recommendations
<p>Overpayment Invoices are showing overpayment back several years:</p> <ul style="list-style-type: none"> ▪ Sometimes these delays are due to failure of Social Security Administration and not intentional failure by the persons with IDD to follow complex procedures. ▪ Persons with IDD can receive SSA overpayment notices of tens of thousands of dollars with no way to for the person with IDD to provide payment. (Notices can go back to when the overpayment first occurred.) ▪ NOTE: Appeal Overpayment Waiver (SSA632)– don't have means to pay it back; against equity in good conscience. ▪ If someone is on SSI overpayment – can't take more than 10% of the benefit. 	<ul style="list-style-type: none"> ▪ Overpayment Invoices should be capped to one year of benefits. (If the delay is not due to IDD failure to report) (PR 1) ▪ IDD and Rep Payee should understand that any repayment schedule shall be reasonable for the IDD and may include deferments/cancellation based on income levels. (Already true for SSI / Add for Title II) (PR 2)

Problems	Recommendations
<p>SSA offers an “aid paid pending” when SSA determines that the person’s physical or mental impairment has improved/ceased. In these situations, called Statutory Benefits Continuation (SBC), the appeal must be filed within 10 days of the Notice of Cessation (starting 5 days after the letter is sent) along with request for continuing cash benefit.</p> <ul style="list-style-type: none"> ▪ This timeframe is inadequate for families who will need to seek council to understand what is happening and how they should proceed. ▪ SSA notices do not include information about SBC even in cases where this applies. 	<ul style="list-style-type: none"> ▪ Change the timeframe for the appeal to at least 30 days if not more. (PR 3) ▪ Include SBC language in notices as appropriate. (PR 4)
<p>Resolution to problems may require an Administrative Law Judge Hearing.</p> <ul style="list-style-type: none"> • Administrative Law Judge Hearings typically are expensive for the IDD who may not have funds to pay for representation. • Family and IDD do not feel comfortable representing themselves in court setting. 	<ul style="list-style-type: none"> ▪ Social Security establish contract with a legal aidsto take these cases pro bono so that person with disability does not have to relinquish 25% or \$6,000, whichever is lower, of their retroactive benefit payment to the attorney. (PR 5)
<p>Difficult to Impossible to Access SSA staff with IDD Experience</p> <ul style="list-style-type: none"> ▪ Reports of long waits on the phone and dropped calls . ▪ Staff are not knowledgeable about the use of benefits and work incentives. 	<ul style="list-style-type: none"> ▪ Provide annual ongoing IDD training. (PR 6) ▪ Ensure that there are designated SSA Staff who can serve as the subject expert for IDD related issues. (PR 7) ▪ Establish a problem management system that tracks open issues and timelines (case number) with guaranteed response times. (PR 8)

Problems	Recommendations
<p>Ineffective Supports for Individuals Experiencing Problems</p> <ul style="list-style-type: none"> • Advocates and attorneys are expensive. Even when they work on contingency, they take a lump sum (25% or \$6K whichever is lower) – and maybe difficult to find for appeals. • Certified Benefit planners are certified through a SSA organization, and the training is arduous. Their knowledge for handling unique/difficult situations or priority to manage problem resolution is not being addressed. These may either be because of a lack of knowledge to address technical problems, bandwidth, or job definitions.² • WIPA are not allowed to help families during an “appeal process”. 	<ul style="list-style-type: none"> ▪ Publish a list of the different types of roles of benefits planners/WIPA/etc., indicate training, responsibilities, and who can assist families with appeals. This list shall be sent to families via the Regional Center (in California), and other support groups, ILCs, and agencies (Department of Rehabilitation). (PR 9) ▪ Need Technical Expert Team to assist Certified Benefits Planners/Advocates with solutions for technical problems. (PR 10) ▪ Expand the role of the Certified Benefits Planner to include representation for helping persons with IDD/families navigate the appeals process. (PR 11) ▪ SSA Hot Line for SSI/Title II questions. (PR 12) ▪ If this is not addressed, then people will just NOT WORK. Who needs this hassle. (PR 13)
<p>Excessive Waiting Periods for Administrative Law Judge Hearing</p> <ul style="list-style-type: none"> • Due to understaffing waiting period for Administrative Law Judge Hearings are between 10-15 months depending on location. National average is 314 days and in OC, it is 16 mos, Fresno is 16 mos, Los Angeles is 19 mos.^{iv} are over one year. Note that then there is additional time waiting for a decision. Although individuals can request provisional Social Security disability benefits, those benefits only cover six months. 	<ul style="list-style-type: none"> ▪ Social Security disability benefit should continue until the Administrative Law Judge Hearing has been completed. (PR 14)

² VCU or Cornell University both make themselves available for ongoing Technical Assistance and help. Additionally, other benefits practitioner that have been in this field for ages, also make themselves available for free TA. So I guess my point is that VCU or Cornell do offer this.

Problems	Recommendations
<p>Penalization of Loss of Medical Insurance based on Administrative Law Judge Hearing Outcome</p> <ul style="list-style-type: none"> • Those pursuing Administrative Law Judge Hearings are being told that if they lose the case, they may forgo their public medical insurance. (This needs further investigation as to what is currently being done and the medical insurance eligibility rights that are being impacted.) 	<ul style="list-style-type: none"> ▪ SSI/SSDI: Requests for Administrative Law Judge Hearings shall not place medical insurance at risk based on hearing outcome. (PR 15) ▪ Other medical insurance information should be provided to benefits recipients, so that they have information regarding alternative medical insurance options. (Currently will likely happen in California – may not be true in other states) (PR 16)

Expedited Reinstatement

If someone's benefits end because of work earnings, one can request that their benefits start again without having to complete a new application. On many occasions, persons with intellectual and developmental disabilities have flare ups in their condition, and/or decompensate due to internal/external factors, preventing them from working at the substantial gainful levels they had in the past. EXR offers a safety-net, of sorts, to account for this. While SSA determines whether the person can get benefits again, SSA will offer provisional (temporary) benefits for up to 6 months.

Problems	Recommendations
<p>(SSI & Title II both) Reinstating SSDI Eligibility Without a New Application – If benefits stopped due to work, you may be able to restart them again to allow receipt up to six months of temporary cash benefits during a medical review to decide if benefits can be reinstated. Medicare and/or Medicaid may be provisionally reinstated.</p> <ul style="list-style-type: none"> ▪ Unclear procedure for expedited reinstatement. ▪ Six months of provisional benefits is inadequate with long wait periods ▪ Problem when medical disability is redetermined without input from family and IWD (See other one-sheet) ▪ “You may also be eligible for Medicare and/or Medicaid during this provisional benefit period.” puts someone at risk for not having medical insurance.” ▪ You request EXR within 5 years from the month your benefits stopped (This becomes an issue without timely notification. For example, if you notify someone that they lost their benefits five years prior they are no longer eligible for EXR) 	<ul style="list-style-type: none"> ▪ Clarify and iron out the expedited reinstatement process in SSA Spotlight Information Sheet. (ER1) ▪ https://www.ssa.gov/disabilityresearch/wi/exr.htm ▪ Provisional benefits should be long enough to allow for medical review; time for the matter to be formally resolved with Social Security. (ER 2) ▪ Current benefits status shall be visible and accurate from mySocial Security account. (ER 3) ▪ Technical Support shall be available throughout the process. (ER 4) ▪ Timeline for any reduction or elimination of benefits should start from time of notification and cannot be back-dated. Unclear as SSA does not require provisional benefits be paid back if found ineligible. Excluding cases of fraud. (ER 5)

Problems	Recommendations
<p>Difficult to Reinstate Benefits</p> <p>The Expedited Reinstatement (EXR) Process does allow for provisional benefits up to 6 months.</p> <p>If benefits ended because the beneficiary worked and had earnings, they can request that the benefits start again without having to complete a new application (EXR). While SSA determines whether the person can get benefits again, SSA can give provisional (temporary) benefits for up to 6 months.</p> <p>Inability/Disability to get Expedited Reinstatement once they are eliminated for work related reasons</p>	<ul style="list-style-type: none"> ▪ If someone is going to lose their benefit, a next step plan must be put in place at least 3 months prior to the loss of the benefit (Plan should be agreed to by an approved agency, loved-one, persons with IDD) (ER 6) ▪ Guarantee Immediate Reinstatement upon loss of employment (Make it a TRUE Safety Net) (within 30 days of applying) (ER 7)
<p>Reinstating SSI Eligibility Without a New Application (SSI & Title II both) - You may be able to restart your SSI cash payments again at any time without a new application.</p> <p>Unclear how the process works:</p> <ul style="list-style-type: none"> ▪ How do you apply? ▪ What are the criteria? ▪ Who makes the determination? ▪ How do you get to the person making this decision? ▪ What is the timeframe for the decision? ▪ Expedited Reinstatement is only for 6 months 	<ul style="list-style-type: none"> ▪ Clarify and iron out the expedited reinstatement process with SSA Spotlight Information Sheet. (ER 8) ▪ Allow for application by Rep Payee or beneficiary on MySocialSecurity (Currently paper process) (If the person is given a 3-month notice that includes the creation of a plan) (Procedure Operation Manual – POMS.) (ER 9) ▪ The expedited reinstatement procedure needs to be reviewed to ensure timeliness and appropriateness. (ER 10) ▪ Technical Support shall be available throughout the process. (ER 11) ▪ Guarantee Immediate Reinstatement upon loss of employment (Make it a TRUE Safety Net) (within 30 days of applying) (ER 12)

Problems	Recommendations
<p>(SSI & Title II both) Reinstating SSDI Eligibility Without a New Application – If benefits stopped due to work, you may be able to restart them again to allow receipt up to six months of temporary cash benefits during a medical review to decide if benefits can be reinstated. Medicare and/or Medicaid may be provisionally reinstated.</p> <ul style="list-style-type: none"> ▪ Unclear procedure for expedited reinstatement ▪ Six months of reinstatement in adequate with long wait periods for Medical Review ▪ Problem when medical disability is redetermined without input from family and IWD (See other one-sheet) ▪ “You may also be eligible for Medicare and/or Medicaid during this provisional benefit period.” puts someone at risk for not having medical insurance.” ▪ You request EXR within 5 years from the month your benefits stopped (This becomes an issue without timely notification. For example, if you notify someone that they lost their benefits five years prior they are no longer eligible for EXR) 	<ul style="list-style-type: none"> ▪ Expedited reinstatement should be long enough to allow for medical review; time for the matter to be formally resolved and implemented with Social Security. (ER 13) ▪ Current benefits status shall be visible and accurate from mySocial Security account. (ER 14) ▪ Technical Support shall be available throughout the process. (ER 15) ▪ Timeline for any reduction or elimination of benefits should start from time of notification and cannot be backdated. Excluding cases of fraud. (ER 16)
<ul style="list-style-type: none"> ▪ Difficult to Reinstatement Benefits when becoming unemployed (Page 33 of the Red Book) (See Procedural section for more details) 	<ul style="list-style-type: none"> ▪ Guarantee Immediate Reinstatement upon loss of employment (Make it a TRUE Safety Net)-should apply until date set by SS/Courts. Should not end due to administrative inability to deal with scheduling. (ER 17)

Conclusion and Next Steps

In this white paper we outlined several observed problems with the Social Security programs for families and persons with IDD who are attempting to improve their situation through employment. Although tremendous energy and funds are being invested by the government, professionals, nonprofits, families, and individuals to enable persons with IDD to achieve competitive integrated employment, fear of loss of benefit, confusion over how to leverage work incentives, the complexity in applying for and resolving issues, has created anxiety among

the IDD community. The result is under employment and increased stress of the families and individuals who most need a sense of security.

The problems and proposed solutions described in this white paper were determined without direct contact with our Federal and State government representatives or the Social Security Administration. The changes proposed include system/software enhancements, education and documentation of procedures and processes, expanded support for individuals and their loved ones by SSA and other organizations, plus legislative changes. Note that Appendix A re-examines the proposed resolutions by categorizing them how they might be implemented. One important consideration is the fact that Social Security does not differentiate between those with IDD from those who become disabled and are unable to work for a period of time.

To move forward, we believe the next steps are as follows:

1. Socialization of this document to other communities and knowledgeable professionals with appropriate updates made based on input. We also will need to gain support from a broad group of nonprofits and organizations who share a common concern and vision for increased employment of persons with IDD.
2. Meetings with representatives from Social Security Administration to discuss the issues raised in this document, to increase understanding and determine if there are existing plans for any of these concerns to be addressed. If not, we hope that they might start to formulate potential solutions and initiate their implementations.
3. Meetings with government representatives to gain support and drive solutions to the problems outlined.

We thank you for taking the time to read this white paper. We hope that you agree that this issue of enhancing employment of person with IDD and guaranteeing a safety net of medical insurance and income, is critical to this community. We look forward to your being a part of the solution.

Appendix A: Table of Implementation Techniques

In this paper we analyzed the problems and proposed resolutions into six subject areas:

1. Employment
2. Work Incentives
3. Continuing Disability Review and Medical Redetermination
4. Medical Insurance
5. Problem Resolution and Appeals Process
6. Reinstatement

Appendix A reexamines the proposed resolutions by placing them in one of six category of implementation methods. This will assist as we look for what problems can be addressed easily or locally, while others may require Congressional action. Note that some proposed resolutions are repeated as their implementation fits into two categories.

1. Legislative Changes: These resolutions require enactment of new or amending existing laws.
2. Family Training: These matters can be addressed with highly available and informative training.
3. Staffing and Training: Implementation of these resolutions can be addressed with staffing within the state of California and training of existing or new staff.
4. New Forms: These resolutions can be addressed by modifying existing or creating new forms.
5. Software and Technology: Some resolutions are best address with modifying existing software or implementing new technology.
6. SSA Procedural Change: These resolutions require process change by the Social Security Administration.

Type of Change	Employment	Work Incentives	Continuing Disability Review	Medical Insurance	Problem Resolution	Expedited Reinstatement
Legislative Change		<p>Let an Individual's Person-Centered Plan within the ITP/ IEP, IPP, or IPE, created by an appropriate agency/school in conjunction with the student/family determine requirements for Student Earned Income Exclusion and allow increase in age to 35 years old. (WI 11)</p> <p>Let an Individual's Person-Centered Plan (e.g. IEP/IPP) created by an appropriate agency/school in conjunction with the student/family determine requirements for 301 benefit versus Social Security. (WI 15)</p> <p>Modify Title II Trial Period/Extended Period of Eligibility Frameworks by making the nine-month trial work period consecutive versus nonconsecutive earnings. (WI 16)</p> <p>Raise income levels to the amount set for Individualized 1619b Threshold Amounts not at poverty level. Note SGA is \$16,200 (\$1350/month) (This is \$5.17/hour working 40 hours). Individualized 1619b Threshold Amounts is \$4,507 per month. (WI 17)</p>			<p>Overpayment Invoices should be capped to one year of benefits. (If the delay is not due to IDD failure to report) (PR 1)</p> <p>Change the timeframe for the appeal to at least 30 days if not more. (PR 3)"</p> <p>Social Security disability benefit should continue until the Administrative Law Judge Hearing has been completed. (PR 14)</p> <p>SSI/SSDI: Requests for Administrative Law Judge Hearings shall not place medical insurance at risk based on hearing outcome. (PR 15)</p>	<p>Provisional benefits should be long enough to allow for medical review; time for the matter to be formally resolved with Social Security. (ER 2)</p> <p>Timeline for any reduction or elimination of benefits should start from time of notification and cannot be backdated. Unclear as SSA does not require provisional benefits be paid back if found ineligible. Excluding cases of fraud. (ER 5)</p> <p>Timeline for any reduction or elimination of benefits should start from time of notification and cannot be backdated. Excluding cases of fraud. (ER 16)</p>

Type of Change	Employment	Work Incentives	Continuing Disability Review	Medical Insurance	Problem Resolution	Expedited Reinstatement
Family Training	Make people aware of supplemental information, such as Spotlight Information Sheets. Address gaps in topics. (E2)				Provide annual ongoing IDD training. (PR 6)	

Type of Change	Employment	Work Incentives	Continuing Disability Review	Medical Insurance	Problem Resolution	Expedited Reinstatement
<p>Staffing and Training</p>	<p>Increase knowledge of local SSA office staff with regards to SSI and SSDI for persons with IDD. (Make people aware of supplemental information, such as Spotlight Information Sheets. Address gaps in topics.) (E2)</p> <p>Provide Technical Expert Team to SSA staff, in addition to the Area Work Incentive Coordinator (AWIC). (E3)</p> <p>Expand AWICs. (Hire in OC) (E4)</p> <p>Unclear unknown potential utilization of the Work incentive Liaison (WIL) (E5)</p>	<p>Ensure that all persons with IDD have access to benefits planners who are trained to act as a guide to work incentives/employment support.. (WI 5)</p>			<p>Provide annual ongoing IDD training. (PR 6)</p> <p>Ensure that there are designated SSA Staff who can serve as the subject expert for IDD related issues. (PR 7)</p> <p>Need Technical Expert Team to assist Certified Benefits Planners/Advocates with solutions for technical problems. (PR 10)</p> <p>Expand the role of the Certified Benefits Planner to include representation for helping persons with IDD/families navigate the appeals process. (PR 11)</p>	<p>Technical Support shall be available throughout the process. (ER4, ER 10 & ER 11)</p>

Type of Change	Employment	Work Incentives	Continuing Disability Review	Medical Insurance	Problem Resolution	Expedited Reinstatement
New Forms		Create an 1619A SSA Spotlight Information Sheet to better define this benefit and how to implement it. (WI 14)		Need a “how to guide” for navigating medical benefits timelines. (MI 2)	<p>Publish a list of the different types of roles of benefits planners/WIPA/etc., indicate training, responsibilities, and who can assist families with appeals. This list shall be sent to families via the Regional Center (in California), and other support groups, ILCs, and agencies (Department of Rehabilitation). (PR 9)</p> <p>Other medical insurance information should be provided to benefits recipients, so that they have information regarding alternative medical insurance options. (Currently will likely happen in California – may not be true in other states) (PR 16)</p>	Clarify and iron out the expedited reinstatement process in SSA Spotlight Information Sheet. (ER 1 & ER 8)

Type of Change	Employment	Work Incentives	Continuing Disability Review	Medical Insurance	Problem Resolution	Expedited Reinstatement
<p>Software and Technology</p>	<p>Integrate the input of Work Incentives / Employment Supports with wage reporting (mySocialSecurity Application) (E 1)</p> <p>Implement a HOT-LINE for people for people with developmental disabilities and their families perhaps you can leverage the Title II and SSI Specialists at Social Security. (E6)</p>	<p>Status should be shown on mySocialSecurity. (WI 12)</p> <p>Modify mySocial Security to ensure IRWE is reported when earnings are reported. (WI 13)</p>	<p>Reporting of income MUST provide the option to specify Subsidies and Special Conditions relative to success employment (job coaching, paid training programs, job modifications made to support the person with IDD). This should be a feature of the My Social Security website/mobile app. (CD 4)</p> <p>My Social Security shall also be updated with email sent to person with IDD and Rep Payee for original notification and all phases and requests. (CD 8)</p>		<p>SSA Hot Line for SSI/Title II questions. (PR 12)</p> <p>Establish a problem management system that tracks open issues and timelines (case number) with guaranteed response times. (PR 8)</p>	<p>Current benefits status shall be visible and accurate from mySocial Security account. (ER 3)</p> <p>Allow for application by Rep Payee or beneficiary on MySocialSecurity (Currently paper process) (If the person is given a 3-month notice that includes the creation of a plan) (Procedure Operation Manual – POMS) (ER9)</p> <p>Current benefits status shall be visible and accurate from mySocial Security account. (ER 14)</p>

Type of Change	Employment	Work Incentives	Continuing Disability Review	Medical Insurance	Problem Resolution	Expedited Reinstatement
<p>SSA Procedural Change</p>					<p>Ensure that there are designated SSA Staff who can serve as the subject expert for IDD related issues. (PR 7)</p> <p>Establish a problem management system that tracks open issues and timelines (case number) with guaranteed response times. (PR 8)</p> <p>Need Technical Expert Team to assist Certified Benefits Planners/Advocates with solutions for technical problems. (PR 10)</p> <p>Expand the role of the Certified Benefits Planner to include representation for helping persons with IDD/families navigate the appeals process. (PR 11)</p>	<p>If someone is going to lose their benefit, a next step plan must be put in place at least 3 months prior to the loss of the benefit (Plan should be agreed to by an approved agency, loved-one, persons with IDD) (ER 6)</p> <p>Guarantee Immediate Reinstatement upon loss of employment (Make it a TRUE Safety Net) (within 30 days of applying) (ER 7)</p> <p>The expedited reinstatement procedure needs to be reviewed to ensure timeliness and appropriateness. (ER 10)</p> <p>Expedited reinstatement should be long enough to allow for medical review; time for the matter to be formally resolved and implemented</p>

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Type of Change	Employment	Work Incentives	Continuing Disability Review	Medical Insurance	Problem Resolution	Expedited Reinstatement
						with Social Security. (ER 13)

ⁱ The Bridges to Youth Self-Sufficiency Project during the period of 2003-2008. Identifying the processes are all the activities of the project of obtaining employment. The processes involve the use the resources or inputs in a project that will eventually produce outputs (e.g., units of service, like number of PASS plans written) and outcomes (e.g., beneficial changes in the student/family). The changes in the formula for reducing benefits was changes from \$1 for \$2 was tested with positive results. “The \$3 for \$4 waiver appears to have helped (increase employment & increase earnings in California), but not enough to offset the increased outlays attributable to this waiver. SSI waivers (work rule changes) that provide a greater incentive to work are worthy of careful testing. The \$3 for \$4, as a freely available (non-contingent) incentive, may not be as powerful in the right direction (i.e., greater self-sufficiency) as it would be as a reward contingent not only on wanting to work (in a verbal sense).

ⁱ 2022 United States Department of Housing and Urban Development Income Limits

ⁱⁱ The issue of technology is not dealt with in this document.

ⁱⁱⁱ [Working While Disabled: How We Can Help \(ssa.gov\)](#)

^{iv} <https://www.ssa.gov/appeals/>