

Recommendations for Changes to SSI and Title II Employment Programs for Intellectual and Developmental Disabilities (IDD)

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Project Summary: Social Security provides essential income for some individuals with intellectual and developmental disabilities (IDD) either through Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) aid.

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/SSDI and the associated Work Incentive System is ineffective and serves as disincentives for those with IDD who wish to work full time.

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

- Increases in the minimum wage to \$15/hour making the number of hours someone can work and stay within SGA extremely difficult.
- The impact of COVID in reducing the accessibility of SSA employees and extending delays in judicial review.
- New programs, such as the Regional Center Paid Internship Program, paying up to 1040 hours per year, without providing IDD and their families with details on how to maintain their benefits.

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. The document looks at the programs, the work incentives, and the problem resolution procedures.

This document limits its focus to problems associated with employment in California; although many ideas could be extended nationally.

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Information Sheets:

1. **Problems with SSI and Employment for Intellectual and Developmental Disabilities (IDD):** This document identifies the problems with the Social Security Supplemental Security Income program for IDD attempting to achieve competitive integrated employment at a life-sustaining wage. Recommendations on policy, procedure, staffing, and software changes that are needed to address these issues.
2. **Problems with Title II (SSDI/CDB) for Persons with Intellectual and Developmental Disabilities (IDD):** This document identifies the problems with the Social Security Title II programs, such as Social Security Disability Insurance (SSDI) for IDD attempting to achieve competitive integrated employment at a life-sustaining wage. Recommendations on policy, procedure, staffing, and software changes that are needed to address these issues.
3. **Problems with SSI and Title II Work Incentives & Employment Supports for Persons with Intellectual and Developmental Disabilities (IDD):** Work incentives and employment supports have been introduced to encourage persons with IDD who are participating in either SSI or Title II programs to seek employment. This document identifies gaps and problems for those who want to achieve competitive integrated employment at a life-sustaining wage. Recommendations on policy, procedure, staffing, and software changes that are needed to address these issues.
4. **Problems with SSI and Title II Resolution Procedures for Persons with Intellectual and Developmental Disabilities (IDD):** Many times, the Social Security Administration takes actions that may eliminate receipt of benefits presently or retroactively. This document outlines the problems encountered by those individuals impacted and the difficulties they encounter in attempting to resolve a dispute related to their benefits. Recommendations are provided about how these problems can be resolved in a timely manner or avoided all together.

Problems	Recommendations
<p data-bbox="82 241 810 275">Complicated System – Difficult to Understand</p> <p data-bbox="82 279 810 352">System Encourages Persons with IDD to Remain in Poverty Status</p> <ul data-bbox="82 357 810 772" style="list-style-type: none"> <li data-bbox="82 357 810 562">▪ 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/mo. <li data-bbox="82 567 810 640">▪ SSI: Reduction in cash benefits is a disincentive to employment (Loss of 50 cents per dollar earned) <li data-bbox="82 644 810 772">▪ SSI Recipients can lose their ENTIRE cash benefits if they earn \$2,165.42 Gross (breakeven point) – problematic given new minimum wage <p data-bbox="82 819 810 966"><i>Persons 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 data-bbox="813 279 1565 1360" style="list-style-type: none"> <li data-bbox="813 279 1565 394">▪ Goal is to provide for ample income to stay off poverty and not have loss of \$ benefit be a concern for why not to seek or be fully employed. <li data-bbox="813 399 1565 546">▪ Reduce the loss of benefit from 50 cents per dollar earned to 25 cents per dollar earned. (This change was successfully executed in the Promise Grant with excellent results.) <li data-bbox="813 550 1565 665">▪ Alternatively, the federal benefit rate (\$841) should be increased to the federal poverty level (\$1,132.50/month) <li data-bbox="813 669 1565 743">▪ Request that California increase the State Supplementary Payment for persons with IDD on SSI <li data-bbox="813 747 1565 1171">▪ Earning requirements should be consistent and set to Individualized 1619b Threshold Amounts not at poverty level. Note SGA is \$16,200 (\$1350/month) (This is \$5.17/hour working 40 hours). Alternative Poverty Income Limits: Individualized 1619b Threshold Amounts is \$4,507 per 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 <i>extremely low</i> and \$3954.17/month as <i>very low</i>.ⁱ <li data-bbox="813 1176 1565 1360">▪ SSI Recipients should not start reduction in SSI benefit until IDD has reached Individualized 1619b Threshold Amounts. (Alternatively, how about starting deduction at earnings above \$2,424.58 = \$4,507 – (2x\$1041.21).
<ul data-bbox="82 1402 810 1591" style="list-style-type: none"> <li data-bbox="82 1402 810 1518">▪ Work Incentives/Employment Supports are complicated and insufficient to address all individualized needs <li data-bbox="82 1522 810 1591">▪ Difficult to Manage Benefits if working with Microenterprise and Gig Jobs 	<ul data-bbox="813 1402 1565 1476" style="list-style-type: none"> <li data-bbox="813 1402 1565 1476">▪ Fix Work Incentives / Employment Supports (See Other Section)
<ul data-bbox="82 1596 810 1824" style="list-style-type: none"> <li data-bbox="82 1596 810 1711">▪ Difficult to report wages and employment supports/work incentives to Social Security when doing wage reporting (mySocial Security) <li data-bbox="82 1715 810 1824">▪ <i>Persons with IDD are advised to provide this information via certified mail or face-to-face at SSA requesting a receipt</i> 	<ul data-bbox="813 1596 1565 1711" style="list-style-type: none"> <li data-bbox="813 1596 1565 1711">▪ Integrate the input of Work Incentives / Employment Supports with wage reporting (<i>mySocialSecurity</i>)

Problems	Recommendations
<p>Medical Redetermination happens sometimes without persons with IDD/Family input</p>	<ul style="list-style-type: none"> ▪ Notification of plans for medical evaluation/redetermination should be sent certified mail to persons with IDD & loved one. It should provide time to provide appropriate documentation.
<p>Difficult to Reinstate Benefits 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) (Should this be in the Policy/procedure section?) ▪ Guarantee Immediate Reinstatement upon loss of employment (Make it a TRUE Safety Net) (within 30 days of applying)
<p>Difficult to Impossible to Access SSA</p> <ul style="list-style-type: none"> ▪ Long waits on the phone / Phone Calls Dropped ▪ Staff are not knowledgeable about the use of benefits and work incentives ▪ Case Managers are not accessible to persons with IDD/Reported Lag Time of SSA Systems 	

Problems	Recommendations
<p>SSDI Trial Work Period Process: Keeps people at poverty levels.</p> <ul style="list-style-type: none"> ▪ Risk of losing cash benefits is a disincentive to employment. (All or nothing for SSDI) ▪ Self-supporting and independent earning levels are inconsistent and below poverty (\$940, \$1310) ▪ Trial Work Period trigger is based on nonconsecutive quarters inadequate measure of ability to earn a consistent income ▪ 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 SSDI Trial Period/Extended Period of Eligibility Frameworks ▪ Make earning quarters Consecutive vs. nonconsecutive earnings ▪ 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
<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 employed (including Gig and Microenterprises) ▪ Difficult to report employment supports/work incentives to Social Security when doing wage reporting (my Social Security) ▪ 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) ▪ Ensure that all persons with IDD have access to benefits planners who are trained to act as a guide to the system ▪ Work Incentives / Employment Supports (See Other Section)
<ul style="list-style-type: none"> ▪ Two year Waiting Period for Medicare (CDB) creates a 2-year gap in coverage 	<ul style="list-style-type: none"> ▪ Eliminate 2-year gap for Medicare (CDB)
<ul style="list-style-type: none"> ▪ Medical Redetermination happens sometimes without the person with IDD/Family input ▪ 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, with adequate time to provide appropriate documentation. ▪ Do not link disability designation with ability to earn a living (Problem with Redetermination) ▪ 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)

Problems	Recommendations
<ul style="list-style-type: none">▪ Difficult to Reinstate 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.

Problems	Recommendations
<p>(SSI Only) Earned Income Exclusions – Provides that SSA does not count the first \$65 of income from employment and \$20 general income before reducing benefits by \$1 for each \$2 earned.</p> <ul style="list-style-type: none"> ▪ \$65 for Earned Exclusion set too low. This keeps beneficiary in poverty. ▪ Disincentive to work 	<ul style="list-style-type: none"> ▪ Reduce the loss of benefit from 50 cents per dollar earned to 25 cents per dollar earned. (This change was successfully executed in the Promise Grant with excellent results.) ▪ 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. ▪ Increase Earned Exclusion from \$65 to the Individualized 1619b Threshold Amounts. Individualized 1619b Threshold Amounts is \$4,507 per month for California
<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.</p> <ul style="list-style-type: none"> ▪ Not individualized – unit requirements should be individually determined. ▪ Age 21 is too young. Many Intellectual and Developmental Disabilities (IDD) will be in college till age 30. ▪ Educators, students, and family are not aware of this exclusion. 	<p>Let an Individual’s Person-Centered Plan (Such as the IEP/IPP) created by an appropriate agency/school in conjunction with the student/family determine requirements for Student Earned Income Exclusion (Allow increase in age and let the ICPP determine the unit requirements).</p> <p>Status should be shown on <i>mySocialSecurity</i>.</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.</p>

Problems	Recommendations
<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).</p> <ul style="list-style-type: none"> ▪ Unclear about what is included IRWE ▪ Reporting procedures for IRWE are unclear. 	<ul style="list-style-type: none"> ▪ Create SSA Spotlight Information Sheet to better explain the process ▪ Modify <i>mySocial Security</i> to ensure IRWE is reported when earnings are reported.
<p>(SSI & Title II both) Plan to Achieve Self-Support (PASS) –Set aside income for a specified period in the pursuit of a work goal (For example education, vocational training, assistive technology, or starting a business as long as the expenses are related to achieving your work goal.)</p>	<ul style="list-style-type: none"> ▪ Create SSA Spotlight Information Sheet to better explain the process
<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>Nick and Scarlett to provide additional information.</p>
<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 	<ul style="list-style-type: none"> ▪ Should happen automatically not clear that it does
<p>Reinstating SSI Eligibility Without a New Application (SSI & Title II both) Expedited Reinstatement (EXR) - 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 month 	<ul style="list-style-type: none"> ▪ Clarify and iron out the expedited reinstatement process with SSA Spotlight Information Sheet. ▪ Allow for application by Rep Payee on MySocialSecurity (If the person is given a 3-month notice that includes the creation of a plan) (Procedure Operation Manual – POMS (Scarlett to check) ▪ This procedure needs to be reviewed to ensure timeliness and appropriateness. ▪ Technical Support shall be available throughout the process

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<p>(SSI & Title II both) Expedited Reinstatement 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 is inadequate 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"> ▪ Clarify and iron out the expedited reinstatement process with SSA Spotlight Information Sheet. ▪ Expedited reinstatement should be long enough to allow for medical review and hearing; time for the matter is formally resolved with Social Security. ▪ Current benefits status shall be visible and accurate from mySocial Security account ▪ Technical Support shall be available throughout the process ▪ Timeline for any reduction or elimination of benefits should start from time of notification and cannot be back-dated.

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 creating 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 classification of Individuals with Intellectual/Development Disabilities to eliminate the requirement for Continuing Disability Review. Alternatively, perhaps you can make it predictable like every ten years and if a person keeps classification for 2 CDR then no future CDR will be initiated. ▪ 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. ▪ 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.
<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 an ability to meet SSA – but this situation can change. (Let’s discuss) (perfect employment disappears.) ▪ If they erroneously redetermine someone indicating that their disability has ceased, then they won’t be able to leverage the Extended Period of Eligibility option. 	<ul style="list-style-type: none"> ▪ Title II/SSI: Medical Improvement must have input from Rep Payee and person with IDD. Designation of medical improvement shall not be determined without a similar vetting as the original determination of the disability. ▪ Expedited Reinstatement needs to be redefined (timeline) to quickly resume benefit without reapplication in case of a significant decline in medical condition.

Problems	Recommendations
<p>Ability to earn SGA as part of the redetermination 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.
<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 IDD to follow complex procedures. ▪ IDD can receive SSA overpayment notices of tens of thousands of dollars with no way to for the 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) ▪ 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) ▪
<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. (All Social Security Attorneys will only work on contingency – need to understand how this might work) • 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 aids to take these cases pro bono. ▪
<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 	<ul style="list-style-type: none"> ▪ SSI/SSDI: Requests for Administrative Law Judge Hearings shall not place medical insurance at risk based on work. These on hearing outcome. ▪ 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)

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<p>Ability to earn SGA as part of the redetermination 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.
<p>medical insurance eligibility rights that are being impacted.)</p>	<ul style="list-style-type: none"> ▪ .
<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 over one year. 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. ▪

<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 (max of 25% or \$6K) – 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. • 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 ▪ Need Technical Expert Team to assist Certified Benefits Planners/Advocates with solutions for technical problems. ▪ Expand the role of the Certified Benefits Planner to include representation of help person with IDD navigate the appeals process. ▪ SSA Hot Line for SSI/SSDI questions. ▪ If this is not addressed, then people will just NOT WORK. Who needs this hassle.
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Problems	Recommendations
<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. Typically, there can be 8 hour waits to speak to someone at Social Security. ▪ 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 benefits for Individuals with Disabilities. ▪ Area Work Incentive Coordinator (AWIC) staff has reduced overtime with broader responsibilities making 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. (Leverage Benefit Information Sheets – Make sure that they are complete and accurate) ▪ Provide Technical Expert Team to SSA staff, in addition to the Area Work Incentive Coordinator (AWIC). ▪ Expand AWICs. (Hire in OC) ▪ Unclear unknown potential utilization of the Work incentive Liaison (WIL) ▪ 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