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Brief on employment issues for people with disabilities:

OVERVIEW:

Over decades there have been many work incentive attempts tried, yet sadly most have failed to make a meaningful dent in the number of people with disabilities fully engaged in the workforce. This document will attempt to explain why and offer some solutions. This is a longstanding, deeply entrenched problem that cannot be solved by one law or regulation change. We propose some short-term solutions combined with a long-term framework to address the root causes of the problem.

On a national level 35.2% percent of people with disabilities are employed. However, that reflects ANY sort of employment ANY time during the year. Only 22% percent work full time, full year. The Colorado numbers are not substantially different. 42.1 % are employed at all; 27.6 % are employed full time, full year. The numbers are lower for people with more significant disabilities and people of color.¹

There are a number of reasons for the lack of employment that range from inferior education with lack of job readiness of those born with disabilities, to the massive disincentives built into the Social Security Disability system. Lack of confidence on the part of people with disabilities who have internalized societal misconceptions about

¹ American Community Survey <http://www.disabilitystatistics.org/reports/acs.cfm?statistic=4>

disability also plays a role. Despite billions of dollars spent on disability programs, there is a complete lack of

Coordination of the various work incentive programs

Accurate information on the rules of the various programs

Competent career counseling that includes benefits counseling

There are numerous disability systems that do not work together.

They include:

Social Security Administration that administers cash benefits for people who have

SSDI (Social Security Disability Insurance) for people who have paid into the system directly or through a parent or spouse in some situations.

SSI (Supplemental Security Income) for people who are disabled who have no assets, no or very low income, and who are not eligible for SSDI due to not having worked enough quarters.

Health and Human Services

CMS: Center for Medicaid and Medicare Services:

Medicare is provided to people with SSDI 29 months after the date of eligibility. Medicare does NOT provide long-term care.

Medicaid is provided to all people that qualify for SSI immediately upon eligibility and in some cases the three months preceding application for SSI.

Administration for Community Living: This agency has a number of functions. Recently the Rehabilitation Services

Administration has been moved to this agency. RSA funds state rehabilitation programs. These programs can provide retraining for someone with a disability as well as other goods and services necessary to help someone obtain, maintain or increase employment.

Department of Education: Responsible for education of children with disabilities, including the transition programs, which provide services for young people aged 18-21.

Department of Housing and Urban Development: Responsible for housing programs.

There have been a variety of failed work incentive programs over the years.² Every person with a disability knows someone that tried a work incentive program only to become mired in a hopeless bureaucracy often in a worse situation than if the person had never tried to work. The reason for the failures is, in large part, that the policymakers have never included those of us who actually use the programs. SSA also does not train the field staff about the programs, but instead rely on regional experts, who are often deployed to work on other projects.

State Flexibility is not flexible: While states are given some flexibility, there are arbitrary or outdated federal regulations that get in the way of states that are able and willing to get it right.

Social Security Definition of Disability: This is at the heart of the problem. Their definition says that a disability is an

² Balanced Budget Act 1997, Ticket to Work and Work Incentives Improvement Act (TWIIA) 1999, followed by BBA (Bipartisan Budget Act 2015)

inability to engage in substantial gainful activity (which is the ability to earn \$1170 a month) in any job in the national economy.³ To get this designation one has to have a medically determinable impairment that meets or equals a listing (a list of specific conditions and severity) or demonstrate that they are unable to do any job in the national economy. In addition to medical evidence, disability determination contractors look at age, education and experience. Many people wait years for benefits, and have to appeal and sometimes go to court. During this process, people with disabilities are often erroneously told that they cannot do any work during this time. After waiting so long, and focusing solely on all that they cannot do, people begin to believe that they cannot do anything. During this wait, they have no income or very little income. They often lose their housing, max out credit cards, and borrow from friends or family if they are lucky enough to have anyone from whom they can borrow. Moreover, often during the process they do not have access to medical care or other supports that are only available to people on a Social Security Disability program. Once they get benefits, health care, and stabilize their lives, they do begin to feel better, but are terrified of showing any progress for fear of losing their benefits.

Once approved for a Social Security program, after months of saying how they cannot do any work, they are given a “ticket” to work. This ticket allows one to go to either a private employment network or a state Vocational Rehab program and receive services. If they are successfully “placed” the employment network is financially rewarded. This is one of the “work incentive programs.”

Categories of people:

³ <https://www.ssa.gov/disability/professionals/bluebook/general-info.htm>

There are two basic groups of people with disabilities who need support in order to work:

People who need Medicaid, usually for long-term care or other expensive care that is only available through Medicaid.

People with disabilities of a severity that make full time or consistent work is nearly impossible.

Each group has specific needs.

People who need Medicaid: These are usually people with physical disabilities, and some with chronic illnesses and controlled mental illness. They need services that are only available through Medicaid. This may include the Medicaid payment of Medicare cost sharing, particularly for people with expensive medications. If their earnings or assets are restricted by their need to get and keep Medicaid, they are forced to restrict or limit their income and do not allow themselves to accumulate assets. The asset limit for most disability programs is \$2000. This dollar amount was set in **1983** and has not changed since then. One cannot be a responsible homeowner, or even a responsible renter or consumer with so little cushion. Depending on the state, the income limit can be as low as a few hundred dollars a month to \$2100 depending on a variety of circumstances. Some states have “spend down” requirements which require people to spend a significant part of their income before getting Medicaid. Clearly this is a disincentive that comes with a burdensome reporting requirement.

Some states, including Colorado⁴, have implemented a Medicaid Buy-In Program allowing working adults to buy into Medicaid and receive both Medicaid and Long-Term Care.

While there are two federal problems with the Medicaid Buy-In Program, it is an outstanding example of one way to make it easier for more people with disabilities to enter the workforce and become financially stable with a job. Those problems are:

Federal regulations require that Medicaid Buy-IN ends at age 65 (states would get no match if they serve people past the age of 65). This was based on an assumption that people retire and get Medicare at 65. The problems with this are:

Retirement age is no longer 65.

No one stops working that young or at minimum retirement age.

Most importantly, Medicare does **not** have long-term care and other services needed by people with disabilities.

After being allowed to work and save money, this requirement will force people with disabilities who took the risk to seek employment to go back to poverty at age 65. These are people who require Medicaid for survival and whose needs are such that it is unlikely they could earn enough to forgo Medicaid. This would involve getting rid of any assets they accumulated. This defeats the point of saving for retirement. Experts say one should not rely on Social Security alone, but these rules force the disabled to do just that.

⁴ The Colorado program is one of the best in the nation with no asset limit at all. Some states barely make it worthwhile to take the risk with low earning limits and continuation of an asset test.

There are no longer Medicaid asset tests for non-disability populations. The 1931 and expansion populations can have any amount of assets and keep Medicaid. Only disabled and elderly have asset limitations. The point of the asset test for long-term care was aimed at middle class or upper class seniors that had a lifetime to plan. These individuals were using Medicaid as an inheritance protection program. Until very recently, this was not a concern of people with disabilities because so few of us lived to be 65 or older. Expanded life spans coupled with the newly acquired right to earn money have changed the landscape.

The law should allow people that have continuously worked for some amount of time (perhaps 2 years to start since the Medicaid Buy-In program is new, slowly increasing up to 5 years) to stay on the program and receive long-term care and continue to buy into Medicaid. Assets accumulated during the Medicaid Buy-In program should be allowed to remain exempt. The federal government should also look at exempting this population from estate recovery under certain circumstances. These circumstances might include allowing a client who worked his or her way off of cash benefits to will their home and assets to a loved one or favorite charity.

Colorado HCPF staff reported that the federal authority (TWIIA) we are using only allows ten days between jobs if someone loses their job. It is very rare (especially at higher levels) for people to get a new job in only ten days. This is particularly true for those with more severe disabilities, those in rural areas, and those in a low frequency occupation. We request a change that would consider someone to be eligible for Medicaid Buy-In and considered “employed” as long as they are receiving unemployment. This would mean the person is available for work and actively looking for work. People with disabilities should also be able to have time for medical

issues if they remain job attached. The more barriers and bureaucracy policymakers create, the less likely people are to leave the cash programs.

The other programs that allow people to stay on Medicaid and retain their disability status are connected with the SSI program. These programs are only available if someone qualifies for SSI, meaning that they are disabled at a young age (or never worked much as an adult). One excellent program is 1619B.⁵ This program allows one to maintain their disability status and Medicaid if they can demonstrate that their earnings are not sufficient to make up the income. One can use the pre-set amounts that social security calculates using the state average expenditures plus the loss of the cash benefits (\$33,000 in Colorado) or an individual calculation allowing someone with very high expenses, such as a quadriplegic, to earn more if they can demonstrate that their Medicaid expenses are higher. There are a few other programs within SSI. All of these programs are little known, and complicated.⁶ The few people that use these programs experience constant anxiety about losing their Medicaid because the local offices do not know how they work and often erroneously terminate eligibility causing them to have to file appeals.

People who are unable to work full time/full year.

Many people with disabilities are able to do some work, but not able to work enough or work consistently enough to get off of disability benefits. The system fails this group on many levels. This includes

⁵ <https://www.ssa.gov/disabilityresearch/wi/1619b.htm>

⁶ <https://www.ssa.gov/disabilityresearch/wi/detailedinfo.htm>

people with cyclical disabilities and those unable to do full time work.

There is a big gap between not being able to do any job in the national economy and being able to work full time in a competitive job with little or no supports. Many people can work some, part time, or with significant supports. Social Security has programs to address these issues but they are very poorly managed. We need public policy that supports people to work as much as they are able, without being punitive towards or bureaucratic for those who still need some support.

When someone is working at a level that is not adequate for self-support, or even when they are trying to get off of Social Security benefits, they must report income monthly. Some income should not be counted, such as Impairment Related Work Expenses ⁷which are costs incurred by the disabled employee related to both their disability and employment that are not reimbursed elsewhere. Social Security does not pre-approve expenses, they retroactively review expenses and different people make different decisions about the same expenses.

There are different rules for SSI and SSDI. A few examples:

SSI allows one to take earned income, subtract \$65 and divide by 2 to get to countable income. They reduce the SSI payment \$1 for every \$2 earned. This allows people to slowly phase out—when they get to \$0 in SSI they still keep Medicaid until they are making \$33,000 even without a special payment standard.

SSDI has a different system—they use SGA model and a beneficiary can have 9 months (does not have to be consecutive) where the

⁷ <https://www.ssa.gov/disabilityresearch/wi/detailedinfo.htm>

person can earn more than \$1130 a month and keep earned income. After that they are deemed able to work.

If a SSDI beneficiary is receiving special consideration from an employer, such as lowered expectations, extra supervision, etc., the extra cost is considered an employer subsidy. This income is not considered when they calculate SGA. SSI has no such consideration even if someone on SSI is receiving an employer subsidy. On the other hand, an SSDI beneficiary is either eligible or not, the amount of the payment does not change, it just goes away.

People become discouraged due to misleading information about work incentive programs.

One “work incentive” program was called expedited reinstatement. The promise was that if someone tried to work and within the first five years failed, that they could get right back on benefits. This was to address the fear of people afraid to try because the application process is so hard. The problem is that it is not real. One can be immediately put back on benefits but it is *only* for a **six-month** period while SSA re-evaluates. Often the fact that the person did work, even if it was not successful, is used against the person.

Overpayments are a significant problem. An overpayment occurs when someone gets a check that they are not supposed to get—but it is not that simple. SSA commonly goes back years and years and the person loses the ability to prove the payment was proper; often SSA does not process income reported then does not reduce the income of an SSI beneficiary or stop the checks for an SSDI beneficiary—then *years* later, SSA tells the person they have been overpaid. To have the overpayment waived one must prove that they were not at fault and that they cannot afford to pay it back.

There are people with disabilities who work, do not report, and know better. These individuals should pay a consequence.

However, there are many more people with disabilities in our experience who either do report, or do not understand what they are supposed to do and try as hard as they can to follow complex rules. When they get an overpayment notice, they find it hard to manage the time consuming waiver process on their own and often do not have self-advocacy training on the regulations and rules

BENEFITS OTHER THAN SSA AND MEDICAID:

Another complication is other benefits. As income increases the other benefits decrease. Some benefits, like food stamps, are easier to give up. A person can simply replace the food stamps with cash that they own. This is a feeling of pride for many. Other benefits, such as housing assistance, is a different story.

If a person was on SSI or on a Medicaid program other than the Medicaid Buy-In, they have no savings. As one starts earning more money, there is a short window of time before the Section 8 housing eligibility is eliminated. In some cases, this means the person has to move because the actual housing unit is tied to a subsidy. Moving is expensive and the individual has not been allowed to save. In some areas, with tight rental markets, it may not be possible to find a unit that is suitable and/or fully-accessible in accordance with the ADA. Many people with disabilities need specific housing such as wheelchair accessible, on a bus line, etc. It's something of a Cliff Effect, whereby the person with the disability must earn a substantial dollar amount per hour, in order to achieve economic self-sufficiency. Yet Medicaid Buy-In is an excellent example of offering a "bridge," and work incentive, in that the person with the disability can keep

their Medicaid coverage and pay in a premium each month, as they begin to earn money.

As people are trying to manage these systems, they are also often new to the workforce or have had a long break from the workforce. They are trying to absorb a faster pace than they had lived, often trying to learn new skills, especially regarding technology, sometimes grappling simultaneously with mild depression or trauma, while trying to manage an ever changing household budget. For each financial gain in pay, benefits are lost or share of costs, such as rent in a sliding scale situation, increases. In addition to working and being up and out more than they have in years, they are trying to follow a myriad of often new rules. They may be suddenly and randomly ordered to attend “redetermination” meetings in the middle of the workday. If a SSI beneficiary says they cannot talk when they are called, they that person with a disability is often told by ?? that the individual will lose all benefits immediately. People with disabilities often receive letters demanding *years* of documentation, despite having done regular redeterminations. IRWE’s may be approved for years at a certain amount, then suddenly a new worker applies a different standard and one can find themselves owing thousands and having to spend hours compiling documentation.

People trying to work their way off of benefits often report feeling like they are being treated as “welfare cheats” or criminals. They report that SSA staff “act like I am doing something wrong...I am just trying to work and follow all of their rules.”

When there is a problem with SSA, there are no staff that are given adequate time to respond to our concerns. Recently someone in our office had SSA think our organizational bank accounts were his—he is on a program with the \$2000 asset limit. Numerous calls,

emails and letters did not clear this up and the work incentive coordinator was not able to just tell the local office they were incorrect. It took **two months** to resolve.

SEVEN IDEAS FOR SOLUTIONS

Short Term Solutions:

Change the requirement that stops Medicaid Buy-In Programs for working adults with disabilities at age 65. Allow people that have been employed under one of these programs to remain indefinitely and to keep any assets accumulated while working. States should be allowed to get FMAP for people in this situation.

Require SSA to develop a process to approve IRWEs in writing ahead of time. Those approvals are in place for at least 3 years. If there is a change, then SSA must provide that change in writing with appeal rights. The same should apply to employer subsidies for SSDI beneficiaries. Otherwise, people in group two think they are OK but may be earning too much, only to have their lives collapse when they cannot sustain the work pace.

Long-Term Solutions:

Create a task force that has some authority to work with SSA, the OIG and leaders from the other disability agencies. Involve some of the national disability organizations but also include a majority of people from the states who live with these programs. The task force should be charged with making recommendations to a congressional committee that will have authority to conduct pilot programs.

The task force could start with coming up with regulations that get in the way of employment.

Analyze overpayments and figure out the extent of the problem from honest workers trying to follow the rules in a dysfunctional system. Create an online reporting system. Consider prohibiting SSA from requesting records past 3 years.

We must re-examine how we define disability. In reality, unless one is in a coma, there is something one can do in the national economy. The current definition is not strengths or assets-based and requires people with disabilities to focus on weaknesses to get needed benefits.

Create national campaign to help people with disabilities understand the rules and opportunities. Require all Vocational Rehabilitation Counselors to understand how employment affects Medicaid and to assist clients that need Medicaid to get on the proper program.

Require Vocational Rehabilitation programs to provide technology and training to people seeking employment who have been out of the workforce for more than 5 years. If someone does not know how to do an email attachment, and does not grasp the concept of the "cloud," they will generally not do well in the work force. Job applicants must have email that they can access. The government should work with Apple or Microsoft to get discounted tablets or smart phones, and with Comcast to get expanded Internet access for low-income people with disabilities.

Incentivize public schools to offer more rigorous curriculums and to achieve stronger outcomes for students with disabilities in high school transition programs. Upon graduation, if not enrolled in college, they should be already in a job, or a job training program.

Set a reasonable national floor for asset limits in disability programs with a way for it to increase annually.

Respectfully submitted

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