



**COLORADO
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These comments are on behalf of [the Colorado Cross-Disability Coalition](http://www.ccdonline.org) (CCDC). CCDC is a statewide social justice organization focusing on disability issues throughout Colorado. Over the past several years we have increased our focus on employment, encouraging employment and assisting people that want to transition from benefits to full employment to do so. The most successful tactic has been the creation of a very successful Medicaid Buy-In Program for working adults with disabilities. We have also worked with and continue to work with our state Vocational Rehabilitation program to make improvements there. We have a long way to go. People with disabilities in Colorado who have full time full year jobs increased by approximately 3% from 2016-2018 (from about 26-29%). People with disabilities are still paid much less than our non-disabled peers. Because the economy in Colorado has been excellent, we have not seen how much of this gain is temporary. What we know without question is that increasing punitive tactics and bureaucratic trickery to make benefit acquisition and retention more difficult has the opposite effect.

Our interest in employment is for many reasons.

- 1) Until we have reasonable employment levels we will not truly be fully integrated into all parts of the community.
- 2) The crushing poverty the disability community experiences can only be solved by increasing employment, both the number of people employed and by achieving pay equity for people with disabilities.
- 3) People with disabilities have a lot to add to the workforce. We have skills and talents and they should be used.
- 4) People with disabilities want to work.

We also see the need to redefine how we think about work. This is not solely a disability issue, some of the changes we seek are changes in the US workforce.

- 1) Work does not have to mean working 40 hours a week somewhere. Part time work, the gig economy, and working from home are all reasonable options in the 21st century.
- 2) We must not look at receipt of benefits and employment as mutually exclusive. Many people will always need some level of benefits (both Medicaid and cash assistance) and they should be not only allowed, but supported and encouraged. This is a departure from current policy where work is punished and people that attempt it are viewed with suspicion.
- 3) People that have been out of the workforce for several years or who have never been part of the workforce often need extensive support over many years to fully and completely reenter.

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- 4) Some level of cushion is needed when people are in between jobs. This will be more necessary when the economy changes. While everyone has this risk, people with disabilities are often more isolated, and less able to do temporary work therefore less able to survive the time between losing one job and getting a new job.
- 5) People with all types of disabilities and at all severity levels have value and can do something. This does not mean that all people that receive benefits could survive without those benefits.

It appears that SSA plans to spend \$1.8 billion to save \$2.6 billion over the next decade. As noted in the analysis, when people are terminated from payment this does affect others and this could create a chill effect and could discourage some people from applying for needed benefits.

While we appreciate the stated intention of helping people get back to work, and agree that the longer one is out of the workforce, the more difficult it is get back into the workforce, we believe SSA is missing the point. The analysis in the NPRM shows a lack of understanding as to why the return to work rate amongst SSA disability beneficiaries is so low.

As an organization run by and for people with all types of disabilities we have direct experience and do understand why the return to work rate is so low. Many of us on staff are people that are or were SSA beneficiaries that have been able to get off or reduce our dependence on these benefits. Even with a very supportive employer and more knowledge of the system than most other beneficiaries the process is excruciating. We assist hundreds of people each year to navigate these systems. The problems are caused by the system not a lack of desire to work and the NPRM does NOTHING to address the root causes: We see the primary causes of failure to re-enter the workforce as follows:

Getting on Social Security or SSI: The process is horrendous. It is demoralizing, long, intense, and terrifying. Most people wait until they are desperate (Unless they have a catastrophic event and are in a hospital with a social worker to assist) because people fundamentally do not want to give up work. Work is more than a paycheck. For many it is an identity, a place that gives one self-worth, a place with social and emotional connections. Even financially because benefits always pay less than the paycheck left behind. Even in the best case scenario, the process can take upwards of six months. Usually it is more like 2-3 years. During this time people are (incorrectly) advised that they should not work at all because social security will look at work negatively. While this is incorrect advice, there is a lot of nuance and documentation required to keep working while applying for benefits. During this time people must fill out form after form focusing on everything that is wrong, every deficit, every ailment and problem. Nowhere in the application process does SSA provide the applicant space to document what one CAN do, rather than what one CANNOT do. It is a traumatic experience. We see people becoming so despondent during this process that they feel suicidal. After going through this process once, people will do anything to avoid having to do it again. The safe move is to not even try to work. Even though SSI says they do not do a continuing disability review (CDR) if someone uses the Ticket to Work, they will do a CDR if there is work activity.

SSA Reaction to Work: When someone does try to work, even a little, SSA reacts with suspicion and accusation. People report work and receive letters that start with an accusation “We have information that you have worked” as if that is something bad. Recently someone who recently went through a disability

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determination process and was found completely disabled tried to increase work hours and was able to find a part time work for four hours a week at \$12 an hour in a supported work environment. That caused a whole new review. Had this individual not had someone to fill out the numerous forms again, they would have stopped doing the additional work. This is not due to laziness or lack of interest in work but due to severe disabling anxiety and inability to understand how to do the paperwork. Why can SSA not start these letters with “Congratulations...thank you for reporting your work? If one works, one must report monthly to the local SSA office. There is no online reporting and the fact that employers report to SSA anyway, seems to be inadequate. They will frequently return documents saying that something was wrong, such as the SSN was written on the wrong part of the page. They ask for paystubs even though most pay is electronic. When people go in for a financial review (for SSI only) they are told they have to resubmit everything because the local office lost the paperwork. We are regularly told the local offices do not have time to enter the information reported. This leads to overpayments (both legitimate and not) which is another barrier to work. Even if one proves the overpayments are not the fault of the beneficiary repayment may still be required. Often people end up in repayment situations because they did not understand how to do the complex paperwork to ask for a waiver (and sometimes did not understand that they could make such a request or appeal a determination of an overpayment). When one reports honestly and still is penalized, and this happens over and over again, one loses the will and sometimes the financial ability, to continue employment. SSA needs to use additional resources to properly enter information reported and to properly match data reported by employers to reduce the need for individual beneficiaries to use an archaic paper reporting process. The tone of communications, nature of communications and process to report work activity is punitive and discouraging. When someone is already struggling with numerous barriers this is often the proverbial straw breaking the camels’ back. Other than a brochure called “Working while on Social Security and How We Can Help” there is no adequate assistance for beneficiaries trying to obtain or maintain paid employment. This brochure makes it clear that one can have SSDI or SSI and work, but the overwhelming belief is that work and receipt of disability benefits must be mutually exclusive.

Getting off benefits is complex: Assuming someone is willing to take the risk to try to get off of SSDI or SSI, one must be able to understand and comply with extremely complex regulations and reporting requirements. There is no universal, accredited, accurate benefits counseling. People have reasonable questions and need to know if they try to work how that affects all benefits, not just SSDI and SSI. They need to know how to keep Medicaid if they have significant medical needs. People rarely go from disability benefits to a job with health insurance. Moreover, for most disabled people private insurance is useless, what we need is Medicaid, not insurance. Private insurance does not cover decent wheelchairs or long term services such as personal care. Many states now have Medicaid Buy-In Programs for working adults with disabilities which is one the few actual programs that does help people return to work. Every state program is different, each is at the whim of the state legislature, and some state programs really are not actual incentives because the earning limits are so far below what one would need to survive, let alone thrive, without benefits. Moreover, these programs are usually disconnected from SSA. While health care is the biggest issue there are other considerations with other programs. If an individual resides in subsidized housing then knowledge is needed about how housing is affected. Even if someone is eventually able to pay market rent, in some areas finding an accessible unit might be impossible. Getting out of poverty requires a lot of planning so simply having more income may not translate into the ability to afford a move during the first year or even the first few years. Most people have to begin part time and inch towards more hours. Different public programs have different reporting requirements. People need to

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be given information in plain language what has to be reported to whom and how often. Having a universal reporting form, or figuring out information sharing would be incredibly helpful. Even SSA programs are not communicated well. 1619A and B are important and highly effective programs to help people on SSI keep their Medicaid. For many people keeping Medicaid is more important than the cash benefit. Between 1619 and the Medicaid Buy-In Programs giving up the cash benefits may be possible, but only if it is done properly. People need to have a plan and many will need assistance implementing the plan. Nothing in this proposal will help---adding more reporting only hinders any hope of getting off of benefits.

Many people have cyclical disabilities. The SSDI disability criteria is all or nothing. Once you earn money for 9 months, you are seen as no longer disabled. People that do well for a period and then crash are afraid to try. While there is the expedited reinstatement process that is not as seamless as it sounds. It does allow someone to get back on SSDI for up to 6 months while SSA evaluates the case. If the evaluation takes longer than 6 months, something common if a doctor has to be found, particularly in rural areas, this is not unusual. Looking at medical records is often a snapshot of a point in time. Even the 9-month trial work period can be broken up so someone could be considered able to return to work because in a period of several years they worked 2 or 3 months at a time on an annual basis. It need not be 9 continuous months. There is a big difference between being able to work 2 or 3 months with several months in between and being able to maintain consistent employment. The proposed regulations appear to be targeting people with cyclical disabilities, such as many forms of serious mental illness. The fear of being under constant review can actually exacerbate the actual disability. The level of toxic stress caused by having one's survival threatened can and will affect actual health outcomes. Again, letting people work when they can and forgoing benefits only when they are able work with an easy, non-punitive way to have benefits immediately restored when the person is not able to work consistently would accomplish the goal of having more SSI and SSDI beneficiaries employed. Forcing repeated reviews will not. Some employment, even if not consistent or permanent, would be preferable to none.

Returning to work is a process not an event. Benefits are taken away too quickly. The simple evaluation of the 9 month trial work period is inadequate as mentioned above. It is easy to get a job, particularly in a good economy. What is harder is keeping the job. When people are out of the workforce for a long time, and in today's fast paced world even a few years can be a long time, they lose both skills and endurance. Work norms change quickly. People returning to work after an absence need supports. Some will need social coaching, some will need to relearn (or learn for the first time) technology skills. Other than some vague references to "Ticket to Work" people are not told about available supports. Even though people on SSI or SSDI are supposed to be automatically eligible for federally funded Vocational Rehabilitation Services, this rarely happens. The process of applying for Vocational Rehabilitation and then implementing it can be many months.

The definition of disability itself is a huge problem and illustrates very outdated thinking. The ability to engage in SGA (which is not enough to live on in many parts of the country) is not a good indicator of disability. The all or nothing aspect of the definition is problematic. Telling people with obvious lifelong disabilities that they are no longer disabled also is a problem. Telling people that they are no longer eligible for certain cash benefits due to earnings (framed as a positive) would be preferable especially if there was a truly safe and easy way to get back on benefits.

The concept of a work incentive: It is a myth that people do not want to work. It is a myth that if you just take away the benefits people will go out and find a job. While some will find a job most on SSI or SSDI

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will not be able to keep it without a lot of support. If the system would focus on what people really need, add some flexibility and become less punitive, many more people would be able to successfully exit. Moreover, most so-called work incentive programs have been designed with no input from people with disabilities or our advocates. If SSA would work with people in the disability community in a meaningful way we could help design programs that might work. The programs created including the “Ticket to Work” are very complicated and tend to simply put money in the pockets of various service providers without real accountability to the disabled beneficiary.

Other Concerns with the proposal:

- 1) Timeframes: If there are going to be child re-determinations at set ages, this should be well communicated and parents should get information requests many months in advance. It appears these CDRs will be done at ages 1, 6, 12 and 18. We experience issues currently with the age 18 CDR because parents are not given the information and forms in advance. It can take months to get an appointment with a doctor. It can take time to get paperwork from schools and medical providers. At age 18, parents are dealing with a plethora of systems supporting the transition to adulthood. We recommend at least a full year and some support to get documentation together. The criteria are different before and after age 18 and there is no real explanation of the difference. This causes parents to send in what they have always sent in and then experience denials, causing appeals, because they used the wrong standards. This is different than actual ineligibility.
- 2) Medical Improvement: This can be a misleading concept. In the mental health evaluation standards in the “blue book” there is a component that grants disability when someone is doing well but that is due to the person being in a highly structured setting for more than a year. This allows for an evaluation of how someone looks based on the support that the person is receiving. Such an analysis should be done universally. It might not be a highly structured setting, but could be that with the demands of work, transportation, getting out and staying out daily, people look more functional (or less disabled) than they are. It is very concerning that SSA sees mental conditions like schizophrenia as non-permanent. Comparing schizophrenia to a broken leg is disingenuous. Moreover, people do not get disability from social security because they break a bone. Most people with schizophrenia have serious functional limitations that last a lifetime. In addition to the psychiatric and related cognitive issues, the medications they are required to take often cause physical disabilities. The same is true for some other serious mental illnesses.
- 3) Redeterminations: It is a myth that there are many people on SSI or SSDI that could easily or even at all just go to work. Many of the people targeted for the more frequent reviews will not be able to complete the detailed and exacting paperwork requirements without assistance. There is not enough assistance to go around and people in desperate need are likely to lose benefits simply due to failure to return the paperwork. Once denied they will need to appeal, and if they cannot find help doing this they will end up homeless or in dire situations. This is a particular issue for those with psychiatric disabilities or brain injuries. Forcing people with these limitations to go through

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reviews every two years is no different than telling someone who is paralyzed to walk up the stairs and if they can do that, they will receive their benefits. Yes, some will get jobs, but SSA has no data on how many will be able to keep jobs. These redeterminations are incredibly stressful and require a lot of work from the entire support system.

You also asked for comments on language that is unclear in any way.

This section appears aspirational. You say you will review cases in a specific amount of time unless you decide for a variety of reasons not to do so. You could simply say you will try to conduct a review of all nonpermanent impairments every three years, as resources allow.

f) *Waiver of timeframes.* We will review all cases with a nonpermanent impairment at least once every 3 years unless we, after consultation with the State agency, determine that the requirement should be waived to ensure that only the appropriate number of cases are reviewed. We will base the appropriate number of cases we will review on such considerations as the number of pending reviews, the projected number of new applications, and projected staffing levels. We will grant such waiver only after good faith effort on the part of the State to meet staffing requirements and to process the reviews on a timely basis. We may also consider availability of independent medical resources. A waiver in this context refers to our administrative discretion to determine the appropriate number of cases to be reviewed on a State-by-State basis. Therefore, under certain circumstances, we may delay your continuing disability review longer than 3 years following our original determination or decision or other review. We would base the delay on our need to ensure that pending reviews and new disability claims workloads are accomplished within available medical and other resources in the State agency and that such reviews are done carefully and accurately.

The section quoted below could be shortened to say “We conduct continuing disability reviews to determine whether or not you continue to be eligible for benefits. Payment ends (but eligibility for some other services including Medicaid may continue) if you show that are you able to earn a specific amount of money without special conditions for at least 9 months.” It confuses people when you say that their disability ends, because in many cases the person remains disabled, they just demonstrate that they are able to engage in substantial employment.

General. We conduct continuing disability reviews to determine whether or not you continue to meet the disability or blindness requirements of the law. Payment ends if the medical or other evidence shows that you are not disabled or blind as determined under the standards set out in section 1614(a) of the Social Security Act if you receive benefits based on disability or § 416.986 of this subpart if you receive benefits based on blindness. In paragraphs (b) through (f) of this section, we explain when and how often we conduct continuing disability reviews for most people. In paragraph (g) of this section, we explain special rules for some individuals who are participating in the Ticket to Work program. In paragraph (h) of this section, we explain special rules for some people who work and have received social security benefits as well as supplemental security income payments.

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Finally, we believe the cost to the public are grossly understated. There are two areas of underestimation.

- 1) The cost to comply with the CDR. This is not just a matter of getting records from one doctor. Other evidence is required. This is going to further stress an already overburdened medical system, especially the mental health system. This will require other social service professionals to help people with the paperwork. It will add calls to crisis lines. It will increase medical and mental health visits as people struggle to comply.
- 2) When people lose their source of income they often end up in crisis. They must turn to food stamps, other forms of general assistance, etc. They rely on food banks and other charities. Many become homeless requiring services at shelters and others who live in public housing will stop being able to pay their portion of their rent. Once someone loses their housing, they are likely to incur numerous other costs. According to the National Alliance to End Homelessness in 2017 someone with long term or chronic homelessness costs the taxpayers more than \$35,000 a year. This is double the average SSDI benefit and more than double the full SSI benefit. Most people with disabilities that lose their housing are not able to find new housing. Even if someone gets a job at the SGA level, they might not be able to retain their housing. If they lose their disability status they might also lose subsidies. If there is a break in benefits, even for a couple months, most people will lose their housing. People on SSI are not allowed to save money. Most people on SSDI do not have the means to save, and may be on other programs that limit asset accumulation. Therefore people using these programs do not have the financial wherewithal to weather a couple months without benefits. They certainly do not have the ability to find and move into new housing.

In summary, CCDC finds these proposed regulations to be bad public policy. It will not achieve the laudable goal of helping people with disabilities enter or return to work. It will increase the poverty of an already vulnerable population. It will add stress to an already overburdened social services system and cause needless suffering to thousands of voters with disabilities and their families. If there is any real intention to help people with disabilities return to work and escape poverty, SSA should work with the disability community to fix the work incentive programs already authorized in law, and bring forth proposals for improved legislation and regulation so that these programs can function appropriately.

We suggest that SSA withdraw this proposal and convene people with disabilities, including people using SSA work incentive programs and people who have successfully exited SSDI and SSI to better understand the needed elements for success.

Sincerely,

Julie Reiskin

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