

10.Ensuring Access to Long-Term Services and Supports for People with Disabilities and Chronic Conditions

Mark Perriello

INTRODUCTION

Gaps in the Support System for Workers with Disabilities

The United States does not currently have adequate programs and policies to provide affordable access to services and supports to working individuals with disabilities and chronic conditions that cause functional limitations. The passage of the Affordable Care Act (ACA) and its requirement that people with disabilities and chronic conditions be able to purchase insurance irrespective of preexisting conditions, without paying more for it, has created new opportunities for people with disabilities and chronic conditions to participate more fully in the workforce. Likewise, for people with mental health conditions, the ACA's expanded requirements for parity between physical and mental health coverage, which built upon the requirements of the Mental Health and Addiction Equity Act of 2008, increases the availability of screening and treatment for people with mental health conditions. Despite the progress made through the ACA and other recent legislation, there still exist significant gaps in programs and services to assist workers with chronic conditions and disabilities who want to continue working when their chronic conditions progress and their functional limitations increase. Some of these health care and long-term service and supports (LTSS) gaps include:

- Affordable access to ongoing behavioral treatments and supports, such as evidence-based peer support models;
- Access to LTSS such as personal assistance services, especially employment based. Virtually no commercial health care insurance provides access to personal assistance services;
- Adequate coverage of durable medical equipment and assistive technologies;
- Affordable access to prescription drug coverage;
- Access to certain rehabilitation and habilitation services; and
- Access to employment-related transportation.

The United States needs to establish or expand programs that support workers with disabilities and chronic conditions without requiring them to first leave the labor force to gain access to those services and supports, or to impoverish themselves in order to qualify and remain poor to maintain eligibility. Establishing these programs is critical, as people with disabilities and chronic conditions are more likely to experience lower socioeconomic status compared with other Americans. This leads to poorer health and a lower quality of life (APA 2015).

Social Security Disability Benefits Easiest Way to Access LTSS

Unfortunately, people with chronic conditions and disabilities who have service and support needs, and who also have work capacity, are often required to apply for income support benefits through the Social Security Act programs in order to access the very services and supports that might allow them to continue working. The federal-state Medicaid program is currently the only program through which the vast majority of people with functional limitations can access the assistance they need. Private long-term care insurance is simply unavailable or, if available, unaffordable to people who already need services or are at high risk of needing to use it. State Medicaid Buy In (MBI) programs provide some access to needed LTSS to working individuals with disabilities, but unrealistic income and asset limits, uneven access to services and supports (insufficient in scope and quantity in many states), insufficient grace periods for unemployment, and lack of portability from state to state, among other reasons, make current MBI programs inadequate. Working individuals with disabilities and chronic conditions in need of LTSS require a program different from the traditional Medicaid program that would provide access to comprehensive coverage, including certain LTSS, without having to impoverish themselves or access income support benefits first.

Creating a Seamless System for Accessing LTSS

The proposals in this paper argue for creating a comprehensive, seamless system of access to LTSS for working individuals with disabilities and chronic conditions. The system would involve three main parts: a national MBI program, improved tax provisions for individuals who pay for LTSS out of pocket, and additional research into creating a new program to wrap around commercial health care insurance to fill in coverage gaps and provide LTSS. The system would be designed to provide affordable coverage to people with disabilities and chronic conditions across income and asset levels with no interruption in affordable access to the LTSS needed to obtain and maintain employment. The three parts of the system are:

1. A national Medicaid Buy In program, which would have:
 - a. Standard minimum asset and earnings limits across the states, providing coverage to all workers with increasing cost sharing and premiums as income increases, and which allow enrollees to save for emergencies, large purchases, and retirement;
 - b. A standard set of services and supports with generous scope and quantity;
 - c. A mandatory minimum grace period for periods of unemployment;
 - d. Reciprocity for assets accumulated during participation in an MBI program in a state with more generous asset limits when an individual moves to another state to take a new job;
 - e. A strong definition of employment; and
 - f. A functional assessment for eligibility.
2. Improvement of tax provisions for the purchase of LTSS: Current tax provisions designed to assist individuals with disabilities and chronic conditions are inadequate to make LTSS affordable, except to those with the highest incomes. The tax assistance available to individuals who pay out of pocket for LTSS could be improved by allowing lower- and middle-income individuals to take a tax credit rather than a deduction, as well as making disability-related expenses necessary for work that occurs outside of the workplace allowable expenses. That would help working individuals with disabilities and chronic conditions afford needed LTSS if the individual chose

not to participate in the MBI program, or if the individual still had out-of-pocket costs despite being enrolled in the MBI program.

3. Study the creation of a program to provide wraparound coverage, including LTSS: The paper proposes to study creation of a program providing LTSS coverage to working individuals with disabilities and chronic conditions that wraps around private health care insurance. This wraparound coverage would fill gaps in coverage for people with disabilities and chronic conditions that exist in private insurance—such as coverage of durable medical equipment and assistive devices, prescription drugs, and personal assistance needs—and provide additional cost-sharing protections. The study should look at requiring workers to take advantage of insurance offered by their employers or purchase it through the marketplace to be eligible. This program would be designed to ensure working individuals get the coverage, services, and supports they need, while limiting the cost to states and the federal government to only the cost of those additional services and supports not covered by private plans. Some features of the new program could include:
 - a. Individuals would pay premiums to purchase this wraparound coverage and copayments for services could apply;
 - b. There would no asset limits for participation; and
 - c. Services and supports would be available based on functional need and functional assessment

Additional study is needed to determine exact program design, whether the program should be public, private or a public/private partnership, and how it would interact with the ACA and Medicaid.

STATEMENT OF THE PROBLEM

Lack of a Support System for Workers with Disabilities: Access to Affordable Home and Community-Based Services and Supports

People with disabilities and chronic conditions that cause significant functional limitations have very low participation in the labor force. Only about 20 percent of people over age 16 with disabilities participate in the labor force, compared to just under 70 percent of people without disabilities (BLS 2015). The unemployment rate among people with disabilities who are participating in the labor force is also twice as high as the unemployment rate for people without disabilities, currently just under 12 percent (BLS 2015). In addition, the percentage of people with disabilities living in poverty is 28.7 percent, also twice the rate for people without disabilities (StatsRRTC 2014a).

The United States has made significant progress in many areas to allow people with disabilities to live in the community independently. The passage of the Americans with Disabilities Act (ADA) created the expectation that people with disabilities be integrated in all aspects of life, including employment.¹ The Individuals with Disabilities Education Act ensures that children with disabilities receive a free and appropriate education. However, the disappointing statistics regarding employment and poverty among people with disabilities persist despite the passage of these landmark laws and the evolution of attitudes regarding the abilities of people with disabilities.

¹ Americans with Disabilities Act of 1990 (ADA), 42 U.S.C. §§ 12101-12213 (2000).

The lack of progress in improving the economic status of people with disabilities can be attributed in large part to the failure of the United States to establish programs and policies that support workers with disabilities and chronic conditions and allow them to keep working when their chronic condition progresses or functional limitations progress (Vallas, Fremstad and Ekman 2015). This is especially the case when a worker with a chronic condition or disability requires access to assistance that is not generally available through standard commercial health care insurance and that an employer is not required to provide under the ADA, as discussed in the introduction. In fact, it is estimated that one in five adults with disabilities living in a community setting has unmet LTSS needs (CRS 2013). The nature of the services and supports will vary depending on the nature of the person's disability or chronic condition, level of educational attainment, and current job and job skills.

This paper focuses on the need to improve access to services and supports for working individuals with disabilities and chronic conditions, but it is important to note that this is only one of the gaps in the current support system (CRS 2013). Working individuals also lack adequate access to vocational rehabilitation and job retraining when the functional limitations created by their chronic condition or disability increase and create the possibility that the worker might not be able to continue to do their current job in the future. State vocational rehabilitation programs provide these services to people with disabilities, but with their limited resources must focus on the unemployed and people with the most significant disabilities, and they lack sufficient resources to even serve all currently eligible individuals in many states (StatsRRTC 2014b).

THE CURRENT SYSTEM

The Social Security Disability Insurance (SSDI) program was created in 1956 (Kearney 2005/2006) to provide income replacement to workers over the age of 50 who could not continue working until they reached retirement age due to a disability or chronic condition. As originally conceived, it was essentially a medical retirement program for workers who could not work until the retirement age. Although the age for eligibility was later lowered, it was never intended to support workers with disabilities, but rather to replace earnings for people with severe disabilities who no longer had the capacity to support themselves through work. SSDI performs that function very well and provides income replacement to more than 9 million workers with disabilities and their families, many of whom would be destitute without it. The SSDI program is vital for the people who receive its benefits, providing more than 75 percent of the income to one in three families that receive it and more than 90 percent of the household income of one in five families that benefit (Favreault, Johnson, and Smith 2013). SSDI has never provided (nor was it designed to) any type of support to the tens of millions of individuals with disabilities who can work. SSDI will always be needed to provide support to individuals whose disabilities and chronic conditions prevent them from supporting themselves, and the current definition of disability is appropriate for an income-replacement program. Rather than trying to adapt this very successful income-replacement program to support workers with disabilities, it would be more effective for the United States to expand or alter other existing programs already designed to support workers with disabilities.

Current Medicaid Options are Insufficient

As mentioned in the introduction, it is difficult for people with disabilities who need LTSS, such as personal attendant care, to access those services while working. For an individual with a disability or chronic condition, Medicaid is the only option for gaining access to those services and supports. Private long-term care insurance is either unaffordable or unavailable due to pre existing conditions,

and paying out of pocket for needed services is not possible for any but the highest earners (UMass 2010).

Getting affordable access to needed services and supports is vital for people with disabilities and essential for becoming and remaining employed and independent. Medicaid is generally the only way to access affordable LTSS for most people with significant disabilities, and it is far from ideal. The services and supports available through Medicaid vary by state, services are often provided through a waiver, enrollment in those waiver programs is often capped with waiting lists, and eligibility is restricted to individuals with very low income and assets. In addition, receiving a disability determination from the Social Security Administration (SSA) is the easiest way to become eligible to receive the services and supports that can allow an individual with significant disabilities to continue to work. Unfortunately, being found eligible for disability benefits from SSA requires the individual to not be working at any significant level, and therefore blocks access to these vital services and supports. It is vital that automatic eligibility for health care coverage for SSDI and SSI beneficiaries (Medicare and Medicaid respectively) be maintained. This paper does not argue for changing that in any way. Rather, this paper is arguing for improving the ability of workers with disabilities to access the supports and services they need without having to apply for Social Security disability benefits.

As previously referenced, Congress gave states the option to create MBI programs in recognition of the fact that many working people with disabilities need access to services and supports to allow them to enter and remain in the workforce (Kehn, Croake, and Schimmel 2010). Forty-four states currently allow working individuals with disabilities and chronic conditions that cause functional limitations to buy in to Medicaid when they earn or have more resources than is allowed for regular Medicaid eligibility (NCD 2015). Unfortunately, these MBI programs vary significantly in eligibility requirements (from no income or resource limit in Massachusetts down to income under 80 percent of the federal poverty level and standard Medicaid resource limits in Virginia as of 2010), as well as the services and supports available and the scope of those services and supports (NCD 2015). This variability limits the ability of people with disabilities to work up to their full potential or maximize their independence, and often prohibits people from moving to another state to take a new job. Surveys and studies show that people with disabilities limit their work and earnings to ensure continued access to the services and supports they need to live and work independently, accessed through the MBI program (Gavin, McCoy-Roth, and Gidugu 2011). In particular, limits on assets and earnings for eligibility purposes causes workers to adjust work behavior to maintain eligibility (Gavin, McCoy-Roth, and Gidugu 2011). This leaves workers with disabilities or chronic conditions that progress with very few options: leave the workforce to get the services they need, apply for SSDI, or impoverish themselves to become eligible. No other affordable options currently exist to assist workers with disabilities in meeting their service and support needs, except for the highest earners who can pay out of pocket.

Current Tax Provisions are Inadequate

Workers with disabilities and chronic conditions who are not eligible for Medicaid but have LTSS needs and pay for them out of pocket can deduct certain expenses from their taxable income through the impairment-related work expense (IRWE) deduction. Eligible workers with disabilities can deduct expenses that “are ordinary and necessary business expenses for attendant care services at your place of work and other expenses in connection with your place of work that are necessary for you to be able to work” (IRS 2014, 13). Several features of the current tax provision limit its usefulness for workers with disabilities. First, it does not help many workers with disabilities with

low or moderate earnings because it is a deduction from taxable income rather than a credit against taxes owed. Second, it excludes expenses an individual incurs that are necessary for work but are not incurred at the place of work (personal attendant care at home to get ready for work, for example).

Capitalizing on the ACA

Workers with chronic conditions and disabilities are now able to purchase commercial health care insurance for the first time through the marketplaces created by the ACA. This coverage expansion creates the opportunity to consider how a new program could be designed to wrap around that insurance to fill the coverage gaps identified earlier in this paper. Medicaid will still be the right program for some workers, irrespective of the historic opportunity created by the private market reforms required by the ACA. However, more study regarding how a new program might be created to help meet the needs of working individuals with chronic conditions and disabilities should be undertaken.

DETAILED PROPOSALS

Creating a Seamless System of Affordable Access to Services and Supports for Workers with Chronic Conditions and Disabilities

As discussed in the previous two sections of this paper, current programs and policies in the United States do not adequately support working individuals with chronic conditions and disabilities with expensive LTSS needs. Ensuring that people with disabilities and chronic conditions have uninterrupted affordable access to any needed LTSS could allow more people with disabilities to work and live independently without ever having to access income support benefits or delay application for income support. This paper proposes to design that system by creating a national MBI program and completely delinking eligibility for the MBI program from the Social Security definition of disability, and by improving and expanding current provisions available to people who pay out of pocket for LTSS. In addition, research should be conducted into ways of offering wraparound coverage to commercial health care insurance that would fill coverage gaps people with disabilities and chronic conditions experience, including LTSS.

A National Medicaid Buy-In

The first component of a seamless system of providing access to services and supports is ensuring that individuals have affordable uninterrupted access to LTSS through an improved and uniform MBI program throughout the United States. The national MBI program proposed here would be designed to address the problems identified in the current state MBI programs in the introduction to this paper. The national MBI program would include the following components:

- *Uniform income eligibility requirements:* Income limits for the MBI program should never limit the amount a person works in order to maintain eligibility and access to LTSS. Unlimited income for eligibility purposes with increasing cost sharing and premiums as income increases should be considered as a potential program design. At a minimum, people with incomes up to at least 400 percent of the federal poverty level for the applicable family size should be eligible to participate in the program. States should be allowed and encouraged to retain higher income eligibility limits if the current MBI program in the state allows participation by people with incomes over the national minimum.

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- *Uniform resource eligibility limits:* People enrolled in the program should be encouraged to save for large purchases and emergencies, as well as retirement. The national MBI program could be modeled after the expansion of Medicaid in the ACA and have no limits on resources for eligibility. If a limit on resources must be placed, enrollees should be able to save at least \$100,000 and remain eligible. Retirement savings should not be counted against that limit. Any resources accumulated during participation in an MBI program should also be excluded from eligibility determinations for other Medicaid categories in the future should the individual no longer be able to work.
- *Definition of work:* The inability to define work for the purposes of eligibility has been raised by states as an issue related to their program design and decisions not to expand eligibility in their MBI programs. A number of different definitions of work could be employed in the national MBI program to limit participation to people who are not otherwise eligible for LTSS. Eligibility could be limited to individuals working a certain minimum number of hours per week (such as 20 or 30). Earning enough to qualify for a quarter of coverage for the purposes of Social Security eligibility during a three-month period could be another approach. Finally, a minimum amount of monthly earnings could be required for eligibility.
- *Reciprocity between states:* If the national program has income or resource limits, an individual participating in an MBI program that has higher income or asset limits than required by the national program must be allowed to enroll in the MBI program in a new state if their income or resources exceed the eligibility limits in the new state, provided the individual would still be eligible in the original state.
- *Standardized services and supports:* The national MBI program would detail the services and supports states would be required to provide to eligible individuals, both in terms of type and minimum scope of services available. Services that could be included are: adaptive aids (general and vehicle), care/case management (including assessment and case planning), communication aids/interpreter services; community support program; consumer education and training; counseling and therapeutic resources; home modifications; housing counseling; personal emergency response system services; durable medical equipment and supplies for long-term duration, except for hearing aids; home health; mental health services, except those provided by a physician or on an inpatient basis; relocation services; residential care apartment complex (RCAC); community-based residential facility (CBRF); respite care (for caregivers in non-institutional settings); supported employment (including individualized placement and support model); supportive home care; vocational futures planning; nursing services (including respiratory care, intermittent and private duty nursing); personal care (home- and employment-based); specialized medical supplies; transportation (non-Medicaid covered transportation services and Medicaid-covered services except ambulance and transportation by common carrier).
 - *Eligibility based on functional assessment:* Eligibility to participate in the national MBI program would not be tied to meeting the Social Security definition of disability, except for the income or asset limitation (as is currently the case), but rather would be based on a functional assessment documenting the need for the services offered through the MBI program. States already do functional assessments for the need for services that could be adapted for this purpose (MACPAC 2014).
 - *Grace Period for Unemployment:* Participants in the MBI program would have a grace period of at least one year (with state options for more generous grace periods) in which they could

continue to be enrolled in the program when they are not working for any reason, provided they continued to pay premiums if applicable.

- *Sliding scale premiums and cost sharing:* The MBI program would set out a basic premium and cost-sharing structure and contain protections for low-income workers with disabilities.

The creation of a national MBI program would not have a significant administrative impact. There would be no real impact on the Center for Medicare and Medicaid Services at the federal level. Most states already have MBI programs and already complete functional assessments for eligibility for LTSS in existing MBI or 1915 waiver programs, so additional administrative burden at the state level would be minimal.

Improving Tax Provisions to Support Workers with Disabilities

As discussed in Section 2, the main tax provision currently available to workers with disabilities and chronic conditions that cause functional limitations is the IRWE deduction, and the current design limits its usefulness for many workers with disabilities. The IRWE deduction should:

- *Be changed to a credit for low- and moderate-income individuals:* Because deductions are often not helpful to low- and moderate-income individuals, the IRWE deduction should be changed to a credit for individuals with incomes under \$100,000. The credit should be refundable for individuals with incomes up to 400 percent of the federal poverty level with a limit on the amount of the refund. Individuals with earnings over \$100,000 would remain eligible for the IRWE deduction.
- *Be expanded to allow for the inclusion of expenses related to the disability or chronic condition that are necessary to work but not incurred at the work site:* Individuals with disabilities have many expenses incurred at home or away from their work site related to their disability or chronic condition and necessary for work, but that are not allowable expenses under the current IRWE deduction. Expenses related to an individual's disability or chronic condition that are necessary for the individual to go to work but do not occur at the workplace (such as home-based personal attendant care) should be allowable expenses in the IRWE credit/deduction.

Wraparound Coverage Program

Additional study should be undertaken regarding the creation of a new program to provide wraparound coverage to commercial health care insurance to cover LTSS, as well as fill coverage gaps identified in the introduction. Individuals participating in the new program would need to have insurance either provided by an employer or purchased through the health insurance marketplaces created by the ACA. Research should be conducted regarding the following features of the program:

- *Public, private, or public/private partnership:* How could such a program be structured so that workers with disabilities have access to the LTSS and comprehensive coverage they need and take advantage of the options for acute health care coverage available through employer-sponsored plans or plans purchased through the ACA marketplace? Should it be a stand-alone program or build on an existing one?
- *Financing structure:* Should the program be a federal program or a state/federal partnership similar to Medicaid? Is a social insurance model appropriate?

- *Cost sharing and premium structure:* How should participants contribute to the cost of the program and the services and supports they receive through it?

ANALYSIS OF THE PROPOSALS

Analysis of the National MBI Program Proposal

The national MBI program would provide working individuals with disabilities and chronic conditions that cause functional limitations affordable access to the service and supports necessary to work and live independently in the community. By removing income and asset limits as eligibility criteria, the fear of loss of LTSS, or the inability to access LTSS while working in the first place, would no longer limit the work activity of individuals with disabilities and chronic conditions. As previously stated, individuals have noted in surveys that the fear of loss of health and LTSS coverage through Medicaid causes them to limit their work activity. This directly addresses the problem described in Section 2.

The improved access to LTSS and comprehensive health coverage while working should also delay or prevent some workers with disabilities and chronic conditions from applying for Social Security disability benefits (Chapman, Hall, and Moore 2013). Results from the Demonstration to Maintain Independence and Employment offers some evidence that providing working individuals at risk of applying for Social Security disability benefits with access to comprehensive health coverage can delay or prevent application for disability benefits (Whalen et al. 2012). However, the results were mixed and the intervention in this demonstration did not provide access to the full array of LTSS that would be available to individuals enrolled in the new national MBI program (Whalen et al. 2012). The extent of the impact the national MBI program would have on SSDI applications is therefore difficult to estimate. No in-depth economic or statistical analysis of the national MBI program proposed in this paper has been completed.

Expanding access to LTSS through the national MBI program proposed in this paper would have costs at both the state and federal levels. Assessing how much it will cost is difficult for a number of reasons. To begin with, the number of working individuals with disabilities and chronic conditions who are not currently eligible for any Medicaid coverage and have unmet LTSS needs is unknown and hard to estimate. Some individuals currently enrolled in state MBI programs would not be eligible for the new national MBI program due to the new stricter definition of work, although the extent of that population of workers is not known because the exact definition of work that would be contained in the new MBI program is not known. There are also a number of cost control levers contained in the proposal that could be adjusted to change the cost of the national MBI (such as income and resource limits, premium structure and cost sharing, required services, etc).

Evaluating this proposal based on near-term cost, however, is counterproductive. Adequately supporting workers with disabilities and chronic conditions that cause functional limitations by providing affordable access to LTSS and comprehensive health care coverage is a necessary step toward continuing the progress that people with disabilities have made toward full integration into community living and employment. People with disabilities need to be certain that their work activity will not jeopardize access to health care and the services and supports they require to maximize their work activity and work up to their capacity. Making this investment in working people with disabilities is the right thing to do and results in many non-financial positive benefits—increased economic self-sufficiency, better quality of life, and better health for individuals with disabilities.

Analysis of the IRWE Tax Deduction Proposal

The IRWE tax deduction improvements suggested in this paper would contribute to the economic well-being and self-sufficiency of workers with disabilities who have long-term care needs. This proposal might have no impact on applications for Social Security disability benefits on its own. However, in combination with the national MBI program, the improvements suggested here should allow some workers with disabilities and chronic conditions to maintain their attachment to the workforce longer than they otherwise would be able to, and delay or prevent them from needing Social Security disability benefits.

The cost of this proposal is difficult to estimate. Data is not publicly available regarding the current utilization of the deduction. Lacking baseline data makes it hard to determine what impact the changes outlined in this paper would have. And, as previously discussed, unmet need for LTSS among working individuals with disabilities is also not readily quantifiable. No formal analysis has been completed on the cost of the improvements to the IRWE deduction proposed in this paper and completing one is beyond the scope of this paper.

This proposal would not have a significant administrative impact. The changes to the IRWE deduction would not require significant additional effort by the Internal Revenue Service or any other administrative agency. There should not be additional administrative cost from this proposal.

INTERMEDIATE STEPS

The concepts and ideas presented in this paper remain in the early stages of development. Law and policy makers interested in pursuing these ideas must take up further study of these proposals in order to determine the extent of their impact on SSDI and the programs' fiscal viability overall.

One challenge that any policymaker is sure to face is the ability to accurately calculate the true cost of expanding and improving these programs, while offsetting any savings to SSDI as a result of more Americans with disabilities and chronic conditions entering and remaining in the workforce. Current scoring methodologies are unlikely to consider potential savings or any increased revenue as a result of an expanded pool of taxpayers. Nevertheless, this remains among likely next steps.

In order to determine true costs and savings, policymakers should consider a range of outstanding questions, such as:

1. What is the cost-per-person for these proposals?
2. Regarding the recommended changes to the tax code, should an existing framework such as the child care credit be utilized?
3. What should be the federal/state split? Should the federal government pick up 100 percent of the costs?
4. Should the wraparound benefit be part of the buy-in, or should there be a different structure altogether? How different would the matching rates be? What would the premium charges be?
5. What are the exact eligibility criteria?

As these questions demonstrate, additional research and discussion must take place in order to fully realize the potential of the proposals in this paper.

QUESTIONS AND CONCERNS

The proposals in this paper argue for expansion and improvement of two existing programs/provisions. This section will lay out questions and raise some areas for additional examination.

Questions Regarding National MBI Program

Political Feasibility?

The national MBI program proposed in this paper would represent an expansion of the states' obligations under the Medicaid program. The current Congress seems unlikely to be supportive of increasing the obligations of states and creating more mandates on states related to coverage. Both the House and Senate budget proposals for fiscal year 2016 contain proposals to block-grant the Medicaid program. The approach of the current Congress toward Medicaid and the rejection by many states of the Medicaid expansion contained in the ACA raises significant questions regarding the feasibility of getting a national MBI program passed into law and implemented at this time.

Enhanced Matching Rate?

Another question in designing a national MBI program is what percentage of the costs should be the responsibility of the federal government and what should be paid by the states. Congress has chosen to enhance the matching rate paid to states to encourage them to take up certain options to improve access to LTSS, especially home- and community-based services. Congress also created an enhanced match for the expanded coverage of single individuals required under the ACA—providing 100 percent federal funding for the first year, then gradually decreasing to a permanent federal share of 90 percent. Increasing the share of the expense of the national MBI program paid by the federal government should be considered, up to and including having the federal government pay 100 percent.

Cost Estimate?

As mentioned in the Analysis section and the Intermediate Steps section, it is difficult to estimate the take-up rate of working individuals with unmet need for coverage and what the national MBI program will cost. The overall cost will also depend on the premium and cost-sharing structure created for the national program.

Questions Regarding Improving the IRWE Deduction

The proposal to expand and improve the IRWE deduction does not raise significant questions or concerns. As this is a longstanding provision of the tax code, there are not likely to be unintended consequences or implementation challenges with making the changes to the IRWE deduction proposed in this paper.

CONCLUSION

The current programs and policies designed to support workers with disabilities and chronic conditions that cause functional limitations leave large gaps in what workers need. These gaps

include, but are not limited to, access to affordable and accessible transportation and housing, paid leave and sick time, a permanent wage supplement for individuals who can only work part time or sporadically due to their disability, and affordable access to long-term services and supports. This paper proposes solutions to address only the final gap: the lack of affordable access to services and supports and fill coverage gaps in commercial health insurance.

This paper proposes several actions to ensure working individuals with disabilities and chronic conditions that cause functional limitations have access to LTSS and adequate health care coverage. First, the current option available to states to provide Medicaid coverage to working individuals with disabilities through the MBI program should be a mandatory eligibility category and should have a federal floor for income and assets and standardized services. Current issues with the MBI programs would be addressed so that an individual would never need to leave the workforce to gain access to needed LTSS coverage and the more comprehensive health care coverage provided through Medicaid. Individuals with disabilities would also be able to earn up to their capacity, take raises and promotions, and move to a new state to accept a job offer without concern regarding losing access to the very service and supports that enable the individual to work in the first place.

Second, the paper proposes to improve the IRWE deduction available to workers with disabilities who have high out-of-pocket costs for expenses related to their disability or chronic condition necessary for work, whether or not the individual participates in an MBI program.

Finally, the paper proposes taking a look at how the new options created by the ACA for the purchase of commercial health care insurance by people with disabilities and chronic condition can be built upon. More research should be undertaken to study the design of a program to provide wraparound coverage to commercial health care insurance in order to provide LTSS and fill in coverage gaps that exist for people with disabilities and chronic conditions in virtually all commercial health care insurance plans.

The proposals in this paper attempt to address only one area in which the current support system for workers with disabilities is inadequate. As discussed, it is difficult to estimate the impact that these changes will have on the number of people with disabilities applying for or receiving SSDI because the course of an individual's disability or chronic condition is impossible to predict, and whether an individual with a disability can continue to work is dependent on a variety of factors including the individual's health. Ensuring that access to needed services and supports does not limit an individual's work effort or earnings necessarily means spending more at both the federal and state levels on the Medicaid program and at the federal level on the tax code. It can cost more to support an individual with a significant disability to work than it would to provide them with income support through the SSDI or SSI program.

Supporting work by people with significant disabilities is the right thing to do, irrespective of whether doing so costs or saves money. Studies show that individuals with disabilities who work experience improved health, economic security, and quality of life, and the United States should invest to achieve those outcomes.

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