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Improving Health Coverage for Americans with Disabilities:
Policy Options for the President-elect and the 111th Congress

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Introduction

People with disabilities and chronic conditions have varying and sometimes complex needs for health and long-term services and supports. Millions of Americans with disabilities receive health coverage through the private marketplace, and many are quite satisfied with this arrangement. Some people's needs and economic circumstances, however, are sufficiently different from those of the general public that meeting their health coverage needs in the same manner as the general population may not be effective or appropriate. In some cases, the failure of private insurance to provide adequate coverage or meet the full scope of this population's needs has led to increased disability—and eligibility for public coverage. Medicaid and Medicare are anchors of the nation's health system, and they play unique roles in providing comprehensive services to people with disabilities and chronic conditions.

In seeking to strengthen the health system, it is important for policy makers to recognize that Medicaid plays a different role than private coverage and is a cost-effective and appropriate mechanism for meeting the acute care and long-term services needs of low-income people with disabilities. While imperfect, one of the virtues of Medicaid has been its ability to evolve as the demands on the program have changed. Medicaid has led the health system in developing models for providing community-based long-term services; it is helping to broaden access to evidence-based mental health treatment; and, it has adapted to promote work by establishing opportunities for people with disabilities to retain Medicaid coverage when they return to work. Medicare coverage provides working-age people with disabilities and elderly adults with broad access to critical services. Gaps in Medicare eligibility and coverage, however, create hardship for individuals and shift costs onto financially burdened Medicaid programs.

Improvements in the delivery system (in Medicaid, Medicare, and private coverage) can be made to improve quality and support cost control efforts. This paper identifies potential administrative and legislative actions that could be taken to bolster the capacity of Medicaid and Medicare to meet the needs of people with disabilities and chronic conditions. Policy options are listed in four key areas:

1. Eligibility and enrollment;
2. Access to services;
3. Program management and delivery system issues; and,
4. Financing.

The options in these areas are described, but are not ranked. Cost estimates are not included.

The policy dialogue about improving Medicaid and Medicare and reforming the health system is taking place at a time of extraordinary economic distress in the country. States are facing large and growing budget shortfalls. Some of the policy options in this paper are priority goals for the states and others provide options that some states may wish to undertake. Still others, however, seek to create more uniformity across the country and increase national standards in ways that have financial implications for state programs. In presenting these options, an implicit assumption is that states will need increased federal support to take full advantage of the ideas for improving Medicaid. As part of the health reform debate, policy makers may wish to consider a more fundamental rebalancing of financial responsibility between the federal and state governments for financing health care for low-income Americans receiving coverage through Medicaid and Medicare.

Eligibility and enrollment

Of the 25 million Americans with a specific, chronic disability, less than one-third receives Medicaid or Medicare.¹ Only individuals who satisfy the Social Security Administration's strict standard for severe and persistent disability are considered disabled. The application process can be daunting, as it is often long and extraordinarily complex. Even then, not all individuals determined to have a disability are eligible for Medicaid or Medicare. Medicaid requires individuals to have low incomes and limited resources. Mandatory eligibility for Medicaid in most states is tied to receipt of Supplemental Security Income (SSI), which provides income support up to 74% of poverty (\$637/month for a single individual in 2008). While states have several options for covering higher income people with disabilities, this flexibility is not evenly utilized by states—and there are many people with disabilities below or near the poverty level that are considered too rich for Medicaid. While Medicare does not limit eligibility on the basis of income, individuals under age 65 must wait a total of 29 months from the date of onset of disability until Medicare coverage begins.

Notwithstanding this complexity, Medicaid and Medicare work well for meeting the needs of millions of Americans with disabilities and they should be strengthened and improved. The scope of Medicaid benefits is unique when compared to private insurance coverage, and the cost-sharing structure is more appropriately geared to low-income individuals. Specific, targeted changes can make it easier for people with disabilities to gain eligibility for these programs.

Administrative Actions

Permit states to use less restrictive income and resource methodologies for SSI-related groups. Section 1902(r)(2) of the Social Security Act permits states to use less restrictive methodologies in determining eligibility for Medicaid. The Centers for Medicare and Medicaid Services (CMS) has interpreted the law to prevent the application of this provision to SSI beneficiaries and related groups. This is important to permit individuals to retain more of their income and remain eligible for Medicaid in order to support community living. CMS could restore its prior interpretation of the law to permit section 1902(r)(2) to apply to SSI and related groups. CMS could also explore options for permitting spenddown to the special income limit (300% of SSI) for persons seeking access to home- and community-based services (HCBS) waiver programs.

Permit states to protect community spouses of medically needy HCBS waiver participants. CMS could reverse a Bush Administration change to longstanding policy to permit states to extend spousal impoverishment protections to medically needy HCBS waiver participants. The current policy creates incentives for individuals needing long-term services to access institutional care in order to ensure that their spouse has sufficient resources to maintain a community residence.

Legislative Proposals

Cover all low-income people, without categorical distinctions, through Medicaid. As policy makers consider the role of Medicaid in the broader health system, they could require states to offer Medicaid to all low-income Americans, as part of a strategy to achieve universal coverage. If this is not feasible, a more limited approach could target low-income seniors and people with disabilities who are especially likely to need Medicaid's scope of services and cost-sharing requirements better suited to low-income people.

Enact the Early Treatment for HIV Act (ETHA). S. 860/H.R. 3326 would permit states to extend Medicaid coverage to low-income people with HIV who are not yet disabled by AIDS. Most people living with HIV/AIDS are ineligible for Medicaid until their condition is advanced (triggering a disability determination) and this bill would support earlier access to treatment.

Restructure medically needy coverage. Medically needy coverage is a state option used by 35 states plus the District of Columbia to permit individuals with income too high for Medicaid to spenddown to coverage.² The option was originally structured for access to nursing home care. The option could be updated to require all states to permit spenddown and to permit individuals to retain more income and resources to better support community living.

Raise Medicaid asset limits to better support community living. In Medicaid, individuals are generally permitted to retain \$2,000 in resources (\$3,000 for couples), with additional exclusions, such as home equity in an individual's primary residence. Increasing resource standards and indexing them to inflation could better support community living, as some home maintenance expenses, such as a roof replacement or furnace replacement could easily exceed these levels.

Eliminate or phase-out the Medicare waiting period. People with disabilities under age 65 must currently wait 29 months from the date of onset of disability until they can receive Medicare. This causes severe hardship and leads to gaps in access to critical services and increased disability. Medicaid provides coverage during the waiting period for low-income individuals, burdening states. Policy makers could eliminate or phase-out the waiting period.

Access to services

Medicaid has always had a broader role than private coverage given its responsibility for the health coverage needs of low-income Americans. For people with disabilities, a key feature of Medicaid is that it integrates acute services (i.e., physician and hospital care, lab tests, etc.) with long-term services and supports (i.e., assistance with activities of everyday life such as bathing and dressing, preparing meals, and managing a home). It also provides more coverage for some services than is typically provided by private insurance, such as physical and occupational therapy—services upon which many people with disabilities rely to maximize and maintain their ability to function. For children, the guarantee of comprehensive coverage through the early and periodic, screening, diagnostic, and treatment services (EPSDT) benefit provides an important investment in identifying and treating health problems to mitigate or minimize lifelong disability.

States are not required, however, to cover the broad scope of services that Medicaid permits. In particular, Medicaid beneficiaries have an entitlement to nursing home care, and while states can offer a range of alternative community services, access to these services can be limited. The challenge for policy makers is to address unmet need for community services and encourage individuals to utilize less costly alternatives to institutional care, all the while controlling costs. In Medicare, broad access to primary and specialty care is especially important for individuals with rare disorders for which there are only a small number of providers with appropriate experience and expertise. The Medicare benefits package, however, is not always well suited for the beneficiary population. The program does not cover long-term services, dental, vision, and other key services. Without fundamentally altering these programs, significant improvements can be made to enable these programs to work better for people with disabilities.

Administrative Actions

Withdraw the rehabilitation services proposed rule. In August 2007, the Bush Administration issued a proposed rule that would restrict the scope of rehabilitation (rehab) services that are eligible for federal Medicaid matching payments. Currently 47 states plus the District of Columbia provide services under the Medicaid rehab option. The rule is subject to a moratorium until April 2009 and was not issued in final form. The rehab option is the primary mechanism for providing community mental health services in Medicaid and is unique in Medicaid for the flexibility it affords regarding where services are provided, the types of providers, and the scope of services (including skills training for certain behavioral health issues). The rule could be withdrawn or revised to protect longstanding state flexibility.

Clarify requirements for states to cover day habilitation and adult day services. The rehab option proposed rule would have eliminated Medicaid coverage of all day habilitation services for people with developmental disabilities. These programs often provide a cost-effective alternative to more costly HCBS waiver services or institutional care. Longstanding adult day programs for persons with dementia (that are similar in many respect to day habilitation programs) have also been threatened by CMS. A 1989 law protected existing day habilitation programs operated under the rehab and clinic options, preventing the Secretary of Health and Human Services (HHS) from withdrawing approval of these programs until a final rule was issued specifying the circumstances under which states may cover day habilitation services.³ CMS could issue a final rule clarifying for states the conditions for operating day habilitation and adult day programs, thereby permitting all states to offer these services.

Clarify that states may pay for the non-room and board components of therapeutic foster care (TFC) programs. The rehab option proposed rule effectively prohibited Medicaid coverage of therapeutic foster care (TFC), an evidence-based practice that provides services for children who, as a result of mental illness, other emotional or behavioral disorders, medically fragile conditions, or developmental disabilities need the level of care normally provided in an institution (often a psychiatric residential treatment facility). CMS could issue guidance to states informing them that they may operate TFC under the same terms that were in effect prior to the proposed rule and encouraging them to do so.

Issue guidance on EPSDT wraparound services for children in benchmark plans. The Deficit Reduction Act of 2005 (DRA, P.L. 109-171) created a new option for states to offer an alternative to the Medicaid benefits package, called “benchmark” coverage. States serving children in benchmark benefit plans must provide wraparound services to ensure that these children continue to receive all medically necessary services under the EPSDT benefit. CMS could issue guidance to states specifying requirements for ensuring that children do not face barriers in accessing medically necessary services.

Issue guidance to clarify that Medicaid-covered children in psychiatric facilities (called institutions for mental disease, IMDs) qualify for physical health services. In 1972, Congress permitted children under age 21 to receive “inpatient psychiatric hospital services”. The Bush Administration reinterpreted the law to permit only inpatient psychiatric services—thus denying federal payment for inpatient physical health services for Medicaid beneficiaries under age 21 in IMDs.⁴ CMS could revert to the prior interpretation of the law.

Issue new federal guidance on Medicaid compliance with the Supreme Court’s Olmstead decision. In 1999, the US Supreme Court decision in the case of *Olmstead v. L.C.* affirmed that the Americans with Disabilities Act (ADA) prohibition of discrimination requires the placement of persons with disabilities in community settings rather than in institutions, when it is appropriate, the individual does not oppose the community placement, and the placement can be reasonably accommodated given the resources available to the state. Since that time, access to community services has not kept pace with growing need. As one measure of unmet need, waiting lists for HCBS waiver services have increased by nearly 88,000 people just since 2002.⁵ CMS could issue new guidance to states describing state obligations to meet the ADA’s integration mandate, as well as continuing to support grants to states to facilitate expanding

community services and expanding cooperation between CMS, the HHS Office for Civil Rights, the Department of Housing and Urban Development (HUD), and the Department of Justice.

Promote routine HIV counseling and testing for Medicaid beneficiaries. The Centers for Disease Control and Prevention (CDC) recommends routine HIV screening in health care settings for all adults and adolescents aged 13-64. Many people with HIV are diagnosed late in their illness, with a 2005 study finding that 38% of people received an AIDS diagnosis within one year of testing positive for HIV. Twenty-one percent of people living with HIV in the United States are believed to be unaware of their status. Policy makers could encourage Medicaid programs to make routine counseling and testing available to Medicaid beneficiaries.⁶

Rescind the Medicaid school-based administration and transportation services rule. In December 2007, the Bush Administration published a final rule that would prohibit all Medicaid funding for school-based administration and transportation services. This rule is subject to a moratorium until April 2009. CMS could issue informal guidance informing states that the rule cannot become enforceable prior to June 1st, rescind the rule, and take administrative action to delay implementation of the rule.

Issue new federal guidance to clarify that hard limits on Medicaid prescription drugs are not permitted. A number of states place limits on the number of prescriptions that can be dispensed in a particular month, but these limits can be breached with clinical justification. A small number of states, however, have imposed hard limits, and do not permit drugs to be dispensed above the limit, even with clinical justification.⁷ Policy makers could review section 1927(d) of the Social Security Act and issue guidance requiring states with dispensing limits to make exceptions in cases of medical necessity.

Relax the Medicare “in the home” restriction on services. When Congress created Medicare Part B, it allowed the purchase of wheelchairs and other durable medical equipment (DME) only if they are used “in the person's home.” Since the Part A program already covered DME in hospitals and skilled nursing facilities (SNFs), Congress did not want to pay twice for the same benefit. Federal rules specify that Medicare Part A pays for DME in hospitals and SNFs, and Part B pays for DME needed in the home. These rules, however, have relied on a restrictive definition of what is meant by “in the home”. Policy makers could reinterpret the rules to consider DME needed in the community as an extension of services needed in the home.

Relax the Medicare homebound rule. The homebound rule defines who is eligible to receive home health services and requires individuals to have a normal inability to leave home, specifies that leaving home must require “a considerable and taxing effort by the individual,” yet permits an individual to be absent from his or her home, at any time, to receive health care, attend adult day care, or attend religious services. These permissible absences from the home have been applied in a very restrictive manner. Policy makers could relax current restrictions to consider someone homebound if they cannot leave their home without technological or physical assistance from others.

Establish a Medicare demonstration program on access to home modifications and safety equipment for persons at heightened risk of fall injuries. A major cost pressure in Medicare

comes from hospital and skilled nursing care associated with preventable injuries. Federal policy makers could use their demonstration authority to test the cost-effectiveness of covering certain home modifications and installation of safety equipment (such as shower rails) for persons with a diagnosis of osteoporosis, and for whom such equipment has been prescribed by a physician.

Legislative Proposals

Enact the Community Choice Act. S. 799/H.R. 1621 would require states to offer a new community-based attendant services benefit under their state plans for persons who require a nursing home level of care. To assist states in implementing this requirement it would also provide for a temporary enhancement in the federal share of Medicaid expenses for these costs. This bill would equalize access to nursing home/institutional care and community services. Policy makers could adopt this legislation to expand access to community services and assist states in meeting their Olmstead obligations under the Americans with Disabilities Act (ADA).

Require states to cover personal care and rehabilitation services. Thirty-two states plus the District of Columbia have elected to offer personal care services under their Medicaid state plan. Forty-seven states plus the District of Columbia offer services under the rehab option. Together, these two options permit states to offer a broad range of physical and mental health services. Congress could require states to offer services under these two options. Since most states already offer these services, it may be a low-cost approach to expanding access to community services. Policy makers should consider minimum standards for the amount, duration, and scope of services, as well as ways to support states in financing their share of these services.

Enact the Empowered at Home Act. S. 3327/H.R. 7212 would make changes to the recently enacted 1915(i) state plan option to provide community-based services. As enacted, states are not permitted to use the option to cover the full population of people receiving HCBS waiver services and they have less flexibility than the waiver program with respect to the scope of services. Further, last minute changes prior to enactment permit enrollment caps and waiting lists—this caused representatives of people with disabilities to oppose this provision. Policy makers could adopt this legislation to make changes to the 1915(i) option to expand the tools available to states for offering community services. Further, this bill includes increased financial support for states to support their efforts to expand community services.

Enact the Community Living Assistance Services and Supports (CLASS) Act. S. 1758/H.R. 3001 is a national, voluntary disability insurance program outside of Medicaid or Medicare under which all workers are automatically enrolled, but can opt-out of participation. Individuals pay monthly premiums and if they develop a disability, the program pays cash benefits to purchase nonmedical services and supports. Medicaid beneficiaries can participate along with non-Medicaid beneficiaries. Policy makers could enact this legislation to add a new financing source for long-term services to take some pressure off of Medicaid programs.

Establish a new therapeutic foster care (TFC) option as an alternative to residential treatment. Existing law permits states to pay for the non-room and board components of TFC. Children in the child welfare system who are enrolled in Medicaid can receive Medicaid-funded TFC, with the Title IV-E foster care program paying the room and board components of this

treatment intervention. There are some children who require TFC, however, who are not involved with the child welfare system. This includes cases where parents have not relinquished custody of their children. These Medicaid children are ineligible for Title IV-E services, thus they do not have a payment source for the room and board costs of TFC. Policy makers could create a new Medicaid service category for TFC for children ineligible for Title IV-E services when TFC is needed as an alternative to inpatient psychiatric treatment.

Establish a modest Medicare community services benefit. There is a fundamental disconnect in Medicare, as a program for seniors and people with disabilities, that its benefits package does not include support for long-term services and supports. Congress could establish a modest community services benefit. This would not replace the need for Medicaid or private long-term care insurance, but could provide significant relief both to individuals and Medicaid programs. In Medicaid, Vermont is testing the concept of providing a limited benefits package to persons who do not yet require a nursing home level of care, with the goal of delaying or preventing the progression of disability. This benefit could emulate this approach in Medicare.

Permit routine HIV counseling and testing for Medicare beneficiaries. Despite CDC recommendations to routinely screen all adults and adolescents age 13-64, Medicare coverage of HIV testing is limited to circumstances when it is medically necessary (i.e. when individuals present clinical symptoms suggestive of HIV infection or when the treating provider has other reasons for suspecting HIV infection).⁸ Medicare prohibits routine, population-based screening for HIV infection. Policy makers could change the law to permit Medicare to pay for HIV screenings for Medicare beneficiaries when it is consistent with current CDC HIV testing recommendations and take administrative actions to encourage appropriate access to HIV counseling and testing for Medicare beneficiaries.

Program management and delivery system issues

Given the diversity of needs of people with disabilities, Medicaid programs must perform multiple functions not required of private coverage or Medicare. Medicaid is responsible for providing health care services to exceptionally vulnerable populations, such as children receiving foster care. It is the major source of financing for community-based mental health services, developmental disabilities services, and HIV/AIDS services. It delivers certain services for which private insurers have limited experience and capacity, such as skills training and other rehabilitative services.

In recent years, states have taken steps to implement evidence-based practices, such as therapeutic foster care (TFC) as an alternative to residential psychiatric treatment for children or assertive community treatment (ACT) programs for successfully supporting the recovery of people with schizophrenia and other forms of mental illness.⁹ They have also taken steps to integrate clinical evidence in managing the prescription drug benefit.¹⁰ In these and other areas, however, some states have done more than others. Additionally, some recent administrative actions (i.e. rule changes or new policy interpretations) have been implemented that create barriers for states in fulfilling these diverse roles or that raise questions for states about whether longstanding programs are in compliance with federal guidelines.¹¹ Federal leadership could

make important improvements in how Medicaid programs are managed and spur states to adopt best practices in order to increase quality, improve accountability, and potentially, lower costs.

Administrative Actions

Withdraw and revise case management rules. An interim final rule making changes to the Medicaid case management and targeted case management (TCM) benefits was issued in December 2007 becoming enforceable in March 2008. It is currently subject to a moratorium until April 2009. Case management services assist individuals in gaining access to needed medical, social, educational and other services. Forty-nine states plus the District of Columbia provide targeted case management services to various groups. The new rules implemented provisions of the DRA, but went well beyond the statutory changes to restrict access to case management and restrict who could provide case management services. CMS could issue a final rule that eliminates the harmful provisions in the interim final rule. Since the interim final rule will become enforceable again in April 2009, action should be undertaken as early as possible to prevent disruptions in critical services.

Work with states and providers to develop new guidance on payment policy. The rehab and case management rules would have restricted states to paying for these services using fee-for-service payments in fifteen-minute time increments. CMS could issue guidance to states informing them that they can use previously approved payment methodologies. This could be followed by a collaborative dialogue with states and community-based providers to consider issues related to financial accountability and documentation requirements. This process should seek to protect state flexibility to determine the payment methodology, while achieving a higher level of accountability and transparency.

Reinterpret DRA exemptions from benchmark plan enrollment. The DRA gave states the option to require that certain groups of beneficiaries enroll in “benchmark” benefit plans that differ from regular Medicaid. Congress exempted certain vulnerable groups from enrollment in these plans, including dual eligibles, individuals with disabilities, and medically frail individuals. CMS rules, however, interpreted this to permit voluntary enrollment in these plans, raising concerns that individuals could be coerced or misled into enrolling in these plans. Policy makers could restore a full exemption from enrollment in benchmark plans for exempted populations.

Issue new waiver policy guidance. The Secretary of HHS has broad authorities under the Social Security Act to waive provisions of the Medicaid law. While waiver programs can be beneficial for covered individuals, they also have the potential to take away critical protections. Policy makers could provide new guidance specifying minimum beneficiary protections that will be required regarding the scope of coverage and other critical issues.

Conduct a comprehensive review of the adequacy of coverage in Medicaid state plans. States have broad flexibility in Medicaid to elect to cover various optional services and to set amount, duration, and scope limits for adults for all services. As policy makers consider an expanded role for Medicaid in serving the low-income population, some differences across states in the services covered and coverage limits may undermine federal goals. Policy makers could

conduct a comprehensive review of coverage policies in states, examining state plans and waiver programs, to make recommendations for areas where new federal standards may be beneficial.

Establish a model practices center within CMS. Each state and territory operates its own Medicaid program. Whereas some of the differences in programs across states reflect purposeful policy priorities, much variation arises because each state separately performs key operational activities on its own. Whether it is developing HIPAA privacy compliance practices, designing billing standards or electronic medical records, or evaluating the clinical effectiveness of services, Medicaid could become more efficient if there was more uniformity and if states had access to new resources to ensure that their operations are consistent with best practices. Policy makers could establish and fund a center within CMS responsible for working with states and other stakeholders to review data and promulgate best practices.

Prohibit payment for hospital “never events” and extend to long-term care facilities. In October 2007, Medicare announced that it would stop paying for so-called “never events”, which are egregious preventable hospital errors, such as performing surgery on the wrong patient. Since that time, a handful of Medicaid programs have adopted similar policies.¹² Policy makers could set a national Medicaid policy prohibiting payment for never events or encouraging more states to adopt such a policy. Further, Medicare’s policy currently excludes long-term care facilities, and this may miss opportunities for preventing adverse outcomes or conserving resources. Policy makers could extend this policy to nursing homes and include such adverse outcomes as pressure sores or the use of physical restraints for convenience.

Develop a national strategy for supporting direct care workers and family caregivers. As states seek to expand access to community services, one major barrier is the absence of a sufficient workforce that is ready and available to meet the direct care needs of persons residing in the community. Direct care work is often physically demanding, wages are often low and benefits limited, and many workers find inadequate opportunities for training and career advancement. Policy makers could develop a national strategy for expanding and strengthening the workforce, and consider policies (such as respite services) to support family caregivers.

Develop a cross departmental plan for increasing access to housing for people with disabilities. A major barrier preventing individuals with disabilities from transitioning from institutional settings to the community is the lack of appropriate community housing. The next President could issue an executive order or other policy action to require HHS and HUD to develop and implement an ongoing strategy for placing institutionalized individuals with disabilities seeking community placements in safe, affordable, and accessible community housing and otherwise expanding access to housing for low-income people with disabilities.

Clarify Medicaid policy to permit mental health providers to integrate primary medical care into their mental health treatment programs. A 2006 study found that persons with serious mental illnesses die 25 years sooner than people without mental illness, and most of this increased mortality is associated with medically treatable conditions.¹³ This has led some parties to advocate for increased linkages between mental health treatment and primary care. Some states have interpreted the Medicaid law as prohibiting providers from billing for two services on behalf of the same patient at the same site, on the same day. While this policy interpretation is

intended to prevent against duplicate billing, it has the effect of preventing providers from integrating primary medical care into their mental health treatment programs. Policy makers could issue guidance to states on mental health treatment and primary care integration that explicitly permits providers to bill for primary medical care and mental health services provided to the same beneficiary on the same day.

Increase federal support for evidence-based Medicaid pharmacy programs. A number of Medicaid programs have embraced clinical effectiveness research to guide their pharmacy management practices. More can be done, however, both to broaden the adoption of evidence-based reviews of drug classes, but also to increase the capacity of states to evaluate comparative effectiveness research. Policy makers could issue guidance to states for promoting best practices, fund comparative effectiveness research, train state staff, and work with states to develop best practices.¹⁴

Develop a demonstration initiative to promote integration of Medicaid and Medicare services. Due to overlapping requirements of the Medicare and Medicaid statutes, it has been challenging to coordinate and manage the care of dual eligibles. Many people believe there are large opportunities to improve quality and control costs if Medicare and Medicaid services could be better integrated. Policy makers could develop a new demonstration initiative, with voluntary participation by individuals, which seeks to continue efforts to test and evaluate different approaches to integrating care and improving care coordination.

Improve formulary access for people with disabilities in the Medicare Part D program. The basic formulary standard in the Medicare Part D program requires plans to cover at least two drugs per drug class. Since the Part D program started, the Bush Administration has issued annual guidance requiring plans to cover “all or substantially all” drugs in six key classes of special importance to people with disabilities and chronic conditions: anticonvulsants, antidepressants, antineoplastics, antipsychotics, antiretrovirals, and immunosuppressants. In legislation enacted in July 2008 (P.L. 110-275), the Congress sought to codify this policy by establishing a process for the Secretary to designate drug classes for special protection. Subsequently, CMS has indicated that they are unlikely to extend special protections to all six classes. Policy makers could protect all six classes, and evaluate whether additional drug classes merit this protection. Further, policy makers could consider other steps to improve the transparency, consistency, and clinical basis for prescription drug plans’ use of prior authorization and other utilization management practices.

Permit AIDS drug assistance programs (ADAP) spending on Medicare drug coverage to count toward TrOOP. When Congress established the Medicare Part D program, drug spending by other government programs was prohibited from counting toward the calculation of so-called true out-of-pocket costs (TrOOP) that triggers catastrophic coverage. The law made an exception, however, for state pharmacy assistance programs. CMS interpreted the law such that ADAPs are not considered state pharmacy assistance programs even though they are operated by states, their purpose is to provide access to pharmaceuticals, they are supported by significant state contributions, and they must ensure that they are the payer of last resort. CMS could reinterpret its rules and determine that ADAPs qualify as state pharmacy assistance programs.

Legislative Proposals

Expand access to care coordination services for people using long-term services and people with complex conditions. A small proportion of Medicaid and Medicare beneficiaries are responsible for a very large share of total spending in each of these programs. Policy makers could enact legislation to expand access to care coordination in both Medicaid and Medicare for people who use long-term services or other persons with complex conditions.¹⁵

Enact the Direct Support Professionals Fairness and Security Act. H.R.1279 would establish a new state option to provide a temporary increase in the federal share of Medicaid for states to implement a plan to increase the wages of direct care workers. Part of the challenge of assuring an adequate workforce of community-based direct care workers is the existence of a wage disparity with public direct care workers (who are largely employed in institutions). Policy makers could enact this bill or take other steps to increase wages, benefits, and job protections for direct care workers.

Promote access to hospital discharge planning services in Medicaid and Medicare. Some repeat hospital stays and institutional placements could be prevented if individuals in inpatient settings had greater access to discharge planning that assesses support needs, and then helps to identify and arrange community services. In many circumstances, individuals are discharged without adequate supports and they end up returning to the hospital. Individuals may be unsure how to organize community services or they may not believe community resources are available, so they end up being discharged from a hospital to a nursing home. For persons with mental illness, insufficient discharge planning and interrupted services on discharge can also increase involvement with the juvenile justice and criminal justice systems. Policy makers could consider approaches to increasing access to discharge planning services in both Medicaid and Medicare.

Review and strengthen the administration of the Medicare Part D low-income subsidy (LIS). Nearly three full years have passed since the Part D program was implemented. Sufficient time has elapsed for policy makers to consider how well the program is functioning and consider improvements. In particular, stakeholders have raised concerns about statutory and administrative policies that create barriers for low-income individuals trying to access LIS assistance. Challenges for beneficiaries include the complexities associated with proving their eligibility for LIS, the very low asset limit that impedes participation, and the churning of both eligibility (movement in and out of LIS coverage) and enrollment in drug plans (reassignments to new plans based in shifts in plan premiums and regional benchmarks) without an adequate understanding of eligibility standards or appropriate access to assistance in navigating the LIS program. Policy makers could consider numerous administrative and legislative actions to make it easier for low-income beneficiaries to obtain and maintain LIS assistance.

Financing

People with disabilities and seniors are major cost drivers in Medicaid. Whereas these two groups comprise only 25% of enrollees, they are responsible for 70% of total spending.¹⁶ Research has found, however, that when adjusting for health status and demographic factors, per

person spending on medical care (which excludes long-term services) is lower in Medicaid than private insurance.¹⁷ Long-term services spending—the part of Medicaid spending not extensively covered by private health insurance—is responsible for a third of total spending and is growing faster than acute care, putting growing pressure on states and the federal budget.¹⁸ Additionally, Medicaid’s responsibility for financing services for low-income Medicare beneficiaries (dual eligibles) has grown over the decades and has become a major burden for states. Roughly thirty-four percent of total Medicaid spending is for services for Medicare beneficiaries—an indication that Medicare is leaving significant gaps in coverage that Medicaid is left to fill.¹⁹ Medicaid does so much, in part, because private insurance and Medicare were not designed to fill so many different roles in the health system.

Federal policy makers may wish to consider the relative balance of financing responsibilities for dual eligibles between Medicaid and Medicare. A range of options exist that could take pressure off of states for paying for services for dual eligibles to make Medicaid financing more secure. Additionally, policies could be used to incentivize states to take actions that achieve federal policy goals, such as expanding access to community services.

Administrative Actions

Withdraw rules that reduce federal support for state Medicaid programs. In addition to the rule changes previously discussed, at least four other rules have been issued in proposed or final form [the cost limit (IGT) rule, the outpatient services rule, the graduate medical education (GME) rule, and the provider tax rule]. Except for the outpatient services rule, each of these rules is subject to a moratorium until April 2009. Collectively, these rules would reduce the federal share of Medicaid financing by more than \$6.3 billion over the next five years. Each of these rules has also been subject to controversy.²⁰ As policy makers look for ways to stabilize Medicaid financing during the current economic downturn, consideration may be given to withdrawing each of these rules. In some cases, more targeted rulemaking may be appropriate.

Legislative Proposals

Provide a temporary increase in the federal share of Medicaid. As currently structured, Medicaid operates in a counter-cyclical fashion such that eligibility and spending rise during economic downturns when states are challenged in financing their share of Medicaid spending. In the last downturn, Congress enacted a temporary increase in the federal share of Medicaid financing, with a requirement that states maintain existing coverage. Current indicators suggest that the national economy is beginning a more severe, and likely more persistent downturn. As of September 2008, twenty-seven states plus the District of Columbia were projecting mid-year shortfalls of more than \$12 billion in 2009, and the recent economic crisis will likely lead to a significant increase in state budget shortfalls.²¹ Policy makers could bolster state programs both to address the immediate downturn, and to establish a trigger to automatically adjust the federal share of Medicaid costs during future downturns.

Increase federal support for community services to encourage rebalancing of long-term services spending. Policy makers, beneficiaries, and advocates all support expanding access to community services, and shifting the proportion of Medicaid long-term services dollars spent in

the community. One approach to accelerating this change would be to establish federal incentives or rewards for states that move forward in expanding access to community services. Policy makers could consider a range of options, such as a temporary or permanent increase in the federal share of financing community services, grants to states to promote rebalancing, or bonus payments for states that achieve certain milestones, such as achieving a balance where 50% of long-term services dollars are spent in the community, with perhaps an additional bonus for spending 75% of long-term services dollars in the community.

Increase Medicare’s responsibility for health and long-term services costs for dual eligibles.

The cost of long-term and other services for dual eligibles that are not covered by Medicare has become a substantial burden on state Medicaid programs. This includes paying Medicare cost-sharing for low-income individuals and paying for Medicaid services not covered by Medicare. Policy makers could consider various steps for relieving states of responsibility for some or all of these costs. This could take the form of an increased federal share of Medicaid costs for dual eligibles or more directly transferring the financing and delivery of some services for dual eligibles to Medicare. Policy makers could also consider providing Medicare coverage for people in the waiting period.

Conclusion

Medicaid and Medicare are essential programs for providing health and long-term services to people with disabilities. Their roles cannot easily be supplanted by private insurance. Reforms to these public programs, however, complement efforts to reform the private insurance marketplace. Significant, achievable improvements and modifications could enable these programs to work better, control costs, and increase quality. As policy makers consider a range of reforms, whether as part of the new Administration’s efforts to improve these programs or as part of a broader legislative effort to achieve health system reform, the options here seek to further the goal of building on what works effectively in public coverage for low-income and other vulnerable groups. These options could also fit into a comprehensive plan to expand private insurance coverage for the general population.

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¹ Economic and Social Research Institute, based on data from the 1994 National Health Interview Survey, Disability Supplement, Phase 1.

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³ See section 6411(g) of the Omnibus Budget Reconciliation Act of 1989 (OBRA ‘89, P.L. 101-239).

⁴ See March 8, 2005 letter to CMS Administrator Mark B. McClellan and Acting Inspector General Dan Levinson from Ranking Minority Member, Rep. Henry A. Waxman, House Government Reform Committee and Chair, Senator Susan M. Collins, Senate Committee on Governmental Affairs, available at <http://oversight.house.gov/documents/20050308110415-98765.pdf>.

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- ⁷ *State Medicaid Outpatient Prescription Drug Policies: Findings from a National Survey, 2005 Update*, Kaiser Commission on Medicaid and the Uninsured, October 2005, available at <http://www.kff.org/medicaid/7381.cfm>.
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