



GEORGETOWN UNIVERSITY

Health Policy Institute

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Mr. Chairman, Senator Kohl, and Members of the Committee,

Good afternoon. I am Jeffrey Crowley, a Project Director at the Health Policy Institute at Georgetown University. Thank you for inviting me to provide a disability perspective to the Medicaid policy discussion over distinctions between mandatory and optional eligibility groups and services. The majority of my work involves examining Medicaid and Medicare policy issues as they impact people with disabilities. Previously, I worked in HIV/AIDS policy as the Deputy Executive Director for Programs at the National Association of People with AIDS (NAPWA), and HIV policy issues continue to be an emphasis within my cross-disability work. I am grateful for the opportunity to provide my views on the impact on people with disabilities of various short and long-term Medicaid policy proposals.

Medicaid works for people with disabilities. Because of Medicaid, millions of children, adults, and seniors with disabilities are able to lead healthy and full lives. Notwithstanding these facts, Medicaid is imperfect and does not meet the needs of all beneficiaries with disabilities. As a nation, we have made great strides in valuing all of our citizens, including individuals with disabilities, yet Medicaid policies can sometimes hold people back by not providing them access to the health and long-term services they need if they wish to remain in their own home and remain fully engaged in their own communities. Nonetheless, the tools for building on Medicaid's success—and expanding access to community services—already exist within Medicaid, and the need to address this significant shortcoming of Medicaid does not lie in weakening the current structure of the program or taking financial resources out of the program.

As the policy debate over the future of Medicaid has unfolded, it has sometimes been frustrating to listen to common assertions about Medicaid. It has been said that Medicaid is broken, its spending is out-of-control, it is unsustainable, and that it is hurting rather than helping the individuals it is intended to serve. While the nation's health system faces many serious challenges, Medicaid is being set up as a scapegoat, and is inappropriately being blamed for a whole host of deficiencies with our broader health system. This is being done to justify radical, harmful change. I would like to help dispel some of these notions of Medicaid's failures by telling you about Medicaid's significant successes at serving people with disabilities.

### **Medicaid's Role for People with Disabilities**

An estimated 9.2 million non-elderly individuals with significant disabilities rely on Medicaid, and an unknown percentage of the 5.4 million seniors on Medicaid also have significant disabilities.<sup>1</sup> For these individuals, Medicaid is generally the only place they can turn to have the full range of their needs met for both health and long-term services and supports.

Medicaid is the largest source of funding for developmental disability services, providing essential support to individuals and families of persons with mental retardation, cerebral palsy and other conditions; it is the largest source of health coverage for people with HIV/AIDS, greatly eclipsing both Medicare and the Ryan White CARE Act as a source of financing for life-saving HIV/AIDS health services; it is the largest source of state and local spending on mental health, providing essential support for community-based mental health services. Medicaid is a

critical source of support for people across the spectrum of disability, including individuals who are blind, persons with traumatic brain injury, individuals with spinal cord injuries, individuals with epilepsy, multiple sclerosis, and various forms of serious mental illness including bipolar disorder, depression, and schizophrenia.<sup>2</sup>

Notwithstanding Medicaid's critical role, it does not cover all Americans with disabilities. Only an estimated 20% of non-elderly people with chronic disabilities are covered by Medicaid.<sup>3</sup> Individuals covered by Medicaid are the subset of the disability population whose disability is so severe that they met a strict standard for disability established by Congress and administered by the Social Security Administration and who have very low-incomes, and meet other financial and residency requirements.

### **Medicaid Eligibility for People with Disabilities**

Much recent discussion has taken place over the difference between mandatory and optional Medicaid beneficiaries. With regard to people with disabilities, the mandatory/optional distinction has no connection whatsoever to the level of disability or the need for health and long-term services. Some parties have characterized optional Medicaid beneficiaries as higher income individuals with less serious need for Medicaid assistance. Virtually all Medicaid beneficiaries with disabilities have extremely low incomes and all have met the same standard for serious, long-term disability.

The majority (78%) of Medicaid beneficiaries with disabilities are mandatorily eligible.<sup>4</sup> These are individuals who are determined by the Social Security Administration to be disabled, and on the basis of their low-incomes and limited resources, they receive Supplemental Security Income (SSI).<sup>5</sup> In 2005, SSI provides an income supplement up to \$579/month, ensuring that individuals with disabilities have income of at least 74% of the federal poverty level.<sup>6</sup> Because this income support is so low, many states provide state supplementary payments.<sup>7</sup>

There are several optional eligibility categories that states can use to extend Medicaid coverage to people with disabilities. I would like to highlight just a few of the primary options available to states:

**Poverty Level Option:** As of October 2001, 18 states plus the District of Columbia had taken up the poverty level option which permits states to extend Medicaid coverage to people with disabilities up to the poverty level.<sup>8</sup> This option is particularly important to many Social Security Disability Insurance (SSDI) recipients. These are individuals who paid into the Social Security system when they were employed, and after they became disabled for five months, they began receiving SSDI. Unlike SSI which supplements income up to 74% of poverty, SSDI payments are calculated from past payroll deductions to Social Security. Higher income workers receive higher SSDI payments if they become disabled. In May 2005, the average SSDI payment for a disabled worker was \$897. This amounts to 112% of the federal poverty level. Therefore, the average SSDI recipient, although, quite poor, has income in excess of mandatory Medicaid standards. The poverty level option gives states the opportunity to extend coverage to some of these individuals.

**Medically Needy Option:** As of 2002, 35 states plus the District of Columbia operated medically needy programs.<sup>9</sup> This option permits states to extend coverage to individuals with extensive needs for health and long-term services who do not qualify for Medicaid as recipients of SSI. Frequently, these are low-income individuals with incomes slightly higher than the mandatory income standard, as well as individuals who may start out with significantly more income, but qualify when their incurred medical expenses are deducted from their income. The opportunity to spend down is particularly important to elderly individuals residing in nursing facilities and children and adults with disabilities who live in the community and incur high prescription drug, medical equipment, or other health care and long-term services expenses.

States have broad flexibility in operating their medically needy programs.<sup>10</sup> Although there is a general rule that once a state decides to make a Medicaid service available, it must make the service available to all beneficiaries when the service is medically necessary, this requirement does not apply to the medically needy. States are permitted to provide a more limited package of benefits to medically needy individuals. States also have broad flexibility in setting the medically needy income limit. Individuals with income above the highest income standard for categorically needy coverage, in states with medically needy programs, qualify for coverage when they incur medical expenses so that their income minus medical expenses is below the medically needy income limit. There is no relation, however between the income standard for mandatory Medicaid (which guarantees income of 74% of the poverty level) and the medically needy income limit. In fact, medically needy income limits are quite low. In 2001, the median medically needy income limit was 55% of the poverty level.<sup>11</sup> Therefore, individuals may start out with income above other Medicaid standards or above the poverty level, but their effective income, after medical expenses are deducted, can be significantly lower than mandatorily eligible beneficiaries with disabilities—and in some states can be exceedingly low.<sup>12</sup>

**Katie Beckett Option:** Twenty states have taken advantage of the Katie Beckett option (also called the TEFRA option), which is a state option created in 1982 that permits states to extend Medicaid coverage to children with significant disabilities who qualify for an institutional level of care, but whose family income would make them ineligible for Medicaid.<sup>13</sup> It permits states to not count parental income when determining financial eligibility for Medicaid. These are children whose need for services and supports is greater than most families can afford, and in the absence of this coverage option, parents may have to consider relinquishing custody of their children in order for them to receive Medicaid assistance in an institution.

**Work Incentives Options:** As of October 2004, 31 states have taken advantage of Medicaid work incentives options.<sup>14</sup> Over the past decade, the Congress and other policy makers have become increasingly sensitized to the barriers of obtaining health insurance coverage for people with disabilities. In many cases, Medicaid beneficiaries with disabilities would like to enter or re-enter the workforce, but have been afraid to do so because of the loss of Medicaid coverage. Even if employment comes with health insurance coverage, this coverage is often inadequate to meet the needs of people with disabilities. Through the Balanced Budget Act of 1997 (BBA)<sup>15</sup> and the Ticket to Work and Work Incentives Improvement Act of 1999 (Ticket to Work)<sup>16</sup>, Congress created new state options for individuals with disabilities to retain Medicaid coverage while working. The BBA and Ticket to Work, taken together, give states the option to provide Medicaid coverage to working people with disabilities up to 450% of the federal poverty level

and to use less restrictive income and resource methodologies when determining eligibility.<sup>17</sup> It is important to note, however, that enrollment in these programs has been limited and they do not account for a significant share of the Medicaid population of people with disabilities. Moreover, when the Government Accountability Office (GAO) looked at states early experience with these programs in 2003, a detailed review of four states found that the majority of participants in these programs had low very incomes with most earning less than \$800 per month.<sup>18</sup>

**Home and Community-Based Services Waivers:** All states plus the District of Columbia, with the exception of Arizona, have at least one home and community-based services waiver.<sup>19</sup> Waivers are very different from the state plan options described above in that states do not need to comply with certain Medicaid rules. While these waiver programs have led to improvements in the delivery and availability of community living services, there are significant shortcomings with waivers—states can use them to extend access to some people with disabilities, but not others based on the type of disability or where individuals reside. Moreover, unlike state plan services, states are permitted to limit access to services. Waiting lists for home- and community-based waiver services can be quite long. For example, Texas has nearly 75,000 people on its waiting list for community living services and the average wait time is one-and-a-half years to receive services.<sup>20</sup>

These waiver programs, like state plan options, are one more way that states have broad flexibility to extend Medicaid eligibility to people with disabilities. Under the section 1915(c) waiver authority, states have the option of providing community-based long-term services and supports to individuals with disabilities at risk for institutionalization. States seeking these waivers have the option to make the eligibility requirements for these programs comparable to those for institutional services, including the 300% rule which permits states to provide institutional services to individuals whose income is below 300% of the current SSI payment level. This option is particularly important to state efforts to extend Medicaid coverage to beneficiaries in the Title II disability programs, including disabled adult children (DACs) who qualify for a Title II benefit and Medicare on the basis of a parent's work history and who have limited independent financial resources.

Although these options respond to differing and sometimes highly specific needs of certain groups within the disability community, they share several important commonalities. States were given these options to respond to important national health policy goals. All of the populations covered by these optional categories meet the same standard of need for Medicaid services as mandatory populations, and the vast majority of individuals receiving Medicaid coverage through these options have very low incomes. It is possible to live in a state with none of these options so that people with disabilities with income of \$600 per month or less have no way to receive Medicaid assistance, no matter how extensive their need for health and long-term services. While state flexibility is an important goal, and state experimentation in Medicaid has led to program innovations, the time for experimentation has passed. An urgent challenge facing the Congress is to ramp up mandatory eligibility for these critical eligibility groups. In the context of strengthening and improving Medicaid, Congress may wish to consider a phased-in conversion of these and other "optional" eligibility categories to mandatory coverage, such as requiring coverage of all people with disabilities living in poverty to have access to Medicaid,

and ensuring that individuals with disabilities residing in all states have the option to spend down to Medicaid coverage.

**Aldora Vinson, Medicaid Beneficiary**

Aldora Vinson is 81 years old and lives alone in Thaxton, Mississippi. Her monthly income is \$597. She suffers from severe diabetes, arthritis, hypertension, and pain. Her medications for these conditions would cost her \$1,177 per month if Medicaid did not pay for them. Medicaid also pays for several other services she requires, including home health treatment, eyeglasses, and medical supplies. In 2004, Ms. Vinson’s Medicaid eligibility was threatened when the state decided to eliminate coverage for her and 48,000 other “optional” seniors and people with disabilities. Subsequent action by the state’s legislature protected her Medicaid coverage.

**Medicaid Services Needed by People with Disabilities**

All of the mandatory Medicaid services, including physician, hospital, and diagnostic services, are critically important to individuals with disabilities—and essentially anyone who seeks out health care. There is one mandatory benefit, however, this is unique to the Medicaid program and which is especially important to people with disabilities.

**Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Services:** The EPSDT benefit ensures that children on Medicaid are screened on a regular basis and if a disability or health condition is diagnosed, the state must cover the treatment, even if the state doesn’t provide the same services to adults in Medicaid. The rationale for this essential protection is that by intervening early, the harmful effects of disability can be minimized, and in some cases lifelong disability can be prevented. The EPSDT benefit also serves as an important tool in assisting children and young adults under age 21 to live in the community.

As the Congress considers changes to the Medicaid program, I strongly encourage you to defend the EPSDT benefit and the principle that children must be regularly screened and treated for health conditions when they arise in order to minimize and prevent disability. This is an essential investment in future generations. As the Congress considers future improvements, you may wish to provide new resources and impose new requirements on states to provide for continued access to community living services when individuals with disabilities become adults and “age out” of the EPSDT benefit. This is especially urgent in light of the fact that one in five young adults with disabilities (aged 19-29) is uninsured.<sup>21</sup>

### **Nick DuPree, Medicaid Beneficiary**

Nick DuPree is a 23 year old resident of Alabama who drew national attention to the community-based services Medicaid provides to children and young adults through the EPSDT benefit. For several years, he led a national campaign to address the problem of young adults who lose access to critical EPSDT benefits when they turn 21.

Nick has a form of muscular dystrophy, and as a result of a botched surgery, he developed an infection that led to significant impairment. He has required the use of a ventilator for the past eleven years. For the past thirteen years, Nick has received Medicaid home- and community-based services—because his family’s private coverage did not provide for in home care. Nick is one of thousands of people with disabilities who relied on Medicaid EPSDT services in order to live at home. In his case, he also relied on EPSDT services to support him in attending college. Despite the enormously positive improvement in Nick’s life made possible by the EPSDT benefit, Alabama was ready to cut him off and put him in a nursing home when he turned 21. Because of the widespread attention brought to his plight, his state established a small scale waiver to permit Nick and a limited number of other young adults to continue receiving community living services. Throughout the country, states routinely reduce or eliminate critical services when young adults with disabilities turn 21.

### Optional Medicaid Services are Essential Disability Services

In the recent policy discussion, Medicaid optional services sometimes have been characterized as discretionary services. The list of optional services are more appropriately characterized as indispensable disability services because they are frequently services not often needed by otherwise healthy individuals, but which play a critical role in meeting the health and long-term services needs of people with disabilities. Quoting a prominent disability advocate, Robert Williams, “there is nothing optional about our need to eat or to go to the bathroom.” Moreover, many people end up in Medicaid after trying, but failing to obtain these services from the private market or Medicare.

## Selected Medicaid Optional Services

### *Acute Care*

- Prescribed drugs
- Medical care or remedial care furnished by licensed practitioners under state law
- Diagnostic, screening, preventive, and rehabilitative services
- Clinic services
- Dental services, dentures
- Physical therapy and related services
- Prosthetic devices
- Eyeglasses
- TB-related services
- Primary care case management services
- Other specified medical and remedial care

### *Long-Term Services and Supports*

- Intermediate care facility for people with mental retardation (ICF/MR) services
- Inpatient and nursing facility services for people 65 or over in an institution for mental diseases (IMD)
- Inpatient psychiatric hospital services for children
- Home health care services
- Case Management services
- Respiratory care services for ventilator-dependent individuals
- Personal care services
- Private duty nursing services
- Hospice care

Source: Kaiser Commission on Medicaid and the Uninsured, "The Medicaid Resource Book", July 2002.

Every Medicaid optional service is essential to some individuals with disabilities. However, there are a few services for whom the need and dependence on these services is so critical, they are important to highlight:

**Prescription Drugs:** All states plus the District of Columbia provide coverage for prescription drugs, a service that is often a cornerstone of treatment for many individuals. It is hard to imagine how anybody could consider prescription drugs discretionary when one considers their role in modern medicine, evidenced by the dramatic decline in HIV/AIDS mortality brought about by the development of highly active antiretroviral therapies in the mid-1990s.<sup>22</sup> Prescription drugs also are an essential service that enables individuals with serious mental illness to live in the community and lead fulfilling and engaged lives. Recent advances in the pharmaceutical management of epilepsy have led to a standard of care where significant numbers of people with epilepsy able to become seizure free. As we look to the future, pharmaceuticals are expected to play an even greater role in improving lives and potentially reducing other Medicaid costs, for a broad range of health conditions.



While states have broad discretion in managing the Medicaid pharmacy benefit, states have been largely responsible in providing broad access to pharmaceuticals, in part because they are cost-effective. In absence of drug therapies, individuals with disabilities incur greater levels of hospitalization or disease progression. Many exciting things are happening at the state level with regard to managing the Medicaid pharmacy benefit and using clinical evidence to drive decision-making over when formulary restrictions and other cost-saving measures are appropriate. Greater reliance on evidence-based medicine, if done properly, holds the potential to produce significant savings for states and improve access to appropriate therapies. At the same time, there is increasing concern that some states, out of a desire to control pharmacy costs, are limiting access to prescription drugs in ways that are harmful to Medicaid beneficiaries. Mississippi and Tennessee are two states that are imposing “hard limits” of providing only 2 brand name drugs per month. Several other states have limits as low as three or four drugs per month, although the majority of these states impose “soft” limits and make drugs available above the cap through prior authorization.<sup>23</sup> Many, if not most, of the drugs used to treat disabilities are not available in generic forms. Moreover, the effective HIV treatment regimens that I referenced for their success at keeping people alive all require three to five brand name drugs. Across the spectrum of disability, many conditions require multiple drugs, and many individuals with disabilities receive treatment for multiple co-morbid conditions. It is not uncommon for people with disabilities to take 10 or more prescription drugs. Given that Medicaid beneficiaries with disabilities must sustain themselves with such limited incomes, often less than \$600 per month, and that Medicaid beneficiaries with disabilities generally have no other source of coverage for prescription drugs, hard limits on the number of prescription drugs individuals can receive are counter-productive and inadequate to meeting the needs of people with disabilities. Again, when the Congress considers longer-term improvements to Medicaid, I urge you to consider strengthening federal standards for the adequacy of the Medicaid pharmacy benefit.

**Physical Therapy and Related Services:** As of January 2003, thirty states plus the District of Columbia provided physical therapy services and twenty-five states provided occupational therapy services.<sup>24</sup> Physical therapy and related services are illustrative of many optional services which may not appear as critical services, except to people with disabilities who rely on them. These services are not commonly used by Medicaid beneficiaries who do not have disabilities. Therapy services, such as physical therapy, occupational therapy, and speech and language therapy are critical to supporting individuals in minimizing the burden of disability and maximizing independence. For example, access to speech and language therapy services may mean that individuals with certain neurological conditions are able to communicate with others. Physical therapy services help people with conditions such as cerebral palsy to maintain control over their muscles—a defining symptom of their type of disability. Occupational therapy services help people with disabilities learn skills for performing activities of every day life and address psychological, social and environmental factors that impede independent functioning. Because persons with disabilities may be more susceptible to certain types of injuries, rehabilitation services are also critical in helping individuals to recover quickly—and to regain and maximize their ability to function in ways that may have been already impaired, due to disability.<sup>25</sup>

**Personal Care and Rehabilitation Services:** As of January 2003, twenty-eight states plus the District of Columbia provided personal care services and forty-three states provided

rehabilitation services.<sup>26</sup> Personal care is a critical mechanism for providing long-term services and supports to individuals with disabilities so that they can live in and participate in life in the community. Many states also cover psychosocial rehabilitation services which, when combined with personal care and targeted case management services, can meet a wide range of service and support needs of persons with mental illness.

Optional services are mandatory for people with disabilities. I began this statement by saying that Medicaid works for people with disabilities. It works precisely because individuals are able to rely on Medicaid, in many states, for a range of optional, disability services that they cannot obtain elsewhere. There is nothing about these services that would justify permitting restrictive limitations. Indeed, efforts to restrict access to these services through arbitrary coverage limits is counter productive. When the level of service provided is insufficient based on what is medically necessary for the individual, real people are subjected to significant and long-lasting harm, and this will likely lead to increased Medicaid costs. Since the mandatory/optional service distinction is an historical artifact that does not distinguish between essential and discretionary services, Congress should consider longer-term reforms that create a more rational basis for permitting states to control costs, yet which do not depend on denying coverage for critical services. Since optional services are essential disability services, states should not be permitted to severely restrict them or eliminate them every time there is an economic downturn.

### **Current Policy Debate**

I understand that this hearing, and much of the Congress' current interest in Medicaid is being driven by reconciliation instructions that call for the Finance Committee to find program savings of ten billion dollars over the next five years—and some level of savings is expected to come from Medicaid. Medicaid is already an underfunded and undervalued workhorse that is sustaining much of the rest of our health system. To the extent that savings come from Medicaid, I would urge each of you to ensure that such savings are as small as possible.

### **Prescription Drug Reforms**

Many Members of Congress have defended budget savings targets for Medicaid by citing a “consensus” that significant Medicaid savings could be achieved by enacting prescription drug reforms, including a move to reliance on average sales price (ASP), and away from average wholesale price (AWP) for purposes of calculating Medicaid prescription drug rebates. While it will be incumbent upon the Congress to ensure that pharmacists are adequately reimbursed for dispensing prescription drugs to Medicaid beneficiaries, this is an area where the Congress should focus its efforts in identifying savings.

Also, when considering longer-term program improvements, this is an area where important changes can be made by building on the successes of certain states to use evidence-based medicine to manage the prescription drug benefit in a way that does not impede access to critical drugs for people with disabilities and others.

## Responding to the Medicare Cost Shift

When Medicare was created, it excluded two important benefits—prescription drugs and long-term care. Attempts have been made over the years to expand Medicare’s role in financing long-term, with limited success.<sup>27</sup> In the meantime, the share of nursing home costs paid for by Medicaid has doubled, from 22 percent in 1970 to a projected 52 percent in 2005.<sup>28</sup> Policy makers have focused almost exclusively on the prescription drug gap rather than the long-term care gap in Medicare, despite the fact that the cost of nursing home care for seniors is twice that of prescription drugs – representing a major cost to states and people in need.<sup>29</sup> An estimated 42% of Medicaid spending is for services for low-income Medicare beneficiaries (individuals receiving both Medicare and Medicaid are known as dual eligibles).<sup>30</sup> Even after the implementation of Medicare prescription drug coverage in January 2006, Medicaid will still be responsible for financing the costs of long-term care for low-income dual eligibles. Congress should look to the Medicare program to relieve some of the financing pressure on Medicaid. In fact, the burden on Medicaid programs for providing services to Medicare beneficiaries is so great that even minor program adjustments could relieve significant pressure off Medicaid. For example, Congress could:

- end or phase-out the Medicare waiting period in which individuals must wait twenty-nine months from when the Social Security Administration determines them to be disabled to receive Medicare. For low-income Medicare beneficiaries, Medicaid steps in to serve as the primary payer until Medicare coverage begins. One possible approach to addressing the problem is the *Ending the Medicare Disability Waiting Act of 2005* (S. 1217);
- require the Centers for Medicare and Medicaid Services (CMS) to amend the manner in which it implements the Medicare “in the home” requirement with respect to power wheelchairs and scooters. This policy denies Medicare coverage of power mobility devices when they are not needed exclusively in the home. Thus, an individual with multiple sclerosis, for example, who is able to navigate their home by leaning against the walls would be denied Medicare coverage for a power wheelchair, even though this is needed for individuals to leave their homes independently, such as to go to the store, visit their physician, or attend religious services. This policy is a burden on Medicaid because, for dual eligibles, Medicaid often ends up paying for these devices, even though it is a Medicare covered service;
- shift responsibility to Medicare for paying Medicare cost-sharing for dual eligibles. Medicaid, not Medicare, is currently responsible for assisting low-income Medicare beneficiaries with paying the Part B premium (\$78.20/month in 2005) and cost-sharing for services under Medicare Parts A and B;
- relieve some of the burden on Medicaid for providing long-term services and supports by expanding Medicare’s coverage of long-term services.

While the current reconciliation process requires savings to the federal government and would not simply permit a substitution of Medicare spending in place of Medicaid spending, Congress has the opportunity to enact program improvements to Medicaid by shifting more of the financing burden for services for low-income Medicare beneficiaries onto the Medicare program. Net savings could be achieved through reductions in or elimination of the \$10 billion in funding

provided under the Medicare Modernization Act (MMA) for the regional preferred provider organization (PPO) stabilization fund. Such a move has been endorsed by the Medicare Payment Advisory Commission (MedPAC).<sup>31</sup> I understand that many Members of Congress are reluctant to consider changes to the MMA before the law's main provisions become operational. Given the immense harm that could come to low-income Medicaid beneficiaries if the bulk of the reconciliation spending reductions is directed at Medicaid, however, this stabilization fund for private plans is simply indefensible. Moreover, while the reluctance to make policy changes within Medicare is understandable, it is unavoidable given the need to address the impending crisis caused by the absence of any transition period when more than 6.4 million low-income people with disabilities and seniors have their drug coverage transitioned from Medicaid to Medicare. Staff at the Centers for Medicare and Medicaid Services (CMS) is working very hard to ensure a smooth transition to Medicare drug coverage for dual eligibles. However, given that the most vulnerable segment of the Medicare population is being moved into the Part D prescription drug program first, with not a single day of overlapping drug coverage by Medicaid and Medicare, it strains plausibility to believe that this transition can be perfectly seamless. There is an urgent need for Congress, prior to January 1, 2006, to establish a short-term, one-time transition period so that individuals can continue to rely on Medicaid if they are unable to access appropriate drug coverage through Medicare, for the first six months of 2006.

Many other policy proposals to cut Medicaid benefits or eligibility, including many positions supported by the nation's governors, are misguided and are a direct threat to people with disabilities.

### Benefits Package Flexibility

The nation's governors and other have advocated for new freedom to tailor benefits packages and give differing benefits to different groups of Medicaid beneficiaries. They have argued that they do not seek to deny any benefit when it is truly necessary, but they do not wish to provide benefits to individuals who do not need them. Nevertheless, it would be very dangerous for the Congress to grant any new benefits package flexibility. New flexibility for states could only lead to new discrimination for people with disabilities.

Historically, the comparability requirement, the provision of the Medicaid law that says that benefits must be comparable among groups of Medicaid beneficiaries has been an important principle and consumer protection. For example, because of the comparability requirement, individuals with HIV/AIDS in the 1980s were able to defend their right to receive AZT (the only FDA-approved antiretroviral medication at the time) when states sought to deny coverage on the basis of the drug's cost. A decade later, the comparability principle having been reinforced to states, meant that when highly active antiretroviral therapy regimens were approved, Medicaid programs provided access to these costly drug therapies without significant disruptions. Today, all parties agree that access to these medications are a good investment for states—and are a profound success.

Moreover, people with disabilities already have experience with states' ability to tailor benefits to specific populations through the home- and community-based services waiver program. What we have seen there is that which populations can access services and which cannot, in a given

state, is not rational. And this can lead groups of people with disabilities to be pitted against each other fighting over inadequate resources. Moreover, despite the success of these waiver programs, they have not been expanded to meet all of the need. Giving new flexibility with regard to the benefits package would not improve Medicaid, and would not address the underlying problem of the need for more resources to meet the unmet need. Rather, it would open up Medicaid to political considerations—and would inevitably lead to winners and losers within the disability community based on sometimes unfounded perceptions of who is “truly needy”. It would move decision-making over who gets Medicaid services they need away from qualified health professionals to program administrators.

### Greater Reliance on the Private Market

Recently, several policy makers, including several Governors, have proposed transforming Medicaid by relying more heavily on the private market to deliver services. Unfortunately, the reality for Medicaid beneficiaries with disabilities is that they rely on Medicaid because the private market has failed them. Private insurance has a long track record of denying coverage for people with disabilities and private insurance benefit packages are designed for healthy working populations. As such, they are wholly inadequate for low-income individuals with disabilities whose eligibility for Medicaid is dependent on being so severely disabled that they are unable to work at a substantial level. In particular, private health insurance does not cover long-term care services and supports.

Moreover, some policy makers have advocated for a greater reliance on private long-term care insurance. While the establishment of a viable private long-term care insurance system may be beneficial for the nation, the existing private long-term care insurance market is inadequate. Coverage that is commonly available is not likely to be adequate to meet the future needs for long-term services and supports; and it is widely believed to not be a cost-effective retirement planning vehicle for most people. Moreover, private long-term care insurance is not an option for people with disabilities, who will be turned down for medically underwritten policies.

### Promoting Personal Responsibility Through Increased Cost-Sharing

Several policy makers have made claims that Medicaid would be strengthened if individual beneficiaries were asked to show more personal responsibility for their care and support. Many persons have complained about so-called “first dollar” coverage for Medicaid beneficiaries.

Individuals with disabilities are already subject to cost-sharing in Medicaid. In fact, when Medicaid imposes cost-sharing, people with disabilities and chronic conditions—people who access the most services—tend to bear the highest burden.<sup>32</sup> A recent analysis found that, on average, Medicaid beneficiaries with disabilities receiving SSI (income of 74% of the poverty level) paid \$441 in out-of-pocket medical expenses in 2002.<sup>33</sup> Therefore, it is not a question of whether people with disabilities should be charged cost-sharing (since they already bear a significant share of their health care costs in relation to their income). Rather, the policy discussion must focus on determining what level of cost-sharing is appropriate given their very low-incomes and extensive needs.

Additionally, Medicaid does not cover all of the health and long-term services needs of people with disabilities who must often spend extensive personal resources on transportation to multiple doctors' offices and to visit other services providers. For persons who receive long-term services, even in the best cases, the level of services provided by Medicaid is inadequate. This means that Medicaid beneficiaries sometimes pay out-of-pocket to supplement what Medicaid provides, or they rely on family members or friends as informal caregivers. There is no documented widespread evidence that Medicaid beneficiaries with disabilities are abusing the system or are refusing to pay cost-sharing when they are able.

### Increased Consumer Direction of Services

Consumer direction, which gives individuals with disabilities greater control over the long-term services they receive, is an important policy innovation that is strongly supported by people with disabilities. A key element of consumer direction is the ability to hire, fire, train, and supervise personal assistance attendants, as well as the opportunity to directly purchase services. Consumer direction, however, is not an appropriate tool for reducing Medicaid spending. Based on the Cash and Counseling Demonstration programs in four states that tested the individual budget (*i.e. voucher*) concept for consumer direction, the Bush Administration developed the Independence Plus Initiative to encourage states to seek waivers that incorporate principles of consumer direction.<sup>34</sup>

Recently, however, some Governors and others have seized on consumer direction initiatives as a “magic bullet” for reducing Medicaid costs. The Cash and Counseling Demonstrations were not intended to save money for states, and they did not yield significant cost-savings for states.<sup>35</sup> Individual budgets and other forms of consumer direction of services may achieve some savings in certain contexts. However, consumer direction should never be used to produce large savings for Medicaid by denying individuals adequate funding to purchase the services they are directing—and consumer direction should not be used to justify the elimination of other vital community living services. Further, different approaches to consumer direction have been used by states that do not rely on individual budgets, but these successful models have not been sufficiently highlighted. As the Congress seeks to identify short-term program savings to meet the Finance Committee's reconciliation instructions, I encourage you to resist any entreaties to rely on consumer direction to produce Medicaid savings.

### Limiting Enforcement of the Medicaid Act

One of the most troubling proposals offered in the context of achieving program savings relates to efforts to limit the use of consent decrees. Consent decrees are voluntary agreements entered into by state and local governments and other parties that can be an important alternative to lengthy trials and complex protracted litigation. They have been especially important in remedying systemic problems. Proposals have been offered that would impose grossly unfair burdens on people with disabilities and others protected by the Medicaid Act and other federal laws. This type of policy change has the potential to harm both the interests of Medicaid beneficiaries and states, and I encourage the Congress not to consider such changes as a means of achieving a budget reconciliation target.

## **Consent Decrees and People with Disabilities: Examples from Connecticut**

Connecticut currently has three agencies which are operating under federal consent decrees for at least a portion of their responsibilities. The Department of Mental Retardation (DMR) is operating Southbury Training School under a federal magistrate pursuant to a consent decree, and has just signed a consent decree (recently approved by the Legislature) to an action brought by the Arc of Connecticut on the DMR's waiting list and the Medicaid requirement for reasonable promptness in providing services to eligible participants. The Department of Children & Families is operating under a consent decree concerning child protective services and children in its custody. The Department of Education (DOE) is operating pursuant to the P.J. v. State of Connecticut consent decree which requires the DOE to take steps to increase the number of students with intellectual disabilities who participate in classes and in extracurricular activities with their peers who do not have disabilities. In each of these cases, the consent decrees resulted from many years of adversarial hearings and negotiations. All require a sustained compliance over many years to achieve the goals agreed upon. Many policies put in place by one administration or one legislature go forward through time, spanning many administrations and new legislatures.

### **Longer Term Solutions are Needed**

After the Congress finishes its work to respond to the short-term issue of meeting the Finance Committee's reconciliation instructions, I hope that the Congress will engage in a process to consider longer term improvements to Medicaid. Strengthening Medicaid cannot be predicated on simply giving states new tools to avoid covering people with disabilities who are eligible for Medicaid and who need Medicaid's assistance. Strengthening Medicaid also cannot be predicated on giving states new tools for giving people less than they need. As the only place to turn for millions of low-income people with disabilities, the only meaningful solutions are those that shore up financing for Medicaid and which ensure that Medicaid does a better job at purchasing services or meeting the diverse needs of its beneficiaries.

The best and perhaps the only way to make progress, is not to look to Medicaid alone for policy solutions. The challenges facing Medicaid are the result of broader failures within our health and long-term care systems. By identifying broad national solutions to respond to the growing cost of health and long-term services we can strengthen Medicaid. By taking serious and meaningful steps to control prescription drug prices, across all payers, we can strengthen Medicaid. By developing trusted, national systems for evaluating new medical technology (so that decisions about who gets new drugs, new devices, and other technology is driven by careful decision-making—and not simply denying the latest technology to low-income Medicaid beneficiaries) we can strengthen Medicaid. By seriously looking at the issues facing the country in financing and planning for future long-term services needs, we can potentially take a lot of pressure off Medicaid—and lead to greater retirement and economic security for millions of Americans. By doing so, we can strengthen Medicaid.

## Ending Medicaid's Institutional Bias

While Medicaid plays an essential role in providing long-term services, this is an area where Medicaid must do better. People with disabilities are looking to the Congress to urgently address barriers that prevent millions of Medicaid beneficiaries from receiving community-based long-term services. Medicaid law requires states to provide nursing home care, but permits without requiring states to provide the same level and types of services in the community. This is called the “institutional bias”. Hundreds of thousands of people with disabilities would like to receive long-term services and supports that enable them to live in their own home, but are forced to be segregated in an institution as their only option for receiving this assistance.

### **Michael Dubois, Medicaid Beneficiary**

Michael Dubois is a 35 year old resident of Gainesville, Florida with quadriplegia following a spinal cord injury in 1983 as a result of a diving accident. He receives Supplemental Security Income (SSI), Medicaid and Medicare. Since his injury at age 16, he has resided in several nursing homes because his elderly parents are unable to care for him. Medicaid pays for the nursing home where he currently resides in Gainesville, Florida. Mr. Dubois applied for the state's brain or spinal cord injury home- and community-based services waiver in August 2000 that would permit him to live in the community. Because of limits on participation in the waiver program, Mr. Dubois remains institutionalized.

The disability community's preferred solution is for the Congress to swiftly enact the Medicaid Community Attendant Services and Supports Act (MiCASSA, S. 401). This legislation would mandate home and community based services for those individuals with disabilities who are in or are eligible for care in institutional settings. Some policy makers have raised concerns with the MiCASSA model out of concern for the potential cost. While the solution to the challenge of providing expanded access to community-based services will require new resources, the disability community is also supportive of several other initiatives that would make incremental progress toward enacting MiCASSA. This includes strongly supporting the Money Follows the Person Act (S. 528), an important first step that would provide for a competitive demonstration for states to receive expanded funding for one-year for each person that a state moves out of a nursing home or other institution into the community. The disability community also strongly supports the Family Opportunity Act (S. 183, also called the Dylan Lee James Act), which would provide states with the option to provide critical support for families with children with serious disabilities. Additionally, there are other incremental steps that the Congress can take to expand access to community-based long-term services. The federal government could assist states in rebalancing their long-term care programs through providing an enhanced match for personal care and rehabilitation services. These approaches could be phased-in over time.

## **Conclusion**

Thank you for the opportunity to provide a disability perspective on a broad range of current Medicaid policy issues. The Aging Committee has historically played a key role in helping Members of the Senate to appreciate the complex issues impacting Medicaid beneficiaries with



disabilities. As you continue your deliberations this year, please permit me to provide any assistance to the Committee that would be helpful in understanding the impact of various policy options on people with disabilities of all ages that depend on Medicaid.

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<sup>1</sup> Congressional Budget Office (CBO) March 2005 Baseline estimate of Medicaid enrollment for 2005.

<sup>2</sup> For additional background information on Medicaid's role for people with disabilities, see: Jeffrey S. Crowley and Risa Elias, *Medicaid's Role for People with Disabilities*, Kaiser Commission on Medicaid and the Uninsured, August 2003.

<sup>3</sup> Jeffrey S. Crowley and Risa Elias, *Medicaid's Role for People with Disabilities*, Kaiser Commission on Medicaid and the Uninsured, August 2003.

<sup>4</sup> *Medicaid: An Overview of Spending on "Mandatory" vs. "Optional" Populations and Services*, Kaiser Commission on Medicaid and the Uninsured, June 2005.

<sup>5</sup> Eleven states are so-called 209(b) states, which take advantage of a provision in federal law that permits them to have more restrictive eligibility requirements than SSI standards for establishing mandatory eligibility for Medicaid for people with disabilities and seniors, as long as the state standards are no more restrictive than the state standards that were in effect in 1972 when the SSI program was established. Individuals in these states with excess incomes must be permitted to "spenddown" to Medicaid eligibility by incurring medical expenses, which when deducted from their income, makes them eligible for Medicaid. These states are Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia.

<sup>6</sup> *Social Security: Understanding the Benefits, 2005*, Social Security Administration.

<sup>7</sup> As of October 2001, 21 states reported providing this supplementary coverage to people with disabilities and an additional 3 states provided this coverage only to persons who are blind. Source: *Aged, Blind, and Disabled State Summaries*, National Association of State Medicaid Directors, 2002.

<sup>8</sup> *Aged, Blind, and Disabled State Summaries*, National Association of State Medicaid Directors, 2002.

<sup>9</sup> *MSIS State Summary FY2002 (Table 3: FY2002 Medicaid Eligibles by Maintenance Assistance Status)*, Centers for Medicare and Medicaid Services.

<sup>10</sup> Jeffrey S. Crowley, *Medicaid Medically Needy Programs: An Important Source of Medicaid Coverage*, Kaiser Commission on Medicaid and the Uninsured, January 2003.

<sup>11</sup> Jeffrey S. Crowley, *Medicaid Medically Needy Programs: An Important Source of Medicaid Coverage*, Kaiser Commission on Medicaid and the Uninsured, January 2003.

<sup>12</sup> For example, as of 2001, Louisiana's medically needy income limit was \$100/month and it was last changed in 1985 and Arkansas' limit was \$108/month and it was last changed in 1988. This is the maximum amount of income the states permit medically needy individuals to keep for all non-health related expenses including rent, food, and other expenses.

<sup>13</sup> Bazelon Center for Mental Health Law, <http://www.bazelon.org/issues/children/publications/TEFRA/fact3.htm>.

<sup>14</sup> White, J., Black, W., and Ireys, H., *Explaining enrollment trends and participant characteristics of the Medicaid Buy-in program, 2002-2003*, Mathematica Policy Research, 2005.

<sup>15</sup> Public Law 105-33.

<sup>16</sup> Public Law 106-170.

<sup>17</sup> Andy Schneider and Risa Ellberger, *Medicaid-Related Provisions in the Ticket to Work and Work Incentives Improvement Act of 1999*, Kaiser Commission on Medicaid and the Uninsured, April 2000.

<sup>18</sup> *Medicaid and Ticket to Work: States' Early Efforts to Cover Working Individuals with Disabilities*, Government Accountability Office, June 2003 (GAO-03-587).

<sup>19</sup> *Overview of State Home and Community-based Services (HCBS) Waivers*, Centers for Medicare and Medicaid Services, <http://www.cms.hhs.gov/medicaid/1915c/mrddadult.pdf>.

<sup>20</sup> Harrington, C. *Medicaid Long Term Care: Home and Community Based Services*. Presented at the Unmet Needs in Personal Assistance Services: Prevalence, Consequences, Costs and Policy Options hosted by Disability Statistics Center at UCSF.

<sup>21</sup> Cooper, B., *Young adults with a disability: Between a rock and a hard place*, Washington, DC: National Health Policy forum; 2001.

<sup>22</sup> For example, in 1997, AIDS-related deaths in the U.S. declined by more than 40 percent compared to the prior year, largely due to highly active antiretroviral therapies. Source: *The Global HIV/AIDS Epidemic: A Timeline of Key Milestones*, Henry J. Kaiser Family Foundation, see <http://www.kff.org/hivaids/timeline/index.cfm>.

<sup>23</sup> Unpublished data. Jeffrey S. Crowley, Kaiser Commission on Medicaid and the Uninsured/Georgetown Health Policy Institute 2005 survey of state Medicaid pharmacy policies.

<sup>24</sup> Medicaid benefits page, Kaiser Commission on Medicaid and the Uninsured website, see <http://www.kff.org/medicaidbenefits/index.cfm>.

<sup>25</sup> Jeffrey S. Crowley and Risa Elias, *Medicaid's Role for People with Disabilities*, Kaiser Commission on Medicaid and the Uninsured, August 2003.

<sup>26</sup> Medicaid benefits page, Kaiser Commission on Medicaid and the Uninsured website, see <http://www.kff.org/medicaidbenefits/index.cfm>.

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<sup>27</sup> Helbing, C. and Cornelius E.S., 1992. “Skilled Nursing Facilities – Medicare and Medicaid Statistical Supplement,” *Health Care Financing Review*.

<sup>28</sup> National Health Accounts, projected prescription drug expenditures for 2004.

<http://www.cms.hhs.gov/statistics/nhe/projections-2003/t11.asp>.

<sup>29</sup> National Health Accounts, Personal Health Care Estimates by Age Group, Fall 2004.

<sup>30</sup> *Medicaid: Issues in Restructuring Federal Financing*, Kaiser Commission on Medicaid and the Uninsured, January 2005.

<sup>31</sup> *Report to Congress: Issues in a Modernized Medicare Program*, Medicare Payment Advisory Commission, June 2005. See recommendation 3a. on page 58.

<sup>32</sup> Stuart, B. and Zacker, C., “Who Bears the Burden of Medicaid Drug Copayment Policies?”, *Health Affairs*, 18(2):201-12, 1999.

<sup>33</sup> Ku, L. and Broaddus, M., *Out-of-Pocket Medicaid Expenses for Medicaid Beneficiaries are Substantial and Growing*, Center on Budget and Policy Priorities, May 2005.

<sup>34</sup> Jeffrey S. Crowley, *An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid*, Kaiser Commission on Medicaid and the Uninsured, November 2003.

<sup>35</sup> See “Lessons about Program Costs (8 b.) (page 43), “While improvement in access to care may be an important program goal under Cash and Counseling, overall costs may increase if access to care is improved, even if cost per month per recipient is constrained,” *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey: Final Report*, Mathematica Policy Research, June 2003.