



### Senate Special Committee on Medicaid Reform Testimony

As a disability rights advocate, I find it laudable and gratifying that the Senate Special Committee on Medicaid Reform is looking for ways to improve Illinois' current system. The need for reform has existed for years, and, unfortunately, too many General Assembly sessions have passed with no attempts at resolution. Like Social Security on the national level, Medicaid reform in Illinois seems a very difficult and daunting task to tackle.

However, as the committee has been given only a month to produce a strategy to change a sweeping and vitally important program in this state, it is essential that every member considers each idea carefully and makes no hasty judgments about what types of reforms the program needs. If the prevailing common wisdom becomes that only cuts to the very core of the Illinois Medicaid system are the answers, we, as advocates, agency directors, and health care experts, will not have provided the answers necessary to "fix" Medicaid. Cutting a program on which so many people depend every day is as nonsensical as wastefully spending on excessive bureaucracy and redundancy in various phases of the program. This is a time for the committee to find the creativity to cut out waste and fraud, while leaving a seamless and more focused program intact.

The national healthcare system is growing exponentially and at an unsustainable rate. There is no debate about that, and the new Affordable Care Act likely will bring change and reform, even if somewhat slowly. However, it is important to remember Illinois' place in the national healthcare picture. According to the Sargent Shriver National Center on Poverty Law's online publication "The Shriver Brief," Illinois' Medicaid billings grew slower than the national average, from 2008 to 2009, at 4.2 percent and only 4.4 percent during the last four years. In FY 2010, the projected national average of medical costs was 7.7 percent, while Illinois was only expected to grow by 7.0 percent. Among all states, Illinois ranks 42nd in per Medicaid beneficiary expenditures. The national average is \$4,575 per Medicaid beneficiary, and Illinois spends \$4,129 per beneficiary. Overall, Illinois effectively minimizes Medicaid cost to the taxpayers and maximizes, for the most part, the federal dollars available. The Illinois Medicaid program spends just \$.39 of every one dollar in general taxes. Therefore, it is reasonable to see in some aspect that the state's Medicaid program is performing much better than many reports, analyses, or opinions conclude.

However, there are many ways to streamline Medicaid in Illinois and provide better services for those receiving benefits from the program. First, we must come to the realization that Illinois institutionalizes more people with disabilities than nearly every other state in the nation. Illinois still warehouses thousands of individuals with disabilities in state operated developmental centers (SODCs), nursing homes, and large ICF/DDs. In terms of spending for small community living opportunities for people with disabilities, Illinois is ranked 51<sup>st</sup> in the nation. Further, Illinois is 47th nationally in funding community services. Yet, this state is fifth in the country on spending for SODCs. The state government spends nearly \$170,000 per person every year on hiding away thousands of people with disabilities in state run institutions. Yet, the irony and tragedy of the current system is that providing the home and community-based services for the same people is much closer to \$50,000 annually. Even as Howe Developmental Center closed on June 30, 2010, the \$30 million in savings, which should have funded more community-based supports and settings, instead, was funneled back to the remaining SODCs.

These facts are illustrative of Illinois' institutional bias toward people with disabilities. Further and worse is the fact that this bias affects how the state government prioritizes taxpayer money. Here is



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a lion's share of the waste the committee wants to eliminate. Simply by providing more home and community-based services, Illinois can save hundreds of millions of dollars by moving people out of institutions, where they can and want to live as an equal member of the community. A recent study cites Illinois as being worst in the nation in providing housing to people with disabilities, and that is where a paradigm shift can occur. By investing in adequate and accessible housing, Illinois saves money in the Medicaid program and, simultaneously, stimulates the state economy by producing jobs in areas like construction, where so many people have seen employment possibilities disappear.

This committee and Illinois' elected officials have a responsibility to comply with the 1999 Olmstead Supreme Court decision and make it possible for people with disabilities to live in the least restrictive environment possible. These are not arbitrary political choices or philosophical debates we can have concerning moving more individuals with disabilities into the community. It is now US law and the right of every member of the disability community to live where he or she chooses. If Illinois does not change the institutional mindset it has possessed for decades, there is no chance for Medicaid reform in this state. We simply will find ourselves walking in the same circles that have always led us to the same dead ends, which are more spiraling Medicaid costs and the complete lack of sensitivity to not only the choice of the disability community but also the thin legal standing on which Illinois finds itself.

To capture more federal funds and ensure Illinois is spending its Medicaid dollars wisely, the committee and General Assembly must consider two very important and similar issues. First, the state government needs to pursue every dollar that comes from the federal "Money Follows the Person" (MFP) legislation. Centers for independent living across the state are trying to help individuals with disabilities move from institutions and nursing homes into their own homes within the community. Yet, Illinois is lax on providing those funds the MFP program offered to states to transition people from an institutional setting to the community. How can the state government and its overseers in the General Assembly allow such mismanagement to continue? If everyone in the state really wants Medicaid reform, this is an ideal place to start.

Second, the Independent Living Movement stresses consumer choice as its main tenet. People with disabilities deserve the freedom to choose where and how they live in every sense of that word. If government officials truly agree with that sentiment, it is time to examine the possibilities of a self-directed care waiver system through Medicaid. This is a cost-effective program, which keeps people with disabilities living in the community and provides them with the resources necessary to live an independent and productive life. Moreover, this is not a groundbreaking idea. Many other states have implemented such a waiver program with great success, and many advocacy groups in Illinois are putting forth the call for this state to move forward with such a program. In fact, a self-directed care waiver is imperative if Illinois, indeed, intends to move away from its history of institutionalization and into a future of inclusion and equality.

Illinois will see less inefficiency in the Medicaid program by reforming some of its current and proposed programs. The Department of Healthcare and Family Services (HFS) is moving forward with a Medicaid managed care pilot program in suburban Cook and five other collar counties. Disability rights advocates need to remain involved in the contract negotiation process with the two managed care organizations (MCOs) that won the bids from HFS. However, after the contract is signed, advocates must still actively participate in the entire managed care process as part of an independent oversight committee, which can act as a guardian of the rights of the people involved in the pilot program. It needs to be independent and comprised of providers and healthcare experts as well as advocates. This type of committee can protect against abuses, lack of direction, or simply wrong decisions they could have terribly adverse effects on consumers within this pilot program area. In addition, as managed care likely goes statewide, this oversight committee can provide



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equal protection against and guidance to the MCOs providing healthcare to people with disabilities throughout the state.

Yet, another area where Medicaid efficiency could increase is in the third phase of this managed care program, which focuses primarily on long-term care needs of seniors and people with disabilities. MCOs have no background in this area and could make what is a sustainable situation far worse. I urge this committee to communicate to HFS that the third phase of this pilot program is untenable for members of the disability community. Without proper education and a proven history of results in providing long-term care needs, the MCOs need to leave this kind of care to the individuals who know how to provide it best. Though this argument may seem as if I am proposing that Illinois gets "stuck with the tab" on the final phase of this managed care program, the truth is just the opposite. By avoiding costly mistakes that HMO will inevitably make in efforts to provide quality long-term care, eliminating phase three saves Illinois, potentially, millions of dollars and the damage that could result in thousands of lives.

One thing this committee must avoid is the idea that these reforms need to happen overnight and that legislation needs to right every wrong in the Medicaid system. Moreover, the mere notion of Medicaid reform is not a political volleyball that one party can bounce to the other. This program is a matter of life and death to many people and provides them with the resources they need to live healthy and dynamic lives. Political agendas must be off the table when discussing any kind of Medicaid reform. To think that Medicaid recipients do not watch closely what happens to their benefits and, subsequently, their lives is foolishness. People receiving Medicaid vote and understand their vote counts. This is no area in which to try to impose political ideology. Medicaid reform requires conscientious thought, sensible ideas, and realistic goals. If those elements fail to find their way into an overall Medicare reform package, more could be lost than simply taxpayer money. It is up to all of us to ensure that is not the case.

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