

Disability Advocacy in a Post-Olmstead Environment  
Vision for the Future of Home and Community Services  
Bob Williams

It is great to see all of you here. Everyone on the faculty has put in an enormous amount of time, creativity and a piece of themselves into this project, which I appreciate enormously as I know you do as well. But, in an important sense the torch is being passed here to those of you here in the region to fashion this project into an effective tool of your own making.

Some describe the ADA and the Medicaid program as being like 2 great polar opposites, which when they collided in L C, v, Olmstead, produced earthquakes of seismic proportions. Perhaps this is so. But, I think we also must recognize that, like after any quake; what we are left with is a changed landscape, that we have the opportunity and responsibility to make better than before.

It is easy to point out places where the, two, are completely out of sync, with each other. It is far tougher to figure out how they can work, in unison, to promote the independence and self-sufficiency of people with disabilities, which are among the expressed purposes, of both Medicaid and ADA.

This is why those of us in the last Administration felt so strongly about organizing these trainings. We hope that in doing so, we could equip a core group of cross disability leaders with the knowledge and skills to help States to implement the ADA and Medicaid, in tandem, with each other.

As we know, progress continues to be made in the numbers of people being able to receive Medicaid community services. This is the good news. But, the reality is that the vast majority of Medicaid long term care dollars still spent on nursing homes.

Moreover, even where Medicaid home and community services do exist, there often are long waiting lists to begin to receive waiver services. And, because service systems developed along disability specific lines, individuals with virtually the same everyday need for, say, personal assistance, but different diagnoses, get very different levels of support. Even two people with the same type and level of disability, face, a strange, either, or, quandary.

They either, have a lot of access to services, or none at all. And, all this is dependent on, such arbitrary factors as where they live in a State, their age, how old they were when they became disabled, or whether they ever lived in an institution.

Because of this, thousands of people with developmental disabilities remain on waiting lists for services nationwide. But, they at least can get inside the door of every State's DD agency. Those with physical and psychiatric disabilities as well as older individuals frequently have no door to even knock on at all. And, while aging parent issues have begun to be best understood in respect to people with developmental disabilities, they cut across disability groups. All of which is to say that we need to expand services beyond a small group of people in a far wider, cross disability, cross generational manner than before. Enter Olmstead.

One of the most important, and over looked things, that the decision emphasizes is, States must plan, implement and administer their services in a fair, and even handed, manner. This means that a State must ensure that no individual, or group of individuals, are discriminated against on the basis of disability.

This is a tall order for many States fill because most are used to designing and providing both Medicaid waiver, and State funded only community services to very narrowly defined groups of individuals with disabilities. From an administrative and programmatic, stance the ADA and Medicaid certainly still allows them to organize their service systems in this manner.

But, the duty a has State to administer services in a fair and consistent manner, also requires it to look across not just some, but all people needing long term services. And, make certain that none of its policies, programs or practices, result in the unjustified institutionalization of any individual or group of individuals with disabilities.

This cannot be done by a State going off and developing such a plan on its own. Because, what we are talking about here is, in the very best sense of the phrase, a political process. One, with a lot of weighing of competing interests and priorities. A lot of give and take; critical trade offs, and ultimately, the buy in of the State, as well as the disability and aging communities.

That's why Secretary Shalala and others of us who were at HHS, until January, consistently encouraged States and the disability and aging communities to sit down with each other, put a side, our respective rhetoric, and begin to walk, and wheel, around each other's worlds. Because, it's only when we take joint responsibility for addressing both the shared, and sometime very unique, dilemmas that policy makers, and those with disabilities face in this regard, that we will see real progress.

As you know, to help achieve these ends, HHS is making substantial grant funding available to States to work with people with disabilities and others, to make Medicaid more responsive to their needs, abilities and life choices.

Each of these grants designed to bring about slightly different results. This is due not so much to what anyone would have rational lee, wanted to make happen but the finagling some of us had to do to get the money through the appropriations process.

However, all of these small grant initiatives clearly advance the goal of increasing the choice and control people with significant disabilities have over their services and thus, lives and futures. Many States may be eligible to receive these grants simultaneously. There is strategic value, therefore, in helping States to use these different grants in a coordinated way to reform to Medicaid.

I am not suggesting that every one of these grant dollars should be spent in, a coordinated fashion, in every State or every instance. This is probably not possible nor necessarily the wisest use of the resources. Nor, am I suggesting that every State should stop what ever they are doing, dismantle their various disability specific, service delivery systems, and replace them all with the ideal, one stop, serve all, service system for the new Millennium, tomorrow. That's also not possible or the wisest course of action to pursue.

But, what I do believe is both made possible through the availability of these grant funds, and required under Olmstead, is that we make these systems less bifurcated, fragmented and arbitrary than they currently are. From an administrative standpoint, States organize, finance and deliver home and community based services in a population specific manner. But, from a policy perspective, it is critical that we find ways to ensure that all people with disabilities who use and rely on Medicaid home and community based services, have the right, and needed supports, to lead lives and futures of their own choosing and direction.

The only way that is ever going to happen, however, is if people with disabilities and families of children with disabilities like those of us in this room, make it increasingly clear to States that they must, move and move quickly, in this direction. To do this, successfully, we must understand how Governors and other State officials tend to frame and think about long-term services.

In February, the National Governors' Association issued its position paper on long-term services reform. While no two Governors are exactly alike, I think we need to use this paper an useful guide to better understanding, and hopefully, having more informed discussions with your State's chief executive and other key policy makers on these issues.

Like most others, NGA views issues of long term services as affecting older persons and their families, almost exclusively. Former Wisconsin Governor, now HHS Secretary, Tommy Thompson, also shares this same basic orientation. This is not to say that the nation's Governors or the Secretary are oblivious to the fact that people with disabilities of every age, from their infancy, well into their elder years, often need access to long-term services.

But, the prism through which they view and therefore, propose to address public policy and financing issues around long-term services is predominantly one of an aging perspective. And, this highlights the need and opportunity we have to join with older persons and their families to make the point loud and clear, that while there are some generational differences, we all want to live in our own homes and communities.

Similarly, NGA is likewise concerned that as those born during the baby boom grow older, many more of us will come to rely on publicly financed long term services, mostly through the Medicaid and to some lesser extent, the Medicare programs. Research is showing declines in the on set of disability among many older people. It is believed that increased income levels as well as improvements in education and health care contribute too much of this.

But, if disability rates are declining among affluent older persons, it is also true that disability among aging people with low to moderate incomes will become more concentrated than it is now. And, if I were a Governor, this would be high on my list of things that might keep me up late nights. Because, in fact, these are the types of folks who are going to put a lot of stresses and strains on Medicaid and Medicare over the next 20 to 30 years.

Those of us in the baby boom generation, however, pose a far more immediate political challenge for Governors as well as other State and Federal policy makers. This is framed in the NGA paper as, being about the need to make such services, responsive to the needs of families who provide eighty percent of the personal assistance people with significant disabilities receive. While this is crucial, casting the issue, in this light, obscures a larger truth.

That as those of us who are baby boomers, begin to reach 65, our expectations for how we want to live out the rest of our lives with, or without disabilities or other chronic conditions, will be increasingly different, and knowing us probably much more in your face, than previous generations of older Americans. This is truly the sleeping giant. For, if we can figure out how best to tap into it and channel it, I believe there is a large reservoir of interest and support on the part of baby boomers, to make sweeping reforms to the way we offer and pay for long term services in this country on a scale, which most probably have never dreamt, possible. This seems particularly true with women in the so-called sandwiched generation who are caring for their own families as well as their aging parents and their in-laws.

Increasingly, though, people from every walk of life, now recognize all too clearly that the long-term services system, if you can call it that, is both antiquated and fatally flawed. What's more they want it fixed. They want it fixed here and now for their parents, and for the day when they might need such services themselves.

This, in turn, might explain why at least in part a fourth major theme, which the NGA champions in its position paper. That is, the need to enact a Medicare prescription drug benefit, and promote ways in which Medicare and Medicaid can better meet the health care and long term services needs of those who are dually eligible for both programs. Whether Congress and the current Administration will enact a meaningful prescription drug benefit, let alone look at how Medicare and Medicaid services and benefits might be better coordinated is an open question. What is interesting though, is that in putting these policy proposals forward, the Republican dominated NGA is suggesting the need for a greater Federal role in financing long term services, particularly those provided in peoples' own homes and communities.

Most of this is, of course, motivated by the States' strong interest in drawing down more Federal Medicaid as well as Medicare funding, especially in the wake of the cost shifting to States brought about by the Balanced Budget Act. But, the fact that the nation's Governors are putting this set of issues on the table provides us with a significant opportunity to also raise questions around the need to begin to move a federally defined community based services benefit package. This is not without risks but terms of future agenda setting; it is in my view, one of the most important areas to begin to focus our attention on right now.

Last but certainly not least, the NGA position paper affirms the Supreme Court's Olmstead decision and calls on the Federal Government to provide States with further assistance to meet the needs of people with disabilities in the most integrated setting appropriate to their needs. This provides us all with a powerful reason to reach out to both the National Governors' Association itself, and more generally, our own Governors to highlight this portion of the paper in particular and to thank them for it.

Understanding where NGA, and therefore, most Governors come down on these issues is important to do for a couple of reasons. The first is that if there is one place, where the proverbial, buck, stops, in terms of how and where Medicaid long term services dollars get spent, it is on your Governor's desk. For, it's ultimately up to the Governor to propose, approve or veto how both State and Federal Medicaid dollars get spent.

Making this already fairly clear line of accountability, even more, indelible, should be high on our priority lists, especially as we approach 2002, when there will be 36 gubernatorial races nationwide. It's also essential to making continued progress on carrying out Olmstead in the States as well. Let me leave you with one more factoid. According to the National Association of State Budget Officers, most States spend 20 percent of their budgets on the Medicaid program, the same percentage most also devote to public education.

Unlike education, however, there is little public understanding or accountability for how Medicaid resources are spent, what services are purchased or what outcomes can be expected to be achieved as a result. It is time not to only ask why that is, but to spur some much needed open and frank public discussions of these issues as well. I hope this is part of what we can be about. Thank you, very much.

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