

President Reagan's Promise

There is really no way to tell this story without a little history first. We, as human beings, have always struggled to understand and cope with people with disabilities. We've seen them as signs of God's displeasure, as demonic or possessed, as causes of shame. We've banished them to unseen places and abhorrent conditions. We've been told we'd be better off to forget them, that they'd be better off with "their own kind".

We even invented special places for them. We gave these places names that made them sound like happy places, names like "Sunland". Sometimes we called them "farms" But happy names could not disguise what they really were. They were institutions, and if that name doesn't conjure up large, impersonal, often cruel places, where people lived in large congregations of the tragically needy, the violent along side the vulnerable, then you've never been to one. They were places whose main goal was to isolate people, to serve the need for "out of sight, out of mind".

Institutions exist today. There are several here in Florida.. They are far different now. They're staffed, for the most part, by caring and dedicated people. They have made attempts to eliminate abuse, to provide more humane living conditions, to treat people like people. They are far less crowded, now. But there are vestiges of those old institutions that remain. One is that they still separate people from the communities in which they truly belong. And another is that they are enormously expensive.

It was a combination of the cruel conditions institutions fostered and their enormous expense to tax payers that led to the demise of most and the reform of others. And the evolution of thought that accompanied their demise produced a couple of landmarks particularly notable to Floridians.

The first was a series of legislative initiatives begun in the early to mid 1970's. Among them was the "Bill of Rights of Retarded Persons" in 1975. Its very existence underscoring the Constitution's failure to assure the "inalienable rights" it purported to define; this Bill of Rights included the rights to humane discipline, the right to personal possessions, freedom from restraint, the right to medical care and treatment, the right to an education, and the right to physically exercise, among others. In hindsight, it is a disturbingly telling document, but at the time it was new and progressive.

Another initiative of the time was the "deinstitutionalization movement" which sought to place people with disabilities in their own communities. It was demonstrated then as it can be demonstrated now, that the same services provided in an institutional setting can be provided more humanely and far less expensively in a community setting. This movement was an unmitigated success but it was first met by many with trepidation. Among the fears, especially among family members who had grown accustomed to institutions, was that communities did not have the capacity to provide the same services that institutions provided such as training centers, appropriate residential settings, and specialized medical and behavioral supports.

So we, through our elected officials, made a promise to our fellow citizens with disabilities. We promised them that if they would give up their institutional placement and move back to the communities to which they belonged, that we would see that they had the services and supports they needed.

In 1981, President Ronald Reagan initiated the first Medicaid Waiver. This too was an important landmark. President Reagan had become aware of the case of a little girl from Iowa named Katie Beckett. She spent the first 3 years of her tragically impacted life hooked up to breathing machines and other life sustaining equipment in an exhaustively expensive institutional setting. The same supports could have been provided to her in her family home with the necessary medical supports for a fraction of the cost incurred at the institution. Her family wanted her home but they could not care for her there because they could not meet the income requirements for Medicaid, which had the primary purpose of serving the poor. President Reagan initiated a program to “waive” the income requirement for people with disabilities. It soon became known as the “Katie Beckett Waiver”.

Today, thanks to President Reagan, all fifty states have Medicaid Waivers. These waivers are different in different states, but in Florida, as in many other states, they provide the basis for those community based services that have largely replaced the institutions. In terms of quality of care they are by all accounts an enormous success. And they still cost significantly less than the institutional alternative. President Reagan, as well as the first President Bush, both championed bright futures for people with developmental disabilities.

Until today, it was a promise kept.

The economic crisis affecting our state and nation is undeniable. Services for people with disabilities have suffered along with every one else. In the state of Florida, despite the rising cost of living and out of control medical costs, the Agency for Persons with Disabilities’ budget is actually smaller than it was in 2005. Show me another government agency that can say the same. And keep in mind, with every dollar of reduction in state funding; our state forfeits a dollar of matching revenue from the Federal government, a dollar of your taxes and mine that goes somewhere else. And while funding for community based services under the waiver has decreased, the list of people with disabilities waiting for those promised services has ballooned to over 19,000 people.

Florida now ranks 49th among the 50 states in funding levels for people with disabilities when measured against per capita income. For every \$1000 of personal income enjoyed by Floridians, a scant \$2.14 is devoted to services for the developmentally disabled. Compare that with New York’s \$9.53 or Louisiana’s \$7.43. In fact, of all the states in the financially strapped Southeast, Florida is dead last. All 48 states that rank above us have economic crises as well, but this is not just a matter of economics, it’s a matter of values, abandoned in our rush to give tax breaks to corporations and the wealthy.

And now, our current Governor, by Executive Order, has imposed an immediate 15% cut to all rates paid to service providers and threatened to extend the cuts into the coming fiscal year. For a service system already on life support, these cuts may prove to be fatal, leading many to stop providing essential services all together. And it's being done with no serious reflection on the lives of Floridians, the most vulnerable Floridians, for whom it will be so destructive. There are others in the Legislature who are opposing these devastating reductions, but in the din for lower taxes and smaller government, their compassion and advocacy is struggling to be heard. You have to wonder how many of those who voted for this Governor and the Legislators who support this move thought they, like Reagan, would protect the truly vulnerable as they whittled away at government waste. How many of those who voted for them believed they would turn their backs on the Katie Becketts of our state? How many believed that this new conservatism would be so devoid of compassion?

President Reagan made a promise to all our fellow citizens with developmentally disabilities. And he backed it with action. How ironic that he is lionized as among our greatest Presidents by the same people who now seek to undo his work.

And that is a promise broken.