



July 29, 2009

To: Senator Rollie Heath, Chairman, and Members of the Colorado Long Term Fiscal Stability Commission

From: Marijo Rymer, Executive Director, The Arc of Colorado

Re: Impact of the current Colorado fiscal situation on Persons with Developmental Disabilities

As you have heard from many people, Colorado's share of Medicaid expenses is one of the big three areas of state responsibilities that is projected to increase significantly over the next several years. Like public education and corrections, Medicaid services are case load driven—the more people in the program, the higher the cost. In addition to an increasing demand for services is the rising cost of healthcare itself.

Colorado Medicaid is public health insurance for low income families, children, pregnant women, persons who are blind or persons with disabilities and the elderly. The Colorado state Medicaid Plan outlines the people, who qualify, the services that the state will cover and the rates paid for those services. Basic Medicaid services must be available to those who qualify. Core services include doctor's appointments, hospitalization, medicine, x-rays, and some therapy. Nursing facility services are also mandated.

Each state decides who will be covered, what services beyond the basics will be included and how much money will be paid to providers. No two state Medicaid plans are alike. The state plan is the contract between the state and the federal government that allows the state to receive matching federal dollars. In the federal budget, Medicaid is an "open ended entitlement" program. That means that the federal government is legally required to pay its share of Medicaid costs regardless of the total amount.

But, there is another piece of Medicaid that many people do not understand—Medicaid Waivers. In 1981, the federal government allowed states to apply for waivers to cover services for people in their homes and communities instead of in nursing homes or institutions. Of Colorado's eleven Medicaid waivers, four are designed for children and adults with developmental disabilities. States establish the eligibility requirements for each waiver, set limits on the number of people to be covered and determine how much state money will go to the programs. When waivers are approved by the federal government, states can receive matching funds to pay for about half of the cost of the programs.

Nursing home services are an entitlement under Medicaid while community services under the Medicaid waiver law remain an option at the discretion of the states.

States can also use general fund dollars to establish services or programs that are not offset by federal Medicaid funding. The Family Support Services program in Colorado falls in this category.

I've attached a description of the four Medicaid waivers and the Family Support Services program covered by General Fund dollars.

Colorado was one of the first states (1982) to shift funding for services for people with developmental disabilities from institutions to community based services. We were a model for other states. We knew that the cost of institutionalization was far more expensive than the cost of community services. Most importantly, we knew that people with Down syndrome or Cerebral Palsy or Autism had the right to live healthy, safe, and productive lives in their own homes or with families or friends. Today, the state operates three facilities for people with developmental disabilities with a total capacity of about 350 people. These Regional Centers in Grand Junction, Pueblo, and Wheatridge generally serve adults with very complex needs.

While we have made significant progress in many areas, we fell way behind in our plan to ensure that all citizens live with dignity in the community:

- In 2007, we ranked 46th among the states in fiscal effort for funding of services for individuals with developmental disabilities and families
- In 2001, the waiting list for Comprehensive Services—residential assistance—increased from 595 people to 1,721
- Since 2001, the waiting list for Supported Living Services increased from 1,777 to 3,871
- In 1993, 50% of people with developmental disabilities receiving state services were employed in the community; in 2008, only 24% were employed.
- Colorado currently ranks 51st among the states and the District of Columbia for special education funding

Today, in Colorado, there are about 8,200 children and adults on waiting lists eligible for services right now or in the next fiscal year. An additional 2,100 are on waiting lists for services thorough 2015. They can wait for services as long as 25 years.

What does that mean?

- It means that a young man like Paul will sit at home for seven years or more when he graduates from high school. Paul needs help to get around in the community and his mother, who had to quit her job and lost her health insurance, isn't strong enough to lift Paul into the car or the bus.
- It means that a family voluntarily places a child with profound autism in foster care because they cannot meet his needs and provide care for their other children.
- It means that a 58 year old woman with Down syndrome goes to a nursing home (where she doesn't belong) when her 81 year old mother dies. (In 2002, there were 5700 people with developmental disabilities in Colorado living with a caregiver over the age of 60—in 2007, the number grew to 8,765)
- It means that our jails “house” people with developmental disabilities who commit minor offenses because there is no place else to go.
- It means that hospitals stretch patient stays as long as possible.

What to do?

I suggest that we first have to decide what we want for our state. Do we believe that one of the purposes of government is to assist people who, through absolutely no fault of their own—need more help than most? Do we believe that all the people in our state have the right to decent, healthy and safe lives?

In 2008, I was fortunate to be the chairperson of the Amendment 51 campaign—a remarkable and gutsy effort mounted by parents, families, service providers and advocacy organizations like The Arc. Amendment 51 proposed a phased in two tenths of one percent increase in the state sales tax to end the wait lists for people with developmental disabilities. It did not pass. But with less than \$300,000 in campaign funds after signature

collection, we were able to reach 800,000 voters who said yes to a very specific tax increase for a specific purpose. Amendment 51 was not a constitutional amendment.

Everywhere we went from Fort Collins to Durango—from one editorial board meeting after another—from conversations with Adam Schrager to Jon Caldera—people agreed (even when they disagreed on almost everything else) that a basic responsibility of government is to help the most vulnerable people in our communities. There was little disagreement about what our tax dollars should do—but disagreement about where they should come from or complaints about how the state sets priorities for spending what we already pay in taxes.

If we do believe that assistance for people with developmental disabilities is a priority then we must figure out how to pay for that priority. The number of people who need assistance is growing rapidly; the number of older caregivers is increasing. Labor costs for people who provide direct care presents an enormous challenge. Maintaining the status quo will not do if we truly believe that assistance for those with developmental disabilities is an important function of government.

We need to take a hard look at how we deliver services in Colorado now. In 1963, Colorado statute authorized Community Centered Boards (CCBs) to be responsible for community services for children and adults with developmental disabilities. There are 20 CCBs in the state that, by statute, are the single points of entry into the system. State and federal requirements that govern billing, service definitions, rates, and more have increased exponentially over the past 46 years. Many new restrictions, most of them financial, are resulting in turning back the clock for hundreds of people with developmental disabilities. People have fewer choices and less control in a system that may be too patriarchal to begin with.

Could we do a better job with what we have? I believe that most people would say yes. From the eligibility determination hoops that families must jump through to onerous reporting requirements to the extraordinary burden on parents to coordinate services, the system is a mess. That doesn't mean that the people being served are not receiving high quality services—for the most part, they are. People who work in the Division of Developmental Disabilities and in HCPF aren't there for an easy ride—they work hard to serve the interests of those with developmental disabilities and to provide good stewardship of public funds. Those who provide direct care for people with developmental disabilities are passionate about their work and care deeply for the people they serve.

Many contend that the system is broken and that we need to start over. Others think that we can fix what we have. I'm not sure that we can keep the system afloat by continually patching the leaks in the boat. We might have a first rate crew but maybe we need a new boat.

Colorado is not the only state facing these problems. Many states are seeing the light and closing state institutions and moving the funding into the community. In Colorado, there aren't any real institutions to close. Some states have developed and funded multi-year plans to end waiting lists. In 2008, the Colorado legislature approved a five year plan to end the waiting list but there wasn't any money to fund it. That year, the legislature did appropriate funds to serve several hundred additional people but there was no money to add more in 2009 and it doesn't look better for 2010. Some states have established priorities to fully serve some groups of people with developmental disabilities and dedicate all new funding to those groups, e.g. high-risk older adults or young people transitioning from school to work. In Colorado, we can barely cover the cost of serving people at risk of being homeless.

Budget constraints, serious changes in federal requirements, and demographic demands have made it hard for Colorado to do much more than take care of emergencies in the past several years.

Many states are streamlining their systems by allowing people with developmental disabilities and their families more control over the services they receive. The philosophy of independent living advocated by people with physical disabilities, the recovery movement in mental health and the general rejection of the idea of nursing homes and institutions as a first choice are coming together in many states to dramatically change systems. In Michigan, state laws allow any individual with a developmental disability to control an authorized sum of dollars to create a support plan. The new Waiver in Wisconsin for people with developmental and physical disabilities as well as the elderly is entirely based on the principle of self-determination. In those states, a case manager or a “life coach” works with individuals and families to set up annual budgets and service plans. An independent fiscal agent who does not administer services pays the bills to authorized Medicaid providers. Some people use their entire budget for supported employment services. Some people don’t function well in groups and need regular one-to-one interaction with a professional and most all of their budget goes for one to one services. Some people need daily personal care at home but don’t need transportation.

An evolving grass roots movement among younger adults with developmental disabilities and their families is clear about the fact that people want to make contributions to their communities. They want more control over their lives. The cost effectiveness of alternatives to cumbersome programs and control (with assistance when needed) over resources is proven.

We have to work together to get over the belief that the only way to “protect” public money is to force people to abide by a set of rules that may not meet their needs. The obligations and rights of citizenship apply to everyone whether they receive public assistance or not. Freedom is at the core of our rights.

Finally, we have to decide how much we are willing to pay to get what we want. There are many things we can do to save money and serve more people now but I suggest that may not be enough. The task before you is to develop a strategic plan to stabilize the state’s fiscal systems. You’ve heard many people say, and I echo them, that the process must start with a clear picture of what we want for our children, grandchildren, our businesses and ourselves. You are assigned the task of developing a plan but I believe that it’s the job of every citizen in the state to take a serious look at our aspirations for Colorado and acknowledge that tax dollars are the dues we pay to live and thrive here and sometimes the dues don’t cover the costs.

Respectfully submitted,

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