

## The Elephant In the Middle of the Room

By: Robert Stack

In my career in the disability field, I have seen time and time again more people with Autism Spectrum Disorders than a half of a decade ago. Now one in eighty-eight children are being diagnosed with Autism Spectrum Disorders, as per the Center for Disease Control (CDC) in a report that came out on March 30, 2012. As the documented incidence increases, everyone is clamoring to figure out why. There is a group that believes the diagnosis is just becoming more sophisticated and there are some that think that it has to do with aging parents having older kids.

In the United States, it is estimated that well over 100,000 adults with severe disabilities remain on a waiting list for residential and adult programs. The bad news is that the list is getting larger as just evidenced by the current news reports. A typical person on the current wait list is a 42-year old male with Autism Spectrum Disorders with a widowed 74-year old mother with significant medical needs. There are many high quality providers in throughout the country to offer appropriate support services. The problem is where will the money come from?

The elephant in the middle of the room is Medicaid. In the political arena there are broad-brush strokes for dealing with Medicaid. As the cliché goes, “the devil is in the details.”

Medicaid is part of the bankrupting quagmire that we need to deal with immediately. The urgency is based on the fact that Medicaid is akin to a lumbering elephant running towards us and in order to stop it and turn it around will take careful planning. Experts have all kinds plans for a total overhaul. One major drain on the Medicaid budget is supporting people with disabilities. As more people with Autism Spectrum Disorders are identified it will become even greater.

If you include Social Security Income (SSI) and ancillary services from both a state and federal perspectives, it is well over \$30 billion. While we know it is expensive, I offer a way to save at least 10% of this expense while improving the quality of life for people with disabilities. This answer is large institutional consolidation for people with disabilities.

To date over 160,000 people with disabilities moved from institutions into community programs. In the United States there remains about 34,000 people with disabilities in institutions. I personally know of a questionable state institution near Albany, New York that currently costs well over one million dollars per person per year. And the real moral enigma is why are we maintaining people in substandard conditions at such an exorbitant costs? In Austin, Texas there is a facility close to a century old with a crumbling infrastructure. Why is there so much push back to close these facilities?

There are various motivational premises for those opposing closure including some family members who are comfortable with existing state institutions and see no reason to change a system that has operated for their family for several years. Some families are afraid that community programs may not offer the same level of quality or they know no other alternative other than the institution.

The scaffolding that needs to be built is between people leaving institutions with those who have been on the waiting list for years. This will bridge institutional Medicaid funding with community needs. The scaffold between institutional funding and community needs will substantially reduce the average per person cost and enable more people to be served with existing resources.

There are those who oppose institutional closure because of a sophomoric notion that their represented communities will be unemployed with limited opportunities. On the surface, it would seem that the closure of institution might feel like a major economic drag. However community placement results in even a greater amount of jobs and with additional residential purchases further strengthens an economic recovery. Historically, vacated buildings are used by colleges, prisons or sold to the private sector for commercial and residential use. Emancipating people with disabilities from large congregate institutions while blending Medicaid resources for people on the waiting list is appropriate treatment of people with disabilities.

The elephant is really the fear of the unknown. The key to a proactive, positive economic and moral decision should be based on educating ourselves about community based programs. There is a problem that can only become larger if we ignore it. The CDC has spoken. We need to do planning and we need to identify resources now. Government leadership on the federal level must work in tandem with states and local leadership to build the scaffold for meaningful, ostensible funding between those on waiting lists for services and those waiting to leave costly institutions.

