

Statehouse, April 7

Remarks by Alfred Bacotti, PhD

It has been almost three and a half decades since families in the Commonwealth who had children with Developmental Disabilities (DD) living in institutions had to fight in court to force government to treat those family members with dignity. Some of you here today were engaged in that fight. You prevailed then and you must prevail again. Today the battle is no longer about securing humane treatment. Now it is a battle to determine whether families have the right to retain the homes that had been given to their children so many years before.

Today advocacy for people with DD is a house divided. Families who have children with DD at home with them are being scared into believing that they must take the homes away from people who have lived in facilities all their lives. They are told their loved ones may have to leave their homes and live in those institutions unless they get the money being spent for those who remain in the institutions. This is far from the truth. People have not been allowed into facilities for over twenty years, unless there was first an effort to provide for them in the community. Only severe clinical needs which could not be met in the community and high costs to maintain a person safely in the community justified placement into facilities.

All families with individuals who have special needs must advocate for the right to choose the place where those individuals will live. They should not have to make such a choice out of fear. If even one family is forced to leave their home then it could happen to anyone. When the state provides support to a disabled citizen, that citizen does not expect to give up their basic right to choose the community in which they live. Make no mistake. People living in facilities today and their families view those facilities as their home.

The decision to close facilities, against the will and without the input of the individuals affected, is a historic moment for us all. Government made decisions to move groups of people who shared a common characteristic in the past. History has not judged those decisions favorably. For example, the forced movement of Native Americans to reservations, the forced placement of Japanese Americans into internment camps, and even the original decision to have families place individuals with DD into institutions all speak to the great errors and suffering caused when government forced people to move. Speak out loudly with one voice to your legislators. Do not let one more forced movement of a group of people, united by virtue of their DD, go into history as yet another tragedy.

There have been two arguments used to promote the closing of facilities, one about saving money and the other about "community first". These arguments have become the rationale for the eviction of people with DD from institutions. The specific savings has proved to be an illusory number. Nevertheless, be assured it is not more cost

effective to provide the same level of services in multiple settings rather than one location. When all the numbers are added together a different story will be told, as it has in the past. This at least demands scrutiny and the legislature should be called upon to put a halt to the speedy closure process now underway so that this can be studied.

As for the “community first” argument, there is a ring to this as with most sound bites. This should not become a debate about whether living in communities is better than living in facilities. Instead, ask yourselves a question.

Who truly believes that “community first” is a better philosophy than “individuals first” or “families first”?

Tell the legislators that they must see each citizen as an individual and accord to each of them the same rights and considerations as every other citizen in the Commonwealth, regardless of where they currently live. Remind the legislators that promises have been made to the people living in facilities and now those promises are in the process of being broken. Ask you legislators not to become part of this path of broken promises.