

July 16, 2015

Dear legislators,

You've heard the stories from individuals and their families who don't want to live in institutional settings, and you've heard the rare sensationalized stories of abuse in institutions, and you've heard from the Kennedys and Geraldo Rivera after their 1965 circa snapshot of life within institutions. You have not heard from the patients, or their families, that choose to live in institutions – who rely on this safety net for their children and siblings. You have not heard their harrowing stories of life in the community, including death, suffering and jail.

At SDC, we have watched the care within institutions far exceed the care given in the community. The families that chose to stay with the developmental center system so many decades ago have worked diligently to improve all aspects of care – a 360 degree change from the 1965 snapshot rehashed over and over by the righteously indignant. The patients that live at Sonoma Developmental Center *have a community*. They have staff who they are familiar with and who they love. These staff are the ones who know how to get a patient with profound intellectual disability to smile, and to bring joy to their lives. They are also often the people who know how to properly feed a patient so that they don't choke.

The patients who remain in the developmental centers are often the most difficult to place – either for their medical needs or their behavioral needs. It is a grave breach in both ethics and societal responsibility to cast them out of their home and their community against their will. You are stripping them of the safety net that has kept them healthy and happy.

Instead, I urge you to meet with the families and the staff to figure out how to provide the level of care and community that these patients have, and deserve. It is a violation of human rights to not keep your covenant with these patients and their families.

Any patient (or family) that wants to live in the community has that right and can pursue that choice. What about the patients (and families) who choose the developmental center?

Keep in mind that when abuse or death happens at SDC, there are layers of oversight and licensing. When abuse or death happens in the community, there is very little scrutiny. No one is held responsible for the deficiencies in the community – it's pretty hard to enforce all the regulations in a dispersed delivery of care system. We must not turn our backs on the most vulnerable members of our society. This is an opportunity for California and the federal government to become a model of excellence, instead of creating yet another government sponsored human rights catastrophe. SDC can continue to serve as a resource in providing specialized medical care to a uniquely vulnerable population. It can continue to serve as a safety net for the small percentage of people who can't be moved without destabilizing their medical or psychological health, as well as for the individuals for whom community living has proven exceedingly difficult.

Just because the percentage of people that require such specialized services is very small doesn't mean we should allow these individuals to be transitioned into settings that may threaten their health and wellbeing. It's easy to ignore a minority without a voice, especially when drowned out by the voices of the Dept. of Justice and Disability Rights agencies, who continue to purport that they are the only ones who know how to advocate for the intellectually disabled. Please, do the right thing, and take responsibility for these vulnerable individuals – who could be your daughter, son, brother, sister, cousin. Start by sitting down with the family members and staff of the individuals living at Sonoma Developmental Center.