

Testimony of Sheila McLeod

Hello my name is Sheila McLeod; I am the mother of three daughter's, two with intellectual disabilities. I have worked over 29 years within the disability service system.

I have worked for 17 years with Vision for Equality's Consumer/Family Satisfaction Teams.

Today I would like to speak with you about the Embreeville State Center and how the Consumer/Family Satisfaction Teams began, we would also like to share a little about what we do.

First a little history about Embreeville State Center

Embreeville State Center was a large institution that served many functions throughout its existence.

POSTED: OCTOBER 19, 1997 QUOTE FROM BRADFORD COUNTY POST

WEST BRADFORD — "At age 103, Ann B. had become too frail to care for herself and too poor to pay for the help she needed. So on the day that Chester County opened a home for the poor in 1800, the woman arrived with her daughter. The registry lists 68 others who climbed the steps of the poorhouse during its first year.

Tattered newspaper clippings also show how the poorhouse, set among rolling hills seven miles west of West Chester, evolved into Embreeville Center, a state insane asylum that once housed more than 1,000 patients. It later became an institution for the developmentally disabled.

As of October 19, 1997 only about two dozen patients remain, and the center is under a 1994 court order to transfer them this year. Federal judges have ruled that the mentally ill and mentally retarded have a right to treatment and rehabilitation in the least restrictive environment appropriate to their condition.

And so, the state, working with family members and advocates for the disabled, has been moving Embreeville's residents to group homes that care for no more than three people at a time.

Advocates for the disabled are watching closely to ensure that patients receive the care they require as they move to group homes in eastern Pennsylvania."

There were many accounts of abusive and neglectful circumstances that led to the filing of the 1994 lawsuit. And now the good news is that through the person centered planning process people would began to experience life in a community setting offering them every opportunity to build relationships, flourish and grow.

I participated in a few of the planning sessions. They were comprehensive and fully inclusive of information identifying supports needed for people to be successful as they transitioned into community settings.

A critical component of the settlement agreement was that all class members were given the promise to live out the rest of their lives in community settings. Class members and Family members were assured that they could age in place and not be returned to congregate settings such as nursing homes unless there was no other option for care. Today we struggle greatly with that promise to support people with changing needs, especially as they age.

In many cases nursing home placement becomes the natural course when a person's health changes. Often times the only thing required to prevent a facility placement are the location of additional supports and or training staff on new care regimes. But for some this planning does not occur.

Our inability to support people to age in place is an insult to the spirit and intent of a well crafted and thought-out agreement such the Embreeville Settlement agreement. We as a society owe it to our aging disability community to do the right thing and allow them to age in their community, with their friends and families in the comfort of their homes. This is something that each of us would want to do, spend our golden days with those closest to us.

Now I would like to share with you an innovative decision that was also part of the Embreeville settlement agreement. The Consumer and Family Satisfaction Teams (CFST) resulted from a federally mandated court agreement. Advocates and Family members of people that were slated to leave Embreeville State Center requested additional monitoring for their family members. Families were very vocal about this. They desired a conflict free and ongoing voice for their loved ones once they moved into the community.

In 1996 Vision for Equality, was awarded a contract to fulfill this provision in the Embreeville Settlement Agreement. The Co-Executive Directors of Vision for Equality, Audrey Coccia and Maureen Devaney are both parents of adult daughters with Intellectual Disabilities. Their vision for CFST was to develop teams consisting of family members, self advocates and concerned citizens who embraced VFE's core values.

Customer satisfaction and service quality are essential elements that are assessed by CFST.

Persons are visited three times a year at home, in the community and unannounced. Reports from each visit capture what is working well for the person. If there are any recommendations they are shared with the County and State for resolution. Team leader Robert Stauffer will talk more about a few of our visits and share some the success stories we have witnessed.

The abbreviated film " Bridges to the Future" will be shared.