

Pennsylvania House Human Services Committee Hearing

Harrisburg, Pennsylvania

March 31, 2014

I would like to thank you Chairman DiGirolamo, and Cruz, Representative Murt and the other members of the Human Services Committee for the opportunity to testify before you today. My name is Audrey Coccia, I am Co-Founder and Co-Executive Director of Vision for EQuality, a statewide advocacy organization that provides advocacy, monitoring, training, and outreach to thousands of people with Intellectual Disabilities and Autism and their families across the state of Pennsylvania.

So far this morning we have heard about the Olmstead Decision, its intent and about Olmstead State Plans that have been successful around the Country. We have heard life stories from individuals who have left state centers and are glad they did and about a previous closings of a Pennsylvania state center, Embreeville where the people who lived there and their families played a pivotal role in their return to community and where when given the proper supports how people who left Embreeville have lived good lives.

I have several questions I would like to ask today:

Do we want to continue the vital work we have achieved in community for people with disabilities?

or

Do we want people to live behind the door in segregated settings or beyond the door in community?

I have been involved in the Disability System for the better part of the last 40 years. I can say unequivocally that during this time our state for the most part has stood in the fore front of change in upholding the rights of people with disabilities and providing opportunity for people to live and flourish in their communities. We were one of the first states to bring the "Right to Education" to every child with Intellectual Disabilities, no child left behind. We have been instrumental in the

closing and downsizing of large facilities where thousands of people were kept often far from home; bringing many people back to their families and communities. With the help of providers we have built a strong community of services and we have through Waivers supported people remaining at home with their families; creating opportunities for people and support for their families. We have seen the results of our hard work in the faces and lives of the many that have benefited from Pennsylvania's strong commitment to community. Pennsylvania had been a leader, proudly on the cutting edge of change for those with intellectual disabilities.

Yet, now in spite of all the benchmarks we have achieved in the past our system in the last decade seems to have taken a downward turn. Sadly, as to those in State Centers in the last few years it has taken on a glacial pace with only small numbers getting a chance to come back to community. Fiscal constraints and limited funding imposed by the State has begun eroding our community building. It has obliged agencies to go out of business or stop any efforts at expansion, or willingness to take on new challenges due to the cumbersome and complex processes now obliged by the Office of Developmental Programs. Some providers have closed workshops or have laid off much needed staff; decreasing oversight and support to the people they serve. We have seen the state change the service definitions so providers can now consider putting as many as 8 people into a group home where in the past there would be 3. We have seen Counties forced into using their decreased Base funds that in the past helped sustain people with no services living with their families to now using these scarce dollars instead to place people in costly segregated settings because no provider will take them in. We are seeing cuts to services for people living at home whose families rely heavily on these supports to keep their love one at home. We are seeing families losing respite, and people losing transportation and being denied specialized services that in the past they would have received. The community system is imploding because the state, intentionally or not is failing it is responsibility to support those who live in our communities.

We are watching our community system shrink to such a point there remains less than a handful of community placements left when emergencies occur and providers are no longer willing to consider opening new homes because of the way the payment system has now been devised. They wait as long as 6 months if they are lucky before they receive a dime. They have to go on faith, the state will provide. The Exception Process to get approval for additional funding to support a person who needs it can take months with no guarantees you will be reimbursed for what you put out to serve the person in the interim. No one can maintain a business, especially not a non-profit this way. Providers are closing their doors to those with exceptional need and more and more people are going to more expensive State Centers, Private Intermediate Care Facilities, and Private Licensed Facilities due to lack of adequate community funding for those with increased behavioral needs. More and more people are going into Nursing Homes that do not need to be there because agencies are turning away medically fragile high cost individuals because there is no longer adequate funding to support them. We are forcing by our lack of commitment all of these people into more costly settings.

I need to ask you do we want people to live in segregation settings or in community?

Instead of keeping our commitment to community as we have in the past we are witnessing the converse. We are sliding down a dangerous, slippery slope, one that is not cost effective or in people's best interest nor that protects people's civil rights. Numbers don't lie. This year alone in Pennsylvania over 236 people with Intellectual Disabilities have been banished to Nursing Homes, which is a 26% increase than the year before. In the last 6-7 years after 40 years of moving people out of Centers we have seen 24 new people admitted who could have been served in community with proper funds. This last year in one county alone over 75 people have been placed into Private Intermediate Care Facilities and Private Licensed Facilities not because they needed to but because provider rates are too low to sustain the person at the level of support they required. In addition

the state has approved the building of a 32 bed Intermediate Care Facility in Delaware County and in another county a 65 bed facility for the medically fragile yet they will scarcely put up funds to open new homes in community, why? We have over 1,200 children in segregated settings instead of having them supported in their own homes with family.

More and more people each day are being driven from family, home and community. Community Living Arrangements are refusing to serve individuals who need one to one support because providers rates are too low to sustain the level of care the person needs and workshops are discharging people who need one to one because the state will no longer pay them to support them. It just doesn't make any sense why the Department is throwing away forty years of community building. Why is ODP willing to spend money for segregated care but unwilling to provide what people need in community? Why have they not developed a comprehensive strategic plan that insures adequate funding to meet people's needs in community and includes the spirit of Olmstead? Unfortunately, the actions of the Department of Welfare and the Office of Developmental Disabilities suggest a strong institutional bias that has left a string of broken promises to the 56,000 who want to live in community and the 25,000 with Intellectual Disabilities and Autism who wait with nothing.

Continuing to underfund the community system that supports people with Intellectual Disabilities and Autism and layering on policies and procedures that ties the system in knots is seriously weakening what once was strong. With all due respect the Department of Welfare and the Office of Developmental Programs has created policies and rates that are strangling the community providers and by doing so placing those with intellectual disabilities living in community at risk.

I want to ask again, do we want people to live in segregated settings or in community?

This year's proposed State Budget provides a combined **11.1 % increase** to segregated State Centers where there are barely **1,000 people** left and to **Intermediate Care Facilities** where **3,000** reside while only proposing a **5.8%** increase for those **56,000** who live in community. **Somehow that just doesn't equate!** Yes, there is a proposed increase of 1,100 people off the waiting list and we are thankful for this but we fear it will be at those who live in community's expense, that we are robbing Peter to pay Paul. For those in community with Autism the budget projects serving only a hundred more while possibly as many as 10,000 wait. The Budget also proposes decreasing base funding once again this year which is the life line of community families who wait with little on no services. ***We are spending 24% of our ODP funding for a little over 4,000 in segregated settings while many of the 56,000 in community including the 4,070 living with families who are in emergency situations and the 10,000 with Autism remain underserved or unserved. Something is wrong with this picture!***

I ask again do we want people to live in segregated settings or in community?

On top of all this we have the Governor's proposals to CMS, the Healthy PA Plan that will administer Medicaid insurance for people with disabilities that will if approved deprive people with disabilities in community who rely on this help of necessary medical care and services, medications, and medical equipment that they desperately need to live and survive. If they need this medical assistance they and their doctors will now have to endure mountains of red tape to get an exception, if they get one at all. Oh, but there are winners that are exempted, you guessed it those who live in State Centers and Intermediate Care Facilities. So what it looks like is happening if you live in a State Center or an Intermediate Care Facility you will get you needs met but if you live with a community providers or with your family you can kiss your services, health and safety oh, and if you have medical or behavioral challenges the chance to live in community good bye.

**I ask again do we want people to live in segregated settings or in community,
we have to decide.**

Our concerns are urgent. We are sounding the alarm. In spite of Pennsylvania's impressive accomplishments during our "golden years", our relaxed vigilance is now jeopardizing our love ones who are living in community. We are witnessing the dismantling of our robust community system. We are encountering a whole caravan of complications that is seriously impacting our ability to serve people well. You cannot sufficiently run a dual system where 4,000 are privileged and the rest are not. Our Governor and State legislators must play a pivotal role in deciding where Pennsylvania wants to go from here in terms of their commitment to ALL people with Intellectual Disabilities. An Olmstead Plan and a robust community service system are imperatives. It is time Pennsylvania rethinks how it serves and supports its citizens with Intellectual Disabilities and Autism. Do we want a segregated system or a community system? Let's remember living in the community is a civil right. The individual with a disability and his or her right to an independent life outside the institution or segregated setting should be respected and for the 70,000 already in community it means our leaders recommitting to them their right to remain and be properly supported where they want to be and belong-IN COMMUNITY.

Again, thank you for this unprecedented wonderful opportunity allowing the families of people with disabilities and their advocates to be heard. We hope our input will be helpful.

Thank you,
Audrey Coccia