

Pennsylvania House Human Services Committee Hearing
Harrisburg, Pennsylvania
November 18, 2013

I would like to thank you Chairman DiGirolamo, and Cruz 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. Vision for EQuality is well known, experienced and trusted in the Intellectual Disability and Autism community.

You have heard testimony here today about the continued concerns about the Waiting List and the process of enrollment, the many who still wait and their need for services, our concerns about Managed Care related to people with disabilities, Adult Protective Services, and the Office of Developmental Programs (ODP)- Vision and Future Plan, all issues of serious concern to our 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 has stood in the forefront of change in upholding the rights of people with disabilities and providing opportunity for them to live and flourish in their communities. We were one of the first states to bring "Right to Education" to every child with Intellectual Disabilities. We have seen the closing of some and the downsizing of other State Centers and we have witnessed the productive, rich lives of those who have returned to their communities. We have seen the establishment of self advocacy groups and emerging leaders within those groups who are teaching others about community, jobs and rights. We have seen the establishment of a community service system that has supported people and their families and has given them the opportunity through support to live at home for many years with their families, in their neighborhoods as contributing members of their communities. In these 40 years we, Pennsylvania have been on the cutting edge of change that has

lead to choice, independence, and freedom for those with disabilities. We have proudly led the way.

Yet, now in spite of all the benchmarks we have achieved our system over the last decade seems to be unraveling. Fiscal constraints and limited funding year after year are eroding our success. It is obliging agencies to consider going out of business, or shutting community homes, closing workshops or laying off much needed staff. We have Counties considering imposed cuts to services for people living at home who rely heavily on base funds for just a little help. We are watching our community system shrink to such a point there remains less than a handful of community placements left when emergencies occur. Providers are closing their doors to those with exceptional need and more and more people are going to state centers, private intermediate care facilities and boarding homes due to lack of adequate community funding for those with increased behavioral needs. More people are going into nursing homes that do not need to be there because agencies are turning away medically fragile high cost individuals who need their help. We are forcing by our lack of vision many people back into more costly settings and decreasing much needed funds to community. All of this is creating instability in our system and robbing people and families of any sense of permanency in their lives and causing them fear that their family member after all their hard work and struggles keeping them home all these years may see them end up in a segregated setting, something they fought so hard to prevent. The last eight years of constant efforts at system changes to our service definitions, billing practices, provider rates and regulations has lead to all of this and has made our system unstable at best. None of these failings in our present system shows foresight or does it make any fiscal sense.

Now on top of this we are presented with now more reform- by the Office of Developmental Disabilities Programs (ODP)-Today's Vision...Tomorrow Reality. This watershed requires our attention. We are at a transforming moment when we must decide whether we as a State and as an Intellectual Disability System want to continue to move towards one community for all or embark on yet another "effort" that may or may not turn out right. Whether we are ready to

attempt to build a house on sand to “right” the system again, one more time; imposing more major changes on an already weakened system with yet new models of services and funding reform. A Plan that wants to use a costly, failing assessment tool (Support Intensity Scale) and tie it to people’s budgets, impose managed care on the most vulnerable in the hopes of saving money and leave costly state centers in place to continue to eat up a third of the budget each year for 1,100 people while 15,000 wait and while it appears cutting 50,000 others back, especially those living at home.

This is not a Plan we as families can promote or support. We must sadly say today we are deeply concerned and frankly worried about the “Vision and Future” direction that is being laid out by ODP for the state of Pennsylvania and our family members. We fear the impressive history that state of Pennsylvania and its many stakeholders including families have built is now about to implode. Continuing to “right” a system over and over again without considering impact time after time has the capacity to collapse all we know and hold dear.

Families are not afraid of change. We know change can be good. Many of us are the very families who challenged the system for change and refused to place our love ones in state centers. We are the families responsible for opening the doors to schools, building community and giving people with Intellectual Disabilities for the first time real lives in community but we are not about to allow our family members to be the possible victims of another failed attempt for reform. Systems as large as this with such vulnerable people should see slow but constant proven reform with measurable outcomes and repeated checks for success and failure.

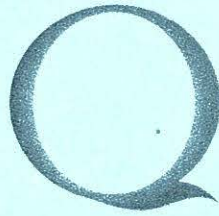
Let us consider in any further changes to our system taking the following multi-tier approach:

- Commit to building a strong infrastructure first to support our ID System before embarking on more system reforms.
- Adequately fund our ID Service System to support the people in it.

- Instead of trying to cost and cap services let us continue to leverage as much federal funding as we can through Home and Community Based funding for services so we can adequately address the WL.
- All changes to the system new and old should be vigorously evaluated for adequacy to protect people and address deficiencies promptly
- Lower costs by utilizing family caregivers building upon their strengths and resources through Home and Community Based Waiver Funds to support people at home for as long as they are able-it is the cheapest way to go.
- Develop an Olmstead Plan that will down size and close all state centers and place a moratorium on any future admissions of people with Intellectual Disability and Autism to state centers and nursing homes.
- Reinvest the monies fro state center closing into the community service system.
- Take the necessary steps to Increase the rates appropriately especially for providers who are willing to support those with compelling needs.
- If change is coming, let it be change that will help people not hurt them or their families or our fragile Intellectual Disabilities System..

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

Thank you,
Audrey Coccia



vision for equality

November 5, 2013

Fred Lokuta, Deputy Secretary
Office of Developmental Programs
Health and Welfare Building
Room 502
Harrisburg, PA 17120

Dear Deputy Secretary Lokuta,

We thank you for the opportunity to respond to the Office of Developmental Programs Futures Planning document. We have spoken to many families and self advocates about the plan. Their recommendations and comments are included in the attached document outlining our comments about each of the objectives in the plan.

As the process moves forward we recommend that ODP proceeds carefully and cautiously, with additional planning that includes input from constituents, each step along the way, and with discussion on how to coordinate changes over time so there is little disruption to those who receive services in the system.

Moving forward we ask that you consider organizing a group similar to the Planning Advisory Committee who can come together on a regular basis to address barriers and discuss progress. We believe a forum similar to the PAC should be developed so that stakeholders and their families have a voice at the table and the public has a forum to understand the process. Open lines of communication both ways should occur so that ODP can hear from people and their families in the community and hear how things are impacting their lives on a regular basis.

It is wise to remind you that when programs or services are cut our sons and daughters and their families suffer. When there are cuts or changes to services or reductions in rates, people's lives suffer and cuts to services come at our loved ones expense.

We have found it difficult to refrain from speaking to issues not addressed by the Futures Plan. We believe that unless and until the old, underlying issues are addressed, a new system cannot take root.

Additionally, we wanted to share some overarching issues and concerns about the existing system and future of our system. Here are our comments:



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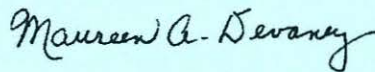
- The focus on developing the new system should be centered on the Person First with the person designing and controlling their own lives and plans.
- There is no discussion in the future plan about eliminating state centers and large ICF's. Plans to downsize and close the state centers need to be made and money saved from the closures should be reinvested in the Community. These segregated centers clearly should not be on the continuum for residential services. Everyone should live fully in community.
- An Olmsted Plan should be developed and followed.
- We are wondering how new planning is going to eliminate admissions into the state centers for those who are seeking community services to help avoid institutionalization, especially for people with physical and behavioral needs.
- Providers are telling us that the flat rates set a few years ago prohibit them from serving some people who have more behavior and physical needs. Other people are getting discharged by providers because their services are too costly.
- We are concerned that the future will see people who currently have services lose them.
- People are losing services presently on a daily basis because of the changes to the ISP process.
- Services are being cut via a phone call, with no opportunity for a hearing. People are not given the ten-day window or opportunity to appeal, thereby denying them their due process rights.
- Bundling of services is leaving people in group homes sitting with nothing to do all day and/or all weekend and many of these people do not have a job, day program or workshop to attend. Some are more segregated than ever.
- The plan does not include a proper approach to ending the waiting list for services and the waiting list continues to grow. We need a firm plan in place to address the waiting list over the next five years so that all Pennsylvanian's in need can be supported in the community with the services they need and funding for their services should NOT be taken from the people who have services.
- New procedures must be designed by DPW, OPD, etc. to assist people and their families in the cumbersome process of accessing services. From the time people register until the time they receive services it takes months or longer. The enrollment system should be designed to be person and family friendly so that services can begin in a timely fashion.
- People that we believe should have been served by the Waiting List Initiative still wait, including a parent who is a 72 year old man who is blind. The process is still in need of correction.
- The Incident Management System and the Adult Protective Services process needs to improve; people are being abused and neglected.
- In writing the regulations, Adult Protective Services should be seen independent and conflict free.
- The changes that have been made to the 6400 and 6500 regulations have been devastating to people. Regulation or policy changes should not be written to harm people but to help them access the services and supports they need.
- Information needs to be provided to people and their families in a user friendly and respectful way.



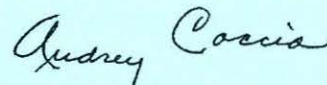
- Language barriers have not been addressed and many resources and power point formats are not translated. Many agencies (including the Support Coordination Organizations) lack translators, and websites are not available in Spanish or in the language of the person. Interpretation services should be available across the state. Currently most events do not provide interpretation.
- ODP should provide the monies necessary to prevent providers surrendering medically fragile and/or older people with disabilities to Nursing Homes where they are getting inadequate care.
- We suggest eliminating the SIS process as the assessment tool. We recommend that the Individual Support Plan be used as the primary assessment tool to determine need. Do not define the essence and needs in a person's life by cost and a dismal assessment such as the SIS. The plan should be developed first and the budget for the plan to follow.
- We would like to see the contract language with providers hold high standards and expectations.
- Create incentives in the system for providers willing to support high end users.
- Seek out providers who have high success models and use them as examples and to also provide training opportunities for other providers across the state to model and learn.
- Hold a conference on systems reform and change so that families, their sons and daughters, providers, SCO's, Counties and others can learn about proven methods of supporting people.
- Support and expand the use of conflict free Independent Monitoring for Quality as a way to benchmark the systems success.
- We have heard there are efforts to "redo" the Everyday Lives principles that many hold as the touchstone of quality for our system. Leave the Everyday principles in place. They have served us well and represent what families and people with disabilities need and want. Let's remember this is about them.
- Managed Care is a way of doing business that has many concerning ramifications and clearly little history of success in populations such as ours. Many states and national organizations have already gone on record about the need for caution before exposing the most vulnerable to a model with no proven success rate. Its impact could be devastating. We urge ODP to think twice before buying into this with so little evidence it can save money without harming people.
- ODP should travel around the state yearly to hold open forums so they can hear directly from people and seek their input.

We once again thank you for giving us this opportunity to share our message with you. Please contact us if you would like to meet with us to discuss our comments.

Sincerely,



Maureen A. Devaney



Audrey Coccia

Executive Directors

cc: Beverly Mackereth



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