

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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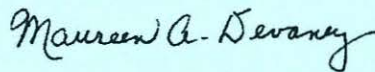
- The focus on developing the new system should be centered on the Person First with the person designing and controlling their own lives and plans.
- There is no discussion in the future plan about eliminating state centers and large ICF's. Plans to downsize and close the state centers need to be made 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.



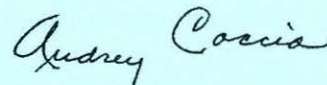
- Language barriers have not been addressed and many resources and power point formats are not translated. Many agencies (including the Support Coordination Organizations) lack translators, and websites are not available in Spanish or in the language of the person. Interpretation services should be available 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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