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COMMONWEALTH OF PENNSYLVANIA
DEPARTMENT OF HUMAN SERVICES

October 15, 2018

The Honorable Gene DiGirolamo, Chairman
House Human Services Committee
Pennsylvania House of Representatives
49 East Wing
Harrisburg, Pennsylvania 17120

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Representative DiGirolamo,

First, I would like to thank you for scheduling a meeting to discuss the concerns expressed by Vision for Equality about the Regulation #14-540, "Home and Community Based Supports and Licensing." The Department always welcomes discussions about ways that we can improve the quality of services and ensure the health and safety of people with intellectual disabilities and autism.

In your letter and in the meeting you shared your concerns about the regulations reducing provider accountability and lessening health and safety protections. The issues that Vision for Equality brought forth about health, safety and quality in our home and community-based service system are real. The Department shares those concerns and has been engaging in a multi-pronged approach to improve quality. This regulatory package is part of that approach. The Chapter 6100 regulations will replace Chapter 51 and strengthen provider accountability and individual protections, specifically, by extending protections across all settings in which ODP is funding services and improving enforceability. Without the 6100 regulations, some protections apply only in licensed settings, though most of the people served by ODP live in private homes. The 6100 regulations significantly strengthen individual protections in the areas of rights, staff training, incident reporting and analysis, use of restraints, program planning and medication administration. The 6100 regulations also provide the Department much greater enforcement power through a robust sanctions section. I can assure you that the final-form regulations do not weaken accountability or protections; rather, provide a stronger regulatory framework than the current Chapter 51 and the current licensing regulations.

During our meeting you had two requests for the Department: (1) that we consider withdrawing the regulations and making the changes requested by Vision for Equality and (2) that we provide the analysis of which issues raised would be appropriately addressed within the scope of these regulations and the mechanisms to address issues that could not be addressed through this regulatory package.

Request to Withdraw the Regulations

Respectfully, the Department will not withdraw the regulations. This regulatory package was developed with extensive stakeholder input. There were over 15 full days of meetings with the work group that included individuals with disabilities, families, advocates, university professors, administrators of county programs, and providers. Vision for Equality was part of this workgroup. Additionally, there were more than 60 meetings with broader stakeholder groups including Vision for Equality and other family members. After receiving public comment from 349 commentators, prior to submission of the final-form regulations, ODP reassembled the workgroup to review the revisions to multiple sections of the regulations. This review included the sections Vision for Equality is requesting changes to now.

The changes requested during the meeting on October 11, 2018 are extensive, involve multiple sections across multiple chapters, were all methodically vetted through the public process and will be met with significant opposition from other stakeholders. There is the very practical concern about the feasibility of making significant changes to the regulatory package, vetting the new changes and responding to the resistance from other stakeholders, and completing the required review prior to the 2-year deadline in the Regulatory Review Act.

Failure to approve these regulations means that Chapter 51 will continue to be the prevailing regulations. Chapter 51 provides less accountability and lesser protection than the final-form regulations. Since the regulations interpret and apply the CMS Home and Community-Based Settings Rule, failure to promulgate the regulations may also jeopardize the Commonwealth's eligibility for nearly \$2 billion of Federal funds.

These regulations are widely supported by stakeholders including family organizations and the risk of withdrawing these regulations at this time is simply too great.

Though the Department is unwilling to withdraw the regulations, the Department will commit to the following:

- Creation of a Provider Quality Oversight Subcommittee of ODP's Information Sharing and Advisory Committee (ISAC). This subcommittee will meet quarterly and review provider performance data related to incident management, licensing inspections, and provider monitoring data. The subcommittee will make quality improvement recommendations to the larger advisory committee.
- Publication of an annual report of ODP's incident management data.

Analysis of Issues Raised by Vision for Equality

During the meeting, Acting Deputy Secretary Ahrens expressed that many of the core issues Vision for Equality (and Kate Fialkowski through her September 24, 2018 letter) raised were outside of the scope of the 6100 regulatory package. We agreed that the Department would provide an analysis of the key issues brought forth, indicating which issues were outside of the scope of the regulations and responding to the concerns. Below is a summary of that analysis:

- **Concerns about the reporting, investigation and corrective actions related to abuse and neglect.**

There are no regulatory changes that could be made within the scope of the 6100 regulations to address the concerns shared during the meeting. Issues relayed were: statutory in nature (lacking a registry for offenders); implementation of statutory requirements (timeliness of protective service investigations, notifications, surveillance reporting); enforcement of statutory requirements (criminal prosecution for failure to report abuse); applicable in protective service regulations (Adult Protective Services, Older Adult Protective Services, Child Protective Services); or Departmental processes as opposed to regulatory subject matter.

- **More detail about abuse must be put back in the 6100 regulations.**

The detail referenced is included in other current statute or regulation. Instead of defining abuse and/or reiterating other state statutes and regulations, the final-form regulation requires compliance with all applicable statute and regulation related to abuse. Because ODP provides services to individuals of all ages in both facility and non-facility settings, Child, Adult and Older Adult Protective Service laws may apply, as well the Neglect of Care-Dependent Person Act.

- **Department conducting unannounced inspections of providers.**

The final-form regulatory package supports this practice. The Department can and does conduct unannounced inspections of providers. The 6100 regulations and licensing chapters contain provisions that providers must comply with monitoring conducted by the Department or Department designee.

- **Request for a provision in the regulation that, for people who have severe communication disabilities and may not be able to clearly designate a person, the provider is required to include family in decision-making, planning meetings, copies of reports, etc.**

ODP primarily provides services to adults. Unless an individual has a court-appointed guardian, the individual has a right to privacy. The Department cannot and will not require providers to violate privacy laws.

In response to family concerns, a provision was added to the final-form regulation to mandate that providers facilitate the involvement of family unless the individual indicates otherwise. This protection for families is a new substantive provision that does not currently exist in statute, regulation or policy.

- **The removal of the requirement for an annual training plan from proposed to final-form regulation and requirement of 24 hours of training annually being insufficient.** More than 140 public comments were received from providers and the IRRC during the public comment period in opposition to the proposed annual training plan. As a result, it was removed from the final-form regulation, based on not only the substantive public comment, but also due to the unnecessary paperwork and cost associated with the paperwork. The provision of the actual training is the important protection, rather than the planning for the training. While several families and advocates opposed the elimination of the annual training plan during the regulation workgroup meetings, overwhelming public comment supported the elimination of this section.

No public comments were received from Vision for Equality or others suggesting that 24 hours of annual training was insufficient. Based on broad public support, the 24 hours of annual training was retained. The current community home licensing regulations have required 24 hours of annual training since 1991.

In the final-form regulation, providers are required to provide all training for staff that is necessary to implement the Individual Plan, including if that amount of training exceeds 24 hours of training annually.

- **Changes from proposed to final-form in the Quality Management section**
The Department received more than 150 public comments from both providers and advocates on the Quality Management section, opposing the prescriptive nature of the proposed regulations. When this topic was discussed with the regulation workgroup, no opposition was voiced to simplifying the quality management requirements. The final-form regulation includes provisions for the basic elements of a sound quality management plan allowing some flexibility which is essential given the scope of service types and providers within the ODP service system.
- **Removal of Emergency Room as a category of incident reporting –**
Emergency Room visits were removed because more than 50% of ER visits are for new or chronic illnesses (in lieu of a doctor visit, i.e., weekend, after hours) that would not be characterized as health and safety risks. Other primary categories for reporting that will capture health and safety risks are "Injury requiring treatment beyond first aid", "Inpatient The

Admission to a Hospital", "Suicide Attempt." Reporting ER visits is unnecessary, costly for both the providers and the Department, bogs down an already burdensome incident reporting system, allows providers to mischaracterize more serious incidents, and results in no added protections for the individuals.

- **Request individuals and families to be notified immediately of all incidents and to receive all incident reports.**

In the final-form regulations, the individual and persons designated by the family must be notified within 24 hours of the incident. The individual or person designated may also request the incident report or a summary of the report. Providers are required to provide the requested report. Because of the high volume of incidents and the level of detail in incident reports, the regulations include language for a person or designee to request such reports and not automatically receive them.

- **Charge that the system does not declare any of the following as neglect/abuse/restraints: failure groom, turning up the heat and turning out the lights to induce sleep – a form of passive restraint, doubling/tripling up on depends to decrease changing, removing mobility devices to seclude individuals, withholding water to decrease bladder evacuation.**

The Department would characterize each of the above as neglect or abuse, including abuse in the form of unauthorized or improper use of restraint, and each allegation of this type would be subject to investigation. If Vision for Equality or any parties present during the meeting have knowledge of such practices, they should report these practices immediately.

- **The individual and/or their legal representative (guardian, etc.) should have the option to bring in an independent investigator especially when there is suspected abuse or neglect. Nothing in regulation prohibits independent investigations. The Certified Investigator program has extensive protections in place to ensure investigation integrity. Certified Investigator training and certification is provided by the Institute on Protective Services at Temple University Harrisburg through contract with ODP. Any incident that a provider is required to investigate may be subject to an additional inspection by the Administrative Entity (County MH/ID Program) and/or ODP. Protective services are an additional layer of independent investigation in cases of abuse or neglect.**

If you would like additional information about departmental efforts to improve the quality of services and address the health and safety concerns that were brought to your attention, we would welcome the discussion.

Sincerely,



Kristin Ahrens
Acting Deputy Secretary

Cc: The Honorable Lisa Baker
The Honorable Tom Murt
The Honorable Alexander Charlton
Melanie Brown
Ashley McCahan