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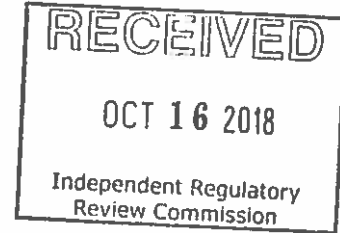


Vision for Equality

Serving People with Disabilities and Their Families

October 15, 2018

Fiona Wilmarth, Director of Regulatory Review
Independent Regulatory Review Commission
333 Market Street 14th Floor
Harrisburg, PA 17101



Re: IRRC Notice of Final Form Rule-Making (Department of Human Services [55 PA. Code Chs. 51, 2380, 2390, 6100, 6200, 6400 and 6500] Home and Community-Based Services and Licensing)

Dear Director Wilmarth:

Vision for Equality is a non-profit whose mission is to assist and empower people with disabilities and their families to seek quality and satisfaction in their lives as well as equal access to supports and services.

We write representing families across the state with very serious concerns about the regulation package (ODP #14-450). We recognize that there are some important improvements contained in this final draft compared to the regulations currently in effect. And we applaud that. However, we believe these regulations will not protect the welfare of the family members being served by the Commonwealth.

Below is recent data that supports our reasons for concern:

- The January 2018 Federal Joint Report "Ensuring Beneficiary Health and Safety in Group Homes," noted many systemic problems across the US including that 49% of ER visits are incorrectly classified (under reported) as minor when they were "severe" and 99% of critical incidents are not reported to law enforcement or state agencies as required.
- The Office of the Inspector General report, "2017 Top Management and Performance Challenges" found that State agency and group home staff lack adequate training to correctly identify and report critical incidents and reasonable suspicions of abuse or neglect. It's very dangerous and problematic in a system where 63% of people who receive 24x7 supports cannot speak and report neglect or abuse.
- According to the State of the States Intellectual and Developmental Disabilities, University of Colorado Report, <http://stateofthestates.org/documents/Pennsylvania.pdf> 73% of people with disabilities live at home with their family caregiver.
- The Office of Developmental Programs held regional provider meetings in August 2018. ODP shared data from the Commonwealth that put individuals at risk, such as:
 - Within a one year time frame, 345 people were taken to the emergency room for bowel obstruction, dehydration, aspiration, seizures. ODP describes these four conditions as the "Fatal Four" -- categories of preventable death.
 - There were 13 incidents of choking while eating are reported each week or 700 in a 2 year period. Of these only 200 were investigated by an ODP-certified investigator (which is self-investigation) and of the 200, almost 50% were found to be caused by neglect.
- The explosive series in The Philadelphia Inquirer exposed abuse and neglect within the provider agency called Blossom. This abuse and neglect of 89 individuals with Intellectual Disabilities and the choking death of one person demonstrate the failure of the system to adequately respond to reports of abuse.

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While the above daunting data was being released this past year, ODP was moving the final regulation package forward. In response to the flood of comments from the provider community to the Regulation changes (those being regulated) with concerns about mounting paper work and compliance issues the proposed requirements were relaxed and reduced in several important areas. We assert that the changes to the language in the regulation package between the proposed and final versions put individuals at risk and fail to address the problems cited in data noted above.

Families need regulations which will strengthen and protect the rights, health, and safety of individuals with developmental disabilities served by the Commonwealth. Regulations must protect served individuals from the kind of abuse and neglect that has occurred and is still occurring in our system. This final version has removed the safeguards and accountability families sought. Most notably:

- Families or Supported Decision Makers are not given adequate access to information, incident reports, records and decision-making opportunities.
- There is no requirement for Emergency Room visits to be reported as serious incidents, and families are not notified immediately.
- The training requirements for staff, necessary to safeguard health and safety, have been significantly reduced.
- The removal of the communication and education sections leads to a climate of warehousing individuals rather than providing opportunities to expand their development and Everyday Lives.
- The role of the family is left to a provider's good faith or leaves the decision-making power solely in the hands of individuals, many of whom will need significant support in reaching those judgments. We want our family members to make choices and decision on their own where they are able, but for the over 60% who have serious cognitive involvement or are unable to speak for themselves due to their limitations or lack of technology those that love them should help support them with those conclusions.

Family members have always served as the eyes and ears for their loved ones and provide oversight to ensure they are safe from abuse and neglect. 73% of people live at home with their families. Their role as stakeholders is not insignificant.

We believe a family's opinion and voice should count as much as a provider's influence, because of the love and concern they have for the welfare of their son, daughter or family member. Vision for Equality does not consider this final draft to adequately provide regulations to protect the loved ones of the families we represent.

Respectfully,

Audrey Coccia

Maureen Devaney

Co – Executive Directors