

# 3160



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October 13, 2018

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

2016 OCT 15 P 4: 14  
RECEIVED

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:

SPEAK Unlimited Inc., is a non-profit organization that has been serving people by providing free advocacy services to families across the Commonwealth since 2004.

I am greatly concerned about the regulation package (ODP #14-450). I do understand that there are changes and some improvements contained in this final draft compared to the regulations that are currently in place. Unfortunately, some of these new regulations fail to protect individuals who receive services and work to disempower their families who have supported, cared for and protected their most vulnerable loved ones for many years.

Families are a crucial natural support that is needed and wanted by many individuals and honestly, families are needed by the state, because their support reduces the need for and cost of state-provided services.

The Commonwealth must create regulations that will protect served individuals from the kind of abuse and neglect that has occurred and is still occurring across our system. Regulations that will strengthen and protect the rights, health, and safety of individuals with developmental disabilities. Regulations that will encourage families to stay involved with their adult children.

I was incredibly disappointed to find in this final version that the much-needed safeguards and accountability that families sought is now missing.

Specifically:

- Families or Supported Decision Makers are not being given access to records, information, incident reports, and are left out of other decision-making opportunities.
- Removal of the requirement that Emergency Room visits are to be reported as serious incidents.

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*to serve those who serve. to help those in need*



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- Families are not being notified immediately when an incident has occurred.
- Training requirements have been reduced when they should have been increased. Lack of training leads to more abuse, accidents, and deaths. How much is the life of one of our adults' worth to the state and to providers? It appears, not enough for sufficient staff training.
- By removing communication and education sections in the regulations, we are heading back to the warehousing of individuals instead of providing opportunities to expand their development and the creation of their Everyday Lives.
- The natural support and care of families is being marginalized by these regulations, the opportunity for a family to be involved is left up to provider's who may or may not be working in good faith.

Please remember, family members are the original protectors of their loved ones. They have always been there to help, to guide, to advocate and to protect. They have provided oversight and reported abuse when providers and others have turned a blind eye as people have been hurt, abused and died. No less than eighty percent of served people live at home with their families. At least 60% of individuals who are served have limited or no language. They need the care and protection of their family more than ever. A family members' role as a stakeholder cannot be ignored. Families need to be heard and respected.

As the mother of a young man who is nonverbal and has a profound intellectual and developmental disability and for the many individuals whom I have served over the years, I would make this suggestion; instead of cutting families out of the decision-making process, instead, require individuals to state that they do NOT want their families involved. Families should be excluded only when explicitly blocked by the individual.

I firmly believe that the voice of the family should be heard and the advocacy of the family should be heeded. Families opinions should be afforded consideration above and beyond that of a provider's influence because their care for their adult child is not based on a bottom line but based on years of care and love.

SPEAK Unlimited Inc. does not support this final draft because it does not provide regulations that will defend and protect individuals who are served by the state. These regulations are not in the best interest of the many families whom I have served without charge over the years.

I ask that this set of regulations be sent back to committee as I know it legally can be and reworked to include and recognize the valuable and valued contribution that families make in an individuals' life.

Respectfully,

Susan F. Rzucidlo

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