

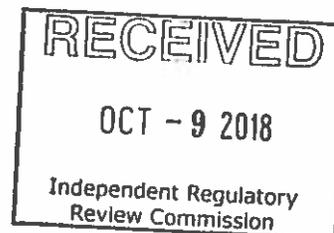


Institute on Disabilities

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October 8, 2018

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

The Institute on Disabilities at Temple University (IOD) is one of the sixty-seven University Centers for Excellence in Developmental Disabilities Education, Research and Service funded by the Administration on Intellectual and Developmental Disabilities, U.S. Department of Health and Human Services. In this capacity, we believe that, everyone deserves the opportunity and support to lead a self-determined life in inclusive communities.

Consistent with this belief, we write in support of this regulation package (ODP #14-540) that will govern the services provided to approximately 55,000 children and adults with intellectual disabilities (ID) and autism who receive home and community-based services, funded under Pennsylvania Medicaid Waivers. We ask you to formally adopt the proposed regulations in this package, to be set forth at 55 Pa Code §6100 *et seq.*

This regulation package represents the culmination of an open and responsive effort on the part of the Office of Developmental Programs (ODP), to engage stakeholders and provide opportunity for input in the drafting of these important regulations. Beginning as early as December

2014, ODP convened a regulation workgroup consisting of 45 individuals, families, advocates, universities, county programs and providers. The IOD participated in this workgroup over a four-year period. Additionally, ODP held 60 meetings with interested stakeholder groups, including the IOD, individuals with intellectual or developmental disabilities, and their family members. Through this process, the IOD and other stakeholders also had an opportunity to provide formal written comments on the proposed regulations. ODP then reviewed and responded to these comments.

On December 19, 2016, the IOD provided written comments relating to several areas including, but not limited to, staff training, quality management, individual rights, person-centered planning, and facility characteristics. ODP's response to these comments shows a willingness to engage in meaningful dialogue and compromise concerning the rights of individuals with disabilities. Although we do not agree with every detail of these proposed regulations, we endorse the adoption of this regulation package because it is a package built on meaningful and open stakeholder engagement, and because it will replace the antiquated regulations set forth at 55 Pa Code § 5100 *et seq.*

We applaud ODP for the following key points emphasized in these regulations:

1. Training is required for all staff who provide HCBS and minimum training standards have been set (§§6100.142-143);
2. A section concerning protecting the rights of children has been added (§6100.56);
3. The need for education of individuals using Home and Community-Based Services (HCBS) about their rights, and how to report rights violations (§6100.181(b); 6100.185(a)), and;
4. The importance of person-centered planning, community integration, and individual choice (§6100.3 (family and friends); §6100.222(a); 6100.223(17)).

Some specifics of the regulations continue to concern us. However, we believe that these areas can and should be addressed through policy, practice, and guidance and do not require further delay in adopting this package.

Specifically, we encourage ODP to revisit the following areas of concern:

1. Staff training – we encourage ODP to incentivize providers who provide staff with training in excess of the 24 hours of annual training required by these regulations. We do not agree that 24 hours is sufficient in terms of minimum training hours;
2. Individual plan process – we encourage ODP to adopt policies and procedures which further emphasize that an individual with a disability has a right to *direct* the person-centered planning process. It is more than just a matter of participation;
3. Day Programs – ODP should significantly reduce the number of individuals that can be served in a day program at any one time. Twenty-five individuals with disabilities in one setting does not promote community integration;
4. Residential Facilities – ODP should require already existing residential facilities to transition to a size of four individuals or less;
5. Supports Brokers - ODP should make clear that supports brokers must comply with these regulations;
6. Incident Analysis Data – Providers should be required to review and analyze incidents on at least a monthly basis. Every three months is inadequate to ensure that incidents do not recur; also, AEs and/or ODP staff should review analyzed incidents to ensure that corrective action is taken when needed;
7. Transition Planning and Process – ODP should set forth specific requirements that supports coordinators must meet to facilitate any meaningful and successful transition. For example, “a transition planning meeting must be held within 10 days of receiving notice that the individual is switching providers”. The current language in §6100.306 is vague, and;
8. Quality Management – ODP should consider data gathered through Independent Monitoring for Quality (IM4Q) interviews as a means to evaluate the effectiveness of the implementation of the HCBS Final Rule in Pennsylvania.

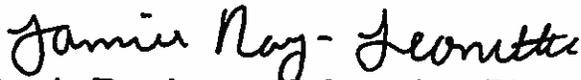
Continued review in these areas can only serve to improve the services provided to individuals with developmental disabilities, and will help ensure implementation of the HCBS Final Rule with fidelity.

We look forward to seeing positive change in the lives of Pennsylvania with disabilities as these regulations are adopted and implemented. Should you have questions, please feel free to contact us.

Respectfully,



Celia S. Feinstein, Executive Director



Jamie Ray-Leonetti, Associate Director of Policy

cc: Kristin Ahrens, Acting Deputy Secretary ODP