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October 13, 2018

Fiona E. Cormack, Director of Regulatory Review (fcormack@irrc.state.pa.us)
Independent Regulatory Review Commission
333 Market Street 14th Floor
Harrisburg, PA 17101

RECEIVED

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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 Cormack:

Previously a summary of my meeting with Acting Deputy Director Ahrens was forwarded to this committee regarding comments on the aforementioned HCBS regs. I hope that the committee will read it by way of background. It is extensive as it identifies my concerns about the group-home system but the comments were not limited to these regulations, specifically. With this letter I submit to you my own contribution on the regs for this committee's consideration.

I appreciate all the hard work that goes into such a comprehensive regulatory package. I know it is a huge effort to get something so large across the finish line especially as there are so many strong voices and competing interests. Typically, at this part of the process people submit to you "thumbs up" or "thumbs down" support or oppose. I'm not going to tell you how great the regs are, or even how I oppose them or what the deficiencies might be.

After all, I am not a paid policy analyst and I don't have the time or expertise to know these 800-1000 pages of code for the new 6100+ regs. What I do know, and intimately, is how the system actually works. There is the code and there is the reality. The Commonwealth is responsible, ultimately, for both. Though I am not a policy wonk, I am a highly-invested family member for a brother who receives 24x7 supports in the HCBS Consolidated Waiver. My brother does not express himself with words, was diagnosed with a "profound" intellectual disability. I have been his primary advocate since our parents died in the 1990's. And in these ~25 years, I can tell you that I have been forced to become expert on reality – how the HCBS waiver group home system works "on the ground" compared to how it is supposed to work on paper. I am just a simple, hard-working, plain-speaking family member. As a result, I've got a simple "bottom-line" kind of thought which results in proposing to you two simple questions for the IRRC; questions that should be asked before your approval and the anticipated regulatory promulgation:

1. What <lack of> quality threshold in the system is acceptable to ODP/IRRC? Or, what level of quality will be returned from these new regs.?

To those who are insured providers, and I say even to the Commonwealth with arms-length management, a human service system may use what is considered an “acceptable” margin of error – that falls into the category “stuff happens” or “nobody’s perfect” or even “there’s always one bad apple.” **You, as the IRRC, have to ask yourselves what quality threshold (critical incidents) is acceptable from a service delivery perspective? Getting it right 70% or 80% of the time?** This is a basic service delivery question. From the Federal data, do you know that critical incidents **are incorrectly reported up to 99% of the time?**(yes, that’s correct, a 1% quality rating)⁰. Or, an example using ODP’s own data (from August 2018 Regional Provider’s meetings which includes Federal investigation in PA) 13 choking while eating incidents are REPORTED each week or 700 in a ~2-year period of which only 30% or 200 were investigated by ODP-certified investigator (also-known-as self-investigation) and neglect was found in 85 which is almost half of those investigated resulting in a 56%quality rating. Yes, it’s virtually a 50/50 guess if the right thing will happen; if the incident is correctly reported; if protocols/regs. are correctly followed. I say 50/50 is overly optimistic.

For the individuals being served and their families, there is no acceptable margin of error. We want zero-tolerance. If a person receives 24x7 supports and staff doesn’t show up, someone will die. If the individual supports plan identifies choking risk and the plan is not followed, someone will die. (Both of these happened with the Provider named at Blossom.) I have had to come to terms with the fact that, statistically, my brother is in the category of “extremely vulnerable” which means it’s almost a sure-thing that he will die of abuse or neglect. And when he chokes (likely, by the ODP regional provider data of Aug 2018 and the “Fatal Four” preventable death synopsis), an un/under trained staff person will start a series of phone calls up through the provider agency. 9-1-1 will not be called (statistically), an ambulance will not be called. Maybe nursing will show up within the hour. More than likely he will die before he ever gets to the hospital. It will be reported as a death. There will never be an autopsy. As his guardian, I might find out about the death within 24 hours, the root cause will never be disclosed. We will get a report if we (families) know to ask for a report, and even then and at the provider’s discretion we will only receive a summary report and the details will be

obscured. I tell you, this is hard to get your heart around. But, this is the reality. This actually happened to my brother Walter in the 1980's. The Commonwealth supposedly fixed the system then. Somewhere in the last 5 years it has unraveled. This is now the most-likely outcome for my brother David.

How do these regs address this scenario, these known facts? Are they enough to move the dial on a 1% quality rating to a 99.9% quality rating? I call your attention to "Accomplishments and Benefits" section of the package, where you will see no improvements in quality for the individual are listed. And, if these regs don't move the dial on quality, should we accept these regulations on the basis of the effective streamlining and "reduced administrative burden" with "significant additional revenue" for the providers? It is a question for you to answer.

2. Who are these regulations for, anyway? Or, how did this process include direct representation of the 53,000 individuals served (in HCBS waiver)?

The above question leads to this next question. Who counts in terms of these regulations? I'm just a simple family member. To me, how the state "counts" comments shows who counts.

This multi-year process was massive, cumbersome and intensive. I have a great deal of respect for all the efforts of ODP, who had to blend multiple systems of regulations and incorporate disparate data from so many providers. But where were the families and individuals and how were they supported to participate? According to the ODP Regulation Packet, public comments were received from 2 individuals, 13 families, 6 advocates, 4 universities, 8 county governments, 4 provider associations, and 291 providers (p 17-19, "Public Comment")⁽ⁱⁱ⁾. If we say there were 1060 provider agencies then there was a 30% participation rate from providers. The number 2 for individuals or 15 (individuals + families) is shocking given there are 53,000 individuals served by HCBS (Reg. package, p4 "Affected Individuals and Organizations") and of which an estimated 30% cannot speak (IM4Q 2016/2017). 73% of people with ID/DD (State of the States) live at home with their families. It just makes me ask a simple question: how were these **primary stakeholders** directly included in this four-year process?

One method of participation could have included lived experience in the form of data on incidents etc. In January 2018, the Feds issued a joint report

(<https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf>) on a “magnitude of danger in group homes.” In August 2018 ODP held regional provider meetings with data from the state (including data from Federal investigation of Pennsylvania). As the final form regulations were issued in August 2018, it suggests that perhaps this data was not taken into consideration. If so, would we have “relaxed” to achieve consensus or would we have used the Federal data as lived experience testimony and given that a priority in the process?

I ask you to consider these two questions in your decision-making process. Regardless of a thumbs-up or thumbs-down outcome, I am suggesting that the IRRC has a continued role to play in the future because surely we have a quality problem that is an order of magnitude beyond what we are disclosing to everyday people. The gaps in quality delivery certainly have their origin, in part, in the regulations. As a family member, and representing an individual served in this system, I trust you to ensure the quality of services to the individuals as well as the administrative efficiency of the system.

Thank you,
Kathryn Fialkowski (Montgomery County PA: 348 Glen Way, Elkins Park)
Sibling of David Fialkowski (Philadelphia County PA)

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[i] US HHS, OIG, ACL, Office for Civil Rights. Ensuring Beneficiary Health and Safety in Group Homes through State Implementations of Comprehensive Compliance Oversight <https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf> Jan 2018

[ii] Final Form Rule-Making, HCBS Services and Licensing, Aug 23, 2018