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Independent Regulatory Review Commission [irrc@irrc.state.pa.us](mailto:irrc@irrc.state.pa.us)

Kristin Ahrens, Office of Developmental Programs [kahrens@pa.gov](mailto:kahrens@pa.gov)

RE: ODP 6100 Final Regulations, IRRC #3160

On January 22, 2015 I was invited to participate as a member of the Chapter 51/6100 Home and Community-Based Intellectual and Disability Services Regulation Workgroup. My perspective for input is as a parent of an adult with an Intellectual Disability and an Advocate through my position as the Executive Director of a small chapter of The Arc working with people with Intellectual and Developmental Disabilities and their families to assure a meaningful life. I have attended most of the workgroup meetings regarding these regulations. My daughter has received wavier services while living at home, and through residential and day programs. She also participated in the workgroup as a self-advocate.

My areas of concern as we worked through the process included:

- individual rights, and process and protections for restrictions related to human rights
- to make sure there was a balance between the needs individuals and families, providers and licensing, with the needs of the individual having priority
- clarity in medication administration process and procedures
- protections for the individual during discharge or transition of services
- amount and type of training needed by staff
- and ultimately that the individual is supported in the least restrictive and most advanced way so their rights and dignity are respected.

As people with disabilities require support to live in the community, it is imperative that we all work together to fine-tune the system to be the best it can be. By WE, I mean people with disabilities; their families, friends, relatives and advocates; the providers of service; the county ID programs; and state program offices. Each party will have a perspective that is different from the others, and as multiple ingredients make a good dish, so will the different viewpoints make an *Everyday Life* a reality. Each person with a disability has a unique set of needs and level of support, therefore these regulations must be general enough to support that spectrum of needs, but specific enough to offer the guidance needed. We will not always agree to how to accomplish this goal, but the ability to voice our unique views ensures those writing and implementing the policies look at the situation from every vantage point.

These regulations are not perfect but are an improvement over the Chapter 51 regulations. It will be critical that ALL stakeholders continue to be at the table to review the guidance that will be required for some sections of the regulations, as well as the effectiveness of the new regulations.

It is also important that ODP continue to strengthen the incident management process so that abuse and neglect is addressed quickly and with transparency, and includes involvement (as appropriate) by the families of the adult individual involved.

I believe these regulations are a big step forward towards that goal and I support their implementation.

Maureen Westcott