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Kroh, Karen

From: Mochon, Julie
Sent: Wednesday, December 21, 2016 8:52 AM
To: Kroh, Karen
Subject: FW: Self Advocates United as 1 - Comments on proposed 6100 Regulations
Attachments: Comments on Chapter 6100 regulations - Self Advocates United as 1.docx

From: Kaye Lenkner [<mailto:klenkner@sau1.org>]
Sent: Tuesday, December 20, 2016 5:10 PM
To: Mochon, Julie
Cc: laurabale0@gmail.com; oscardrummond@hotmail.com; Savannah Logsdon-Breakstone; Ernie Roundtree; Sharon Harper-Young; Regina Richmond
Subject: Self Advocates United as 1 - Comments on proposed 6100 Regulations

Hi Julie,

Thanks to you, Karen and Denise for your time last week.
It was greatly appreciated.

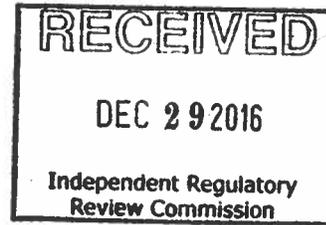
Attached are the comments from SAU1.
Please let me know if you have any questions.

I look forward to hearing more about all of the comments in January.

Happy Holidays!

Kaye Lenkner
klenkner@sau1.org
Operations Manager
Self Advocates United as 1, Inc.

Our mission is to support the self advocacy of people with disabilities for positive impact in our communities and in people's lives.



Comments on Chapter 6100 regulations

Proposed Rulemaking

Self Advocates United as 1, Inc.



Self Advocates United as 1, Inc. is a group of people with developmental disabilities with a mission to support the self advocacy of people with disabilities for positive impact in our communities and in people's lives.

Self Advocates United as 1, Inc. appreciates the PA Department of Human Services' and the Office of Developmental Programs' efforts to tackle the updating of these regulations and the efforts to involve stakeholders, including several self advocates and family members, in the work of the update.

Our current leaders are 10 people who experience intellectual disabilities and/or autism, including Oscar Drummond, Carolyn Morgan, Laura Bale, Lori McFarland, Steve Dorsey, Khalil Hills, Ernie Roundtree, Matt Stinner, Larry Kubey, and Savannah Logsdon-Breakstone. Our current staff includes 3 self advocates and 4 family members. The impact of our communications of newsletters and teleconferences includes hundreds of self advocates across the state, and in our 10 years of work we have heard from thousands of self advocates about what they want and need in their lives.

Our comments below reflect the opinions of our 10 leaders and our 4 staff members, and our best understanding of the views of the thousands of self advocates with whom we have interacted over the years.

- 1) Training for all staff, even those who do not have physical contact with individuals, and volunteers is critical to the safety and wellbeing of all people who may receive supports. Cultural competency, person centered thinking and planning, abuse identification and reporting responsibilities, and individual rights are all extremely important. Positive intervention must be included as training for anyone.
 - a. In regards to 2390.49 Annual Training section (b) (3), (4), (5): These specify "who work alone with individuals". Please adjust this to ensure that not only those who work alone, but if working with others someone have the required amount of training. Otherwise it could be 2 volunteers neither of whom have training.

- 2) The expansion of individual rights is vital and must be kept. Every self advocates is as deserving of his or her individual civic rights as any other citizen of our state, and human rights we all expect.
 - a. Please add the following civic rights:
 - i. the right to free assembly
 - ii. The right to complain to, and seek help from, the government

- b. Negotiation of choices: We recognize the value of a process of individuals with differing views to negotiate choices to minimize the potential violation of another's rights. We feel the procedures of the provider around negotiation should be clearly defined and explained to the individuals involved and suggest that negotiation training is made available for the provider's staff. Providers (including life share providers) should facilitate the "home" rulemaking as a group effort with everyone involved, every time someone new enters or leaves the home.
 - c. We are concerned that the informing and explanation of individual rights annually is insufficient. We recommend that a review is done on a more frequent basis, such as monthly. In fact this reinforcement would benefit the provider staff as well.
- 3) We prefer the Person Centered Support Plan (PSP) and much of the content.
 - a. Dangerous behaviors must be clearly identified before the consideration of rights modification is addressed. This is vague; smoking is a dangerous behavior; drinking is a dangerous behavior; dating can be a dangerous behavior. The definition of dangerous behavior must be clearly defined and caution must be used to not include the possible moral judgements of the provider or family. The person receiving support must be included in the discussion of what is considered dangerous behaviors and why it is considered dangerous. He or she must be educated in the potential consequence of the dangerous behavior and if in agreement, in the solutions developed in the PSP to reduce or manage the dangerous behavior.
- 4) Use of positive intervention:
 - a. Again the definition of dangerous behavior must be clearer. "An action with a high likelihood of resulting in harm" can apply to so many things. It could include physical acts but also those acts which could lead to legal consequences (theft, harassment, etc.).
 - b. We are in agreement with the prohibition of all restraints.
- 5) Facility Characteristics: We fully support all aspects of the physical environment that support the person to feel their place of living is their own home.
 - a. Must keep lock and a key for their home and bedroom
 - b. Must keep lease and ownership
 - c. Reasonable limits for furnishing and decorating must be more clearly defined. We visit many group homes that look like a model home for a decorating magazine, not a place where people actually live.