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Self Advocates United as 1, Inc.
Supporting the self advocacy of
people with disabilities for positive impact since 2007

October 12, 2018

Fiona Wilmarth, Director of Regulatory Review
Independent Regulatory Review Commission
14th Floor
333 Market Street
Harrisburg, Pennsylvania 17101

RE: Self Advocates United as 1 Comments on IRRC Regulation # 3160 and
DHS Regulation # 14-540, titled "HCBS and Licensing."

Dear Director Wilmarth:

Self Advocates United as 1 (SAU1) is a Pennsylvania non-profit with a mission to support the self advocacy of people with disabilities for positive impact in our communities and in people's lives.

Founded in 2006 by people with developmental disabilities, incorporated in 2013, and independence gained in 2015, SAU1 continues to grow in membership and involvement of people with disabilities with a focus on those with intellectual disabilities and/or autism. Our Board of Directors are all people with disabilities and our staff are people with disabilities or family members. We come from 15 counties across the Commonwealth. Most receive supports and services through the PA Office of Developmental Programs, Department of Human Services.

We fulfill our mission in large part through peer empowerment events and activities to support self advocacy in nearly every county of the state. We reach, talk with, and most importantly, listen to over a thousand self advocates each year. They tell us the same things - the desire to be in control of their own lives. They want their civil and human rights respected. They want meaningful relationships that they themselves choose. They want to communicate in the way that works for them. Most want to live in their own home with the people they choose. The statistic that most people live with their families is true - but the real question that needs to be asked is how many WANT to live with their

Main office: SAU1, 428 S. Main St, Suite 2, Greenville, PA 16125
East Office: SAU1, 718 Arch Street 6N, Philadelphia, PA 19106

Anytime Message Line
724 588 2378



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families. The answer when we ask that question is that most yearn for a home where they get the supports they need to live independently of their family.

We gather and share the messages of the people we meet at regional and statewide coalitions, government advisory committees, councils, and other groups. Our members have testified at state hearings and at the public hearing for the closing of Hamburg State Center. The views and opinions of people with disabilities must be heard when decisions are made about our lives.

Many of our members were involved firsthand in the process of the writing of the IRRC Regulation #3160 and DHS Regulation #14-540, titled "HCBS and Licensing", and many others participated in review and commenting. From the first day of working on the regulations, then Deputy Secretary Steve Suroviec made it clear that the voice of self advocates was to be at the table, respected, and listened to, and Deputy Secretary Nancy Thaler continued to promote that practice. We appreciated the PA Office of Developmental Programs' commitment throughout the long process to inviting input from, hearing from, and considering the views of, all stakeholders including family members, providers, supports coordinators, agencies, and most importantly, self advocates themselves.

The messages we shared, and the basic human and civil rights for which we advocated, were often met with strong resistance by other stakeholders. This was not surprising to us. For far too many years, our rights have gone unrecognized by many of our families and providers under the guises of "for our own good" and "for our safety". The current statistics of abuse and neglect of people with disabilities, often by the very people who are supposed to be caring for them, clearly show that many have not been "safe", and neither are most "good". The increase in what is termed "behaviors" we know firsthand to often be communications that life is not good, and yet it is the behavior that is addressed, not the underlying issues.

These regulations are about the quality of our lives first and foremost. They will move PA closer to recognizing and respecting the individual civil rights of people who are full citizens of the state and this country. Don't allow us to continue to be treated as lesser beings because of our disabilities.

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SAU1 fully supports the IRRC Regulation #3160 and DHS Regulation #14-540, titled "HCBS and Licensing.

Sincerely,

Laura Bale, President of the Board - Montgomery County

Board members:

Oscar Drummond, Past President and Founder - Philadelphia

Frances Keeny, Treasurer - Cumberland County

Maria Martin - Westmoreland County

Lori McFarland, Secretary - Bucks County

Carolyn Morgan, Founder and past Vice President - Philadelphia

Ernie Roundtree - Monroe County

Matt Stinner - Dauphin County

SAU1 statewide Staff:

Evan Anderson – self advocate - Mercer County

Renee Benise - self advocate - Blair County

Christine Breakstone - family member - Venango County

Teri Brewer - family member - Delaware County

William Brewer – self advocate - Delaware County

Paul Fogle - self advocate - Lebanon County

Josh Harper – self advocate - Philadelphia

Sharon Harper-Young - family member - Philadelphia

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John Knorr – self advocate - Blair County
Gretchen Laudenslager - self advocate - Bucks County
Angie Lavanish - family member - Blair County
Kaye Lenkner - family member - Mercer County
Nekody Lenkner - self advocate - Mercer County
Savannah Logsdon - self advocate - Venango County
Sam Maxwell - self advocate - Crawford County
Chris Moore – self advocate - Philadelphia
Regina Richmond – family member - Mercer County
Grayson Rumsey – self advocate - Allegheny County
Gabriel Smaglik – self advocate - Luzerne County
Matt Smith – self advocate - Mercer County
Matt Venturini – self advocate - Allegheny County
Robert Zotynia - self advocate - Luzerne County

cc: Tom Wolf, Governor

Devon Grant, Executive Director, Governor's Cabinet and Advisory
Committee for People with Disabilities

Gene Digirolamo, Human Services Majority Chairman, House of
Representatives

Angel Cruz, Democratic Chair, House of Representatives

Teresa Miller, Secretary, Department of Human Services

Kristin Ahrens, Acting Deputy Secretary, Office of Developmental Programs

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