Association for Individuals with Intellectual Disabilities

(Formally Woodbridge Developmental Center Parents Association)
PO Box 4605
Metuchen, NJ 08840
assoiciation4iid@gmail.com



To: Chairman Steve King

U.S. House Committee on Judiciary Subcommittee on Constitutional and Civil Justice

Re: March 6, 2018 Hearing – Examining Class Actions against Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IDD)

Class action lawsuits have been a nightmare for individuals with intellectual disabilities residing in ICFs in NJ...... A nightmare that has caused many individuals with ID to lose their lives.

I am the sister and guardian of a profoundly intellectually disabled 63 year old sister and the president of the Association for Individuals with Intellectual Disabilities, formerly the Woodbridge Developmental Center Parents Association in NJ. Due to a settlement agreement between the state of NJ and NJ Protection and Advocacy, the state of NJ agreed to move 600 residents form NJ's ICFs in 5 years. The governor established a Task Force and two ICFs were closed in 2 years. Mortality rates which were typically 2% per year in NJ ICFs soared especially for the individuals with the most severe and profound disabilities.

The closure process for my sister's home at NJ's Woodbridge Developmental Center (ICF) had a dramatic and tragic impact on the individuals from the ICF and their families. They are not "resilient to change" as some de-institutional advocates would like you to believe. They got sick, had more seizures and many passed away. There were 27 deaths at my sister's ICF in a 3 year period between the announcement of closure in July 2012 and June 2014. This is an increase from the typical 2% mortality rate to 28%. But for those in my sister's cottage #18 where some of the most impaired were living the death rate actually doubled.

I ask the Committee to take two steps to protect the choice of families and guardians and improve the quality of care:

- (1) Require DOJ to Initiate a comprehensive investigation into the cause of the unspeakable number of deaths occurring across the country and suspend activities aimed at displacing fragile Americans from licensed ICFs/IDD in good standing, (see Chairman Goodlatte letter to AG Sessions, 12-6-17) and
- (2) Require DOJ, under its authority and P&A advocacy attorneys, in Rule 23(b) (2) class actions, to respect the right of choice under *Olmstead* by surveying the wishes of the families of ICF residents *before* deciding whether to bring a class action and, if they do bring a case, respect the wishes of the families as to whether they want their loved ones to be part of the action.

ICFs/IID play a vital role in providing life-sustaining services to America's most intellectually disabled citizens and vindicate the choices of the families and guardians with I/DD in class action suits, as clearly required by ADA and Olmstead, and encourage the administration to work with the states to put an end to the systemic problems in group homes that threaten serious harm.

Thanks you for this opportunity to submit comments and requests on federal policies which affect our families and citizens.

Respectfully submitted,

Joanne St. Amand, President
Peter Banos, Vice President
Robert St. Amand, Treasurer
Michelle Grossmann, Assistant Treasurer
Patricia Bixel, Executive Administrator

Association for Individuals with Intellectual Disabilities P.O. Box 4605 Metuchen, NJ 08840

(732) 259-7960 Jrst.amand@verizon.net