

I object to the Executive Budget Proposal to downsize Intermediate Care Facilities (ICFs) which will significantly impact the continuum of services available to individuals with intellectual and developmental disabilities (IDD).

I am a parent of an IDD individual and member of Disability Advocacy Alliance (DAA).

DAA has learned that the Department of Developmental Disabilities and the Intermediate Care Facility (ICF) provider associations have reached an agreement to remove the most punitive measures to ICFs from the Executive Budget. I am relieved that reasonable minds have prevailed and the health and safety of our loved ones has been protected for now, but our concerns are not fully addressed.

Families and guardians were not included in these negotiations and we want to make clear that we strongly disagree with the ICF downsizing and conversion benchmarks which have been newly inserted into HB 64. These are ramped up goals from the "Grand Bargain" from which families and guardians were also excluded. The goals do not reflect the widespread perspectives of caring Ohioans. In only five weeks, nearly 20,000 petition signatures from families, guardians and friends of the developmentally disabled were lodged with the House Finance Committee on Health & Human Services objecting to the closing of large ICFs. To ignore the perspectives of these constituents - especially families and guardians - and to pretend this bargain was "grand" is wrong. It does not reflect the health, safety and quality of life needs of residents which parents and guardians hold as primary. Certainly, the deafening silence of phone calls and testimonies from guardians asking for residents to be transferred from large ICF homes should ring loudly in lawmakers' ears.

With respect to the benchmarks, their very nature wantonly defies individual choice and need, the hallmarks of *Olmstead* and the Americans with Disabilities Act (ADA). To buffer ICF residents and taxpayers from the ill-effects of these risky and financially costly targets, DAA asks that the following common sense policies be put in place:

- Verify the wishes of the alleged 2,500 ICF residents on wait lists for waivers by contacting the guardians of these individuals in writing. This statistic is unfairly used as an excuse to convert ICF beds to waivers. It is common knowledge that guardians of ICF residents have long forgotten their loved one is on a wait list or have them on the list to insure against the possible closure of ICFs due to the regular attacks on the ICF program. Guardians should respond in writing if they are happy with current ICF placement or prefer a waiver or a smaller ICF setting.

Please note that state funded Advocacy & Protective Services, Inc. (APSI) guardians must produce an individual certifications of residential need to guard against blanket treatment of their wards, 1,458 of whom reside in ICFs.

- Provide yearly reporting on the effects of the downsizing and conversions which detail health status of residents, including deaths; unexpected hospitalizations and other unusual incidents; the frequency of licensed nursing contacts; the frequency of therapy services; the extent of community integration including employment and the number of recreational outings and quality of them; the psychological well-being of residents; the satisfaction of guardians. This information is already collected during quarterly and yearly Individual Habilitation Plan (IHP) meetings.

Reporting should also look at the fiscal health of ICF providers and the ability for providers to continue to maintain the level of services as cost-effectively as prior to the Grand Bargain. This fiscal review should include flagship ICF settings as well as smaller ICF and waiver settings.

DODD and providers must be willing to halt downsizing and conversions if ill-effects outweigh benefits to protect ICF residents, taxpayers and citizens on DODD wait lists; individuals on wait lists may become crowded out of services as the inherent inefficiencies of smaller settings cause DODD system costs to increase.

The nearly 20,000 petition signatures collected by fellow parents and family members was fueled by love and concern for our children. The power of parental love can achieve remarkable outcomes. Nothing speaks with more care. We are sure you have experienced this in your own lives. DAA simply asks that parental love and the authority which follows is respected by all parties so that decisions which affect the well-being of our children desist from being made without our input.

Respectfully submitted,

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