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Old Lyme, CT
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S.B. 463 AN ACT CONCERNING THE DEVELOPMENT OF A FACILITIES AND
RESOURCES PLAN FOR PERSONS WITH INTELLECTUAL DISABILITY

I am a parent of a young man who has an intellectual disability (ID), the Department of Developmental Services (DDS) Regional Advisory and Planning Council Co-chair for the south region and a CT DDS Families First advocate. I fully support the original intent behind this bill as that concept came from a discussion a few advocates, myself included, had with several legislators. The original intent was for a task force to come up with a thoughtful plan to properly care for two segments of the ID population, as it is currently lacking: those with ID and mental health issues (5-10 are in the ER each week according to DDS) and the aging population with more complex issues such as Alzheimer's. The bill as it is currently written does not reflect the original intent. DDS families need a work group/ task force that will bring the stakeholders together to put forth an appropriate and thoughtful plan similar to what the Medical Assistance Program Oversight Committee, under Public Act 16-142, is doing through their Developmental Disabilities Work Group.

I respectfully request that more appropriate language be substituted to reflect this bill's true intent. The testimony in opposition to the bill reflects the current bill language. In a recent conversation with the Arc of CT's Director of Advocacy and Policymaking, she agreed that we don't have a plan in place for these two segments of the population and wondered if the ID Partnership would be able to assist with a plan.

As the Public Health Committee knows, DDS puts forth a five year plan for the agency. Families felt that the most recent plan was lacking substance. It calls, in part, for the future of DDS planning to be done by those appointed to the ID Partnership. There has been no input from families appointed to the Partnership and no transparency. SB 246 passed unanimously in both chambers last session and called for the ID Partnership to have better representation of the many clients DDS serves and their needs. As of this date, that has not occurred and

there is no statute requiring an ID Partnership. DDS has had three commissioners in five years and the upcoming election could result in a new commissioner. DDS families have brought many issues/needs for consideration to the Public Health Committee in the past three years: the need for better communication to families from the department (SB 294), real data on the residential waiting list (SB 246), a pilot for an array of residential models (SB 296), mental health issues (SB 463) and grad funding (SB 400). There needs to be an overall robust plan to serve the DDS clients and their families. Until then, we will continue to address the needs piecemeal through legislation. I hope this committee will allow the true intent behind this bill to pass with a language change and the work group/task force can put forth a thoughtful plan to give DDS families an answer to two of these unmet needs.

Sincerely,

Lauralyn Lewis