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32nd Ohio Senate District

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Senator Capri S. Cafaro- Interested Party Testimony HB 483- DODD MBR Senate Finance Committee May 24, 2016

Chairman Oelslager, Vice-Chairman Coley, Ranking Member Skindell, and members of the Senate Finance Committee. Thank you for allowing me to provide testimony on HB 483, the Department of Developmental Disabilities MBR.

Last year, more than 100 families and nurses stood before the Senate Medicaid Committee to express the necessity to keep open the doors of both Youngstown Developmental Center and Montgomery Developmental Center. Families spoke of the devastation they felt at the thought of their loved ones being moved away from them, in most cases, too far to visit often or at all. Nurses spoke of the implications of moving developmentally disabled people from their home, the place they had lived happily and safely for years, to group homes with new people and new staff who would have to learn their specific needs. The theme was the same across the board. These families and nurses feared for the lives and well-being of their clients and loved ones.

The Senate Medicaid Committee listened to hours of testimony and saw the possible implications these closures could have. A closure commission for developmental centers, modeled after mine and Senator Schiavoni's dual sponsored bill (SB 62), was added to the budget in the House and kept by the Senate. Governor Kasich, on the other hand, did not see the implications of these closures and chose to line item veto the commission.

Approximately one year after Youngstown Developmental Center (YDC) received notice they were to close in 2017, almost 60 patients have been moved to group homes. **Five patients, all described to be in good health prior to their move, have died within months of being removed from their home at YDC.**

I have gathered stories from staff and families of the Youngstown Developmental Center. I would like to share these stories with you today.

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Client One: 84 year old client that should have been the last to leave was moved in early November. She was a very, very severe case (non-verbal, very frail, osteoporosis, etc.) The group home planned to move her around in the new home to off ground support centers. The new group home said that they could not stay in the house all day with her so she will need to be moved from her house to workshops, doctors etc. They also planned to move her with a lift. She needed to be picked up like a baby. She was too frail to be moved with a lift.

Current Status: Deceased --This client died less than one month after leaving YDC. She essentially died of starvation. She needed one-on-one feeding, four times a day which could sometimes take up to an hour but group home staff would not do this.

Client Two: 67 years old client was confined to a wheel chair, uses a feeding tube, and catheter. She was in good health prior to leaving YDC. She had lived at YDC for thirty years. After two weeks in the group home, she was in and out of the hospital and then ultimately ended up in a nursing home because the staff couldn't care for her.

Current Status: Deceased-- This client died about five months after leaving YDC.

Client Three: When a YDC staff member was at the hospital, they heard a familiar voice and found that one of their former clients had been dumped off at the door. Group home staff does not get paid to take clients to the hospital so they simply left him. He needed heart surgery.

Current Status: In Hospital-- The group home didn't watch after him enough and he is back in the hospital.

Client Four: This client requires daily seizure medication. Per YDC Staff, it was difficult to get her to take it but they made it work even if it took hours. Group home staff couldn't get her to take her medication. The group home was advised by physicians to call YDC to get advice on how to make her take them. The group home never called.

Current Status: In Hospital – Group home staff has not found a way to give the client her medications.

Client Five: This client requires catheters every day. The group home he was sent to did not want follow this treatment, so they stopped.

Current Status: In Hospital-- He is now in the hospital and the prognosis is not good.

Client Six: Once clients leave YDC, they are not supposed to have any contact with them. Group homes staff came back to YDC to ask for help transporting this client to group home because they could not get them to go. He wanted to stay at YDC.

Current Status: In Another Developmental Center—This client was blacklisted by the group home he was to be sent to (which is rare and bad for the group home) and is now in a developmental center elsewhere.

In the month of May: Six total residents have been/will be moved out of YDC. Of these six, one needs to be tubed and is in bad health and another is severely asthmatic. YDC staff stated if they are not being given the same level of care they are receiving at YDC they will die in a month or less.

YDC started with about 92 clients when they were told they would be closing. They are now down to 34 clients with a year left before they are to close their doors forever.

These stories are truly a travesty and the worst part is that we warned this could happen. We were warned and we were not able to stop it. This is our second chance to make right what should have been done in the first place. This is our chance to potentially stop the untimely deaths of our most vulnerable citizens.

In light of this information, as well as in response to House Bill 483, I support the following four amendments.

SC0035: This amendment places a moratorium on DD transfers until the closure report is complete. It is my hope that we can prevent more innocent lives from being lost until we are sure what the repercussions may be.

SC0038: This amendment adds that in addition to the House Leader, the Developmental Center Closure Report is also sent to the Senate President, as well as both Minority Leaders. It seems as though this may have just been a drafting error in the House version, but we would like to ensure that all parties are able to read the report in a timely manner.

SC0037: HB 483 requires that MR/DD personnel must be able to read and write in English. There is concern that this could negatively impact certain centers, like the DD center in Columbus that serves a large Somali population. The amendment changes the requirement to have fluency appropriate to the "population that they serve". It also requires the MR/DD personnel to have cultural competency training to ensure the best care for all Ohioans.

SC0036: This amendment requires the Department of Developmental Disabilities to study the waiting lists for home and community-based services provided by the county boards. The study would be broken down by county and would include information like how many individuals are on the waiting list for each waiver, their average ages, and how long they have been on the waiting list. It could also include any other information the department deems important.

I think that we have seen the unfortunate consequences of what happens when don't fully research, review, and understand changes made to policies that directly affect this incredibly vulnerable population. The results of the changes made to the Youngstown Developmental Center should show us that we cannot take risks with their lives. I ask you to support these amendments in hopes that we can protect the DD population. Thank you for allowing me to testify on behalf of HB 483 and I would be happy to answer any questions you have at this time.