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My name is Penelope Barsch and I am from Meriden. Thank you for the opportunity to submit comments on the draft five-year plan developed by the Department of Developmental services. While I am pleased to know that the department has identified goals for the agency, it is more important than ever that DDS address the specific real-life needs of the individuals served by the department.

As a parent this plan is critical to the future health and wellbeing of my son. Ensuring that our loved ones live in a supported and inclusive community environment is essential and the programs and services developed by the DDS must reflect this approach.

Our voices provide important feedback and highlight the need for additional resources.

The story of my son and myself at his former group home are truly frightening. The most recent incident was when he complained of right-side pain for a week and was encouraged and one day, forced to go to day program. His communication is limited. He used his iPad to facetime my sister and myself to ask for "911". I went immediately to the ER where the agency said he was going. Rather than brining him right away, they took him on the run to bring others to day program and he arrived 2 hours later. He was not diagnosed at the ER even though he had blood in his urine. A few days later he was sent by ambulance to the hospital. He had sepsis from a kidney stone. He had emergency stent placement and then was in the critical care unit. Because I was part of a federal lawsuit to allow family in the hospital, I remained with him for his weeks stay. He then went to Apple Rehab because of the inability of Mosaic to care for him.

My challenges with advocating for my son with Mosaic were so very troubling. So many substantiated cases of neglect. Investigations took so long to complete and give recommendations. Refusal of the agency to accept recommended supports from DDS after a PAR. I was treated with

such disrespect by management. The horrible story is documented with communication to DDS. DDS was responsive but they seemed to have limited ability to impact my son's MAR, IP and behavior programs.

I realize the pandemic has had an impact on all. This was not a matter of staffing. This was a matter of an agency not wanting a knowledgeable parent to advocate and monitor the supports which were agreed upon. No parent should have to go to the lengths I did without assistance from an advocate to intervene.

My son transitioned to a new agency on Friday from Apple Rehab. RMS agreed to accept him and are awaiting his personal items from the former agency. There was no offer from Mosaic to help demonstrate transfers of my son who is fully dependent and requires to use of many different types of equipment. It has been a nightmare for the past two years. Somehow DDS needs to reprimand

I am guardian for another individual and have never had challenges with advocating and ensuring his health and happiness. There needs to be more oversight and advocacy support for families. Both my son and the man I am guardian for are in day programs which are supportive and kind.

Thank you for the opportunity to comment. I look forward to your feedback, seeing the revised plan and the opportunity to work together in this process.

Penelope Barsch