

My name is Adrienne Benjamin, I live in New Britain with my husband and 20 year old daughter who has severe intellectual disabilities as well as autism. My daughter attends the DDS Newington Respite Center for long weekends. It is a wonderful resource for our family, with consistent, excellent staff. I know she's safe there, and we enjoy a break for 4 weekends a year.

I have served on the Council for Developmental Services for the last few years, and am currently the Chair. I am submitting my opinions, not those of the Council. I feel fortunate to have gotten to know several members of the DDS leadership from my time on the Council, and I feel compelled to say they are exactly the type of people I would want to head DDS. I find them dedicated to the DDS population, very knowledgeable, hardworking and determined to keep moving forward, despite the numerous obstacles facing the agency.

The Five Year Plan leaves me with several serious concerns. (As I say this, I do realize that a lot of work went into this, and that it's an enormous undertaking). A 5 Year Plan, is a way for DDS to identify areas to improve, and chart a future path. But, equally important is the task of informing the Legislature about the very significant obstacles facing DDS families. It is an opportunity to tell the painful truth about the lack of essential services facing over a thousand of our families. While the report does explain many areas of progress over the last 5 years, it falls short in making clear the urgent needs of so many people the agency needs to serve.

Specifically, it states that there are 657 people who are either on the Emergency or Priority One Waiting List for residential services. Yet, after stating that very alarming fact, there are no real details given about how to address this. For example, it would be helpful to delineate the number of Emergency situations from the Priority Ones. (Yes, these numbers are not static, but in my mind, an "Emergency" is not the same as a "Priority One", and should not be treated as such.) In addition, it would clarify a lot if the Level of Need and the ages of the parents for these 657 people were illustrated in a graph or chart. This would help identify the number of families with the most desperate needs, as well as identify the number with far fewer needs. A similar approach was taken a few years ago when the Legislature committed 4 million dollars to provide residential services to over 100 families whose parents were age 70 and over.

I received the following official DDS data from October 2016. There are 13,551 DDS eligible people for whom DDS has LON information. I constructed a simple graph that divides this universe of DDS eligible people into two groups. The graph shows that the Level of Need (LON) of the smaller group (5169) is lower, between 1 through 4, while the larger group (8382) has a higher LON, between 5-8. Of course, every individual is unique and the LON is a broad assessment tool, but it's clear that a large majority of our family members have quite significant LON's. I feel it's important for the legislators to understand this. I have shared this graph with DDS leadership and I hope they include it, or a similar one in the 5 Year Plan, as it make the situation facing DDS families clearer. There are another 3000 DDS eligible people who do not yet have LON scores for a variety of reasons, so the graph does not reflect those needs.

I also think the 5 Year Plan needs to remind the legislature that each July, for the foreseeable future, there will be approximately 300 graduates who will need day services. This has been a serious crisis for the last 2 years, with families frantic about obtaining funding for their child's services when they finish school at age 21. As with the people on the residential waiting list,

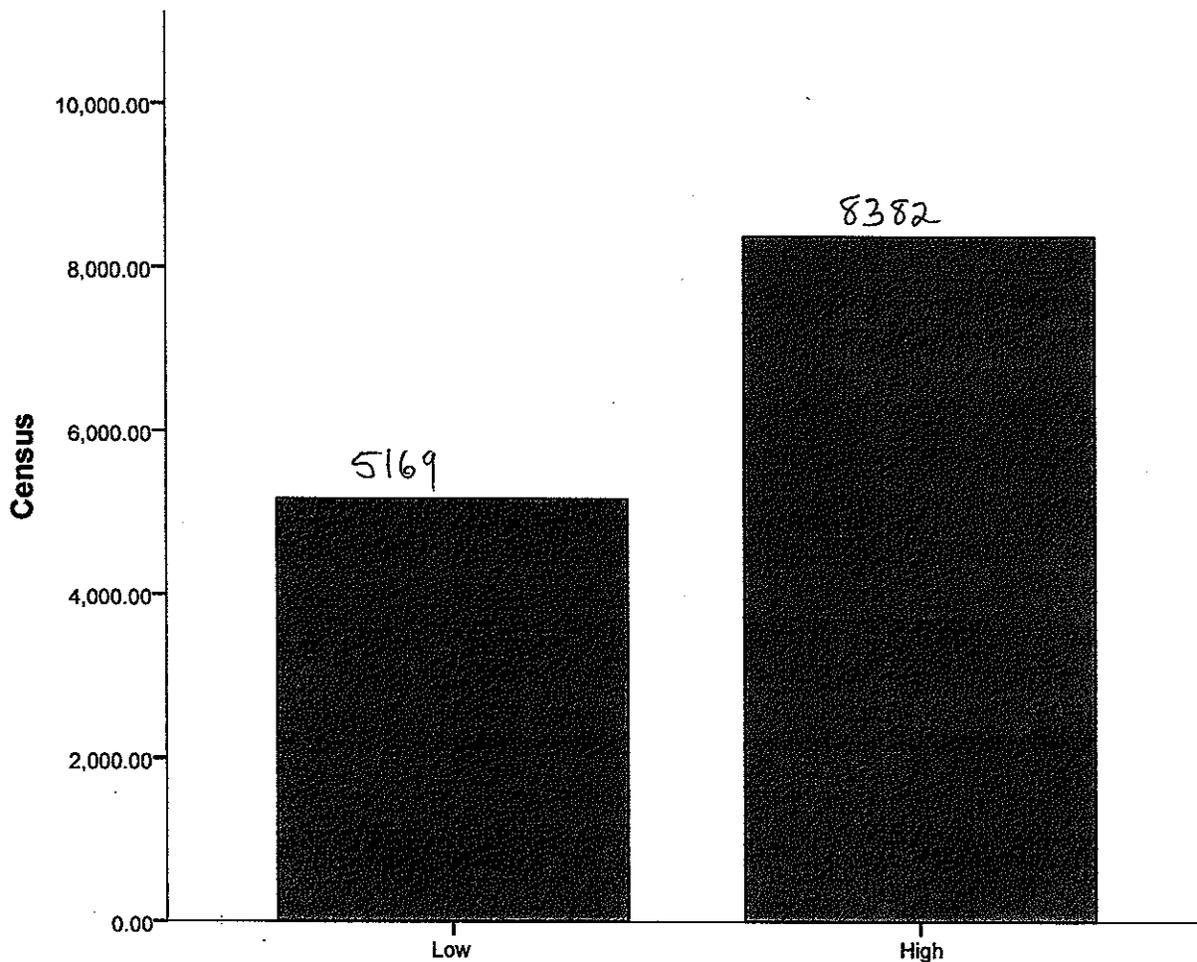
some will have quite modest needs, while others will need intensive day supports. DDS has the LON's for each graduate and could give an estimate about the resources that will be needed during the next 5 years.

There are several graphs on page 8 and 9 which illustrate positive outcomes for those receiving DDS services. This is very encouraging to see, and I'm glad those graphs are included. But, due to the lack of a corresponding graph illustrating the numbers of people who do not have access to DDS services, it paints a distorted picture. It's essential to tell the whole story, and I hope this information is included.

I understand that informing the Legislature of the serious needs facing DDS families is no guarantee of obtaining these resources. However, Legislators always have many issues to address and how can they make an informed decision without clear information about the very difficult situation facing a significant number of Connecticut's DDS families?

Thank you for the opportunity to give feedback.
Adrienne Benjamin

Low (1-4) versus High (5-8) LON Census 2016



These numbers are based on 13,551 DDS individuals
(There are another 3174 who don't have LON scores yet)

DDS LON #s as of Oct 20, 2016

Unofficial GRAPH made by parents: Adrienne Benjamin + Steve Horowitz

12/5/16