

DDS Five Year Plan Testimony
CT DDS Families First, Inc.
by
Richard D. Rothstein
December 2016

Good afternoon, Commissioner Murray, Deputy Commissioner Scheff and the DDS management. Thank you for all that you and the staff and provider agencies do for families. Thank you the opportunity to offer comments on the draft of the DDS Five Year Plan for 2017-2022.

My name is Richard Rothstein, I am the father of and plenary guardian for Spencer, a 33 year old son with intellectual disability, autism and a variety of complex medical issues. Spencer has been in DDS licensed residential programs of HARC, Inc. since the age of 8. Our family is very appreciative of the supports that Spencer receives through DDS in his home and at his day program.

As I believe you all know, I have been actively involved in the advocacy movement since Spencer was diagnosed as a very young child. I have also served in leadership and various professional capacities over these years. At this time, I serve not only as Treasurer of CT DDS Families First, I am the vice chairperson of the DDS North Region Advisory and Planning Council, have attended all meetings of the Council on Developmental Services during the past year.

Today, I am speaking on behalf of CT DDS Families First, a 501(c)(3) independent nonprofit organization formed and operated entirely by parents, grandparents and siblings of those with intellectual and developmental disabilities.

Our goal is to educate and advocate, working closely in partnership with families, other advocacy, educational and provider organizations, the administration, legislators (including the I/DD caucus) and the general public. Besides the overall funding level of DDS, our primary focus has been on the waiting lists for services, particularly the residential waiting list.

Families First is very supportive of DDS and its management and like others, we recognize the need for continued evolution of the agency. However, we strongly believe in DDS being a separate agency dedicated to the policy, monitoring, case management, and providing of services principally through contracting with private non profit providers.

For years, it has been recognized that DDS faces enormous challenges in meeting the needs of all of those it is legislated to serve. These challenges have only been made greater by the fiscal issues that the State of Connecticut as a whole has been and apparently will continue to face. Total spending has been, at best, flat – and Federal dollars received through expansion of waiver programs continue to replace state taxpayer dollars. These have been opportunities lost to expand services without increasing state dollars expended.

Without question, in the current and most recent fiscal year, DDS management resources have been additionally stretched to deal with the OIG Report, closure of two out of five regional centers, conversion of more than half of the state operated CLA's to private providers.

The preparation of a Five Year Plan for any business, organization or agency is a daunting task. This is made more difficult by the current fiscal environment. However, we feel it is vital to include in the plan the needs of our residents so that we can focus attention of the legislature and the public on finding ways to serve these needs within our resources.

The DDS Five Year Plan draft is, in our view, very broad and general, lacking many of the specifics that are necessary to be a plan which will help guide all of us, including families and the legislature, to the future of DDS. We received the same comment about the plan from several people - "It seems to be a plan to make a plan". Another frequent comment "What is in this plan to give us hope, particularly for residential services?"

Our view (after reviewing Section 17a-211-attached) is that there are critical elements that must be included in revisions to the plan before it is finalized.

Most significantly of these is that the plan does not address what is required for the plan

under Section 17-211(a)(6) – which requires that the plan “estimate the type and quantity of staff and client services that will be needed over the life of the plan”. How many new graduates will be in need of day programs? How many and what type of residential services will be needed? How many will require respite services, family support grants or behavioral health services? How many individuals will age out of DCF or educational placements? What will the changes be in the numbers of those at Southbury Training School and the three remaining regional centers. Some of this information is fairly easy to estimate. Others, particularly the need for residential services, require the implement of a census to gather additional information. When will all these services be needed? How many will no longer need services or need different ones.

Admittedly, we are in a very tight fiscal environment. This information is vital in order to set appropriate priorities within DDS within our appropriated funding. It is vital to assist others including the legislature to prioritize the core services of DDS in the overall budget of the State of Connecticut.

We believe that the administration's creation of the ID Partnership between DDS, DSS and OPM is an important strategic step for serving those with intellectual and developmental disability in the future. We understand that the ID Partnership has already been created, committees and subcommittees have been formed, members have been appointed, and that some meetings have already taken place. Representation of families on these committees and subcommittees should be in significant numbers should and come from a broad spectrum of advocacy groups and families including those with differing levels of need and experience. We need a service system for the future that meets the needs of all.

Specific action steps and timelines should also be reflected in the plan for the work of the ID Partnership. A high level of transparency about the meetings, plans, etc. of the ID Partnership is vital.

A recent project within DDS alone included only one family member in a group of

approximately ten. It is our belief that better results will be achieved more quickly with more significant and diverse family representation.

The Council on Developmental Services and the Regional Advisory and Planning Councils should also be employed and made a more integral part of the agency's various planning and project efforts.

We also encourage a very high level of transparency in the function and activities of DDS, the ID Partnership and improved regular communication to the advocacy groups, councils and, of course, families.

Additional strategies, action steps and timelines for dealing with the challenges we have today, at least on a short term basis. What can we do now to reduce all of the waiting lists for services.

Since the plan covers a five year period, although not required by statute, we would suggest that some type of periodic update status be used to keep all informed of progress, problems in achieving the goals of the plan.

We look forward to working closely with DDS in any way that we can be helpful. Families First and the individuals and families that we meet and have contact with day in and day out, want a strong DDS service system for the future, one that offers a continuum of options. Let's work together to do what it takes to make that happen.

Again, thank you for your time

Sec. 17a-211. Five-year plan. Public hearings. Submission to legislature. (a) In 1991, and every five years thereafter, the Department of Developmental Services shall develop and review a five-year plan in accordance with this section. The plan shall: (1) Set priorities; (2) identify goals and objectives and the strategies to be employed to achieve them; (3) define the criteria to be used in evaluating whether the department is making progress toward the achievement of such goals and objectives; (4) identify changes in priorities, goals, objectives and strategies from the prior plan; (5) describe and document progress made in achieving the goals and objectives outlined in the prior plan; and (6) estimate the type and quantity of staff and client services that will be needed over the life of the plan.

(b) Every five years, the department shall hold public hearings on a complete draft of the plan and, in January, 1992, and every five years thereafter, the department shall submit the final plan and a transcript of the public hearings to the joint standing committees of the General Assembly having cognizance of matters relating to public health and appropriations and the budgets of state agencies.