

From: [Brita Darany von Regensburg](#)
To: [Carvalho, Joseph](#)
Cc: [aut/ Darany,Tibor](#)
Subject: Friends of Autistic People- FAP- Re: COPY of Testimony for the DDS Hearing (Please ignore preceding email submitted just prior to this one)
Date: Tuesday, January 18, 2022 2:42:58 AM

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Dear Commissioner Sheff,
Dear Joseph,

(Please ignore the preceding email submitted as it has duplications)
Thank you for allowing me to submit testimony at last week's hearing on your Draft for the DDS Five-Year Plan.
As requested I am forwarding it to you again. It is also a draft given the short time given for submission.
See below.

You were concerned about my commentary on the deterioration of quality of life in my daughter's RHD group home that I described and the veiled threat by the AID investigator after we - my husband Tibor Darany and I - submitted a List of complaints, which they actually had substantiated. I have also forwarded to you that list a couple of days ago. I want to mention here that the AID is under the umbrella of the DDS and we were surprised about the reaction to our complaint. We felt punished and even threatened for submitting a complaint of abuse & neglect to protect our daughter.

I hope this was an oversight. Tibor and I would welcome a meeting with you to discuss among others the health concerns that we have regarding the treatment of our daughter.

Thank you for your concern and I look forward to your response.
Sincerely,
Brita

Brita Darany von Regensburg
President, FAP-Friends of Autistic People
[203 661 8510](tel:2036618510)
www.autisticadults.org



----- Forwarded message -----

From: **Brita Darany von Regensburg** <fap.autismct@gmail.com>
Date: Wed, Jan 12, 2022 at 11:31 AM
Subject: Fwd: Friends of Autistic People- FAP- Re: Testimony for the DDS Hearing
To: Carvalho, Joseph <Joseph.Carvalho@ct.gov>
Cc: <cscully@thearcct.org>, aut/ Darany,Tibor <tibor4d@optimum.net>

Dear Commissioner Scheff,

Thank you for the opportunity to submit a (unfortunately in the short time that was given) rough draft of my testimony regarding the DDS 5-Year Plan.

I look forward to hearing from you and potentially being on a committee to develop further improvements to the plan.

Thanks so much,

Brita

Brita Darany von Regensburg

Testimony for the DDS hearing on the 5-Year Plan, January 12, 2022

I am the mother of an adult daughter who has profound nonverbal Autism with a high level of need, LON. She lives at a CLA group home in Trumbull that Friends of Autistic People was instrumental in getting the DDS to open in July 2000, at a time when there was barely a home focused on adults with Autism. First, I would like to join Win Evarts in thanking the DDS and group home management for valiantly working to keep the group home Running during the times of the Covid. The issues addressed below are pervasive ongoing issues not all related to the current pandemic.

I wish to point out at the outset that I fully agree with the comments presented by Nina Nagy regarding the need to improve the group homes of our children with autism. It is absolutely true that DDS policies and activities are centered around health and safety and, I might add, basic creature comfort- room and board.

The homes are regulated by the DDS only along those areas at the expense of everything else and there is little if any consideration given to the quality of life of the group home residents. Let me highlight here some of the issues where corrective actions are required.

1. There is NO TRANSPARENCY. Hiding behind HIPAA regulations, group home management is not accountable to the parents of the residents as a group, and the residents' individual requirements are ignored with the excuse that they cannot be dealt with due to the needs of other consumers. We are told that our daughter is „doing too much“, such as receiving weekly medically necessary Music Assisted Therapy and Speech Therapy, wants to participate in Special Olympics and needs PT (to ameliorate her scoliosis), and her housemates need some staff time also. We request that in group homes a Parent-Staff Association be created patterned after the PTAs of the public schools to jointly address issues and find solutions

2. The MENTAL HEALTH needs (issues created by high Anxiety and changes due to staff rotation, such as lack of sleep, painful GI issues, outbursts, etc.) and OT/PT needs of the residents are ignored. Non-verbal residents are yelled at by under-trained staff, they are made to sit quietly to make it easier for staff to run the home.

3. The residents' civil rights are ignored. Activities that are part of normal life are rationed or made not available often under the pretext of lack of staff or vehicles. These are both in-house and outside activities. Among others these include staff not doing activities with them at the house such as cooking, puzzles, games, crafts etc. or taking them out for swimming, to their social groups in the community, potential horseback riding, shopping even for basics etc. Limiting doctor prescribed physical exercise such as walking when it is just a little bit cold as staff does not bring cold weather clothing or simply don't like walking. Refusing to participate in the Special Olympics. Not engaging the residents in community life, Festivals, shopping at favorite stores (Dollar store, Michel's, etc), cutting existing relationships previously justified under the cover of Covid.

4. Medically necessary tools such as the iPad for communication are practically ignored (just lying in the office, not charged or used as a toy), and appointments for speech and other therapies are mostly not taken seriously. Medical prescriptions such as spinal-issues-based PT and swimming are seemingly scoffed at as parental manipulation.

5. Not providing materials for arts and games, not fixing leaky grout and 10-plus year old paint in our daughter's room, but spending funds on a 65" TV (replacing a big 45" screen) that is primarily watched by staff instead of engaging in activities with residents are evidence of misplaced priorities.

6. When parents speak out asking for corrective actions they are openly threatened or sometimes just made to feel that if they are not satisfied, they can take their child elsewhere.

7. To Aging parents it is suggested to drive to the group home from considerable distances to take their child to medical appointments or to other activities as staff is busy.

8. There is a lot of misrepresentation by the home manager and care provider management takes no corrective action.

9. Complaints to the Abuse and Neglect Department (A & N), even when substantiated, lead to no results. Abuse and Neglect must not be under the same umbrella with the DDS! Self-regulation just does not work. A & N should be transferred to another CT State Agency.

10. IP meetings - unless you have a very good case worker taking your child's Rights very seriously - are rushed and perfunctory. Reports by most of the IP team members incl the Day Program Provider are either not presented or vague. The Individual Plan (IP) should have identified specific goals and measurements of progress or real progress will rarely be achieved. Parental requests at the IP meetings for training toward, and finding, Employment - in particular customized employment - should not be - but are ignored - likely because our daughter has profound nonverbal Autism.

These are just some of the issues that could be corrected with more transparency and if there was a Parents-Staff Association to discuss group home issues without fear of repercussions. Many parents are tight-lipped as they are in fear of having their adult child with severe Autism expelled from the group home and what would happen to the child when they are no longer alive.

Sincerely,

Brita Darany von Regensburg

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