

DDS Autism Spectrum Disorder Advisory Council (ASDAC)
10:00am-12:00pm
Legislative Office Building
Room- 1C
300 Capitol Avenue
Hartford, CT 06106

Meeting Minutes
March 11, 2015

Members Present: Commissioner Morna Murray, Jennifer Bogin, Representative Cathy Abercrombie, Sara Reed, Carol Ryan-Hanlon, Jim Loomis, Yana Razumnaya, Bill Halsey, Judy Dowd, John Molteni, Beth Leslie, Zachary Laudano, Nikki Richer, Sara Lourie, Ann Gionet, Lynn Ricci, Ruth Eren, Lois Rosenwald

Members Absent: Wendy Campbell, Marcia Eckerd, Kathy Marchione, Robert Shea, Maria Synodi, Doriana Vicedomini

Call to Order: 10:04 am

Welcome and Introduction:

Representative Cathy Abercrombie welcomed Commissioner Morna Murray

Commissioner Morna Murray introduced herself to the Advisory Council

Review and Approval of Minutes from 10/22/14 Advisory Council Meeting:

Motion to Approve, Zachary Laudano seconded the motion

Review and Approval of By-Laws (drafted 10/23/14):

- Sara Reed indicated that the bylaws need to mention a pediatrician to be consistent with the statutes Ann Gionet suggested that the Office of Early Childhood should be added and that Jenn and Sara should request a representative. Jenn will discuss with Commissioner Murray.
- Jenn suggested that there were enough changes that a vote should be delayed until the April 22nd, 2015 Advisory Council Meeting so that members have time to consider their positions.

Public Comments: No public comments

Autism Spectrum Disorder Division Updates (see attached power point presentation):

Deb Anderson, Project Manager:

- Autism Spectrum Disorder Division Resource Specialists
 - 51 Resource visits in the last year to families on the waiting list

- That they present to families, support groups, provide packets with resources and information.
- Assessing 3 and 4 year-olds. Testing, scoring and summarizing helps to prepare young children for early autism waiver.
- Answer family questions about social security and Medicaid
- Feasibility study:
 - funding approved to integrate into one online resource database; a useful product for families and individuals. Will increase accessibility. Available to those with internet. System for verification, additional information. Autism resource guide.
 - Social Recreation project - RFP pending. Pilot project to provide a short term community mentor for adults. Contractor will perform partnership with community agencies. Addresses needs of individuals
 - Training -
 - Direct care orientation, Benhaven. Approximately 96 individuals trained or will be trained.
 - ASRC – 3 hour work shop, additional workshops
 - MOU with University of CT Health Center training
 - Professional development curriculum expected October of this year.
 - Memorandum of Understanding with Southern for school personnel training
- Service delivery implementation
 - RFP - hospital beds, gaps in services with individuals with Autism Spectrum Disorder. Very few psychiatric beds. Most acute and complex symptoms. Located in existing hospital setting.
- Next priorities:
 - Implement Programs Review Committee recommendation.
 - Survey of individuals on waitlist. Online survey system
 - Survey to current waiver participants. Data to gain more information on housing and employment
 - Revising DDS direct support training (work with training and credentialing subcommittees)
- Early Childhood Autism Waiver –
 - 30 children, age 3 to 4.6 enrolled in waiver
 - Receiving in-home behavioral and life support
 - 4.6 start transition process of next phase
 - Two Case Managers met with families and provider team
 - Providing monthly check-ins, go to homes to assist families with necessary paperwork and discuss goals
 - Positive changes already noticed with children

Jenn thanked all involved

Questions/Discussion:

- Discussion about the plan to discontinue Early Childhood ASD Waiver given the implementation of the Medicaid mandate to cover medically necessary autism services under EPSDT through aged 21. There was some concern about this.
 - Timeline
 - Funding
 - Implications of ending waiver
 - Care coordination services
 - Current wait list for ECAW services (12 children, in the process of applying for Medicaid services)

- Update from Credentialing Committee
 - Committee continues to meet. Focus turning more towards different interventions.
 - Addressing the issue of direct care staff, info they received.
 - Training through Benhaven is focused on adults. Concern on training for children. May be irrelevant.
 - Idea to look at materials available in the public domain to add to that and work with Benhaven and training committee.
 - Providers that provide services on the waiver have to attend Orientation Level I and II training. Complete within 30 days. We also have the new studio at DDS so they can up the video capabilities as well. Would like to have a call for those interested.

Program Review and Investigations Report:

- Five recommendations directed at Council itself
- Discussion:
 - Would be good to have someone from DMV on transportation committee. Person giving test should be trained to work with individuals on the spectrum.
 - Question (re: transportation) what do other states do? Comments
 - May want to look at Ohio. Has a lot of programs.
 - ASRC has done research into this issue and hasn't found anything
 - Thought it best to discuss as a council as all are busy. Transportation in CT is a challenge. Clearly an important avenue. What are our priorities as a council for the next year?
 - Biggest issues are employment and housing. Huge problems.
 - Statistics say 80% on the spectrum are unemployed. Unacceptable. Lack of social skills to succeed. Need more help.
- Commissioner Murray thanked everyone for the recommendations and thanked Yana. She added that it is difficult to separate these priority areas into distinct categories – that you can't separate transportation from housing and employment. Need to consider accessible transportation. Looking at for

all individuals with disabilities. Some of the comments and questions included:

- Whether anyone from the State Department of Education has been invited to sit on the Council and the answer is yes, they have been an active participant
- Question about the next steps for implementing the feasibility study as it is very relevant to what's happening. It is the intention but it takes time, energy and focus and needs to have Council direction. There are many initiatives underway so there is a need to balance everything. Limit to amount of things that can be done as a Council.
- Several people cautioned that they don't want to study the study. They would rather focus work on the recommendations.
- The Council identified employment housing and employment as major issues some time ago. The group said it was time to refocus work on these.
- Coordination is key. If people are pulling in the same direction, the more successful they will be. Some frustration was expressed that the Council was not part of the report. They want to better coordinate with the legislature, DDS, etc. and asked how to make this happen?
- Some discussion about the gravity of the issues identified and that most disability groups are dealing with the same issues. Discussion about who else should be asked to assist with the Councils efforts in these areas. Especially with the reality that there is likely not to be large infusion of new resources
- The group decided to put together smaller groups to focus on the major topic issues and have the group look outside the state for funding - feds, private funding.
- Some discussion about meeting more often than quarterly and that if people are feeling their time at Council meetings is making a difference, they will come
- Subcommittees will take time but focuses efforts in specific areas.
- Subcommittees can they invite people off of the council
- Struggle with identity and purpose. Not sure if we have a clear mandate to do anything except collect information and bring forward. Should define the purposes of subcommittees before voting
- DDS sits on federal grant applied for, 811, should be looking at things that are already going on.
- A lot of housing activities in many agencies. Should build on existing infrastructures.
- Some feeling that there is not enough coordination with education. Transition piece is not something we are talking about. Recommendation to discuss how BRS and DDS can talk together more.
- Function of committee is to advise Commissioner. The more information we have the better to make strong recommendation.
- Gather information on transportation, housing, etc. and bring back to group for recommendation and decide. Place subcommittee can start.

- Would like to see us move beyond this. Not as familiar with things going around housing. Need to move forward.
 - We have two individuals on committees who are self-advocates. Voices are powerful. Amount of voices from the spectrum really needs to be beefed up. Would like to see this. Want to increase self-advocates
 - Next steps. Need to figure out what subcommittees will be doing. Many different perspectives. Suggested streamlining, one smaller group, action group. Look at groups and pick one. Should pick a priority to move forward on
 - Next meeting April 22nd. Volunteers?
 - Suggested 3 Groups looking at areas and bring back to group. Willing to be involved in this.
 - Should have a well-defined product. Should designate 2-3 people to come back and talk to us.
 - Should look at research literature. What has been evaluated and what works.
 - Subcommittees are invited us to drop in on social skills groups to hear opinions.
- Informal vote:
 - All in favor of 3 subcommittees: 13
 - All in favor of 1 subcommittee: 5
 - Subcommittee Chairs
 - Lynn Ricci & Judy Dowd (Housing)
 - Yana & Debra Anderson (Transportation)
 - John Molteni (Employment)

Ellen Livingston: Director of Autism Services at Value Options.

- Provided information on current work. Autism Services team, phone system, fax line
- 4 peer coordinators, (3 vacant positions) looking to address individuals on team. Contact Ellen and HR.
- Value options is holding a family forum on April 14th in Rocky Hill. Will share information to families.

New Business:

- Topic posed to the Council
 - It was suggested that a future meeting discuss the recently released report on Newtown & its implication and a possible response from the council.
 - A lot of concern by families since Newtown. Fears, backlash, lost with this issue, sadness.

- Misinformation in the public about ASD. Feels it needs to be addressed, how this particular horrific event has affected our families.
- Maybe some kind of product. Report, office of child advocate. Partner with them. To communicate how this group collectively wants to deal with what happened and our role.
- Facilitated piece of conversation would not be a public forum. Somewhere where they would feel free to discuss. It is up to us as the advisory council to say something.
- Working with families of adults on the spectrum let you hear personal stories of how Newtown has affected their family members from keeping their jobs.
- Many individuals on spectrum have concerns, confusion. Something to think about

Sara Reed and Lois Rosenwald will be the point people on this going forward.

New Business:

Autism Awareness Day April 8 at capitol at 10

Next meeting April 22 10-12

Adjournment: Motion to adjourn. Zachary Laudano second at 12:00pm

Next meeting is Wednesday, April 22nd 2015

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