

Family Empowerment Task Force
2011 Conference at the Capitol

Summary

On June 18, 2011, a group of 77 parents, siblings, guardians, caregivers and self-advocates who receive services from DDS gathered in the Old Judiciary Room of the Connecticut State Capitol Building to plan specific actions for the coming year. The gathering also served the group's mission by a) building community among families and individuals who receive services from DDS, b) educating those families and c) educating legislators and public officials about the needs of those families.

A description of the group and a copy of the conference agenda are attached as Exhibits 1 and 2. Copies of the worksheet and instructions that were used by the attendees to propose projects for the group are attached as Exhibits 3 and 4.

Before they engaged in the planning exercise, attendees heard from a distinguished panel of experts from government and private agencies. Biographies of the panel members are attached as Exhibit 5. The purpose of the panel was to inform conference attendees about critical issues that affect the DDS services. Each panel member made a brief statement about their perspective and then they responded to questions from the audience. The 28 questions submitted by attendees are listed in Table 1.

Following the panel discussion, participants engaged in the project planning exercise. The twelve specific actions that were proposed by the group are listed in Table 2.

Finally, participants were asked to evaluate the Conference using the questionnaire that is attached as Exhibit 6. Forty-five (45) survey forms (58%) were returned. Everyone who returned a survey form enjoyed the conference and felt that it produced a meaningful outcome. Ninety-eight per cent (98%) indicated they would attend another conference of this type. Eighty-nine (89%) said they would like to attend a family picnic with this group at a location in Central Connecticut sometime in September. Eighty-two per cent (82%) said the group should keep the name. Table 3 contains the salient comments from sections 3, 4, 7 and 8 of the questionnaire.

Together, the contents of Tables 1 – 3 are a catalog of current concerns among families that receive services from DDS. The Family Empowerment Task Force will now use this information to craft appropriate events for families and collective actions to be directed at state government.

The Family Empowerment Task Force thanks The Arc of Connecticut for financial and administrative support of this event.

Table 1. Questions for the Panel

1. What solutions would DDS propose to prevent families who accept respite services from dropping off the residential placement list? Families, desperate for support, accept one level of care only to be disqualified from another.
2. Can DDS provide adequate oversight to insure the quality of private programs as budgets are reduced? Would private oversight be a cost effective option?
3. How will DDS help persons with I.D. to Age in Place and avoid institutionalization in later years?
4. Are there any plans to eventually have a “single track” private provider system?
5. How can family members partner with DDS to ensure a safety net for years to come?
6. Is DDS taking a global perspective on change for persons with I.D.? Is there something to be learned from the approaches other countries are taking to support this population?
7. What can families do to obtain services during the June – November funding gap for students who age out of school systems?
8. Will DDS push in-home services (ABA, IRI, like CAM therapies) for autism to be covered by insurance and free money up for other services?
9. How will DDS work with SDE to insure that DDS doesn’t bear the burden of providing additional services because school districts have failed to do their job as mandated by the IDEA?
10. Would you tell us about the Autism Project, the Autism Waiver and funding thereof?
11. As Southbury training School is closed, will monies that were allocated there be moved to the private provider agencies?
12. If the state employee unions do not agree to concessions, will the state cut funds to the private providers (that do not employ state workers?)
13. How will you maintain quality and reduce turnover at private agencies while private employees are paid so much less than state workers?
14. Why does it appear that DDS is cutting funding for community activities such as drama, dance, music and gym as these activities align with the DDS Mission Statement and placement in a group home would be more expensive?

Table 1. (continued)

15. What collaboration is there between DDS and DMHAS to better address the needs of DDS consumers with mental health concerns? Why doesn't CCPA include DMHAS while they call for collaboration between DDS and DSS?
16. What is being done to eliminate the waiting lists?
17. What happens to the individual with I.D. who has no resources, only SSI, and no living parents?
18. How do we get the legislature to address the chronic underfunding of these services?
19. What strategies can be implemented to publicize that private providers are funded principally by government?
20. What is the long-term vision for residential services? Can residential and day service funding be consolidated for each person? How to best spend the funds we have? How to educate parents about this?
21. How can we help private non-profit service agencies to hire and retain quality staff?
22. How can we assure that funding cuts will not affect the self-determination and person-centered planning that we feel works best for our family member?
23. What is being done to find out why there were millions of dollars available but not spent by DSS for elderly and people with disabilities, as reported in the newspaper?
24. How does DDS plan to privatize?
25. How can a parent get her child's DDS records transferred from one region to another without waiting for five years?
26. What is being done to provide transportation for our family members?
27. Does DDS have plans to make communications by case managers a greater priority?
28. Can the private nonprofit social service providers anticipate any kind of future funding increase from the State in the near future – as operating costs rise?

Table 2. Proposed Project Objectives

1. Establish a rating database that contains information on providers, including medical services, employment services and home support services that would be readily accessible to all interested parties.
2. Provide more knowledge about the process for obtaining competitive employment via Connect-ability and other state offices that many people don't know about.
3. Clarify the criteria for obtaining residential placement. Educate families to residential options and planning for those options. Ask persons with I.D. of their desire of where to live.
4. Raise awareness and increase the visibility of families who have a member with an intellectual disability by increasing FETF membership to at least 500, making noise and telling our stories to the legislature – among other activities.
5. Provide a bigger voice for families. Involve younger families. Involve siblings. Videotape stories and send to the legislature.
6. Improve transportation for individuals who have disabilities and are seeking employment and social services.
7. Design a model transportation program in the communities served by accessible taxis and explore using DDS funds to assist with the cost of the taxis.
8. Increase contacts and communications between DDS, its provider providers and families served by DDS.
9. Educate school systems, legislators, professionals and service providers about the need to serve each disability individually and on-going from early intervention into age-out and adulthood.
10. Educate and inform state and federal lawmakers about needs of consumers and benefits of privatization.
11. Improve access to expertise that can respond to families' questions wherever they are on the spectrum of needs that DDS serves by organizing DDS away from case management to departments responsible for overseeing areas that impact the consumer's life, i.e. transition, money follows the person, issues that arise in adult services.
12. Get to know your staff.

Table 3. Salient Comments from Conference Survey Forms

Nine people said that the room's acoustics were bad.
Two people suggested that Saturday is not a good day for this event.
Two suggested that the event was too long and we should limit responses to questions.
Two requested that we add a self-advocate to the panel
Two suggested that we get a bigger room.

Following are singular comments from the survey:

Add a representative from the State Department of Education to the panel.
Have a panel of parents
Have more open questions
Allow more interactive Q&A.
Limit discussion of project management.
Allow more time for breakout groups.
Allow more time for questions.
Allow more time for networking.
Add workshops.
Take more input from self-advocates.
Email announcements beyond our Facebook and Yahoo groups.
Compile member stories, then print and distribute at the Conference.
Publish better parking directions.
Increase attendance.
Develop outreach to pre-transition parents
Strengthen communications with DDS Advisory Councils.
Have more family involvement.
Provide a gluten-free lunch.
The room was too cold.
Submit questions to panel members in advance.
Invite public officials to a social event.

Ideas for names:

Family 7 Advocacy Empowerment Team
Who will care for my child... a task force of concerned families
Concerned Families for Care
Families Against Declining Service
Family Action Committee... Enough is Enough?
Concerned Parents...
Parents for...
Citizens for Nonprofits
A memorable acronym
add "CT"