

**Regional Family Support Planning Councils  
2009 Annual Report**

## **Regional Family Support Planning Councils 2009 Annual Reports Summary**

Included in this binder are the individual annual reports for the 9 RFSPC's. The following activities have been completed by the councils:

### **Public activities:**

- Outreach events – 8 events conducted
- Public forums – 8 forums conducted
- Provider fairs – 5 fairs held
- Surveys – 2 formal surveys conducted
- Advocacy – various members contacted legislatures statewide; participation in national and statewide conferences; participation in statewide and national policy committees; served on several Executive Boards
- Monitoring activities
- Evaluation of DDD Family Support system
- Accomplishments/Benchmarks
- Long- and Short-term recommendations
- Identification of training needs
- Recommendations for reallocation of funds
- Recommendation for allocation of new funds
- Recommendations for additional funds

### **Public activities**

The councils organized and conducted the above mentioned activities throughout the state in an effort to educate families on various issues that directly impact on their ability and efforts to support and assist their family member living at home. With many changes occurring within DDD the councils planned a number of events with a focus on informing families of these new directives (eg, introduction of families to the new single point of entry via DDS, new Community Care Waiver, County-based Family Forums to introduce families to the initiative to partner with a county human services official, self-directed/fee for service direction). In addition, the councils invited provider agencies to present to families on services/supports available to families.

### **Monitoring activities**

As reported over the past several years Family Support contracts continue to be unavailable for review by the councils for all regions. This remains a source of extreme frustration on the part of the councils in regards to their limited ability to oversee and recommend allocations especially during this time of unfavorable economic outlook for families with a family member with a developmental disability living at home. One of the most important responsibilities of the Family Support Councils is to gather, monitor and recommend changes to family support programs based on the needs expressed by families in their region in balance with contracts, level of service (LOS) and performance. This has never been more important in New Jersey with a reduction in

family support funds and highlights the need to use the limited funding available in creative ways to meet the ever increasing number families on waiting lists and new families eligible for DDD services/supports being added at a rate of 1,500 families per year. In an effort to maintain councils' involvement in the allocation/reallocation of funds within provider contracts several councils met with DDD Regional and County Family Support Coordinators and provider agencies separately throughout the year to review family support programs, LOS, and customer satisfaction. While the discussions provided at least some insight into the current status of program contracts allowing for some direction in making recommendations for reallocation of funds, it did not allow for in-depth review of contractual standards in relation to LOS and customer satisfaction. This lack of response to repeated requests for this information by the councils over the past several years has lead to an overwhelming feeling on the part of the councils that their voice is not respected. Thus, the need for more open dialogue, building of trust, and mutual respect is essential for the coming year.

### **Evaluation of Family Support system**

The following were identified as major areas of concern by families at the various public events held over the year:

Dissatisfaction with the quality and accessibility of services by DDD – thousands of families continue to struggle with caring for their loved one at home without any family support services, waiting lists for services are unacceptably long

Dissatisfaction with customer service provided by DDD case managers – while some case managers have very large caseloads (300-400 families as reported by DDD) there is often a lack of knowledge of services/programs, no attempt to probe by case managers to determine family needs in order to match services, lack of follow-up by case managers, and, in some cases, a lack of understanding/compassion for families and what they are dealing with on a daily basis

Lack of services/supports – long waiting lists, families waiting for years for even one family support service, agencies reporting they do not receive referrals from DDD and as a result programs are not filled while families are told there are no slots

Lack of transportation to programs – issues for working parents and older parents unable to continue to transport their loved one

Difficult intake process – lengthy document, lack of assistance in completing the application, currently it takes 6-12 months to register with DDD

While the overall term “self-directed supports” (encompassing Self-determination, Real Life Choices, Self-directed support, etc) is not considered Family Support in terms of definition and funding, the programs include supports/services identified and provided as Family Support. Overall individualized programs incorporate many elements of Family Support (eg, in- and out-of-home respite, hotel respite, after work programs, recreational programs, etc) and many individuals in Self-directed supports participate in programs used by other families not currently able to create a “self-directed” program for their loved one due to lack of funding. Families currently in the self-directed programs have identified the following issues surrounding these programs. These issues are of concern as more families are being encouraged to move into these types of programs.

Lack of assistance with the various self-directed supports programs (ie, Real Life Choices, Self Determination, Self-directed Supports) – difficulty in researching, obtaining, and coordinating their own services, providers not being reimbursed

Additional issues not defined as Family Support but of great concern discussed by families in every region:

Lack of residential openings –

This is a major issue raised by families and identified in previous years. Many caregivers are aging and it is becoming more difficult for older parents/caregivers to care for their loved ones especially those with demanding physical disabilities and/or medical issues by both the consumer and aging caregiver

Inclusion of the councils in the Family Support Task Force under Assistant Commissioner Ken Ritchey to review current statewide practices to ensure that supports are provided in an equitable and consistent manner has continued over the past year. This has provided a forum for the Councils and DDD to interact and exchange ideas on various programs and issues affecting the families of New Jersey. While this has allowed for a thorough review and redesign of the Cash Subsidy program it was a very slow process and the revised process is yet to be realized 2 years after the implementation of the Task Force.

### **Accomplishments/Benchmarks**

Some Councils were able to increase mailing list databases through various outreach events which will provide for a greater reach to families within their regions.

Increased interaction with various local committees and organization to create awareness about the needs of the DD population in their towns and counties.

Four trainings were held in the spring of 2009 with a total of 22 members attending. Two sessions focused on reviewing contracts, budget recommendation timelines, and HIPAA for the more experienced members and 2 focused on basic training for new members. More trainings are planned for the coming year.

While some Councils increased their membership over the past year, most have either lost members or have been unable to add new members to their Council despite the numerous outreach activities and fairly good attendance at these events. There is a general perception that this may be the result of several factors including the inability of family volunteers to attend meetings due to the tremendous responsibilities between work and caring for their loved one, frustration with the lack of response on behalf of DDD to provide the necessary information to allow the Councils to fully perform their duties (ie, lack of contracts, LOS reports, customer satisfaction surveys).

## Recommendations

Retain active members and recruit new members in most Councils.

Increase advocacy activities to all NJ legislators to ensure no further cuts are made to the DDD Family Support budget as the waiting lists have not decreased over the past years but only increased. To educate the legislatures on the growing needs of aging caregivers for housing, respite care, assistance with transporting their loved one to activities and appointments.

Development of generic brochure for use by all Councils to provide the same information to families throughout the state.

Review/revise Circular #39: Family Support Service System before March 30, 2010 – DDD in conjunction with NJCDD has created a system of family support designed to be flexible and to strengthen and assist families who provide care in their homes for a family member with a DD. The circular applies to all eligible persons with DD and/or their families as well as the agencies under contract for family support programs with or regulated by DDD.

Design new contract cover sheet with information needed by councils to review contracts and LOS reports. Review “timeline” for contract review to allow recommendations to allocation/reallocation of funds as identified by the councils.

Monitor and solicit feedback from consumers on DDS system of intake and referral.

Family Support should to be a separate line item and not included under an umbrella of other programs, e.g., day programs, tutoring. Family support programs are not currently receiving any new funding. These essential programs are lost when combined with other unrelated programs. The Division needs to make this a separate line item to bring Family Support programs into focus. Families are being **severely underserved** and with 1,500 individuals being added each year without new funds the situation is becoming dire.

Regional and County Family Support DDD Coordinators should work closely with each RFSPC in obtaining information on family support programs for their counties to assist Councils in the assessment and recommendation of allocation of funds based on LOS and customer satisfaction in conjunction with family needs as gathered during outreach events and surveys.

Councils need to be active partners in developing policy and services for family support programs. The Task Force purpose is “To ensure a statewide system of family support that includes equity, accountability and consistent statewide practices.” The forum should be used for this purpose but has developed into a platform for DDD to inform Councils of changes in funding allocations and other changes after the fact. This is not in keeping with Family Support legislation which specifies that the Division is to manage resources based on family needs and input. RFSPCs reserve the right to make recommendations

about which provider(s) receive funding on a case by case basis as these funds become available whether through new funding or from under spending.

As reported in past years, accessible and affordable after school/work programs are in demand across NJ. Transportation is a major gridlock in the success of these programs. Councils and DDD need to work at the local level to identify creative ways to meet this need.

### **Identification of training needs**

DDD Case management training is needed in several areas:

How to ask/probe the families to help identify what the most appropriate supports are needed at any particular time. To ensure the information provided to families is consistent between case managers within the same region as well as across the state.

Sensitivity training for case managers as well as how to deal with emergency situations. Case managers aren't aware of "trigger" words such as "crisis", the term used by DDD to let case managers know when a client is in danger of causing harm to themselves or others or if a caregiver is unable to continue care due to their own health/family crisis. Training is critical to provide a safety net to families caring for a disabled family member. This is an issue that has been repeatedly reported in the past.

Council training in the following areas would allow members to be more effective information providers to the many families they come in contact with at the various outreach events:

- Real Life Choices/Self-Directed Supports
- Updates on waiver developments
- New intake procedures
- DDS directed services

Continue training for new members as well as contract reviews

### **Funding recommendations**

#### Reallocation

As stated previously Councils have not received contracts for a number of years and as a result most Councils recommend that allocated funds remain the same in programs performing at least 85% or above capacity. In general councils recommend that any unused funds be reallocated to Cash Option Respite and After School/Work programs as these are among the most requested supports by families statewide. To this end, waiting lists need to be established and kept current so that unused funds can be distributed in a timely manner. Any under spending by providers needs to be identified on a regular basis so that the funds can be reallocated to families on the waiting lists. Other specific reallocation recommendations can be found in the individual reports.

## New/Additional funds

Although there were no new or additional funds available the past fiscal year, it is imperative the Division recognizes the significant further strain the lack of funding puts on families throughout the state. With 1,500 individuals entering the system each year the waiting list for almost every family support/service offered by the Division continues to grow, not only due to the increased number of families in need of assistance but also as a result of the lack of or reduction in funding and lack of oversight by the Division of existing contracts and councils due to the inability to review contracts. It is more important than ever that contracts be reviewed and monitored to ensure that funding for family support programs be utilized in the most appropriate and efficient way based on input from the Councils who act as the voice for the families by geographic region.

As mentioned earlier in this summary as long as an existing program is operating at 85%, we recommend that any additional funds that become be reallocated available to cash subsidy with the possibility of exploring new programs. It is also recommended that families receive money for respite. It should be at the discretion of the families who will care for their loved one in the event that they receive this service and funding.

In the event that additional/new funds become available, new programs should be explored as requested by families. Areas for future consideration include:

- Improved transportation to permit people with developmental disabilities who want to and are able to work to get to jobs.
- Increased supports and services, such as in-home respite providers, respite providers to take individuals to appointments and social gatherings, for aging family members to meet the needs for caring for older family members with DD (i.e., older consumers require more supports and older caregivers also require increased supports themselves).
- Real Life Choices being an alternative for a limited number of families, the majority of families continue to receive traditional services. These services do not maximize the individuals' potential and are geared to accommodate a general consensus – without “self-directed” supports individuals must participate in programs designed for groups of individuals sometimes across a wide age range that may not be age-appropriate for all attending, cannot design their day around individual interests and abilities.

## Additional comments

The councils recognize the recent efforts by the Division to maintain an open dialogue by including council representatives in Assistant Commissioner Ken Ritchey's Task Force and other forums. However, there is frustration on the part of the members in being left out of discussions on identifying funds moved from the Family Support budget during the fiscal crisis, only learning of these decisions after the fact. The knowledge and experience families have should not be overlooked. In fact the Family Support legislation clearly

specifies that the Division is to manage appropriated resources according to the Councils recommendations based on input from families in their regions.

Over the next year the Statewide Council needs to recognize the extraordinary volunteer efforts on the part of the Council members. These volunteers continue to work diligently on behalf of families throughout New Jersey – attending monthly meetings at the regional level, quarterly statewide meetings, various monthly Task Force and committee meetings, organizing and manning public outreach meetings - despite difficult situations caring for family members with developmental disabilities at home while also holding down jobs. Recognition on the part of the Division for the outstanding commitment demonstrated by these individuals would also help to boost morale and foster future volunteer efforts.

**Regional Family Support Planning RFSPC #1  
Annual Report 7/1/08 – 6/30/09**

**RFSPC #1: Serving Morris, Sussex and Warren Counties**

Council Membership

Margaret Hefferle (Chair RFSPC #1/State RFSPC Chair/State Rep) – Morris

Elizabeth Patterson (Vice-Chair) - Morris

Martha Clavadetscher (Secretary/State Rep) - Morris

Patricia Lillman - Sussex

Walter Tietz – Warren

Barbara Reddington - Morris

**Introduction**

This year saw less than full membership for Regional Family Support Planning Council (RFSPC #1) with 5 vacancies on the council remaining unfilled despite ongoing recruiting efforts by remaining council members. Margaret Hefferle continued as Council 1 Chair and as state-wide rep; Beth Patterson was voted in as Vice-Chair. The remaining council members continued their recruiting efforts (both on an individual basis and at outreach events), focusing primarily on Warren and Sussex counties as these counties continue to be under represented in the current RFSPC #1 membership.

RFSPC #1 remains committed to serving the families of region #1 in the coming year as we strive to diversify our membership and build on our prior skills/expertise in our role as advocates for family support.

**1. Public Input Activities**

In fiscal year 2008-2009, RFSPC #1 participated in two large successful outreach activities, and three smaller events. The first outreach was in conjunction with UCP; representatives from RFSPC #1 participated in an aging caregiver's forum hosted by UCP and the NJ Association of Community Providers on March 21, 2009 in Randolph, NJ. Council members served on a panel and hosted an information table to recruit new members and provide information on RFSPC #1 activities. Through this event we also expanded our mailing list in an effort to more broadly advertise our future events. Our members also participated in an open forum/discussion on housing and support services available to aging caregivers. The event was very well attended and provided an opportunity to discuss new ideas/models/approaches that address persistent housing and respite care needs.

The second large outreach event was a Disability Provider Fair and Open Forum hosted by RFSPC #1 in Morris County at the Frelinghuysen Arboretum on May 9, 2009. This open forum was organized like a 'health fair', where consumers were able to visit tables hosted by each of the 15 participating providers and ask questions, collect information, and enroll in mailing lists. Attendance was excellent, well over 200 and a large number of

consumers voiced their concerns and stayed for the presentations and Q&A session held during the last hour of the event. This Q&A session provided RFSPC #1 with ongoing feedback on the needs of our families. These included:

- Continuing barriers to families in getting and maintaining needed services exist, both from the DDD and area service providers.
- Questions regarding Real Life Choices/waiver, especially regarding enrollment, scope of services, and use of these funds.
- Questions regarding the proposed Greenwald Bill and its effect on housing waiting lists.
- Concerns about waiting lists for current housing, family support services, (especially respite) and employment programs for area consumers.
- Limited availability of in-home and other respite services, particularly for families of older consumers
- Continuing concerns voiced by consumers/families about the lack of knowledge of available services by some DDD staff and the disparity of services provided from caseworker to caseworker within DDD.

The event concluded with the distribution of RFSPC #1 information flyers and surveys to participants with a request that consumers from all counties in Region #1 consider joining the RFSPC #1 as members. Interested members and the public were also encouraged to attend the Council's monthly meetings at Morristown Memorial Hospital.

In addition, representatives from RFSPC# 1 briefly presented information on what the Family Support Councils do, provided written materials, and an opportunity to be added to the council's mailing list on three other occasions. Participants were also urged to attend meetings and to become council members at these outreach events.

**1/22/09** Basic Rights in Special Education workshop Sparta, NJ Sussex County.

**3/11/09** RFSPC Outreach: Celebrate the Children Wharton, NJ Morris County.

**3/26/09** Basic Rights in Special Ed. workshop Phillipsburg, NJ Warren County.

## **2. Monitoring Activities**

In 2008-2009, RFSPC #1 continued to expand and update its mailing list, particularly with regards to Warren and Sussex Counties. Unfortunately, RFSPC #1 was unable to make individual site visits to providers during this fiscal year due to constraints of time, personnel and the unavailability of current provider contract information due to ongoing reorganization of the DDD/relevant state departments and the lack of a statewide coordinator/contact person.

## **3. Evaluation of the System**

Based on the information collected in the returned RFSPC #1 Consumer Satisfaction Surveys and the May 4<sup>th</sup> Open Forums, the RFSPC #1 identified the following issues with family support services in Region #1:

- 1) Dissatisfaction with the quality and accessibility of services offered by DDD and provider agencies.
- 2) Dissatisfaction with the customer service provided by DDD, particularly with regards to:
  - a) Knowledge of available services/programs for disabled individuals in NJ;
  - b) Returning telephone calls and staff follow up
- 3) Confusion and lack of knowledge about the state's Real Life Choices program, specifically re:
  - a) Eligibility requirements.
  - b) Enrollment procedure.
  - c) Difficulty encountered by some disabled consumers in researching, obtaining and coordinating their own services;
  - d) Service providers not getting reimbursed under the current program.
- 4) The need for specific services, including:
  - a) Easily accessible and housing services.
  - b) Transportation to employment/recreational events;
  - c) Cash subsidy option;
  - d) Centralized source of information (i.e. website, annual directory) on available support services;
  - e) Greater consumer choice of services/agencies.
- 5) Difficulty accessing and/or maintaining support services due to insufficient information and systems issues (i.e. waiting lists, bureaucratic 'red tape', inconsistency of services offered from county to county, inability to find/retain qualified workers).

Generally, consumers and families continued to voice frustration with the current system and were very vocal in identifying the services they needed. In conjunction with ongoing concerns about long waiting lists for housing, respite services, and adult day programs, there was much interest and discussion of the Greenwald Bill at all outreach forums.

#### **4. Accomplishments/Benchmarks**

Unfortunately, RFSPC #1 continued to be understaffed during the 2008-2009 fiscal year. Thankfully, attendance by remaining members was good at the eleven regular business meetings that were held during the year, on the third Tuesday of the month at Morristown Memorial Hospital. As previously noted, RFSPC #1 continued expansion of its mailing list. Council members also participated in five organized outreach events and were active in Statewide Council meetings. Each of these outreaches provided RFSPC #1 with useful information on consumer needs and suggestions.

#### **5. Short/Long Term Recommendations**

Based on consumer feedback, RFSPC #1 has several recommendations:

Short Term recommendations:

- 1) For the fourth consecutive year we recommend that a contact person, ideally within DDD, be assigned to each RFSPC for purposes of supplying needed family support provider information/documentation. As noted, this liaison would expedite our receipt of information needed to determine which service contracts are due for renewal, to assess the quality of each provider's services and to make informed recommendations regarding the allocation of regional funds for support services. This individual would also ensure individual Planning Council can continue to fully meet their mandates if interruptions in support personnel occur.
- 2) Region # 1 needs additional DDD case managers to meet growing consumer demand and provide these case managers with regular trainings that impart accurate, up to date information on family support services available in Region #1, specifically the more remote/rural areas in Sussex and Warren counties.
- 3) DDD training of case managers and other personnel should continue to stress the value customer service, including prompt response to consumer inquiries and periodic follow up with clients to assess changing service needs and/or service eligibility requirements.

Long term recommendations:

- 1) RFSPC #1 will continue to focus recruitment efforts in Warren/Sussex County to fill the open seats on the council, much more needs to be done to support our efforts via DDD at their trainings (such as lifeline for the Journey presented by the FSCNJ) and by the CDD.
- 2) RFSPC #1 will continue outreach and education efforts into fiscal year 2009-2010, including regular mailings of the updated brochures and Consumer Service Surveys, at least three planned outreach events and hosting of events to promote dialogue between DDD, providers and the RFSPC #1. This year we plan to host our open forum in Sussex County to capture the attention of the FAST team being developed by DDD there in October.
- 3) Any additional/discretionary state funding should be directed into providing additional family support services and decreasing current caseloads for DDD case managers.
- 4) As an alternative, the state should also consider allocating any discretionary funds to the expansion and/or development of those 'high priority' service needs of respite, transportation, and housing identified earlier in this report.
- 5) Relevant state agencies should utilize the expertise of the Planning Councils in all regions when planning/implementing services and allocating family support funding.
- 6) The state should ensure better information for consumers and facilitate networking by developing a comprehensive handbook/website of support services available for each region in conjunction with DDD and all RFSPCs.

## **6. Identification of Training Needs**

As requested in its 2006-2007 and 2007-2008 reports, RFSPC #1 would appreciate updates/training regarding the Real Life Choices program as it has received many consumer inquiries on this program. Education/training in this area would allow our members to offer better and up to date information and guidance to the public, especially at our outreach events.

Once the ongoing reorganization efforts are completed, the Family Support Academy should institute trainings to focus on the changes to state policies/procedures. As the responsible agencies in the state are currently reorganizing their budget, contract and other procedures, trainings on these topics must be included in future Family Support Academies once the state has finalized these new measures. Due to the small number of council members doing this work a request that the trainings be brought to the northern region or individual councils might ensure better attendance. As noted in previous reports, the state might consider the development of an online training module for all RFSPC members statewide. This could be posted on the state site and would allow Council members to train at their own pace, and at their own time and to consult resources as needed.

## **7. Recommendations for Reallocation of Funds**

RFSPC #1 recommends that funding allocated to Warren, Sussex and Morris Counties concentrate on continuation and expansion of in home respite in an effort to reduce service waiting lists housing services also continue to be important to families. In circumstances where there are no qualified respite workers available (especially in more rural communities) we recommend funding to support “stresspite” services so families can more easily locate and hire their own staff. Finally, if additional funds become available in 2010, our Region #1 families have expressed the need for additional outside respite, afterschool programs, job training, and transportation.

Please note the RFSPC #1 reserves the right to make recommendations about which provider(s) receive these funds on a case by case basis as these funds become available.

## **8. & 9. Recommendations for New/Additional Funds**

Based on the feedback received during the past year, RFSPC #1 recommends that funding focus on the following:

- 1) Support of the Greenwald Bill to help create expanded housing opportunities in our region and statewide.
- 2) Expansion of existing support services, specifically in the areas of respite, transportation, housing, employment and recreation.
- 3) Establish better information resources for consumers, either via a website and/or a consumer manual (this should include resources for obtaining qualified in-home respite workers).

- 4) Make the availability of the 'cash option' for respite services consistent throughout Region 1.
- 5) Reduction of DDD caseworker caseloads and ongoing caseworker training.
- 6) Increase the availability and consistency of support services in all counties of Region 1.

**REGIONAL FAMILY SUPPORT PLANNING COUNCIL**  
**ANNUAL REPORT – 07/01/2008/ to 06/30/2009**

Council #:     2    

Counties Served: Bergen, Hudson, and Passaic

**Council Membership**

Chair: Frank Fiore  
Marge Kahn  
Nancy Moreno  
Andrea Torres

Vice or Co-Chair: Feliciano Lim  
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1. Public Input Activities  
When a Provider Fair was held on June 12,2009 for Bergen County at the Blesham Gymnasium of the Bergen County Special Services, a Public Forum portion was also held. Questions as well as suggestions were given to the council and to the DDD representatives that attended the fair. Linda Lewis-Day from DDD gave a presentation on Community Care Waiver.

2. Monitoring Activities  
Two members of the council are still current members of the task force that Assistant Commissioner Ken Ritchey is heading regarding the cash subsidies that are being given to families in the state of New Jersey. The task force has made and given their recommendations to DDD for implementation. The task force is now looking at other issues to be addressed and to prioritize.

Additionally, members of the council have been attending the Tri-County meetings held quarterly by DDD with the providers of Bergen, Hudson, and Passaic counties.

3. Evaluation of the Family Support System  
The evaluation of the Family Support System is currently on going since 2 members (Frank Fiore and Fel Lim) are part of the task force mentioned above. One issue that the task force will look into is the definition of family support with respect to its expansion or contraction as it may have changed over time.

4. Accomplishments/Benchmarks  
Within the last 3 years, the council has held a Meet and Greet of the providers, and a public forum and a provider fair for the past 2 tears. We're also involved in the task force mentioned above. We've been providing referrals to families who have approached the council for information and assistance.

The recent Provider Fair and Public Forum in Bergen County was well attended. We were notified that no such event had taken place in Bergen County for quite some time. We are targeting Passaic County as the next Provider Fair and Public Forum.

As a result of the Provider Fair and Public Forum, there are some interested individuals who would like to attend our next monthly meeting with the council's

hope that they'll eventually join as members of council #2. We are still recruiting for volunteers in Passaic County but still find it challenging. Hopefully, we'll be able to recruit representatives when we do the next Provider Fair and Open Forum in Passaic County.

5. Long and Short Term Recommendations

We're reiterating once more that council #2 needs to be able to electronically access the contracts of providers for monitoring. We believe that electronic access by councils in general will greatly ease the burden of monitoring.

6. Identification of Training Needs

Some council #2 members did receive training this past year on reviewing contracts. We hope to see more training schedules in this coming year especially for the new members in our council.

7. Recommendation for Allocation of Funds.

As of now, we have not received any updates to allocation of monetary resources to Brain Injury and Spina Bifida from past recommendations. We are in constant communication with Anne Maiello-Lacey (Director of Family Support Services, Northern Region) on resource allocation.

8. Recommendations For New Funds.

There has been no notification of any new funds to be allocated for 2010.

9. Recommendation For Additional Funds.

None at this time.

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Frank Fiore, Chairperson

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Feliciano Lim, Co-chairperson

# **ANNUAL REPORT GUIDELINES**

## **Annual Report 6/30/09**

**Counties Served: Union and Somerset**

### **Council Membership**

**Co-Chairs:** Kim Szermeta/Bonnie Brien  
Peter Phillips  
Marilyn Kuna  
Venita Martin  
Donna Mascola

## **Public Input Activities Conducted**

### **Public forum**

One public forum was held April 29, 2009. The Assistant Commissioner, Ken Ritchey, presented an update on the planned changes within DDD including new case management system (DVR), Community care waiver, residential waiting list, closure of DCs, etc. After the presentation, attendees Mr. Ritchey asked questions and made suggestions regarding the DDD system and supports.

Approximately 230 attended the meeting. Midland School was very gracious and the accommodations were excellent, staff was extremely cooperative in setting up additional seats as the crowd exceeded our expectations.

Held at:  
Midland School  
94 Readington Road  
North Branch, NJ

Highlights of open discussion at end of presentation:

- **Housing/Residential options** – overwhelming need for residential placements, elderly parents very concerned about their loved one as they can no longer manage their adult child's care and wonder will happen once they are gone – want transition for their child while they can assist with the transition.
- Independent living with surrounding supports
- **Transportation** needs
- More/better programs for marginal/mild MR persons (lost in the cracks)
- Respite-longer programs, two weeks rather than one, more notice from division – called last minute, UCP excellent program and much needed
- Training on how to navigate the system for parents
- **Ineffective case management** - need better training as they seem to all have a different answer to the same question
- Need mentors for both parents and client

- Need after school programs in most districts

#### **Advocacy activities**

- Continued dialog with DDD throughout the year as described under “Monitoring Activities Conducted” below
- Members contacted legislatures throughout the year in regards various issues including family support budget, Greenwald Bill A3625, funding for local after school program

#### **Public conferences**

- Members participated in the following conferences:
  - Self Directed Support Conference Together is Better: Connecting to the People and Places in the Community for the Life You Want hosted by the Elizabeth M. Boggs Center
  - Boggs Center Lecture Series presentation: Engineering Independence – George Braddock

#### **Committees, meetings, trainings**

- Members participated in the following activities:
  - Task Force committee on DDD Cash Subsidy program: recommendations made to Ken Ritchey and Jennifer Valez, final comments/revisions made, final recommendations to be made to DDD
  - Members to attended Family Support trainings given May 30

## **Monitoring Activities Conducted**

### **Interaction with DDD**

The situation from last year has not changed in regards to the Council not receiving Annex A or LOS reports from DDD. Council 3 had the Regional and County Family Support Coordinators continue to attend a number of the monthly meetings in an attempt to learn more about what DDD was hearing from their side in regards to family and provider needs, what programs are well attended, etc. In turn the Council informed the coordinators of the needs of the families in Somerset and Union counties based on public forum input, agency reports, and interaction with individual families. While closer relationships were developed, the Council experienced much frustration in the lack of information provided by DDD despite numerous requests for specific information/follow-up.

The Council continued to receive LOS reports directly from the provider agencies. Fewer agencies compared to last year sent reports via e-mail which were reviewed by the Council. The Council also continued to invite agencies to monthly meetings to discuss their LOS report and learn what they are hearing from their families. This has been very productive in learning more about what they need to provide better supports to the families – what programs are well attended, waiting lists, what can be improved. The

Council will continue this process into 2009-2010 as there continues to be a lack of information provided by DDD.

## **Evaluation of the system**

- Based on the outreach activities and discussions with provider agencies the Council reports there is poor communication between the division and the families in general – there continues to be significant frustration on the part of families in that the information provided to families is inconsistent between case managers. There is no probing by the case managers to determine what a particular family needs; there is a lack of knowledge of programs and other sources on the part of case managers. While the Council recognizes case managers are often handling very large case loads this should not translate into poor response time and poor or lack of direction/information for the families.
- Council 3 has been participating in the Family Support Task Force established by DDD under the guidance of Ken Ritchey to review current statewide practices to ensure that supports are provided in equitable and consistent manner. Recommendations will be made to the division on various issues and systems as requested.
- The Council has concerns about the feedback we are hearing from agencies, families and committees in regards to funding disappearing for a variety of programs such as in-home respite, cash option respite, and camp funding. Improved communication is needed immediately to confirm where any budget cuts are being made to family support funds. The Councils are not being given a seat at the table with the Division and during the current time of sever financial crises it is **imperative** that the Councils are included in any discussions regarding the budget for family support.
- The lack of cooperation from DDD in supplying agency contracts and LOS reports to the council continues – this has been an ongoing problem for over 6 years

## **Accomplishments/Benchmarks**

- The Council has successfully built stronger relationships with the Regional and County Family Support Coordinators in terms of better communication and establishment of quarterly meetings to discuss current programs, LOS reports, and waiting lists/referrals.
- Successfully relocated meeting location to closer for all current active members.
- The Council has successfully recruited 1 new member and is currently contacting another potential new member.

## Long and Short Term Recommendations

- Establish new mailing address.
- Development of a standard brochure for all regional family support planning councils. Once created, each council can modify as needed. This enables the same message to be sent to all families throughout New Jersey. This was recommended in the annual report last year.
- Improve communication and shorter response time between provider agencies and DDD. It has become apparent in speaking with both parties that there is a significant lack of information/assistance provided to the agencies on the part of DDD.
- Designate liaisons for each of the provider agencies within Somerset County. The hope is that new members from Union County will join the Council over the next year who can be trained and become liaisons with those agencies in Union County.
- Family Support needs to be a line item and not included under an umbrella of other supports. These programs are not currently receiving any new funding and these essential programs are being lost when combined with other unrelated program. Families are being **severely underserved** and with 1,500 individuals being added each year without new funds the situation is becoming dire. The Division needs to make this a separate line item to bring these programs into focus.
- Councils need DDD organization chart so they can better assist their families in navigating the system and reaching the appropriate individual when trying to access supports or needing assistance with a problem.
- Families need earlier notification of approval on camp enrollments – families often do not know about the status until the week prior to camp or in many cases not knowing if any of the cost will be supplied by the Division.

## Identification of Training Needs

**The needs presented were recommended last year and continue to be needed:**

- Sensitivity training for case managers as well as how to deal with emergency situations. Case managers aren't aware of "trigger" words such as "crisis", the term used by DDD to let case managers know when a client was in danger of causing harm to themselves or others or if a caregiver is unable to continue care due to their own health/family crisis. Training is critical to provide a safety net to families caring for a disabled family member. This is an issue that has been repeatedly reported in the past.

- Case manager training on how to ask/probe the families to help identify what the most appropriate supports are needed at any particular time. And to ensure the information provided to families is consistent between case managers within the same region as well as across the state.
- Recommend the training provided to the Councils in May and June be provided on power point slides and/or video for members that could not attend as well as any new members as they join the Councils.

### **Recommendations for reallocation of funds**

- The council is extremely frustrated by the lack of information provided by the Division in regards to the recent budget crisis and funds returned to the Treasury – specifically the \$4 million from Family Support services. The council would like to see a spreadsheet of what funds were returned on a line by line basis.
- Although the councils have been actively involved in Task Force meetings over the past 18 months, there seems to be a general feeling that council input is listened to but not seriously considered when making decisions. Further, the councils are not told what is being discussed and acted on until after the fact.

### **Recommendations for new funds**

N/A

### **Recommendations for additional funds**

N/A

**Regional Family Support Planning Council # 4**  
**P.O. Box 56**  
**Bloomfield, NJ 07003**  
[www.njcdd.org](http://www.njcdd.org)  
[rfspc4@yahoo.com](mailto:rfspc4@yahoo.com)  
**County Served: ESSEX**

**Chair: Rebekah Novemsky**

**Co-Chair: Tamar Mitchell**

**Members**

**Maria Divins**

**Jennifer Herrada**

**Alice Hirsh**

**Mary Howley**

**Daisy Johnson**

**Darlene Reeves (Statewide Representative)**

**Annette Smith**

#### **Message from Council 4**

We are optimistic but yet concerned about the recent proposed move on the part of the State to close five (5) of seven (7) developmental institutions within the next five (5) years. While Council #4 would have liked to focus and solicited feedback from families in Essex County around institutional care versus community housing, we were not able to spend as much time on the critical issue of community integration and deinstitutionalization.

Thus, we are very interested in learning more about how Bill A3625 will impact on families, communities, and limited resources. How or will deinstitutionalization impact DDD's budget for family support services?

#### **I. Public Input Activities**

During fiscal year 2008-2009 RFSPC #4 in conjunction with the Family Support center of New Jersey held a Winter Phone-A-Thon Public Forum on March 4, 2009. The purpose and intent of the phone-a-thon was to allow families to have their questions answered pertaining to DDD and complete a brief survey over the phone from the comfort of their homes without having to find child care and transportation during the cold winter month. We did not receive as many phone calls as we had expected because there was a mix up with the 1-800 phone number that callers were supposed to use. The original flyer that was sent out to Essex County families did not have the correct 1-800

call-in number on it. Although the Family Support Center did an excellent job with re-routing calls approximately 10 callers phoned in with questions pertaining to DDD services. This number was far less than we had anticipated but we attributed the low numbers to the error on our part with the incorrect phone number. However not all was lost, we were able to collect a total of 175 completed surveys by mail. Fortunately, the survey was attached to the phone-a-thon flyer and many families completed the survey and returned it without ever utilizing the 1-800 number.

RFSPC #4 also participated in a provider fair at the Turtle Back Zoo in West Orange on September 13, 2008 hosted by the Department of Health and Senior Services- Special Child Health Services. We were able to distribute one hundred (100) bags with literature: flyers and brochures about the RFSPC to consumers and families from Essex County. A total of eight (8) surveys were collected during this provider fair and the Council was able to get twenty-eight (28) additional families to sign-up on the mailing list. In addition, Council #4 held its own Spring Provider Fair at the Birchwood Adult Day Center in East Orange on May 16, 2009. Thirteen (13) agencies which provide services to the DD population were present at the provider fair to talk about their programs, services, and share their information with families. Fifty-one (51) families were in attendance at the provider fair and an additional nineteen (19) surveys were collected. This year RFSPC #4 was able to collect a total of 202 surveys in 2008-2009 which will be used to evaluate the system.

## **II. Monitoring Activities Conducted**

- RFSPC#4 did not conduct any site visits with the three (3) Providers who hold Family Support Contracts during the 2008-2009 year. Existing contracts with the three Providers were not reviewed and we will be requesting at some point copies of satisfaction surveys from Provider and/or our Family Support Coordinator.
- Council #4 meets quarterly with Family Support Coordinator- Lori Milford and Mary Semler to review family requests for cash subsidy and the waiting list for services.
- Annette and Rebekah were members of the Family Support Cash Subsidy Task Force which was spearheaded by Assistant Commissioner Ken Ritchey.

## **III. Evaluation of System**

Based on information collected from the RFSPC survey, the following data was generated from two (2) of open-ended questions on the survey.

**Question #7: “Are you generally satisfied with DDD services?”**

Of the 202 surveys collected more than half of the respondents were satisfied (114) with DDD services. 73 respondents were not satisfied, 14 were satisfied sometimes, and eight (8) had a non-applicable response. The respondents between the ages of 41 and older were more satisfied with services at a rate of almost 2 to 1, while the younger adult group ages 21-40 were satisfied by a slim margin. Satisfaction with services seemed to correlate most obviously with the provision of services currently received, and somewhat with satisfaction with case manager, even in the absence of services. Those just entering the DDD system were more likely to be satisfied. The most common reason stated for dissatisfaction was lack of services (29), followed by inability to reach case manager (27), in addition to not being told of available services (96); rudeness by case manager (5); misinformation provided by case manager (3) and turnover of case managers (2). Other reasons included unhappiness with services provided (4) and communication difficulties with a non Spanish speaking case worker (1).

**Question #8: “What type of services does your family need or what services you would like to receive additional about?”**

Respite was the most noted item respondents needed or wanted more information about, followed by after school programs, financial assistance, transportation and residential placement. Responses are summarized below: Respite (27); after-school programs (26); financial assistance (22); transportation (15); residential placement (14); recreation (14); day program for adults (13); behavior therapy (7); summer programs (6); equipment (6); home modification- wheel chair accessibility (6); home health care (5); medical care (4); getting child to doctor (2); speech therapy (2); vocational training (2); assistance with filing for guardianship papers (2). **Other:** wills, legal advice, estate planning, adult medical day program, weekend activities, after work programs, WAE Center, salary compensation for parent not being able to do work outside of home, advocate for school services (Individualized Education Plan), Life management program, in-home services, social skills enhancement program, jobs, driving instruction, low income housing, and sign language.

**IV. Accomplishments/Benchmarks**

- Council #4 was able to add three (3) new members to our council this year thanks to the recruitment efforts of our Chair. In addition, Council #4 was able to nominate a Co-Chair to assist Chair in carrying out responsibilities.
- We are very proud of the fact that we are able to have regular quarterly meetings and easy access to the DDD Family Support Coordinator to obtain budget information.
- Council #4 had a high rate of return on surveys that were mailed out and we are pleased that our outreach efforts were successful and well attended.
- Members of Council #4 were able to assist three (3) families. Two (2) families were referred to us by NJCDD (Pat and Tasha) for follow-up support and referral services in Essex County. While another family was referred to us for assistance by a School staff member after his student's family was denied eligibility by DDD. We were able to direct and assist all families.

## **V. Long and Short Term Recommendations**

### **Short term:**

- RFSPC #4 will focus on retention of existing members and recruitment of new members that will reflect the diversity of Essex County. (i.e. male, developmental disability, bilingual, etc.)
- We will update our mailing list and send out our updated council brochure.
- Obtain assistance with translating survey into Spanish

### **Long term:**

- Monitor and solicit feedback from consumers on new DDS system of intake and case management.
- Establish contact with NJ legislators and do more as a Council to put the concerns of Essex County families in writing.

## **VI. Identification of Training Needs**

- RFSPC #4 veteran and new members need training in reading, monitoring and evaluating contracts.
- Advocacy training for Consumers/Families- "How to Navigate System"

## **VII. Recommendation for re-allocation of funds**

No recommendation for re-allocation of funds can be made at this time as RFSPC #4 has not been involved this fiscal year with reviewing contracts to determine which family support services are actually benefiting families and working best in our region.

**VIII. Recommendation for new funds**

Not sure if new funds are available?

**IX. Recommendation for additional funds**

The council will place topic item on a regular council meeting agenda for discussion

**REGIONAL FAMILY SUPPORT PLANNING COUNCIL #5  
ANNUAL REPORT  
07/01/08 – 06/30/09**

**Council # 5**

Counties Served: Hunterdon, Mercer and Middlesex

**Council Chair:**  
**Chair:**  
Nelly Shoham  
Byra

**Council Co-**  
  
Ellie

**Council Membership:**

Ellie Byra/ State Rep  
Sandy Dunleavy  
Tina Johnson  
William Robins  
Nelly Shoham/ State Rep.

**1 - PUBLIC INPUT ACTIVITIES CONDUCTED**

**Each council is required to complete three methods of public outreach – one of which must be a Public Hearing**

- **The Council held and/or participated in three public forums:**

1. **RFSPC#5 participated in an interactive Public Forum**

Together with Parents Educating Parents and the Ewing Public Schools, RFSPC#5 participated on a public forum and provider's fair on November 12, 2009. This forum was guided exclusively to families in the township.

- ❖ Various organizations were present informing families about their services, i.e. Arc of Mercer, various Sports programs, DVR, DDD, Family Support Center, etc.
- ❖ The College of New Jersey was also present to invite individuals with intellectual disabilities to participate in their programs.

2. **RFSPC #5 Co-sponsored a Forum**

In partnership with The Perth Amboy Public Schools, Department of Special Services, RFSPC#5 held a Public Forum on October 15, 2008 at the Robert Wilentz School in Perth Amboy.

- ❖ Attendance exceeded 40 families, most Spanish speaking and in need of translators.
- ❖ 10 providers also participated and offered their services.
- ❖ The forum was guided to transitioning individuals, however most attending families had children in elementary and middle schools.
- ❖ An impressive attendance and participation of the school staff was noted.

3. **RFSPC # 5 Held 1 Public Forum.**

RFSPC #5 held a Public Forum and Provider's Fair for Mercer County residents at the Mercer County Special Services on October 25, 2009.

- ❖ Although the weather conditions were poor, we were glad to have 43 families attending.
- ❖ An overwhelming 15 agencies participated and expressed much interest in serving the community.
- ❖ DDD, DVR and Mercer County Board of Special Services also attended.
- ❖ DDD speakers offered information about the benefits of being registered with the Division and explained registration procedures.
- ❖ DVR also explained registration guidelines and benefits
- ❖ Refreshments were provided by "A Touch of Class", a program sponsored by The ARC of Mercer County.

- **RFSPC # 5 held one public outreach**

### **Outreach membership meeting**

RFSPC#5 held an outreach to individuals interested in becoming members on May 15, 2009 at the East Brunswick Public Library.

- ❖ Because of budget cuts, library was closed earlier, therefore meeting was held at the Gazebo, a cross from the library.
- ❖ 15 prospective members expressed an interest in the council and were invited.
- ❖ Only 3 parents attended although other family members are expected to join us to future meetings.
- ❖ One prospective member will be considered as a liaison, since she works for one of the providing agencies.
- ❖ We expect positive results from all attendees.

**RFSPC#5 members participated, individually, in several public outreach activities.**

- **Advocacy work:**
  - Autism, state and national conferences
  - Maintained continuous dialog with DDD
- **Participated in the following public conferences:**
  - Guardianship meeting at the Middlesex Arc
  - Self Directed Support Conference and other lectures hosted by the Boggs Center
  - Family Support Applications, Connections, Pathways to adulthood, Transition to adulthood.
  - Housing conference sponsored by the Arc of Middlesex
  - Housing conference sponsored by Neighbours, Inc. and SHA
  - Family Support Focus groups
  - Coalition of Families at the Arc of Middlesex
- **Chaired, organized or helped create the following organizations & programs in our communities:**
  - Served as Trustee, Board member and Board Secretary of the Hunterdon Outreach Programs (HOP).
  - Organized, chaired and participated on “DREAMS” parent support group in Dunellen
- **Participated in the following committees, meetings and trainings:**
  - National Public Policy Meeting, Washington DC.
  - Some of the members participated on the Task Force Committee for Cash Subsidy

- Care givers conferences
- One member serves on Executive Board at CDD, Boggs Center and the NJP&A
- Participated in most of the meetings of the Family Support Coalition.
- Attended to various dialogs with the Division.
- Were part of DDD Council National Meeting
- Participated on local support groups
- Participated at the Statewide Parent Leadership Summit
- Attended the University Centers of Excellence (UCE) national meetings.
- Participated at the PADD & disability rights of NJ

**RFSPC # 5 Published no Newsletters**

- We also translated our pamphlet into Spanish to meet the needs of our area.

**2. MONITORING ACTIVITIES CONDUCTED**

**Description of activities conducted to monitor the implementation of the system, i.e., surveys, information gathering from providers and professionals in the field, attending meetings, interviews with stakeholders, review of provider satisfaction surveys, or public forums and families**

- Some Council members attended regularly the Task Force meetings on implementing a new system for the Cash Subsidy program.
- **Public Survey**  
A survey was distributed and completed by families. During all the public forums and outreaches that RFSPC# 5 participated; enclosed results.

The following are our comments and information offered by families during our outreaches:

- ✓ Only 45% of the families were registered with DDD; many families had little or no knowledge of the Division and its services.
- ✓ Many Child Study teams, in public schools, are not familiar with the Division's services, thus, unable to inform families.
- ✓ Families find it difficult to locate and contact their case manager at the Division.
- ✓ After school programs with transportation means [either from the program or from school district(s)] have long waiting lists while others are in need of clients or being closed down for lack of transportation.

- ✓ Parents are often looking for affordable recreational activities; in many cases they are not aware of what is offered and/or the programs are filled to capacity.
- ✓ Lack of appropriate transportation is the main concern in all types of programs offered.
- ✓ Parents are in need of **Social skills programs, Saturday programs & hotel respite**. Families themselves need respite from the daily stress of caring for their loved one with intellectual disabilities.
- ✓ Families need **specialized diagnosis, evaluation and therapy** services.
- ✓ **Self Directed Day Services:**
  - Although some families are enjoying the benefits of this program, many families find it unattainable due to the difficulty of obtaining transportation.
  - Parents also find it difficult to find the ultimate goal of this program since, in many cases budget is not enough, it does not cover housing nor does it fund for a provider to oversee the very intricate logistic involved in the program
  - Many active programs are now experiencing waiting lists
  - Families are apprehensive after experiencing recent changes although they were told budgets/services were committed for the life of the individual
  - Families find it difficult to find support workers.

### **3 - EVALUATION OF THE FAMILY SUPPORT SYSTEM**

#### **This is our Council's analysis of Family Support System based on the activities described in 1 and 2**

- The council appreciates the efforts Mr. Ken Ritchie who has involved the councils in the decision making on the Cash Subsidy.
- Families are unclear and unhappy about the future of case management with the limited information they receive from the Division.
- In all of our forums an overwhelming amount of parents approached the DDD table to register only to obtain a piece of paper with instructions. DDD should keep track of such families; contact them to ease this process while showing interest and good will.

- DDD’s registration form is very lengthy and difficult to complete, some parents complain that by the time form reaches the division the information supplied is no longer accurate.
  
- **After school programs** continue to be in **high demand throughout the region.**
  - Some programs are not filled because the Division is not referring clients to the agencies.
  - Transportation is a deterrent in cases where the agency or the school district does not offer it.
  - When programs are filled to capacity; families are forced wait for an opening while no other service is available.
  - Many agencies are not willing to modify their program to address the needs of children.
  - After school programs in the high school level do not exist.
  - The council recommended a new and innovative after school program sponsored by The Family Resource Network but it was never implemented due to the long delays on “RFP” within the division and we have no idea where the money went.
  
- It is undeniable that the most important issue for mature individuals is **housing**; although families now are aware of their place on “the waiting list” their situation has not changed. Families feel that the Division has not taken the necessary steps to provide a solution to this problem.
  
- We understand DDD can provide a language translation service; however, this is not widely known or utilized by case managers and families. Many districts are in dire need of translators.
  
- Councils are still unable to evaluate provider contracts and level of services although training in that area has been provided.
  
- Satisfaction Surveys that are filled out by families and mailed back to the providers may not be accurate because families may not be comfortable responding directly to their provider agency.
  
- Transportation
  - ❖ Transportation is needed for school districts to attend after care programs.
  - ❖ Transportation is also needed for adults who cannot drive to work.
  
- Families are also in need of summer and recreational programs.

- DDD has not provided families, case managers and councils with sufficient information on accessing services.
- Adult services, especially in the area of more medically or behaviorally involved individuals, do not exist. Programs, which are in high demand and short supply, include quality adult day services, residential placements, after care programs, specialized senior services and behavioral programs.
- Families are suffering because of the limited family support funding during this year.

#### **4 - ACCOMPLISHMENTS & BENCHMARKS**

**This section is a report on the areas of improvement our Council has recognized as a result of our activities and how we will measure future success.**

- Our council sent an informational letter to Senator Joseph Vitale regarding the function of the councils and the need of reimbursement of the funds submitted thru the waiver to DDD.
- We had numerous meetings individually and as a council with other participants in the family support system and with providers regarding budget advocates
- Council members participated in several informative conferences, which kept us better informed. i.e.: Community Care Waiver meetings, Family Support Coalition regarding the budget, various workshops offered by the Boggs Center related to Self directed series, etc.
- The council saw an increase in public awareness about RFSPC #5 through our relationships and activities with the providing agencies, some schools, community groups, families and consumers.
- We increased the RFSPC#5 data base by 91 families

#### **5 - LONG AND SHORT TERM RECOMMENDATIONS**

**This is our Council's recommendations for improvement in the system, both immediate and long term.**

- There is a need for regional meetings between case managers and council members to learn what each one can do to help the other.

- The Division should change registration procedures, i.e.: client approach, registration form, follows up etc. Time line of over 1 year reviewing applicant's documentation for acceptance is not acceptable.
- There is a general impression that case managers need to be more sensitive to the needs of their clients; in some cases they are judged based on social economic status, number of classified individuals in a family etc. Other case managers downplay the reasons for existing programs and feel they should be cancelled but are not aware of how important such programs are for many families
- There is a statewide need **for Recreation and afterschool programs** for people **with behavioral issues**. Hotel respite, afterschool programs, recreational programs and other program variations for behavioral individuals should be addressed.
- **Counseling, behavior modification, crisis intervention, and home training** are required by families; these resources are minimal and hard to find.
- **Cash Option respite:**
  - The Division needs to be reminded that pay scale has not increased in many years while the cost of living has sky rocketed.
  - Families need to be trusted to hire the appropriate respite workers.
- **Once again, we must insist, - the needs of Aging caregivers must be addressed** at all levels:
  - Housing, - long, slow moving waiting lists that give little hope to older caregivers. Families worry about what is going to happen to their family member once they pass
  - Care giver is no longer able to take care of the person with disabilities; he/she needs help with daily activities.
  - Aging care giver is unable to transport the person with disabilities to their daily activities.
  - Additional respite supports, home nursing care and medically based respite, transitioning to residential placement, day programs, job placement and more financial aid are in great need.
- While **"Self Directed Day Services"** is a good, innovative program, issues such as transportation, budget limitations and logistics should be addressed.
- The council has not seen any improvement on **transportation**. This is still a major issue for adults unable to drive; they need to get to their jobs or higher education. After

school care programs are unable to offer their services because children are not being transported from their schools.

- Providers are eager to start new, innovative programs but get discouraged by the Division's lengthy "RFP" procedures. Something should be done to expedite such requests.
- Council members need to be active partners in developing policy procedures and services for the 26,000 families receiving family support in the state of New Jersey. DDD should also include councils when family support policy changes take place.
- While the council applauds the Division's interest in easing case manager's work load, we feel it might not address the particular needs of families of children and adults with very personal, individual issues.
- The council also has reservations regarding DDS's ability to handle the many individual situations case managers handle in a daily basis.
- DDD should improve outreach to families, especially regarding Family Support Services and to non-English speaking families.
- Families want to know that there is a **coordination of services**, across the daily routine and over the lifespan of an individual. Transition through all phases of life is not coordinated; families feel unprepared to address each level of change in the person's life; i.e.: home to school to afterschool, recreational care or school to adult services.
- Behavioral supports are needed as an integrated program that develops behavioral management strategies across all areas of an individual's environment and life span. This would include during transition from childhood to adolescence and from adolescence into adulthood. It should also include supports for in-home care, as well as during school or program and in the community. This would eliminate the need for developmental placements.
- We need to be partners in any further discussions regarding new implementations and concerns about the future of case managers in the state. Without the participation of case managers, family issues can get blown out of proportion and become very costly.

## **7. RECOMMENDATIONS FOR REALLOCATION OF FUNDS**

**This Section is based on our Council's analysis of the December overview of Contracts submitted by DDD**

- Councils should be notified when any part of our recommendations need to be re-directed.

- New programs (RFP) should be followed-up by the Division; Family Support Coordinators need to notify their status to the councils.
- It is our understanding that \$87,802 of FY08 was utilized as a “one time” contract. We recommend any family support funds for our region that have not been used be distributed as follows:
  - \$50,000 – New Horizons for Autism to help individuals in our region
  - Balance to be put into Cash Option Respite in our region.

### **8. RECOMMENDATIONS FOR NEW FUNDS**

**This is a description of the allocations of new funds that were made available to our council during the reporting period.**

- **NEW DOLLARS FY10 ALLOCATION \$0**
- **ANNUALIZED DOLLARS FROM FY 10 –**

We recommend any family support funds for our region that have not been used or have been allocated as an annualized item for FY08 be distributed as follows:

- \$50,000 – New Horizons for Autism to help individuals in our region
- Balance to be put into Cash Option Respite in our region.

### **9. RECOMMENDATIONS FOR ADDITIONAL FUNDS**

**This section is an estimate of what it would take to meet the need in our counties**

The council appreciates the efforts of the current administration to an open dialogue and hopes it continues in all aspects of family support. The knowledge and experience families have in the everyday care of their family member should not be overlooked; it can be a useful tool to develop new programs and systems.

REFSC#5 strongly feels that all Regional Councils and the Statewide Council must continue joining forces with all other advocacy groups and family members in the state to work on family support budget issues.

It is imperative that we make our families and their needs visible to our legislators and our communities. The needs of our families are not being met, recognized or supported by existing community based programming and funding.



Regional Family Support Planning Council #6  
(Monmouth and Ocean Counties)

Annual Report 1 July 08 to 30 June 09

Michael Brill – Chair  
Walt Fernandez – Vice-Chair

Council Members

Malkie Biegeleisen  
Michele Drumright  
Sheilah Garry  
Sarah Logan  
Melanie McGackin  
Helen McGeoch – Liaison  
Jane Tallman  
Ed Viebrock  
Jane Ye

Regional Family Support Planning Council #6  
(Monmouth and Ocean Counties)  
Annual Report 1 July 08 to 30 June 09

1. Public Activities

October 9, 2008 – Council 6 Public Forum-Ocean County

March 12, 2009 – Council 6 Public Forum-Monmouth County

2. Monitoring Activities

Council members are still no longer permitted to attend Cash Subsidy meetings or provide input which was considered in distributing funds, due to HIPAA concerns. We did meet with representatives of several provider organizations: New Horizons in Autism, The Arc of Monmouth, The Special Children's Center, and others. Still waiting for DDD to provide Annex B's for agencies providing family support services in Monmouth and Ocean Counties.

3. Evaluation of the Family Support System

Council 6 continues to distribute information regarding available services and promotes training for families where applicable. We continue to receive inquiries regarding services from family members who are unable to obtain them from traditional channels. Family support is still communicated by 'word of mouth' more so than any other means. The issue of Cash Option Respite is still a critical one, with nearly 900 families on the waiting list.

4. Accomplishments/Benchmarks

Our October Forum, although not as well attended as our Spring forum, was still highly successful with 50% more people attending than the previous year. The important lessons learned regarding the event the previous year were incorporated this year and attendance improved. Our March forum was well attended with more than 100 participants and 19 providers. We plan to continue the two (2) forums with one in the Spring and one in the Fall.

As you aware there was no addition funding for Family Support and in fact the budget was cut by an additional \$4 million at the end of June.

The council now has a permanent membership on the Monmouth and Ocean County CIACC, where we provide input on issues facing our constituents.

We have attending numerous meetings to provide input and to receive information regarding programs and policy issues in our area. Some of the meetings have been with:

- The Children’s Home Society of New Jersey, Healthy Children Healthy Communities
- National Caregivers Conference
- Manalapan Mayor’s Committee on Special Needs Forum
- Assistant Commissioner Ritchey’s Family Support Task Force
- One Council member sits on the Board of The Arc of Ocean
- Olmstead committee for Advocacy and Family Partnership
- CIACC-Monmouth and Ocean Counties

We have been active in presenting and distributing information about the council to the following:

- Special Children's Organization For Parents and Educators (SCOPE)
- Marlboro Family Resources in Education and Development (FRiEnD)
- Pt. Pleasant Neptune High School SEPTA
- Knights of Columbus providers fair
- POAC

## 5. Long and Short Term Recommendations

Increase the number of contacts with Legislators to provide them insight to the needs of people with disabilities and their family as well as the quality of outreaches to PTA’s/PTO’s as well as local Special Education Advisory Councils.

Continue to run two Forums per year to increase the numbers of families contacted.

Capitalize on the connections already established with the Legislators that have attended our events.

We plan to invite some of the 14 agencies providing services in our area (48 Contracts) to speak to the council regarding their needs and for ways that we can work together to provide families the support they need.

We need to find a way to reduce the waiting list for Cash Option Respite in Monmouth and Ocean counties as the list is too long with some families waiting years for available funding.

#### 6. Identification of Training Needs

Council members would benefit from HIPAA training to permit them to attend Cash Subsidy meetings and other meetings where sensitive information may be discussed.

Training is needed for medical professionals to make them more aware and sensitive to the needs of our population.

Council members would benefit from training on the latest activities by DDD, NJCDD, and others so that they are up-to-date on what is happening in our community, but scheduling conflicts have arisen.

#### 7. Recommendation for Relocation of Funds

As always there is a need for more family support dollars; it needs to be a permanent budget item. In the coming year we will still attempt to get a response from Camp Oakhurst regarding the demographics of the people they provide services, this agency has repeatedly ignored requests for information, hopefully be able to reallocate some funds from their program.

#### 8. Recommendation for New Funds

In this environment funds are still needed for respite services; there are almost 900 families in Monmouth and Ocean County on the waiting list for cash option respite.. In addition accommodations are necessary for families needing more than 60 hours per quarter. We would like to explore the option of using new respite funds when money is available (families that would be added, not those already receiving funds) at 10 hours per month instead of 20; it would allow us to provide some respite to twice as many people, since we have a limited amount of funds.

Additional funds also need to be provided to improve transportation to permit people with disabilities who want to and are able to work to get to jobs.

#### 9. Recommendation for Additional Funds

Same as item 8

## 10. Other

We have been fortunate that we have been able to fill all available slots, but it is difficult to maintain due to the needs of family members and people with disabilities.

We would also like to thank Angie Cardon and Ann Weber-Rodriguez for their support and assistance, they have been a real asset to us and the families we support.



County, and it was the first time it was held on a Saturday. It was also the first time held at the Bancroft School.

### **March 3, 2009**

Public forum at Burlington County Special Services. Various speakers attended such as Peg Kinsell-SPAN, Eileen Plunkett-DDD, James Kilrain-OTC, John Lundburn-SSI, Ed Green-DVR, Pam Myers-Social Ministry at Wiley

### **March 18,2009**

Resource Fair at Jewish Family and Children's Services (Katz), Cherry Hill, NJ. Table was maintained by two council members. Literature, surveys and other forms were taken by approx. 100 people and service professionals. The event at JCC was successful. The helpers at this event were Kim Coll and Margo Morrison.

### **April 23, 2009**

Open Forum held at the Eastern Regional High School, Voorhees, NJ. We had approx. twenty-five parents and staff members present. Council members present were, Debra Flagg, Mike Marue, Margo Morrison, Susana Medina and Nancy Foster. Panel included Jim Gullo and Jeanette Marquez from DDD, Elizabeth Guzman and Nohemi Andujar from DVR, Lorna Cunningham from OTC, Ken Dubois and Joanne Rusnak from ARC of Camden County. Jim Herbert from SSI dropped off some info but could not stay. Questions were mostly concerning where to get information about college and employment opportunities.

### **Special Contributions**

Kim Coll informed the group that she had written a book, Friends Helping Friends which discusses events and activities that may be useful for individuals with developmental disabilities.

Barbara Coppens has received the Community Building Award from the NJCDD for going above & beyond the call of duty.

## **2. MONITORING ACTIVITIES CONDUCTED**

Surveys, mailing list forms, council information, newsletters and other information are always on display and/or handed out at all of the above activities plus many other small opportunities that we attend. All of our council members are always looking for more opportunities to gather information and to make families aware of the council. The greatest opportunity for this usually is the one-on-one contact with those who attend meetings, talk with on the phone, or at Open Forums and Providers Fairs.

Representatives from DDD and other groups are now calling us for permission to give out our numbers to help the families they represent.

**Open Forums, Outreaches and Surveys produced the following testimonies:**

- The need more community based recreational services or programs for adults with disabilities
- Respite
- The need for home health aides and other in-home supports.
- Behavior supports in the home for severe behaviors
- Cash Subsidy / Voucher Stipend
- Camp
- Assistive Devices
- Transportation services
- Medical / Dental Assistance
- Housing Assistance
- Parent Education
- Estate, Transition Planning & Guardianship
- Knowledge of available services
- Parent Advocacy

**3. EVALUATION OF THE FAMILY SUPPORT SYSTEM**

The fact remains that the numbers show the growing needs, but this issue remains at a standstill. With lack of supports and caseloads increasing, there are concerns that DDD has not been able to provide any supports to many families. The families are not aware of the process that takes place after graduation. There continues to be an ongoing concern regarding our children that are aging out of the school system with no program to attend, or job placement. School systems are not equipped with enough information for students for transition and other career options. Due to the lack of funding, the majority of our children who are graduating will more than likely remain at home. Camden City continues to be our focus as well as other areas within Camden County. Due to the increase of the Latino population, we are honored to have members that can attend the outreaches and are more culturally sensitive. There have been several families that have come forth that have expressed their concerns and inquired of existing agencies that can address their needs. Until additional funds are released, it remains nearly impossible to accommodate families coming into the system.

As stated last year, families should be receiving Family Support information when registering for DDD services. This will help the families understand that there are more factors involved in receiving services. Also, Family Support recommends that provider's services look at services needed by the families registered with DDD and provide more individualized care and services to the individual, rather than a generalized program.

**4. ACCOMPLISHMENTS/BENCHMARKS**

Council 7 has continued to become larger within this past year. Attendance at our meetings has increased and we are at full membership with Liaisons and volunteers. Our current goal is to hold our provider's fair annually and possibly twice per year due to the growing population and demand of services.

## **5. LONG AND SHORT TERM RECOMMENDATIONS**

Sometimes we neglect to use the unique and knowledgeable talent of each person that is a part of our own council. Since we have such committed council members and liaisons, three of whom are bilingual we have been able to reach more people than ever before. One short term goal would be for each of our dedicated people to reach out to the special needs members of their own local community, letting them know who we are and gathering information on their needs. One way we can do this is to open more communication with our local school district's child study team, giving them our information that they can use and pass on to the parents. This would include using our buddy-up system initiated by our Chair, Debra Flagg, and a positive follow-up routine. If we are in communication with the system and the parents on an ongoing basis they will be more apt to call on us when help is needed. We can also run an ad in our local newspaper to announce an open forum.

Many of the needs of our families still seem to center around after school programs and local activities. Therefore, we will make it a long term goal to work with our local recreation departments and school districts to organize the needed programs in our area. We will contact existing programs that can possibly guide or aide our local communities in this endeavor.

We continue to make contacts in Camden County and held a Providers' Fair in Haddonfield, NJ last fall. Several open forums were attended including one at the RC Molina School in Camden City. Many of these contacts stemmed from an Open Forum we held at Cooper in Camden. The Providers' Fairs have such a tremendous impact on so many families and providers. Because we have been asked by so many families and providers when we are having one again in Burlington County, we will be having one in September 2009 for Burlington County.

The communication has improved on a regional level with DDD partly because they are always invited to our open forums but there still needs to be more. We need to follow-up with individual case managers or to make sure they are giving out our trifold when the initial application is sent. It would also be beneficial for both parties if we could have at least a meeting quarterly to review information.

## **6. IDENTIFICATION OF TRAINING NEEDS**

The council's recommendations are that formal training sessions needed would continue to be offered more frequently to capture and train new members. We need to go back to the basics. Family support should evaluate the current needs of families and reflect on the changes that are needed for our families. With the creation of many newsletters and public displays, we have become more knowledgeable from the families and have been successful in reaching out to them. With the continuing changes in the system and the growth of Real Life Choices remains complicated to the families and would be beneficial for council members to receive updated information. The need to research other venues for new services remains another priority of the council. It would be helpful if our information was bilingual to assist in our growing population of other cultures.

## **7. RECOMMENDATIONS FOR REALLOCATION OF FUNDS**

Although the council has not received contracts for some time, our recommendation remains that the allocated funds remain the same as all projects and programs are running at least 85% or above. Should any additional monies become available, we suggest it go into cash subsidy as request for this request continues to fall short to DDD. Until additional money is received, it is uncertain as to what other options families have for their loved ones to receive services. New programs should be explored and better care should be given to our loved ones. As stated last year, we ask that the cash subsidy request go back to once a year instead of every two years.

## **8. RECOMMENDATIONS FOR NEW FUNDS**

Due to the population of people with disabilities increasing every year by nearly 1,500 or more, the issue remains for Family Support to become a line item in the budget. Also, recommendations for funds were given to DDD to show how this money should be spent. As long as an existing program is operating at 85%, we recommend that any additional funds become available for cash subsidy with the possibility of exploring new programs. It is also recommended that families receive money for respite. It should be at the discretion of the families who will care for their loved one in the event that they receive this service and funding.

## **9. RECOMMENDATIONS FOR ADDITIONAL FUNDS**

In the event that additional funds would become available, the council feels that new programs be explored. With Real Life Choices being an alternative for some of our

families, there are those who continue to receive traditional services. These services are not maximizing our loved ones potential and are geared to accommodate a general consensus. Our loved ones individuality is not supported by current existing services.

## Council # 8: Serving Salem, Cumberland and Gloucester Counties

### Council Membership

<p><b>Chair:</b> Nancy T. Ivins (Gloucester)</p> <p><b>Vice-Chair:</b> Daphne Jackson (Gloucester)</p>	<p><b>Members:</b>                  John Rubis (Gloucester)                  Bernice Miedzius (Gloucester)                  Agnes D’Agostino (Cumberland)                  Jean Gross (Cumberland)                  Frances Mitch-Ratcliff (Cumberland)                  Dale Lively (Salem County)                  Patricia Alston (Salem County)                  Sally Myers (Salem County)</p>
<b><i>Liaisons to Council #8:</i></b>	
<p><b><i>The Arc Gloucester:</i></b>                  Ana Rivera, Executive Director                  Brenda Powell, Director of Development                  Brenda Scardefield, Associate Director for Family Support</p> <p><b><i>The Arc Salem:</i></b>                  Shirley Brooks, Associate Executive Director</p> <p><b><i>The Arc Cumberland:</i></b>                  Debra J. Parker, Executive Director</p>	<p><b><i>Archway Programs:</i></b>                  Fran Goldstein, Coordinator                  Respite/REFIL/Positive Encounters</p> <p><b><i>Family Resource Network:</i></b>                  Carrie Ruffin, Director of So. Regional Services</p> <p><b><i>Statewide Parent Advocacy Network:</i></b>                  Susan Coll-Guedes, Parent Group Specialist</p> <p><b><i>Former Council Members:</i></b>                  Verna Bullock-Lewis, Former Chair</p>

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## 1A. PUBLIC INPUT ACTIVITIES CONDUCTED

### I. Outreach for Council Members:

Beginning this year with only 5 members, Council 8 worked aggressively toward increasing its membership. We identified the need for Council Members in our newsletter, through our provider liaisons, as well as the Council on Developmental Disabilities’ magazine, which resulted in e-mail contacts, telephone contacts and attendance by prospective members at Council 8 meetings. Our efforts have resulted in the addition of 5 new members to Council 8 during 2008 and 2009. We currently have 10 members. Several members have been involved in family support for many years and are due to retire as members. We continue to outreach to families to locate new members to fill our remaining opening and to step in as replacements for retiring members.

**II. Mailing to DDD Mailing List:**

Input was solicited from families by means of a survey which was sent out in May of 2009 to the Division of Developmental Disabilities mailing list consisting of 1,745 families in Cumberland, Salem & Gloucester Counties. This mailing also included an informational newsletter which shared feedback to families from our public outreach and information regarding new programs available to families this year.

**DDD Mailing List Survey Responses:**

Council 8 received 72 survey responses from families in response to our mailing to the DDD mailing list as of the end of the fiscal year. The results of the surveys are summarized as follows:

PRE-SCHOOL 7 SCHOOL AGE (5-21), 30 ADULT 21 + 35  
Gloucester Co., 35 Cumberland Co., 27 Salem Co., 8 Atlantic Co., 1 Camden 1  
\*\*\*\*\*  
\*\*\*\*\*

**1. Do you receive family support services or funding for these services from DDD? Please list which services you currently receive.**

**Pre-School**

- Need to find out what services he is eligible for 2
- Cash subsidy 2

**School age**

- Cash subsidy 19
- Respite, 11
- No 2
- Summer camp
- Arc
- Receive help paying for diapers

**Adult 21 +**

- Respite 7
- Cash subsidy 5
- No 4
- Inclusive recreation 4
- Summer camp 2
- RLC
- Tuckahoe respite
- Out n About Family voucher
- Residential Waiting list
- Sat program at Arc Cu.
- Work (supported employment)
- Job at Easter Seals

**2. Is there a Family Support Service that you need that is not available to you? Please explain how the service would help your family.**

**Pre-School**

- Need to know services available **2**
- Transportation to medical and school appointments and translation services. Mom speaks only Spanish.
- Know more families who have Angelman's Syndrome.
- More help (age 4)
- Stipend for gym and music

**School Age**

- Respite **3**
- Yearly cash subsidy **3**
- After school care **2**
- Behaviorist trained in ABA for in home help.
- Counseling mentor
- Speech therapy
- Summer camp in August. also  
More funding for special diet and supplements, therapies.  
Big brother type tutor--to get him out in the community.
- Recreation like YMCA but for disabled, computer room, pool, gym, reading and movie room, a place to have their birthday with friends and family, game room, fund raising committee for parents.
- Health Insurance.
- Transport chair for back and forth to school on bus and long trips
- I need another service for my other son
- Home health aide to bathe Philip put on bus in AM take off PM get ready for bed 2-3 days a wk.
- Adult programs closer to Vineland, Millville, Seabrook, Bridgeton.

**Adult 21 +**

- Stipend **5**
- Respite **4**
- Not sure what services available- **3**.
- Using respite for a weekend away for a couple times a yr.
- Services, organization, get togethers for mild traumatic brain injury (adults) which would allow her to be more independent. Also a service for client and family members to go out together to movies, shows etc..
- Access Link. Do not pick up from home if don't live near a bus stop.
- More adult recreational activities in Salem co.  
Better job opportunities in Salem co.  
More awareness of general public of the positive influence of our population.  
Public housing, group homes etc.
- Physical therapy.
- After work program until 5:30 PM.
- Fix bathroom. This year asked for money to buy tires for van.
- To pay for services to whomever I choose to sit with my son.
- Stipend money to help with transportation costs that we provide as caretakers and reimbursement for respite care, that which we are responsible to provide for ourselves.
- Buy clothes, go on trips, furniture.
- Take son bowling and basketball.
- Cooking class

**3. Do you have any comments that you would like to share about family support services that you are currently receiving or have received or about the provider of the services.**

### **Pre-School**

- I know there is help out there that comes to the children's home to help them after school.

### **School Age**

- I found the behaviorist from Delta T was untrained to work with special needs children. Trained workers cost anywhere from \$ 100 per hour -- often times not enough money is allotted to employ such persons.
- Is there an equipment exchange available for children transitioning to larger or different pieces? -- without the hassle of insurance and vendors. I myself ordered a **larger** gait walker than she could handle, following my therapist's advice.
- Cash subsidy checks every yr. 4
- They do not give you as much as you request for the subsidy.
- WE liked using cash option for respite.
- Funding and info on guardianship.
- Weekend camp.
- More respite.
- More suitable day programs.
- Difficult to get Medicaid and health services for child.
- Post graduation education classes.
- Would like to be more in touch with Case manager.

### **Adult 21 +**

- Cash subsidy **4**
- Recreation programs and transportation to them. **2**
- More screening for staff doing respite
- My son has Autism and doesn't get help from anyone except his mother and father. DDD is a real joke. They have never helped at all. My concern is, should something happen to me, or my husband what will my son do? Our family can't be bothered taking him.
- Camp Joy is a wonderful Camp
- First Student Bus company is difficult to deal with and very short when asked a question.
- Sat. respite is excellent.
- Respite when programs are off and parents must work.
- I feel safe with a family member sitting with my son. I had a bad experience in the past. One respite sent me a man who became obsessed with my younger son. One respite sat and picked the dead skin off her feet, and threw it on my living room rug.
- Disappointed in the changes for respite care. An organized on-line bulletin board sorted by age.
- Services to continue without making family compliance more difficult and insure against future reduction of supports.
- In 5 yrs. I received one letter, and that was to update us on Tracy's position on the waiting list for a program. Recently DDD sent a letter to inquire if services were still needed. My concern is that there is very little communication regarding the person served, their changing needs etc. (age (36 works at Ross Dress.
- RLC
- I still feel the caregiver family member should be able to use this money as needed without having someone else you can't trust. It makes no sense to pay someone to take your child to a function such as Special Olympics practice and you get in your car and follow because you attend and support your child.
- Get my son on a bowling team.
- Overnight respite in our own home or the ability to convert it to cash option to use my private person to provide the care. It would make a smoother transition.
- Don't know what financial help or support is available.

**4. Have you requested a family support service from DDD that has been denied? If so please provide details.**

**Preschool** --all replied **NO**

**School age**

- Yes -due to funding reasons.
- Summer camp
- 2 week camp
- No service for adult program

**Adult 21 +**

- Abilities center admission delayed due to health reasons.
- Vehicle modifications denied by 2 programs, currently on hold by state.
- My son has a behavior problem it is not being addressed.
- Cash reimbursement for family member to baby- sit my son
- Cash subsidy was every other yr.
- Weekend respite
- RLC

**III. Open Public Forum Meeting in Gloucester County on September 15, 2008**

Attendance: 30 Family Members, 8 DDD Reps., and 3 Council 8 Members

Families were anxious to talk about their concerns. They expressed much concern about not knowing, "What is available and how to find out more information."

There was much interest in the Family Resource website [fscnj.org](http://fscnj.org) as a source of available programs.

Topics that received lots of attention were

1. Cash Subsidy
2. Summer Camp
3. Recreation programs (both through DDD and locally)
4. Behavioral issues and services available

Other topics that were discussed were

1. After-school programs
2. Ramps
3. Out of home respite
4. Residential supervised apartments
5. Hydrotherapy
6. Respite/cash option
7. The program Pathways
8. Assistive technology sources
9. Social Security Disability Services

**IV. Open Public Form Meeting in Salem County on October 27, 2008**

Attendance: 15 Family Members (6 individuals attending with their families), 4 DDD Representatives

This has been one of the best attended RFSPC meetings in Salem County. Families seemed more than interested in expressing their views.

One over-reaching theme was, “Where do we go to get the resources?” Many families asked “What is out there and where do we get it.”

One family stated that Salem county families have not been signing up for DDD’s waiting list. There still seems to be a persistent fear that the state will take their children.

Another family felt that there was a need to know each other in the county. That way when someone was in need others can help.

Families discussed issues specific to their own need.

Theses included;

Getting job training

No heat in the apartment.

Is a child with CP eligible for DDD services

Medicaid

RLC

Recreation programs

Literacy programs.

Traumatic Brain Injury waiver

#### **V. Open Public Form Meeting in Cumberland County on November 24, 2008**

Attendance: 29 family members, 3 DDD representatives and 3 Council 8 members were present

Families in Cumberland brought up a common theme of “How do we get services.”

There were concerns that, “Nobody is telling families what services are out there, and how to access them.”

One issue that got a lot of attention was Guardianship. There is a lack of understanding about why it is needed and how to obtain it. Parents had many questions about POA, Living Wills, and what is the process and how funding is obtained.

Families spoke of individual concerns and problems and they included these topics.

1. How to obtain special equipment
2. Inclusive Recreation
3. Residential Waiting List.
4. RLC
5. Catastrophic Illness Fund

6. Dental Services
7. Cognitive Therapy and Behavior programs
8. IEP help
9. Hotel Respite

**VI. End of Summer Bash – Picnic at Camp Sun ‘N Fun September 6, 2008**

We distributed checklist surveys to families as they entered the camp for the picnic and asked them to complete the surveys.

15 Survey Responses were received, which provided us the following feedback:

PLEASE CHECK OFF THE TOP THREE SERVICES YOU NEED OR FEEL WOULD HELP YOUR FAMILY THE MOST INCLUDING THOSE YOU ALREADY RECEIVE

OUT OF HOME RESPITE CARE 8  
 CASH SUBSIDIES 7  
 VOUCHERS 5  
 SELF ADVOCACY TRAINING 5  
 AFTER SCHOOL CARE 4  
 CASH FOR RESPITE SERVICES 4  
 IN HOME RESPITE CARE 4  
 ESTATE AND TRANSITION PLANNING 4  
 MEDICAL AND DENTAL CARE NOT OTHERWISE COVERED 4  
 PARENT EDUCATION AND TRAINING 4  
 SPECIALIZED NUTRITION AND CLOTHING 3  
 PERSONAL ASSISTANCE SERVICES 2  
 TRANSPORTATION 2  
 HOME AND VEHICLE MODIFICATIONS 2  
 SPECIALIZED DIAGNOSIS AND EVALUATIONS 2  
 DAY CARE 2  
 EQUIPMENT AND SUPPLIES 2  
 SERVICE COORDINATION

OTHER

BOOKS, VIDEOS, USED ELECTRONIC SWAP

COMMENTS

1. PICNIC WAS A LOT OF FUN
2. PLEASE KEEP UP THE GOOD JOB
3. EMPLOYMENT AT LEAST 10 HOURS A WEEK
4. VACATIONS FOR YOUNG ADULTS AWAY FROM FAMILY
5. I SHOULD HAVE SOME KIND OF HELP WITH KEVIN WHO IS BLIND
6. NEED HELP WITH CHILD CARE DUE TO MOVING--ALSO NEED RAMP TO HOUSE

## **VII. Other Outreach: Phone and E-Mail Contacts**

A. Council 8 maintained an e-mail list and phone number which was publicized on our surveys and in our newsletter. We responded to numerous phone calls and e-mails primarily related to the following topics:

- Council 8 membership inquiries
- Council 8 meeting date and locations
- Requests for assistance with advocacy issues
- Questions about DDD services and how to get them
- Mailing list issues
- Guardianship questions

B. We are working with our provider liaisons to obtain feedback on their programs. The Arc of Salem County provided us with summaries of two satisfaction surveys that they conducted during this fiscal year. They received 38 responses to their October 2008 survey and 37 responses to their May 2009 survey. The family support programs covered by these surveys include in-home respite, hotel week-end respite, and drop-in Saturday. All consumers responding to the survey indicated 100% satisfaction with the programs. There was an overwhelming indication that these services are greatly needed and are helping the families to keep their family member at home. Some of the responses were that the time allows the family to take care of errands, the program is a life-saver, and that there are mental health benefits to all concerned. A few people indicated the benefit to the person served by providing an outlet, a break from the caregiver and a chance to go out socialize, meet people and do different things under the care of responsible supervisors. Families consistently indicated a need more hours and more workers.

### **1B. PUBLIC ACTIVITIES FOR THE NEW FISCAL YEAR (PLANNED & ACTUAL)**

Council 8 plans to hold 3 Public Outreach meetings and conduct another written survey during the 2009-2010 fiscal year.

We plan to continue to aggressively seek new members, build liaison relationships with providers and continue to work towards getting our surveys out to families.

We also plan to seek out opportunities to participate in any community events or provider fairs that we become aware of, in order to provide additional outreach to families.

We will continue to forward information to families via the Council 8 e-mail distribution list.

We plan to mail our survey and newsletter to our mailing list during the next fiscal year.

We will continue to revise and update our Council 8 e-mail and mailing lists, working to increase the number of people on our lists.

We will continue to work with our provider liaisons to obtain input about their programs and feedback from their satisfaction surveys.

## **2. MONITORING ACTIVITIES CONDUCTED**

We received a copy of the Family Support Contracts and the Level of Service Reports (“LOS”) from DDD. On March 23, 2009, Sandra Firman, DDD County Administrator for Cumberland and Salem Counties, came out to our meeting to discuss the contracts with us. Sandra reviewed what information the contracts include and the LOS reports. We discussed what kinds of recommendations we could make if there was additional funding available. The providers must provide written reports to the County Administrator and do online reporting. We were advised that the contracts are not being rewritten every year unless there was a change in the program description. We relied upon the LOS report and our meeting with DDD to monitor the family support contracts.

Survey results also provided Council 8 with a means of monitoring the perception of our families of the Family Support Services.

## **3. EVALUATION OF THE FAMILY SUPPORT SYSTEM**

1. There are major changes taking place in the Family Support System and DDD needs to communicate these changes with the Family Support Planning Councils. Changes are already in effect of which our council was not officially made aware.
  - Council 8 Chair Nan Ivins attended a meeting in Gloucester County on August 27, 2009, which was entitled “Navigating the New System,” which provided information to families about the Community Care Waivers, Waiting List Changes and Individualized Budgets. This new system has replaced the Real Life Choices program. The way that families receive services and names of waiting lists have changed. This information should have been shared with the Family Support Planning Councils. We need to be aware of changes as they occur. We should be involved with this process.
  - We learned through Task Force Meeting feedback that \$4 million dollars was reallocated from Cash Subsidy for the 2010 fiscal year to support day programs for families on the waiting list. This information should have been shared directly with the Family Support Planning Councils.
2. The family support system is failing to meet the needs of the families it serves due to inadequate funding. There have been no increases in family support funding to keep up with the growing number of families served. Additionally, we recently

learned that \$4 million was reallocated from family support cash subsidy to support day programs.

- Level of Service numbers which we reviewed in March of 2009 which reflected contract data as of January 2009 showed 9 programs operating at or above 90%, and 7 more operating at over 100%.
3. The role, function and responsibilities of the Family Support Planning Councils need to be reevaluated based upon the dramatic changes taking place in the family support system.

#### **4. ACCOMPLISHMENTS/BENCHMARKS**

##### **Outreach to families:**

Council 8 held open public meetings in all three counties we served. We had representatives from DDD in attendance to answer questions.

We created distributed surveys and a newsletter to all families on the DDD mailing list.

We held an out reach event at Camp Sun 'N Fun in Williamstown, NJ, and obtained survey responses from all families who attended this event.

##### **Agency Liaisons to Council 8:**

Council 8 has successfully built liaison alliances with all but one of the contracted family support provider agencies.

##### **Meetings:**

During 2009, Council 8 held regular meetings on a rotating schedule amongst the three counties that we serve.

##### **Council address and telephone:**

Council 8 maintains a regular mailing address, e-mail account and telephone contact system to ensure that families can reach us.

##### **Council 8 Membership:**

Council 8 is currently working with many prospective new members. After attendance at three meetings, they will be eligible to submit an application for membership. We have filled 5 of our 6 openings, and once we fill all of the slots, we will begin to replace retiring members with new members.

##### **Contracts:**

Council 8 has worked with DDD to obtain copies of all existing contracts, reviewed contracts and LOS reports with DDD.

**Training:**

NJCDD held several family support training meetings this year. The meetings were attended by two new members and one existing member.

**5. LONG AND SHORT TERM RECOMMENDATIONS****Regional Recommendations**

Families have expressed a dire need for safe, affordable after school care. We continue to recommend that a DDD fully subsidized after school program be established in Gloucester County in the area where the need is most highly concentrated. More specifically, we recommend that the program be placed in the Deptford, in the vicinity of the Gloucester County Special Services School District's Bankbridge School programs. We further recommend that transportation be included with this program so that children in nearby schools can be transported safely to the program.

**STATEWIDE RECOMMENDATIONS: DDD**

- A. **Family Support Line Item**: Council 8 recommends that Family Support be made a line item in both the Division of Developmental Disabilities budget and the Department of Human Services budget. Families are being forgotten again and the amount of funding allocated to family supports is not keeping up with the number of families entering the system. We need regular increases in the family support budget, and we believe that having Family Support as a line item in the budget will help keep the focus on the families who provide most of the care with only a small fraction of the funding.
- B. **DDD Policies**: Council 8 recommends that the Division of Developmental Disabilities establish and publish statewide policies to fairly distribute respite, cash option, cash subsidy, after school care, and all other family support services and programs that they provide. The current system seems to rely on rules made by individuals rather than a consistent set of guidelines.
- C. **Information to Registered Families**: Council 8 recommends that the Division provide information to families about programs and services that they can request in a clear and concise manner. A recurring theme in all of our outreach is that families need to know what is available and what they can ask for in the form of assistance in caring for their loved one at home. Although funding may not be available for all programs for all families, a system of advising families of services that are available and placing families on appropriate waiting lists needs to be established so that when funding becomes available, families can benefit from programs that are available.
- D. **Public Outreach by DDD**: The Council also recommends that the Division provide the public outreach that is mandated by the Family Support Legislation to families with loved ones with developmental disabilities in order to reach the thousands of families that are not on the Division's registered list. Newspaper

advertisements, bill board advertisements and Public Service Announcements are several methods that should be utilized.

- E. **Task Force Recommendations:** The Task Force purpose is: “To ensure a statewide system of family support that includes equity, accountability and consistent statewide practices.” This forum should be used for its intended purpose but is apparently being used by DDD to advise of changes to family support funding allocations or any other changes to the family support system. This information should be shared and discussed with the Family Support Planning Councils both at the statewide and regional levels.
- F. **Communication:** DDD needs to keep the Family Support Planning Councils in the communication loop regarding changes not only proposed but already in effect. The councils should be consulted, informed and should be a part of the process of systems change in the Family Support System. We should not have to find out second hand about changes that have already taken place in the system.

#### **STATEWIDE RECOMMENDATIONS: NJCDD**

1. We continue to recommend that the NJCDD hire an outside, professional facilitator to work with the Task Force currently being facilitated by DDD. We strongly believe that it is not in the best interest of the families we serve to have the Task Force be led by the Agency that we are seeking to change.
2. The Family Support Survival Guide was in the process of being updated but has not yet been completed or made available to the family support planning councils. Council 8 recommends that this manual update be completed as soon as possible and be made available to family support planning councils both in hard copy for distribution to members and via electronic copy.
3. We also recommend that a video or PowerPoint presentation of the training materials used in the recent family support training meetings be developed for orientation of new Council Members and Chairpersons.
4. Training meetings which were held this year for new and existing members should be repeated at least annually.
5. Provide in depth training directly to all Councils and partner with them in getting accurate information out to families about new regulations in DDD, and Changes in the way DDD plans to conduct business
6. Council 8 was asked to produce copies of annual reports for the past 5 years and also to provide details about our council members and the dates they became council members. We questioned why NJCDD did not have the files. We have learned that the files were lost when the NJCDD offices moved recently. Our council files are maintained in the chairperson’s basement and are not always

complete. They are also at risk of being damaged or destroyed as a result of the way they are stored. We strongly recommend that our council files be stored in an electronic format and backed up to ensure the security of the data.

## **6. IDENTIFICATION OF TRAINING NEEDS**

There is an ongoing need for materials to train new Family Support Planning Council Members as well as new leadership.

Family Support Planning Councils will require training in the new DDD regulations and changes in the way DDD plans to conduct business. Trained Councils can be an effective means of reaching families through their ongoing outreach efforts. Families will need a long transition time to understand new directions in knowing about and how to obtain services.

## **7. RECOMMENDATIONS FOR REALLOCATION OF FUNDS**

Council 8 recommends the reallocation of any unused family support funds which are available at the end of this fiscal year be used to fund an After School Cash Option to help families defray the cost of paying for private after school programs.

We strongly recommend that waiting lists be established for respite requests, recreation, after school fund requests and cash subsidy requests so that any unused funds that are available that need to be distributed quickly can be reallocated to families in the manner that they have indicated is most urgently needed. Excess funds that are not utilized by contracted agencies should be reallocated immediately to go to the families who need Family Support Funds for the purposes indicated by the families. Families should be informed that they are being placed on a waiting list when they contact DDD for services and not simply denied services based on lack of funding.

## **8. FUNDING RECOMMENDATIONS**

Although recommendations for funding are irrelevant at the current time in light of the inadequate funding of family support programs and the removal of cash subsidy funds from our budget, Council 8 continues to recommend the following:

1. Any funding that becomes available, whether new or by reallocation, for our region should be used to address the need for an after school program with transportation at a convenient location in Gloucester County as indicated in the needs survey results obtained by Council 8.

2. A portion of any funding in excess of item 1 above should be distributed to programs with a LOS of 85% or better.
3. The remainder of any available funding should be allocated to cash subsidy, after school cash option and recreation cash option.

## **9. RECOMMENDATIONS FOR ADDITIONAL FUNDS**

- A. The State of New Jersey should allocate an additional three million dollars for every year that we have received no increase in Family Support funds, in order to keep up with the increase in the number of families being served by Family Support dollars.
- B. Each year the additional funds that are allocated to Family Support should be increased as follows (these are cumulative):
  - By the cost of living (using any reasonable, standard cost of living index)
  - By the cost of the additional services that are provided each year in order to accommodate the approximately 1500 new families that are added to the Division's registered list each year
  - By the amount needed to satisfy the added levels of service needed for family support due to aging of the consumer population (i.e. older consumers require more supports and older caregivers require increased support).



## *Atlantic, Cape May*

Regional Family Support Planning Council #9

PO Box 84

Somers Point, NJ 08244

Telephone: (800) 216-1199 option #1

**DATE:** July 10, 2009

**COUNCIL MEMBERS:** Mary Ann Philippi, Chair

Monica Jarvis, Secretary

Elizabeth Hawkins, Active Member

Michelle Archie, Active Member

Mario Mercado, Active Member

Diana Daly, Active Member

### **PUBLIC INPUT ACTIVITIES CONDUCTED**

Atlantic County Special Services Back To School Night

Council 9 set up an information table at this training with over 50 teachers, parents and advocates in attendance.

Presentations at Family Support Groups

Mary Ann Philippi gave presentations on Council 9 to a variety of family support groups in the region.

Group members completed surveys on family supports.

### **MONITORING ACTIVITIES CONDUCTED**

Atlantic County Open Forum and Vendor Fair

Surveys were distributed to individuals attending the open forum and an open question and answer time

with DDD representatives was held. Families reported:

1. Difficulty in contacting their DDD case manager,
2. High case manager turn over,
3. Lack of knowledge on what supports are available,
4. Trouble with gaining access to DDD services/rejected applications,
5. Difficult transition from school to adult life,
6. Needing family supports that are not available including needing after-school program, and
7. Problems finding transportation in rural areas.

### **ACCOMPLISHMENTS/BENCHMARKS**

1. Started Friday Night Drop Off Programs at the ARC of Atlantic County,
2. Started Sunday Drop Off Program at the JCC in Margate, Atlantic County,
3. Started Saturday Drop Off Program in second location at the JCC in Margate,
4. Increased attendance and membership,
5. Higher participation of families residing in Cape May County, and
6. Added 100 new names to their mailing and email list.

Council 9 was instrumental in clarifying the rules of membership in Regional Family Support Planning

Councils and inviting back family members of disabled people (not registered with the DDD) who were interested in serving on the council.

ANNUAL REPORT 2007-2008

### **IDENTIFICATION OF TRAINING NEEDS**

1. Continue outreach at public events and through email to inform stakeholders on services.
2. School district case-managers need training to understand their role in helping to identify individuals who may qualify for DDD services.

3. As new individuals attend council meetings, inform them on the role of the RFSPC's, the Family Support Act of 1993, DDD services and eligibility and the by-laws of Council 9.
4. Increased awareness of DDD services in Atlantic and Cape May Counties.

### **EVALUTATION OF THE SYSTEM**

The majority of families have not heard of the Family Support Act of 1993, or the role that Regional Family Support Planning Councils hold in advising the DDD.

Many individuals express frustration with the DDD application process and difficulty in obtaining services. In our region, the DDD offers the following supports and services:

1. Respite, cash-option respite,
2. Hotel respite,
3. Funding for Camp-by-the Sea Summer Camp,
4. After-School Program at Atlantic County Special Services,
5. Weekend Drop off respite programs,
6. Cash subsidy/voucher,
7. Equipment and supplies, and
8. Emergency Respite (ARC Atlantic County).

Council 9 has taken parent input on available services and found that families who are eligible and receive these services are satisfied. However, contacting individual case-managers and the application process are areas of concern for parents.

Barriers to services and groups most at risk for being under-served are:

1. Rural location/limited transportation,
2. Single-parent families/child care issues,
3. Families without access to internet,
4. People with disabilities and mental health/behavior issues,
5. Families with non-traditional work hours (for example, casino workers), and

6. Limited English proficiency.

It is important to be aware of these high risk groups and consider ways of outreach to meet their individual needs.

## **LONG AND SHORT TERM RECOMMENDATIONS**

Council 9 recommends the following system changes:

- 1. Increased communication between DDD and clients including regular mailings, email and phone contact,**
2. Partnerships between DDD and other community organizations and agencies including Early Intervention, doctors, hospitals and schools,
3. Application Process: DDD Applications available to organizations, agencies and as a pdf for download on the internet,
4. Clearer guidelines for eligibility, and
5. Increased communication between DDD and Council 9.

## **FUNDING RECOMMENDATIONS**

The Statewide Council voted in 2007 to make recommendations for Family Support New Money, in the amount of \$200,000 to go to two organizations: Spina Bifida and the Brain Injury Association. This decision gave individual Councils less money for their region. Council 9 made a stipulation that the money that Spina Bifida and the Brain Injury Association received from Council 9 *stay* in the region to bring much needed programs to the families of Atlantic and Cape May Counties.

As of July 2008, Spina Bifida and the Brain Injury Association have not started any programs in Atlantic or Cape May Counties. Families in Atlantic and Cape May Counties have “paid” for family

support services that are not available in this region. In the future, Council 9 would like to be exempt from recommendations of this kind made by the Statewide Council. Unfortunately, there is no formal record of the vote that took place at the Statewide Meeting in May 2007.

Families in Atlantic and Cape May Counties have requested the following supports:

1. Create After-School Program in Cape May County,
2. Create Summer Camp in Cape May County,
3. Increased funding for Summer camp,
4. Community-based respite and recreation programs (Cerebral Palsy of NJ), and
5. Nursing care for medically fragile clients.

*Statewide Family Support*

*c/o The New Jersey Developmental Disabilities Council*

*PO Box 700, Trenton, NJ 08625-0700*

*TELEPHONE: (609) 292-3745 TDD: (609) 777-3238 FAX: (609) 292-7114 HOTLINE: 1(800) 216-1199 WEBSITE: <http://www.njddc.org>*

## **Regional Family Support Planning Council Trainings 2009 Report and Evaluation**

### **Session: I**

**Arc of Atlantic County, Egg Harbor, N.J.**

**Date:** Saturday May 9, 2009      **Time:** 10AM to 1PM

**Presenter:** Ann Hutchinson, Contract Admin. Southern Region

**Total Attendees:** Six      **Councils Represented:** 2, 7, 8, and 9

**Topics Presented:** Annex B's: How to Read and Use Them  
Service Providers' Role: Reading and Monitoring Contracts  
Budget Procedure Process; Timelines  
HIPAA

**Response to Surveys:** #1 Very informative  
(See Attached Form) #2 No negative responses  
#3 More sessions on contracts

### **Session II**

**Arc of Atlantic County, Egg Harbor, N.J.**

**Date:** Saturday May 16, 2009      **Time:** 10AM to 1PM

**Presenters:** P. Krupka, T. Jones

**Total Attendees:** Six      **Councils Represented:** 7, 8, and 9

**Topics Presented:** DD Act; Family Support Act  
Application Process for RFSPC Membership  
How To Run Meetings  
Bylaws  
Mailing Guidelines Update  
Outreach: Events, Surveys

**Response to Surveys:** #1 Very Informative  
(See Attached Form) #2 No negative responses  
#3 Being kept up to date on current issues

### **Session III**

**Arc of Somerset County, Manville, N.J.**

**Date:** Saturday May 30, 2009    **Time:** 10AM to 1PM

**Presenters:** K Crawford, M. Darrell Contract Admin. Northern Region

**Total Attendees:** Seven      **Councils Represented:** 1, 2, 3, 5, and 7

**Topics Presented:** Annex B's: How to Read and Use Them  
Service Providers' Role: Reading and Monitoring Contracts  
Budget Procedure Process; Timelines  
HIPAA

**Response to Surveys:** #1 Very Informative, Good group size, In-depth contract info  
(See Attached Form)    #2 No negative responses  
#3 Medicaid, SSI

**Session IV**  
**Arc of Somerset County, Manville, N.J.**

**Date:** Saturday June 6, 2009    **Time:** 10AM to 1 PM

**Presenters:** P. Krupka, T. Jones

**Total Attendees:** Three      **Councils Represented:** 4 and 5

**Topics Presented:** DD Act; Family Support Act  
Application Update for RFSPC Membership  
Budget Procedure process  
How To Run meetings  
Bylaws  
Mailing Guidelines  
Outreach, Events, Surveys

**Response to Surveys:** #1 Well organized; History of Family Support  
(See Attached Form)    #2 No negative responses  
#3 Training further North

RFSPC Training 2009  
Overall Outcome and Observations

Total Attendance for RFSPC Members: 22 (including presenters) 33

Council 6 (Monmouth and Ocean) was not represented at any training.

Members enjoyed the small groups and as a result felt more comfortable to engage with the presenter and to ask questions.

The trainings were well presented and enjoyed by the participants.

Contracts was the one topic that the members wanted to have a more in-depth training.

Atlantic and Somerset County ARCs facilities and meeting rooms were perfect for holding the trainings. Their staff were very welcoming. Pat sent Thank-you's to the DDD presenters and to the staff we worked with at the ARC sites.