

GATHER

MONITOR

FAMILY SUPPORT

SURVIVAL

MANUAL

RECOMMEND

SO YOU WANT TO BE A REGIONAL FAMILY SUPPORT PLANNING COUNCIL MEMBER . . .

If you are reading this, you probably have been asked to join your Regional Family Support Planning Council. What does that say about you? The principles in the Family Support Act put families in the driver's seat in making important decisions and recommendations about the way services and supports to families ought to look in New Jersey for people caring for an individual with developmental disabilities in their home.

REGIONAL FAMILY SUPPORT COUNCIL MEMBERS ARE:

- MONITORS
- EVALUATORS
- INFORMATION GATHERERS
- INFORMATION PROVIDERS
- PARTNERS



In a nutshell, it says that you are the voice of the families in your region.

By forming a partnership with the New Jersey Division of Developmental Disabilities, you and your Council can make services and supports reflective of what the families in your region say they want and need.

This opportunity is not only important and significant, it is like no other place in the country. **THERE IS NO OTHER STATE IN THE NATION WITH OR WITHOUT FAMILY SUPPORT LEGISLATION THAT PLACES SUCH A SIGNIFICANT ROLE ON FAMILY MEMBERS IN ITS PROCESS!!!**

Enjoy your chance to use the knowledge and skills you can contribute to this process and be a part of history in the making!

HISTORY OF FAMILY SUPPORT IN NEW JERSEY

Beginning as far back as 1989, organizations that serve or advocate for people with disabilities and their families began to realize the necessity for and importance of providing support to families in order to keep their family member with a disability at home.

The New Jersey Developmental Disabilities Council funded the first respite programs in the state in the late 1980's. Realizing the growing need to expand these programs beyond demonstration projects, the Council held Family Support hearings throughout the State. By the hundreds, People expressed the significant need to support families in various ways.

A "white paper" was written that formed the principles and values upon which Family Support Legislation would be based. This paper received the support of Senator Donald De Francesco and Assemblywoman Maureen Ogden, and was translated into what is now known as "the Family Support Act."

The movement of this legislation was conducted by families throughout the state. a petition With 10,000 signatures proclaiming the need for the FAMILY SUPPORT ACT was presented to Assemblywoman Ogden at a rally on May 4, 1992. A Family support Steering Committee of advocates and family members pushed the legislation through both houses. On March 29, 1993, Governor Jim Florio signed the Act into law.

Continuing in the family driven, family controlled spirit of the Act, then-Division Director Bob Nicholas agreed to let a group of family members write the regulations that would implement it. From July, 1993, through August, 1994, these families met on a regular basis and wrote the regulations - a feat we are told has not been done anywhere else in the country. The regulations went through the process and were finally adopted on January 4, 1995.

From that point, the Developmental Disabilities Council hired a coordinator and the regulations began to be implemented. Seven years later we still struggle with the enormity of the task. Families continue to drive the process and work in partnership with the service delivery system to create the best possible services and supports for families in New Jersey.

THE NEW JERSEY FAMILY SUPPORT ACT OF 1993

THE NEW JERSEY FAMILY SUPPORT ACT makes a strong philosophical statement about families who care for an individual with developmental disabilities in their home and their need to support them...

SUCH AS:

- **ALL INDIVIDUALS HAVE THE RIGHT TO BELONG TO A FAMILY UNIT WHERE ENDURING RELATIONSHIPS CAN BE FOSTERED.**
- **FAMILIES ARE THE MAJOR PROVIDERS OF SUPPORT, CARE, AND TRAINING FOR THEIR FAMILY MEMBER WITH A DEVELOPMENTAL DISABILITY AND ARE CONTINUALLY SEARCHING FOR WAYS TO SUPPORT THEIR RELATIVE INSTEAD OF PLACING THEM OUTSIDE THE HOME.**
- **FAILURE TO PROVIDE NEEDED SUPPORTS CAN RESULT IN PREMATURE PLACEMENT IN A SETTING OUTSIDE THE HOME.**
- **TO BE EFFECTIVE, FAMILY SUPPORT MUST: SUPPORT THE ENTIRE FAMILY; BE EASILY ACCESSIBLE; BE FLEXIBLE; BE CULTURALLY SENSITIVE AND INDIVIDUALIZED.**
- **FAMILIES THEMSELVES ARE ABLE TO DEFINE THEIR OWN NEEDS AND SELECT THEIR OWN SERVICES.**
- **FAMILY SUPPORTS MUST BE CHOSEN BY FAMILIES, CONTROLLED BY FAMILIES AND MONITORED BY FAMILIES.**

IN ADDITION, THE ACT:

Creates nine regional Family Support Planning Councils throughout New Jersey

Creates a Statewide Family Support Council

Creates the position of Statewide Family Support Coordinator to work under the direction of the New Jersey Developmental Disabilities Council (NJDDC) in

(CONTINUED ON NEXT PAGE)

Defines family support as a SYSTEM that should strengthen and promote families rather than a PROGRAM.

Elaborates on what that system should include...

- ✓ AFTER SCHOOL CARE
- ✓ CASH SUBSIDIES
- ✓ COMMUNICATION AND INTERPRETER SERVICES
- ✓ COUNSELING SERVICES
- ✓ CRISIS INTERVENTION
- ✓ DAY CARE
- ✓ EQUIPMENT AND SUPPLIES
- ✓ ESTATE AND TRANSITION PLANNING
- ✓ HOME AND VEHICLE MODIFICATION
- ✓ HOME HEALTH SERVICES
- ✓ HOMEMAKER ASSISTANCE
- ✓ HOUSING ASSISTANCE
- ✓ MEDICAL AND DENTAL CARE NOT OTHERWISE COVERED
- ✓ PARENT EDUCATION AND TRAINING
- ✓ PERSONAL ASSISTANCE SERVICES
- ✓ RECREATION SERVICES
- ✓ RESPITE CARE FOR FAMILIES
- ✓ SELF ADVOCACY TRAINING
- ✓ SERVICE COORDINATION
- ✓ SPECIALIZED DIAGNOSIS AND EVALUATION
- ✓ SPECIALIZED NUTRITION AND CLOTHING
- ✓ THERAPEUTIC OR NURSING SERVICES
- ✓ TRANSPORTATION
- ✓ VOUCHERS
- ✓ AND OTHER SERVICES AS IDENTIFIED BY THE FAMILY


WHAT COUNCILS DO

-  **GATHER INFORMATION**
-  **MONITOR**
-  **RECOMMEND**

PUBLIC FORUMS:

- ✓ **SHOULD BE WIDELY ADVERTISED**
- ✓ **SHOULD NOT BE HELD IN THE SAME LOCATION EVERY YEAR**
- ✓ **SHOULD FOCUS ON WHAT FAMILIES NEED - NOT ON HOW TO SOLVE THEIR PROBLEMS**
- ✓ **SHOULD BE THOROUGHLY DOCUMENTED**

OTHER METHODS OF INFORMATION GATHERING ARE . . .

 **SURVEYS:** A statewide survey has been developed in order to obtain consistent information. Councils have the opportunity to ask a region-specific question on this survey.

 **OUTREACH ACTIVITIES**

 **INFORMATION SHARING SESSIONS WITH PROVIDERS**

 **INFORMATION SHARING SESSIONS WITH THE DIVISION OF DEVELOPMENTAL DISABILITIES**

PARTNERING WITH OTHER ENTITIES TO GATHER AND SHARE INFORMATION

“Meet Your Case Manager Nights,” Provider Fairs, community activities such as events at the mall, conference and workshop presentations, schools, etc.

MEETING WITH COMMUNITY MEMBERS WHO PROVIDE SERVICES TO FAMILIES TO DISCUSS INCLUDING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

ALL INFORMATION GATHERING ACTIVITIES SHOULD BE THOROUGHLY DOCUMENTED (FOR EXAMPLE: THE NUMBERS OF FAMILIES ATTENDING, WHAT WAS DISCUSSED, ANY CONCLUSIONS RESULTING, WHAT WILL HAPPEN NEXT, ETC.).

SEE GUIDELINES FOR REPORTING PUBLIC FORUMS AND OUTREACH IN “RESOURCE” SECTION



WHAT COUNCILS DO

- GATHER INFORMATION
- ✓ MONITOR
- RECOMMEND

- EACH YEAR IN DECEMBER, THE DIVISION OF DEVELOPMENTAL DISABILITIES (DDD) PROVIDES YOUR COUNCIL WITH A COMPREHENSIVE REPORT OF ALL EXISTING CONTRACTS IN THE STATE. THE DDD STATEWIDE COORDINATOR WILL MEET WITH YOUR COUNCIL TO ANSWER ANY QUESTION YOU MAY HAVE ABOUT THIS REPORT.
- EACH COUNCIL IS RESPONSIBLE FOR REVIEWING THE EXISTING CONTRACTS IN THEIR REGION ON AN ANNUAL BASIS.
- DDD MUST LET YOU KNOW 90 DAYS BEFORE A CONTRACT IS TO EXPIRE
- ANY QUESTIONS ABOUT CONTRACTS SHOULD BE DIRECTED TO YOUR REGIONAL FAMILY SUPPORT LIAISON.
- CONTRACTS REQUIRE THE PROVIDER TO CONDUCT SATISFACTION SURVEYS ABOUT THEIR SERVICES. IF THE PROVIDER WILL NOT SHARE THESE SURVEYS WITH YOU, LET YOUR REGIONAL FAMILY SUPPORT LIAISON KNOW.
- COUNCILS MAY REQUEST A MEETING WITH A PARTICULAR PROVIDER TO GATHER INFORMATION ABOUT THEIR SERVICES OR CONTRACTS.

TIP: See Contract Evaluation Report Guidelines in **RESOURCE SECTION**



WHAT COUNCILS DO

- GATHER INFORMATION
- MONITOR
- **RECOMMEND**

- **THERE ARE TWO KINDS OF RECOMMENDATIONS COUNCILS MAKE TO THE DIVISION OF DEVELOPMENTAL DISABILITIES (DDD)**
- **ONE IS RECOMMENDING NEW SERVICES AND SUPPORTS IN YOUR REGION. THIS IS DONE WHEN THERE IS AN INITIATIVE IDENTIFIED IN THE BUDGET TO CREATE NEW SERVICES.**
- **YOUR COUNCIL CAN RECOMMEND NEW KINDS OF SERVICES OR SUPPORTS THAT CURRENTLY DO NOT EXIST IN YOUR REGION OR YOU CAN RECOMMEND EXPANDING EXISTING SERVICES.**
- **WHEN THIS HAPPENS, DDD WILL INFORM YOUR COUNCIL THAT FUNDS HAVE BEEN RECOMMENDED BY THE GOVERNOR FOR THE NEXT FISCAL YEAR (JULY 1 - JUNE 30) THIS HAPPENS SHORTLY AFTER THE GOVERNOR ANNOUNCES HIS BUDGET RECOMMENDATIONS, USUALLY IN LATE JANUARY.**
- **YOUR COUNCIL MUST THEN MAKE PRELIMINARY RECOMMENDATIONS TO DDD ABOUT HOW THIS NEW MONEY SHOULD BE ALLOCATED.**
- **AFTER THE BUDGET IS FINALIZED —USUALLY BY JUNE 30— YOU THEN HAVE A SHORT TIME TO FINALIZE YOUR RECOMMENDATIONS. THIS MEANS YOU HAVE ALMOST FOUR MONTHS TO DISCUSS, REVISE AND REFINE YOUR RECOMMENDATIONS WITH DDD.**



- **COUNCILS SHOULD TAKE ADVANTAGE OF THIS TIME SO THAT NEW PROGRAMS CAN START UP QUICKLY AFTER THE BUDGET IS FINAL AND MINIMAL MONEY GOES UNSPENT.**
- **THE OTHER TYPE OF RECOMMENDATIONS ARE ABOUT EXISTING CONTRACTS.**
- **DDD MUST NOTIFY YOUR COUNCIL 90 DAYS BEFORE A CONTRACT IS TO EXPIRE.**
- **COUNCILS MUST DO THEIR HOMEWORK AND GET ANY QUESTIONS ABOUT THE CONTRACT ANSWERED BEFORE IT IS RENEWED.**
- **YOUR QUESTIONS SHOULD BE BASED ON WHAT YOU ARE HEARING IN YOUR INFORMATION GATHERING ACTIVITIES.**
- **REGIONAL FAMILY SUPPORT PLANNING COUNCILS CAN RECOMMEND CHANGING, REDUCING OR DISCONTINUING EXISTING CONTRACTS.**

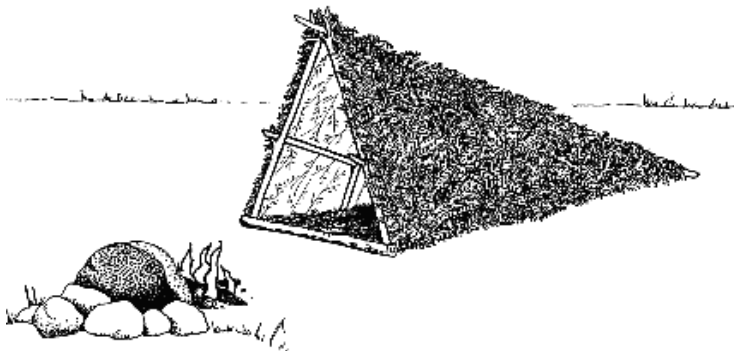
ESTABLISHING A DATABASE

THE GOAL OF ALL OF YOUR ACTIVITIES SHOULD BE TO ALWAYS INCREASE THE NUMBER OF PEOPLE YOU REACH OUT TO.

EACH COUNCIL MAINTAINS A DATABASE OF NAMES OF FAMILIES THEY CAN CONTACT WITH THEIR ANNOUNCEMENTS OR INFORMATION AND TO RECEIVE INFORMATION FROM THEM.

THIS DATABASE CAN INCLUDE PEOPLE WHO ARE NOT KNOWN TO DDD.

IT IS NOT ADEQUATE TO ONLY USE DDD'S MAILING LIST WHEN YOUR COUNCIL IS TRYING TO OBTAIN INFORMATION ABOUT THE REGION IT SERVES.



REGIONAL FAMILY SUPPORT PLANNING COUNCIL ACTIVITY CYCLE



The activities of the RFSPC should be based a progression of activities that culminate in the production of the Council's Annual Report which is due on July 15. The timeline outlined below will assist RFSPC's in getting all of the required activities and tasks completed in order to include all of the required elements in their Annual Report.

JULY

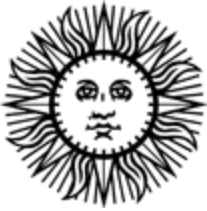
- **SUBMIT ANNUAL REPORT TO FAMILY SUPPORT COORDINATOR BY THE 15TH**
- **RECEIVE FINAL FY BUDGET ALLOCATIONS FROM DDD BY THE 15TH**

AUGUST

- **HOLD ANNUAL PLANNING MEETING**
 - 1) **IDENTIFY PUBLIC INPUT ACTIVITIES. (ONE MUST BE A PUBLIC FORUM)**
 - 2) **SET PUBLIC FORUM DATE. (LOCATION SHOULD BE ROTATED THROUGH OUT YOUR COUNCIL SERVING AREA)**
 - 3) **DEVELOP TARGET AGENCIES/POPULATIONS/AREAS FOR OUTREACH**
 - 4) **DEVELOP LIST OF OTHER ACTIVITIES FOR YEAR - "MEET YOUR CASE MANAGER", COMMUNITY ACTIVITIES, ETC.**
 - 5) **ASSIGN DUTIES TO EACH RFSPC MEMBER**
 - 6) **SET UP CONTRACT REVIEW PLAN**
- **FINALIZE SPENDING RECOMMENDATIONS WITH DDD REGIONAL STAFF**

SEPTEMBER - NOVEMBER

- **HOLD PUBLIC FORUM**
- **CONDUCT OTHER PUBLIC INPUT ACTIVITIES**
- **CONDUCT IDENTIFIED OUTREACH ACTIVITIES**



DECEMBER

- REVIEW "OVERVIEW OF CONTRACTS" RECEIVED FROM DDD BY THE 15TH
- SUBMIT QUESTIONS ABOUT OVERVIEW TO DDD
- REVISE CONTRACT REVIEW PLAN AS NEEDED BASED ON REVIEW

JANUARY - FEBRUARY

- BEGIN ANALYSIS OF PUBLIC INPUT INFORMATION GATHERED, OUTREACH INFORMATION GATHERED AND ALL OTHER INFORMATION GATHERING ACTIVITIES.
- RECEIVE PRELIMINARY BUDGET ALLOCATIONS FROM DDD 15 DAYS AFTER GOVERNORS BUDGET IS ANNOUNCED (USUALLY IN LATE JAN).
- DEVELOP PRELIMINARY RECOMMENDATIONS FOR NEW PROGRAMS FOR THE DIVISION OF DEVELOPMENTAL DISABILITIES.

MARCH

- SEND PRELIMINARY RECOMMENDATIONS FOR NEW PROGRAMS TO DDD
- ONGOING FOLLOW-UP DISCUSSIONS WITH REGIONAL STAFF RE: RECOMMENDATIONS

APRIL - MAY

- CONDUCT NEW MEMBER OUTREACH ACTIVITIES
- CONTINUE FOLLOW-UP WITH DDD REGARDING SPENDING RECOMMENDATIONS



JUNE

- ATTEND RFSPC ALL MEMBER ACADEMY
- BEGIN ANNUAL REPORT - REMEMBER EVERYONE SHOULD CONTRIBUTE!!!



WHAT CHAIRPERSONS DO

- **EACH COUNCIL HAS EITHER A CHAIRPERSON AND VICE-CHAIRPERSON OR CO-CHAIRS**
- **CHAIRPERSONS ARE NOT THE ONLY PEOPLE ON THE COUNCIL TO DO ALL OF THE WORK**
- **CHAIRPERSONS MAKE SURE THAT ALL OF THE WORK GETS DONE ON TIME**
- **YOUR CHAIRPERSON IS YOUR LINK TO THE STATEWIDE COORDINATOR AND STATEWIDE COUNCIL**
- **THE CHAIRPERSON SHOULD LET COUNCIL MEMBERS KNOW WHAT IS HAPPENING AROUND THE STATE**

CHAIRS MUST MAKE SURE THAT YOUR COUNCIL . . .

- **MAKES EVERY MEMBER FEEL WELCOME AND HAS AN IMPORTANT JOB TO DO**
- **SUBMITS MEETING MINUTES TO THE STATEWIDE FAMILY SUPPORT COORDINATOR**
- **SUBMITS REPORTS ON PUBLIC FORUMS AND OUTREACHES TO THE STATEWIDE COORDINATOR**
- **SUBMITS YOUR RECOMMENDATIONS ABOUT MONEY AND CONTRACTS TO THE APPROPRIATE PEOPLE IN DDD AND TO THE STATEWIDE COORDINATOR**
- **SUBMITS YOUR COUNCIL'S ANNUAL REPORT TO THE STATEWIDE COORDINATOR**
- **SUBMITS ALL THE NECESSARY NEW MEMBER INFORMATION TO THE STATEWIDE COORDINATOR**
- **SUBMITS COPIES OF ALL CORRESPONDENCE SENT BY YOUR COUNCIL TO THE STATEWIDE COORDINATOR**
- **SPEAKS ON BEHALF OF YOUR COUNCIL**
- **RELAYS CONCERNS EXPRESSED BY YOUR COUNCIL TO THE STATEWIDE COORDINATOR AND DDD STAFF WHEN APPROPRIATE**



WHAT THE STATEWIDE FAMILY SUPPORT COORDINATOR DOES

- **WORKS UNDER THE DIRECTION OF THE DEVELOPMENTAL DISABILITIES COUNCIL IN CONJUNCTION WITH THE DIVISION OF DEVELOPMENTAL DISABILITIES.**
- **ADOPTS, REVIEWS, AND REVISES, AS NEEDED, A STATE FAMILY SUPPORT PLAN THAT IS DEVELOPED BASED ON THE ANNUAL REPORTS OF EACH RFSPC.**
- **PROVIDES ADMINISTRATIVE SUPPORT AND TECHNICAL ASSISTANCE TO RFSPC'S.**
- **CONDUCTS PRESENTATIONS AND WORKSHOPS ABOUT FAMILY SUPPORT IN NEW JERSEY.**
- **SERVES AS A NON-VOTING MEMBER OF THE STATEWIDE FAMILY SUPPORT COUNCIL**
- **IS THE DIRECT LINK TO ALL RFSPC CHAIRPERSONS AND STATEWIDE REPRESENTATIVES AND OTHER STATE AGENCIES.**

THE STATEWIDE FAMILY SUPPORT COUNCIL

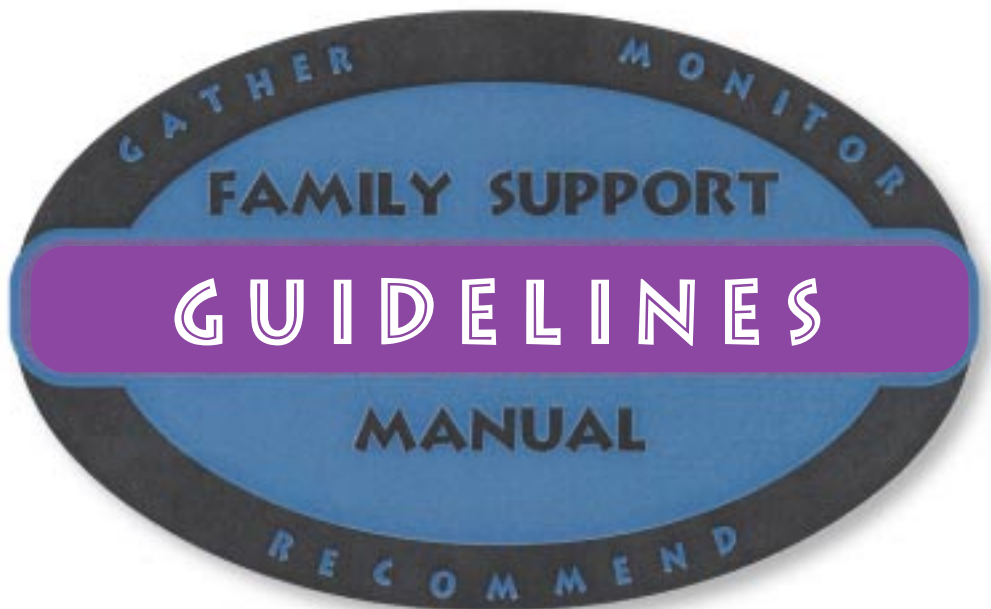
MEETS QUARTERLY FOUR TIMES A YEAR

IS MADE UP OF TWO REPRESENTATIVES FROM EACH COUNCIL

APPROVES THE STATEWIDE FAMILY SUPPORT PLAN

ALLOWS COUNCILS TIME TO NETWORK AND SHARE IDEAS

MAKES DECISIONS AND TAKES ACTION ON STATEWIDE POLICY ISSUES



REGIONAL FAMILY SUPPORT PLANNING COUNCIL APPLICATION FORM GUIDELINES

Names of individuals interested in Regional Family Support Planning Council membership shall be maintained by the Regional Family Support Planning Council and/or Family Support Coordinator. Nominees shall be taken from this list, Regional Family Support Planning Council's Application Form (See Forms).

Guidelines:

1. Individuals interested in becoming a Regional Family Support Planning Council Member must fill out an application.
2. Application is kept on file with the council and/or the Family Support Coordinator.
3. When vacancies occur on the councils, nominations shall be taken from applications on file first.
4. All nominees must have an application

A copy of a newly appointed member's application must be sent to the Statewide Coordinator

COMMON VENDOR MAINTENANCE FORM (CVM) GUIDELINES

The Regional Family Support Planning Council members shall serve without compensation beyond reimbursement reasonable transportation, child care, and other costs related to being on the council.

In order to receive any reimbursements, directly from your council's checking account or from the State Treasury, you must complete a Common Vendor Maintenance Form (CMV) Form. (See Forms)

Complete the following areas:

1. VENDOR CODE: Social Security Number
2. NAME: Full name beginning with first name
3. ADDRESS: Street address or P.O. Box
4. ADDRESS2: Apartment number, if applicable
5. CITY/STATE/ZIP: City, State, and Zip Code

Skip Country and Contact

6. PHONE: Phone number beginning with area code
7. REASON FOR FORM: Check New Vendor (new council member) or Add Location Code (change of address)

Completed form should be mailed or faxed to:

Nancy Sample
New Jersey Developmental Disabilities Council
P.O. Box 700
Trenton, N.J. 08625-0700
(609) 292-7114 (fax)

New Jersey Developmental Disabilities Council
Family Support Service System
Reimbursement/Spending Guidelines

The Regional Family Support Planning Councils/Members shall serve without compensation beyond reimbursement for reasonable transportation, childcare and other costs related to serving on the council.

In order to receive any reimbursements you must complete a State of New Jersey Payment Voucher, PV 6/93. (See Forms)

GUIDELINES:

REGIONAL FAMILY SUPPORT PLANNING COUNCILS

1. Each RFSPC is allowed up to \$4,000 per year for expenses related to travel, childcare, PO Boxes, phone lines, postage and other related costs.
2. Each Council is allowed extra funds, not to exceed \$500, for one major outreach activity per year. Budget approval for this event must be obtained from the Family Support Coordinator.
3. The Family Support Coordinator is responsible for monitoring the expenses incurred by each Council and periodically advising Councils of their balances.
4. Councils maintaining their own checking accounts are responsible for adhering to the guidelines set forth for that purpose and are responsible for monitoring their allotment.
5. All purchases above \$100 MUST receive prior approval from the Family Support Coordinator.
6. Postage costs may not exceed \$100 per quarter, per Council. All larger mailings must be coordinated with the DD Council office to go through the Capital Post Office.
7. All requests for reimbursement for Council related expenses MUST be approved by the Council Chairperson and follow established procedures for reimbursement.

COUNCIL MEMBERS

1. Council members serve without compensation beyond reimbursement for reasonable transportation, childcare and other costs related to serving on the council.
2. Reimbursement is allowed for childcare expenses for all children within the family unit

up to the age of 16, except for children with developmental disabilities for which there is no age limit.

3. Childcare reimbursement may not exceed \$10.00 per hour.
4. Entertainment expenses incurred for family members cannot be reimbursed.
5. Travel is reimbursed at \$.31 per mile for automobile mileage from home to and from destination.
6. Tolls are reimbursed in full upon submission of receipts.
7. Requests for reimbursements that require more expensive childcare and travel will be reviewed on an individual basis. The Family Support Coordinator and the Deputy Director will approve such requests and record the reason(s) for doing so in writing.

PROCEDURES:

1. All individuals requesting reimbursement must complete the required W-9 application process.
2. A State of New Jersey Payment Voucher PV 6/93, must be submitted at least annually.
3. The payee of Payment Voucher must be the Regional Family Support Planning Council member.
4. For childcare reimbursement the following information must be provided:
 - Date of Service
 - Name of Family Support activity
 - Hours/Days of service
 - Total Amount due
5. For travel reimbursement the following information must be provided:
 - Name and date of Family Support Activity
 - Total miles traveled
 - Receipts from other transportation costs, if applicable
 - Toll receipts
 - Total amount due
6. Upon review and acceptance, the Coordinator will submit the invoice to the Fiscal Officer for reimbursement.
7. Any questions, regarding the invoice will be resolved with the participant before it is processed.

GUIDELINES FOR RFSPC MAILINGS

- All Regional Family Support Planning Councils large mailings must be coordinated through the DD Council Family Support Coordinator.
- All large mailings must be mailed through the DD Council office in DD Council envelopes. No RFSPC funds may be used for large mailings.
- Requests for materials for reproduction and/or envelopes must be made at least two weeks prior to date needed.
- When mailing to the DDD list, RFSPC's are responsible for requesting DDD mailing labels through the regional Family Support liaison within the time frames identified by the region.
- The DD Council Family Support Coordinator will attempt to coordinate pick-up and delivery of mailings or materials for mailings to the extent feasible. If adequate notice is provided accommodations can be made in most situations

The following procedure shall be utilized for all mailings:

- The RFSPC shall prepare envelopes for mailing. Envelopes must be sealed.
- If the mailing is for the RFSPC list, the Council will also label the envelopes.
- Prepared envelopes are then delivered to the DD Council office for delivery to the Capital Post Office.
- If the mailing is from the DDD list, the Council must make arrangements through the regional family support liaison to deliver the prepared envelopes for labeling.
- The DDD Statewide Family Support Coordinator will ensure that the envelopes are delivered to the Statewide Regional Family Support Planning Council Coordinator at the DDC. Envelopes will be mailed through the Capital Post Office.

MAILING LIST FORM

Regional Family Support Planning Councils' should always look at every opportunity that is available to expand their mailing list. Although the DDD mailing list is available to all councils; it is the hope that through "outreach" you may reach families that are not yet in the system.

Guidelines

Regional Family Support Planning Councils:

Encourage families to fill out Data Base Entry Forms (**See Forms Section**)

By filling out the form families are added to both the Developmental Disabilities Council Database and their Regional Family Support Planning Council's Mailing list. Families will receive free publications of their choice, have the opportunity to be contacted by one of the DD Council's project coordinators, and will receive all information and newsletters pertaining to their Regional Support Council.

Every attempt should be made to have families fill out the forms, and the councils should collect Data Base Entry Forms from families at an event.

Data Base Entry Forms collected at a council event should be given to the member that is responsible for the council data base (**See Mailing List Information**).

Families should be added to your mailing list. Don't forget to keep a record of all additions!

Send entry forms to: **Gail Hodges, Clerk**
NJ Developmental Disability Council
PO Box 700
Trenton, NJ 08625-0700

Please send correspondence indicating that the forms have been entered into the council database.

Data Base Entry Forms Mailed Directly To Developmental Disabilities Council

Gail Hodges will periodically send packets of Data Base Entry Forms out to each council's designated member for entry into council's database. The entry forms sent out by Gail have already been entered into the Developmental Disabilities Council Database.

**MAILING LIST INFORMATION SHOULD BE INCLUDED
 IN YOUR ANNUAL REPORT!!!**

REGIONAL FAMILY SUPPORT PLANNING COUNCIL PUBLIC FORUM GUIDELINES

Each Regional Family Support Planning Council shall develop and implement a method of obtaining public input that provides the opportunity to express comments and share concerns and information about family support in it region. This is called a **“Public Forum.”** The Regional Family Support Planning Council’s roles are to **receive information** as a means of gathering data for recommendations to the Division of Developmental Disabilities.

GUIDELINES:

Public Forums should be held in a different location annually to ensure all interested individuals are represented

Public Forums will be held at a time and place that is convenient for families

Public Forums should be widely advertised:

- Flyers
- Mailings
- Media
- Internet

Public Forums need to be thoroughly documented; the report should include:

- Description of forum
- Number of people attending
- Types of individuals participating - families, DDD staff, providers, school district personnel, special health services professionals, community/municipal entities (i.e. YMCA, recreation, Office on Disability, town councils, etc.) childcare services professionals
- Documentation of information gathered

Summary

Remember:

- A copy of the Public Forum Report should be submitted to the Statewide Coordinator
- Information gathered from Public Forums should be a resource tool when determining recommendations
- Information gathered from Public Forums should be included in Council's Annual Reports.

Tips For A Successful Public Forum:

Sign in for all Individuals wishing to speak

Set a time limit for speakers

Panel made up of RFSPC members; prepared to listen and document

Brief introduction:

What is Family Support/Act of 1993?

Define RFSPC and what we do

Purpose of Public Forum

Expand mailing list - Opportunity to display magazines and sign families up for DDC Database and RFSPC's mailing list

LISTEN, DOCUMENT, REVIEW, RECOMMEND!!!!

REGIONAL FAMILY SUPPORT PLANNING COUNCIL OUTREACH GUIDELINES

Based on the needs of the region the Regional Family Support Planning Council serves, along with a minimum of one Public Forum at least two additional means of obtaining public input shall be utilized to ensure all interested individuals are represented.

Outreach provides a wealth of information needed to assist the councils in their recommendation making process. Everything that you do is an information activity, and should be documented no matter how small the event may be. See examples of outreach activities in “What Councils Do “ (Gather Information) section of the manual. The activities do not include Surveys or Public Forums.

GUIDELINES:

Identify your method of outreach:

- Membership
- Presentations
- Information sharing session with DDD/Providers
- Collaborative Events - “Meet Your Case Manager Nights”, Information tables, Community Events, etc.

Membership

- Advertise: Families Magazine, Monday Morning, Council Newsletters/Web Sites, DDC Web Site
- Go through application file, and list of names compiled through phone conversations and advertising
- Contact Statewide Family Support Coordinator for any applications and names that may be on file at DDC
- Set date of Membership Meeting; will meeting be devoted to membership only or will part of the meeting concentrate on council business?
- Contact and invite interested parties
- Extend invitation to Statewide Coordinator to attend (will be responsible for bringing publications, mailing list forms, applications, etc.)

Membership Meeting:

Welcome/Introductions

What is Family Support?

Role of the Regional Family Support Planning Council

Comments/Questions

Application Forms filled out when applicable

Nominations/Voting process - The Regional Family Support Planning Council members will nominate members to reflect the cultural, economic, ethnic, geographic, and disability diversity of the region it serves.

Summary

Remember: Membership Meetings need to be included in your annual report

Presentations

Where will the presentation take place?

Who are you presenting to?

Who is representing the council? Each council should have at least 2 council members attending a presentation:

Presenter

Recorder - write down information

DDD Representative *optional* (Request a DDD Rep. by contacting your Regional DDD Family Support Coordinator to present and answer questions pertaining to DDD)

Contact Statewide Coordinator for materials needed

Have handouts or packets available (publications, mailing list forms, newsletters, etc.)

Have a sign in sheet available

Presentation:

Introductions/Welcome

Who is in the room? Parents, Teachers, Child Study Team, etc.

Who is registered for DDD?

DDD Rep. - Eligibility and process

Brief history of family support

What is family support?

Role of the Regional Family Support Planning Council

Council Specific Information

Comments/Questions

Fill out RFSPC Applications/Mailing list forms

Recorder should document all responses, concerns, requests, issues, etc.

Summary of Outreach

√Submit a copy to the Statewide Coordinator

√Information gathered from presentations should be included in each Council's Annual Report.

Information Sharing Sessions DDD/Providers

√Invite DDD/Provider(s) to a council meeting or schedule a meeting with DDD/Provider(s)

√Document who attends meeting

√Be prepared to listen and document needs, concerns, recommendations, and issues that DDD/Provider(s) express

√Be prepared to ask questions

DO YOUR HOMEWORK BEFORE ATTENDING A MEETING!!

√Prepare a summary of meeting

√Information Sharing Sessions should be included in Council Reports

Collaborative Events

√Advertise (depends on the event)

√Prepare materials so you can document the number being distributed (folders).

√Expand mailing list - have families fill out mailing list forms

√Be prepared to talk about the role of the Regional Family Support Planning Councils

- √Opportunity to recruit members
- √Listen to families - Opportunity to hear from families
- √Document event
- √Copy of outreach to Statewide Family Support Coordinator
- √Include documentation in Council Report

Creativity and unique approaches to outreach will help ensure the greatest possible input. Your method of outreach is your means of gathering information and the collection of data that will assist you in preparing your recommendations for the Division of Developmental Disabilities.

**Remember:
EVERYTHING YOU DO IS BASED ON THE RESULTS OF OUTREACH!**

CONTRACT EVALUATION REPORT GUIDELINES

Determine your method of reviewing contracts:

- Each member is responsible for at least one contract
- Form a Monitoring Committee

Monitor old money/contracts as well as new money/contracts

Create a Contract Monitoring Schedule (See example of RFSPC #6 Monitoring Schedule)

Review contract before expiration date, Annex A

Each Regional Family Support Planning Council shall receive notification from DDD 90 days prior to the expiration of a family support contract for the council's input regarding reallocation of funds, modification of Annex A's or B's and/or discontinuation of the contract.

No notice/contract: send a letter to your Regional DDD Family Support Coordinator. (see sample)

Create an evaluation method (see example, RFSPC#6 check list system and results)

Request Satisfaction Surveys in writing from Providers

Questions and concerns should be directed in writing to the DDD Regional Family Support Coordinator; copy of letter should be sent to Statewide Family Support Coordinator, i.e. Low level of service, Provider refuses to supply Satisfaction Survey

Attend review meeting with DDD and Provider - Review Meetings should be scheduled in a timely manner

Request copy of changes to contracts

Summary of contract reviews (see example)

Contract evaluations should be included in Council's Annual Report

SAMPLE**REGIONAL FAMILY SUPPORT PLANNING COUNCIL #6**CONTRACT EVALUATION REPORT

April 1, 2001

The Family Support Act of 1993 states that the Regional Family Support Planning Councils “shall monitor the implementation of the system and provide recommendations to the coordinator regarding family support services”. Since its inception in 1995, RFSPC #6 has been carrying out this responsibility by concentrating on New Initiative spending.

This year the Monitoring Committee took on another task. Previously, we had been concentrating on *new* money expenditures and new contracts. Now we also turned our attention to the core of the family support budget, old contracts budgeted for each year with “old money”. We began studying each contract as it came up for renewal. As each service was reaching its expiration date, the Monitoring Committee examined the “Annex A” part of its contract. A checklist was created from the points addressed in the Family Support Act. (See Appendix A.) We rated the contents of this narrative section of each contract using this checklist. Then the committee tallied a final sum. (The alphabetical chart of final score results is found in Appendix B.) This system gave the committee an objective, baseline score by which we could compare similar services. It also allowed us to annually judge improvement and positive change to a contract as it came up for its annual review. In addition, anecdotal comments were listed. Noted were missing forms, positive areas and detracting contents. These comments were to be points for consideration when the Council met with agency staff to discuss their respective contracts. Unfortunately, these review committee meetings did not take place.

After applying the checklist system, the committee would decide on the following course of action. If a contract showed inattentiveness to the philosophy of the Family Support Act, the Council would notify DDD of this in writing before the contract was to be renewed. Should the contract exhibit blatant noncompliance, the Council would recommend to DDD that the contract not be renewed.

To date, the Monitoring Committee has scored all contracts in the satisfactory range (over 50). We made DDD aware of the fact that one contract contained unsatisfactory content in its section regarding eligibility for that service. It is stated that a family is not *eligible* for the after school services if they are already receiving traditional respite. That section has been changed and the contract now includes the DDD form listing the priority criteria for eligibility. On a positive note, we found that no contract showed blatant disregard for the family centered system as outlines in the Family Support Act of 1993. Therefore, the Council did not make the recommendation not to review any existing contracts.

RFSPC #6 Monitoring Committee did find many areas for improvement in several contracts. Some did not address the need to do background checks when hiring direct care workers. (New legislation now enforces this matter.) Only a small number of agencies offered transportation to and from their site. Several programs failed to make good use of community resources. A few had questionably high administrative cost in their contracts. Lastly, two contracts listed poor attendance, yet they continued to receive full funding each year. The Council intends to discuss these matters further with DDD and the agencies in question. We also will be more diligent in making sure that the DDD contract review committee meetings are scheduled in a timely manner. These meetings are great opportunities for the parties involved (DDD, Provider Agencies, and RFSPC #6) to take care that the contracts truly express the services rendered. It is an annual chance to update and improve. Also the results of the agencies' consumer evaluation results should be discussed at this time.

Some very positive points which were noted by the Monitoring Committee were; the inclusion of the Cash Option in all of the traditional respite supports, the mention of consumer evaluation forms and advisory boards, the flexible allocation of hours used by each family, an awareness of the client's need for recreation the use of volunteers to keep costs down, the use of fundraising in order to supplement services, accommodations made because of the schedules of working parents, and the recognition of the families' input (RFSPC #6) in the "Document of need" section of the contracts.

In addition to the checklist method, additional techniques were also used to measure the effectiveness of the Family Support services. In some cases, the committee visited the site to observe the program in progress and speak with the family members of those attending. Also the Council mailed out a Satisfaction Survey and the Council tallied the results. Of the 136 families who responded, 73% said they were satisfied with the service they were receiving. Some reasons for their dissatisfaction were *no respite worker available, money for the Cash Option not enough*

In the future, the Monitoring Committee must spend more time at the program site or enlarge the committee to include satellite families. These families would come from participants in the service and would chart how well the provider is implementing what it states in its contract. This involvement would lead families into monitoring the services it receives. Thus moving on step closer to the goal of the Family Support Act, this is to create a Family Support system where services are "chosen by families, controlled by families, and monitored by families".

Submitted by: Cathy Beahan, Patti Blume, Jane Tallman, Pam Whitehead

APPENDIX A

CONTRACT MONITORING SCHEDULE

<u>Expiration Date</u>	<u>Annex A</u>	<u>Annex B</u>	<u>Letter</u>	<u>Review Meeting Date</u>	<u>Attended</u>
December 31 <i>Camp Oakhurst</i> <i>Epilepsy</i> <i>Spina Bifida</i>	Sept.15	Oct 15		November	
March 31 <i>DRC</i>	Oct.15	Jan.15		April	
June 30 <i>Brain Injury</i> <i>Community Options</i> <i>C.P. of M/O</i> <i>Eden</i> <i>Mon. Arc</i> <i>Ocean Arc</i>	Jan. 15	April 15		July1	
September 30 <i>New Horizons</i>	April 15	July 15	12/16/99	Oct. 1	

REGIONAL FAMILY SUPPORT PLANNING COUNCIL #6

Contract Monitoring

Name of Agency _____ *DATE* _____

Type of Program _____
(After school, Respite, Cash Subsidy etc.)

Rating 1 to 5 (low to high)

- 1. Family driven _____
- 2. Flexible _____
- 3. Use of Community Resources _____
- 4. Provides Transportation _____
- 5. Consumer Satisfaction _____
- 6. Annex A Modification _____
- 7. Waiting List Procedure _____
- 8. Staff Background Checks _____
- 9. Staff training _____
- 10. Accommodates all D.D. _____
- 11. Cost effective _____

COMMENTS

**Ms. Diane Goettler
Contract Administrator
Division of Developmental Disabilities
CN 726
Trenton, NJ 08625-0726**

Dear Ms. Goettler,

The regional Family Support Planning Council #6 in accordance with its duties under the Family Support Act of 1993 is monitoring all family support services available to families living in Monmouth and Ocean counties. The Monitoring Committee reviews the contracts for each of these services as the contracts come up for renewal. The committee includes the following activities in its analysis:

- a. Reading the Annexes A and B of the contracts.**
- b. Informally speaking with families who have used the service,**
- c. Visiting the facility to observe the program when applicable,**
- d. Meeting the Director and Staff, and**
- e. Rating the “family friendliness of the service.**

May 6, 2000
Diane Goettler
Division of Developmental Disabilities
Office of the Assistant Director
Lower Central Office
PO Box 726
Trenton, NJ 08625

Dear Diane,

According to the Family Support Act of 1993, it is the duty of the Regional Family Support Planning Councils to monitor the Family Support services in their region. In order to fulfill this responsibility, Council #6 has formed a sub-committee to review provider contracts as they come up for renewal.

Our schedule indicated the next contract being reviewed would be DRC. The renewal date on the contract is March 31, 2000. The submission dates for the Annex A and B forms are October 15 and January 15 respectfully. Please send the Council three copies of this contract for the committee to review. Also, kindly let us know the scheduled date for your final review conference. A member of our monitoring committee will attend. Thank you.

Sincerely,

Cathy Beahan, Chair

cc Robert C. Lowe

ANNUAL REPORT GUIDELINES

Based on the results of public input and monitoring activities, each Regional Family Support Planning Council shall develop, by June of each year, an annual report for submission to the Office of Constituent Relations and Community Outreach the appropriate Regional Assistant Director and the Family Support Coordinator.

Following are guidelines to assist you in writing your Annual Council Report. Reports should include everything listed within the guidelines, however, feel free to include all other information that is important to your council and region.

**Regional Family Support Planning Council Annual Report - 07/01/01 - 06/30/02
Forms are available. (See Forms)**

Complete Council identification information on top of form

1. Public Input Activities Conducted

Each Council is required to complete three methods of public outreach, one of which must be a public hearing. In this section include the following:

- Description of outreach
- Dates of public outreach conducted
- Number of individuals attending
- Types of individuals participating - families, DDD staff, providers, school district personnel, special child health services professionals, etc.
- Information gathered from the activity

2. Monitoring Activities Conducted

Description of activities conducted to monitor the implementation of the system, i.e., surveys, information gathering from providers, professionals in the field, attending meetings, interviews with stakeholders, review of provider satisfaction surveys, etc. In this section include the following:

- Types of activities conducted
- Dates activities were conducted
- Numbers of participants
- Description of data collected

3. Evaluation of the system

- Describe your Council's analysis of the Family Support System based on the activities described in 1 and 2. In this section include the following:
- Is there awareness of the services and supports available? Is the system flexible?
- Does the system strengthen and promote families that provide care to a family member with a developmental disability?
- Are families selecting and designing their own services? How do families give feedback to the system?
- Are families satisfied with the supports they receive?
- Are families aware of the Family Support Act?
- What is the diversity of the families served?
- Are there groups who are being underserved or unserved? Why? i.e., type of disability, ethnicity, age, etc.
- Are families aware of systems other than DDD that can support them?
- Are there gaps in services?
- Are there unnecessary duplications in the system?

4. Accomplishments/Benchmarks

- This section should be utilized to report on the areas of improvement your Council has recognized as a result of your activities and how you will measure future success. In this section include:
- Increases in awareness of DDD and Family Support in your region
- Increases in numbers coming out for public hearings or other outreach activities
- Decreases in numbers of complaints received
- Improvement in level of satisfaction with services
- Higher level of service in contracts
- Description of creative initiatives recommended
- Improvement in communication with stakeholders
- Description of goals to improve all of the above and timelines for doing so.

5. Long and Short Term Recommendations

This section should list your Council's recommendations for improvement in the system, both immediate and long term. Do not include your funding or training recommendations here. These should be recommendations pertaining to systemic issues such as: service delivery, case management, eligibility criteria, contracting, etc.

6. Identification of Training Needs

This section should include all training need areas identified through outreach and monitoring activities. Include in this section:

- Who should be trained - parents, case managers, school district personnel, etc.
- What training is needed?
- How often
- By Whom

7. Recommendations for reallocation of funds

This section is based on your Council's analysis of the December Overview of Contracts submitted by DDD and review of contracts and should include the following:

- Should existing contracts be modified to allow the provider and families more flexibility?
- Are existing contracts written in accordance with the principles established in the Family Support Act?
- Should the provider base be expanded in your area?
- Comments on level of service
- Is there equitable distribution of resources in the region?

8. Recommendations for new funds

This section should provide a description of the allocation of any new funds that were made available to your Council during the reporting period. Please highlight new and creative initiatives and list any recommendations for adding to existing contracts or cash subsidy amounts.

9. Recommendations for additional funds

This section should provide an estimate of what it would take to meet the need in your region. Please include back-up data, such as information on waiting lists, gaps in service etc., which supports why you are making this recommendation

Remember: These are guidelines—Feel free to add information you think is important.



GATHER

MONITOR

FAMILY SUPPORT

FORMS

MANUAL

RECOMMEND

**THE FAMILY SUPPORT ACT OF 1993
REGIONAL FAMILY SUPPORT PLANNING COUNCIL'S
APPLICATION FORM**

Date_____

Name_____

Address_____

County_____

Phone Numbers (H)_____ (W)_____

E-mail Address_____

Why are you interested in serving on a Regional Family Support Planning Council?

The Family Support Act mandates that council membership reflect the cultural, economic, ethnic, geographic and disability diversity of the region it serves. The following questions are optional, but are intended to assist in creating more diversity and inclusiveness within the councils.

Age of family member with a developmental disability_____

Family member's disability_____

Ethnic background_____

Please return this application to your Regional Family Support Planning Council or to the Family Support Coordinator c/o New Jersey Developmental Disabilities Council, P.O. Box 700, Trenton, N.J. 08625-0700 or Fax, (609) 292-7114

**Regional Family Support Planning Council
Annual Report - 07/01/01 - 06/30/02**

Council # _____ Counties Served _____

Council Membership

Chair _____ Vice or Co-Chair _____

_____	_____
_____	_____
_____	_____
_____	_____

1. PUBLIC INPUT ACTIVITIES CONDUCTED

2. MONITORING ACTIVITIES CONDUCTED

3. EVALUATION OF THE FAMILY SUPPORT SYSTEM

4. ACCOMPLISHMENTS/BENCHMARKS

5. LONG AND SHORT TERM RECOMMENDATIONS

6. IDENTIFICATION OF TRAINING NEEDS

7. RECOMMENDATIONS FOR REALLOCATION OF FUNDS

8. RECOMMENDATIONS FOR NEW FUNDS

9. RECOMMENDATIONS FOR ADDITIONAL FUNDS



The New Jersey Family Support Act of 1993

Makes strong philosophical statement about families who care for an individual with developmental disabilities in their home and their need to support them...

Such as:

- All individuals have the right to belong to a family unit where enduring relationships can be fostered.
- Families are the major providers of support, care, and training for their family member with a developmental disability and are continually searching for ways to support their relative instead of placing them outside the home.
- Failure to provide needed supports can result in premature placement in a setting outside the home.
- To be effective, family support must: support the entire family; be easily accessible; be flexible; be culturally sensitive and individualized.
- Families themselves are able to define their own needs and select their own services.
- **FAMILY SUPPORTS MUST BE CHOSEN BY FAMILIES, CONTROLLED BY FAMILIES AND MONITORED BY FAMILIES.**

Creates nine regional Family Support Planning Councils throughout New Jersey

Creates a Statewide Family Support Council

Creates the position of Statewide Family Support Coordinator to work under the direction of the New Jersey Developmental Disabilities Council (NJDDC) in conjunction with the Division of Developmental disabilities

Defines family support as a **SYSTEM** that should strengthen and promote families rather than a **PROGRAM**.

Elaborates on what that system should include: after school care, cash subsidies, communication and interpreter services, counseling services, crisis intervention, day care, equipment and supplies, estate and transition planning, home and vehicle modification, home health services, homemaker assistance, housing assistance, medical and dental care not otherwise covered, parent education and training, personal assistance services, recreation services, respite care for families, self advocacy training, service coordination, specialized diagnosis and evaluation, specialized nutrition and clothing, therapeutic or nursing services, transportation, vouchers and other services as identified by the family.

DIVISION CIRCULAR #39 (N.J.A.C.10:46A)

**DEPARTMENT OF HUMAN SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES
EFFECTIVE DATE: April 17, 2000
DATE ISSUED: May 1, 2000**

(Rescinds DC #39 issued on April 17, 1995)

I. TITLE: FAMILY SUPPORT SERVICE SYSTEM

II. PURPOSE: The Division in conjunction with the New Jersey Developmental Disabilities Council, must create a system of family support that is flexible and designed to strengthen and promote families that provide care at home for a family member with a developmental disability.

III. SCOPE: The circular applies to all eligible persons with developmental disabilities and/or their families. The circular also applies to agencies under contract with or regulated by the Division.

IV. GENERAL STANDARDS:

The remainder of the circular is the adoption of the “Family Support Services System” as it appears in N.J.A.C. 10:46A.

Deborah Trub Wehrlen
Director

SUBCHAPTER 1 - GENERAL PROVISIONS**10:46A-1.1 Purpose; authority**

(a) Pursuant to N.J.S.A. 30:6D-33 et seq., the Division of Developmental Disabilities, in conjunction with the New Jersey Developmental Disabilities Council, must create a system of family support that is flexible and designed to strengthen and promote families that provide care at home for a family member with a developmental disability.

(b) A Statewide family support policy must acknowledge that families themselves are able to define their own needs and select their own services; within available resources, family supports must be chosen by the families, controlled by families and monitored by families.

The system of Family Support shall include, but not be limited to:

- After school care;
- Cash subsidies;
- Communication and interpreter services;
- Counseling services;
- Crisis intervention;
- Day Care;
- Equipment and supplies;
- Estate and transition planning;
- Home and vehicle modification;
- Home health services;
- Homemaker assistance;
- Housing assistance;
- Medical and dental care not otherwise covered;
- Parent education and training;
- Personal assistance services;
- Recreation services;
- Respite care for families;
- Self advocacy training;
- Service coordination;
- Specialized diagnosis and evaluation;
- Specialized nutrition and clothing;
- Therapeutic or nursing services;
- Transportation;

Vouchers;

and Other services as identified by the family in accordance with N.J.A.C. 10:46A-2.3.

(d) The Commissioner shall establish income, need and other criteria in accordance with the Administrative Procedure Act, N.J.S.A. 52:14B-1 et seq.; to ensure that the expenditures for the Family Support System are within the limits of available funding.

(e) The amounts of funds for family support services shall be subject to the funding available in the current fiscal year.

(f) Adults with developmental disabilities should be afforded the opportunity to make decisions for themselves, live in typical homes within their own communities and exercise their full rights as citizens. Adults with developmental disabilities should have options for living separately from their families, but, when this is not the case, families should be provided the supports they need, within available funding limits.

10:46A-1.2 Scope

The provisions of this chapter shall apply to all eligible persons with developmental disabilities and/or their families. The provisions of this chapter also apply to agencies under contract with or regulated by the Division of Developmental Disabilities, within the Department of Human Services.

10:46A-1.3 Definitions

The following words and terms, when used in this chapter, have the following meanings, unless the context clearly indicates otherwise:

“Adult” means any individual 18 years of age and older.

“Developmental disability” means a severe, chronic disability of a person which:

1. Is attributable to a mental or physical impairment or combination of mental or physical impairments;
2. Is manifest before age 22;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitations in three or more of the

following areas of major life activity, that is, self-care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living or economic self-sufficiency; and

5. Reflects the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

6. Developmental disability includes, but is not limited to, severe disabilities attributable to mental retardation, autism, cerebral palsy, epilepsy, spina bifida and other neurological impairments where the above criteria are met. (N.J.S.A.30:6D-25.)

“DDD Family Support Coordinator” means an employee of DDD designated by the Regional Administrator to coordinate the region’s family support service system.

“Developmental Disabilities Council” (DDC) means the Federally mandated State planning and advisory board composed of 28 members appointed by the Governor.

“Division” or “DDD” means the Division of Developmental Disabilities within the Department of Human Services.

“Family” means the family member with a developmental disability and his or her parents, siblings, spouse, and/or children, or uncompensated caregiver.

“Functional services” means those services and programs available to provide a person with a developmental disability: education, training, rehabilitation, adjustment, treatment, care and protection. (N.J.S.A. 30:4-23)

“Family support” means a coordinated system of on-going public and private supports, services, resources, and other assistance, which are designed to maintain and enhance the quality of life of a family member with a developmental disability and his or her family.

“Family Support Coordinator” means a coordinator working under the direction of the Developmental Disabilities Council (DDC) who shall be a person qualified by training and experience to perform the duties of his or her office.

“Level of service” means the contracted number of units of service to be delivered and the actual number of units of service delivered.

“Parent” means the biological or adoptive parent or uncompensated foster parent or legal

guardian.

“Resident” means a person who is a domiciliary of New Jersey for other than a temporary purpose and who has no present intention of moving from the State.

“Supports” means those services other than residential services provided by the Division, which will help the individual remain in his or her living situation.

“Uncompensated caregiver” means the person, including, but not limited to, a parent, sibling, spouse, child, grandparent, step family member, aunt, uncle, cousin or legal guardian, who without monetary payment cares for the family member with a developmental disability and with whom the family member with a developmental disability resides.

SUBCHAPTER 2. ELIGIBILITY CRITERIA

10:46A-2.1 General Eligibility

(a) A person determined to have a developmental disability in accordance with the requirements of N.J.A.C. 10:46 and who is a resident of the State of New Jersey, shall be eligible for family support services.

1. In accordance with N.J.A.C. 10:46, a person with a developmental disability can be determined to be eligible for functional services.

(b) A person with a developmental disability must either live with a family member or an uncompensated caregiver. The requested family support services are provided to support the family.

(c) The DHS and any publicly funded agency which provides family support services shall assist families in obtaining all other sources of funding, such as Medicaid or private insurance, before using funds available for the purpose of this chapter.

10:46A-2.2 Who May Apply for Family Support Services

(a) Requests for family support services may be made by:

1. A competent adult on his or her own behalf;
2. An uncompensated caregiver;

3. A parent, family member or a legal guardian of an incompetent adult; or
4. The parents or legal guardian of a minor.

10:46A-2.3 Requests for Family Support Services

(a) Requests for family support services shall be made to a regional office of the Division.

1. An individual not previously determined eligible for Division services and who is requesting family support services shall contact the regional intake worker to initiate the eligibility process.

2. If an individual is eligible for functional services of the Division, requests for family support services shall be made to the assigned case manager.

(b) The request shall be made by telephone, in writing or by appearing in person to the appropriate regional office of the Division as noted below.

Northern Region:

(serving Sussex, Warren, Morris, Bergen, Passaic and Hudson Counties)

1-B Laurel Drive
Flanders, NJ 07836
Phone: (973) 927-2600
Fax: (973) 927-2689

100 Hamilton Plaza
Room 905
Paterson, NJ 07505
Phone: (973) 977-4004
Fax: (973) 279-5069

Upper Central Region: (serving Essex, Somerset and Union Counties)

59 Main Street
West Orange, NJ 07052
Phone: (973) 324-2000
Fax: (973) 324-2022

153 Halsey St., 2nd Fl.
PO Box 47013
Newark, NJ 07101
Phone: (973) 693-5080
Fax: (973) 648-3999

Lower Central Region: (serving Mercer, Middlesex, Ocean, Hunterdon, and Monmouth Counties)

240 West State Street
6th Floor
PO Box 700
Trenton, NJ 08625
Phone: (609) 292-4500
Fax: (609) 292-4219

Juniper Plaza
Suite 1-11
3499 RT. 9 North
Freehold, NJ 07728
Phone: (732) 863-4500
Fax: (732) 863-4527

Southern Region: (serving Camden, Atlantic Salem, Cape May, Gloucester, Cumberland and Burlington Counties)

101 Haddon Avenue
Suite 17
Camden, NJ 08103-1485
Phone: (856) 614-3400
Fax: (856) 614-3688

Route 30 & Elvins Avenue Hammonton, NJ 08037 Phone: (609) 561-5070 Fax: (609) 561-1895

Minimum information submitted shall include, but not be limited to:

1. The name of the person for whom family support services is requested and the presenting disability;

2. The specific family support services requested;
3. The length of time specific family support services will be needed, if known;
4. The name, address and telephone of a family contact person; and
5. Such other information as needed, by the Division, to consider a person's request.

(d) The family shall be notified within 10 working days by telephone, or in writing, by a DDD regional family support coordinator or casemanager of the approval, denial, modification or status of the requested family support services.

(e) A DDD regional family support coordinator, in conjunction with the individual, family and regional staff, will evaluate the needs of individuals and their families who are receiving family support services and the availability of family support resources on an ongoing basis.

(f) Individuals who disagree with a Family Support Service decision may appeal the decision in accordance with the provisions of N.J.A.C. 10:48-1, Appeal Procedure.

SUBCHAPTER 3. FAMILY SUPPORT COORDINATOR

10:46A-3.1 Role of the Coordinator

(a) The Family Support system shall be administered by the Division, in conjunction with the Family Support Coordinator working under the direction of the Developmental Disabilities Council.

(b) The Division of Developmental Disabilities shall develop an agreement with the Developmental Disabilities Council regarding the role and authority of the Coordinator.

(c) The Family Support Coordinator shall:

1. Coordinate efforts by the Regional Family Support Planning Councils and public and private agencies, including but not be limited to:

i. Identification of services provided by different agencies; and

ii. Planning with all entities to insure that gaps in services are filled.

2. Adopt, review and revise, no less than annually, a State Family Support Plan, that is based on the annual reports of the Regional Family Support Planning Councils, which shall:

- i. Assess needs, establish goals, and set priorities for the provision of family supports for individuals with developmental disabilities;
 - ii. provide for outreach and coordinated delivery of family supports;
3. Provide administrative support services to each of the Regional Family Support Planning Councils and the Statewide Council;
 4. Participate as a non-voting member of the Statewide Family Support Council;
 5. Develop and implement a training plan for family support as identified by the Regional Family Support Planning Council in the annual reports; and
 6. Respond to public inquiries and requests for information regarding family support.

SUBCHAPTER 4. REGIONAL FAMILY SUPPORT PLANNING COUNCILS

10:46A-4.1 Membership

- (a) The need to establish additional councils or merge existing councils shall be evaluated within one year and annually thereafter by the Statewide Family Support Council in conjunction with the Regional Family Support Planning Council(s). Councils can be added or merged as the needs indicate. Minimally, there shall be one council per region.
- (b) Each Regional Family Support Planning Council shall be comprised of no more than 11 members. All members shall be either a person with a developmental disability or a family member of a person with a developmental disability.
- (c) All members shall serve a two year term. No member shall serve for more than seven consecutive years.
- (d) All Regional Family Support Planning Council members shall receive initial orientation and ongoing training and support.
- (e) The Regional Family Support Planning Council members will nominate members to reflect the cultural, economic, ethnic, geographic and disability diversity of the region it serves by soliciting information of interested individuals.

(f) As terms expire, individuals will be nominated by the Regional Family Support Planning Council membership, reflecting the cultural, economic, ethnic, geographic and disability diversity of the region it serves.

(g) Names of individuals interested in Regional Family Support Planning Council membership shall be maintained by the Regional Family Support Planning Council and/or Family Support Coordinator. Nominees shall be taken from this list.

(h) All Regional Family Support Planning Council members shall be appointed by the Commissioner, Department of Human Services.

(i) A chairperson and vice-chairperson shall be elected for each Regional Family Support Planning Council. These individuals, or two other designated representatives as chosen by the Regional Family Support Planning Council, shall serve on a Statewide Family Support Council.

(j) The Regional Family Support Planning Council members shall serve without compensation beyond reimbursement for reasonable transportation, child care and other costs related to serving on the council.

(k) Regional Family Support Planning Councils shall meet at least quarterly. Individual councils may establish more frequent meeting schedules based on the needs of the council.

(l) No member of the Regional Family Support Planning Council who is an employee or board member of an agency under contract with the DDD providing family support services shall cast a vote on any matter which would provide a direct financial benefit to that agency.

10:46A-4.2 Responsibilities of the Regional Family Support Planning Councils

(a) Each Regional Family Support Planning Council shall work to establish and expand family support in its region.

(b) Each Regional Family Support Planning Council shall develop and implement a method of obtaining public input that provides the opportunity to express comments and share concerns and information about family support.

I. Public input shall include public meetings, that are held locally at a time and place that is convenient for the families.

2. Attendance records and written minutes shall be made available to the Family Support Coordinator and the DDD.

3. Based on the needs of the region the Regional Family Support Planning Council serves, at least two additional means of obtaining public input shall also be utilized to ensure all interested individuals are represented.

(c) Each Regional Family Support Planning Council shall monitor the implementation of the family support system to ensure that the system is meeting the mandates of the legislation and the extent to which family-centered outcomes are achieved. Monitoring shall, at a minimum, address the following:

1. The effectiveness of the public awareness and outreach activities supported by the Division of Developmental Disabilities and the Developmental Disabilities Council;

2. The diversity of the individuals and families accessing the system in comparison to the demographics of the area;

(d) Each Regional Family Support Planning Council shall receive from DDD by December 15, of each year, figures representing the allocation of existing resources for family support at State and regional levels.

(e) Each Regional Family Support Planning Council will be informed by DDD about any anticipated funds for family support no later than fifteen (15) days following the release of the proposed State Budget. Within thirty (30) additional days, each Regional Family Support Planning Council will submit for discussion an initial written proposal regarding the expenditure of those funds to DDD in accordance to the needs represented by the families in their region.

(f) Each Regional Family Support Planning Council will be formally notified about any new funds for family support no later than 15 days following the Division's notification of receipt of funds. Within 30 additional days, each Regional Family Support Planning Council and DDD Regional Office will finalize the recommendations for the expenditure of those funds.

(g) Each Regional Family Support Planning Council shall receive notification from

DDD 90 days prior to the expiration of a family support contract for the council's input regarding reallocation of funds, modification of Annex A's or B's and/or discontinuation of the contract.

(h) Based on the results of the public input and monitoring activities, each Regional Family Support Planning Council shall develop, by June of each year, an annual report for submission to the Office of Constituent Relations and Community Outreach the appropriate Regional Assistant Director and the Family Support Coordinator which shall include:

1. A description of information gathering process from the previous year;
2. Monitoring results and data collected;
3. Evaluation of the family support system for the area of the region the council serves including an analysis of the equal distribution of funds;
4. Long and short-term recommendations for new programs or supports that can best meet the needs of the families that reside within the region that the Council services;
5. Identification of training needs for family support;
6. Summary of the ongoing recommendations for reallocation of funds within existing family support contracts, including recommendations for the reallocation of funds within an existing family support contract, modification Annex A's and B's, and discontinuation of an existing contract identified as not meeting needs; and
7. Recommendations of additional funding needs for the next fiscal year.

(i) Each Regional Family Support Planning Council's annual report shall be made available, upon request, through the Family Support Coordinator.

10:46A-4.3 Statewide Family Support Council

(a) The membership and responsibilities of the Statewide Family Support Council shall be as follows:

1. The Council shall be comprised of a chairperson and a vice-chairperson, or two other designated representatives, from each Regional Family Support Planning Council.
2. The Council shall elect a chairperson and a vice-chairperson each of whom will serve for a minimum one year term.
3. The Council shall meet a minimum of once every six months.
4. The Council shall come together for sharing of information, concerns and problem

solving. Attendance records and written minutes will be made available to each Regional Family Support Planning Council and the Family Support Coordinator.

5. The Council shall annually approve the Statewide Family Support Plan adopted by the Coordinator for submission to the Commissioner and the Director of DDD.

(b) The Statewide Family Support Plan shall be made available, upon request, through the Family Support Coordinator.

STATEWIDE FAMILY SUPPORT COUNCIL

BYLAWS

ARTICLE I - Name

- A. The name of this body shall be the Statewide Family Support Council

ARTICLE II - Authorization, Purpose, Duties

- A. This Council is authorized under The Family Support Act of 1993, P.L. 1993, Chapter 98 for the purpose of the sharing of information, concerns, and problem solving. In addition the Council shall develop consensus on issues of statewide concern, make recommendations to the Division of Developmental Disabilities on Statewide Family support Policy and annually approve the Statewide Family Support Plan.

ARTICLE III - Membership

- A. The Council shall consist of 18 voting members.
- B. The chairperson and vice-chairperson, or two other designated representatives from each of the nine Regional Family Support Planning Councils (RFSPC) shall serve.
- C. The designation of representatives shall be reflected in the minutes of the Council if the representatives are not the Chair and Vice-Chair.
- D. Changes in designated representatives must be reported to the Chairperson and Statewide Coordinator, at least 24 hours prior to a Statewide Council meeting.
- E. Changes in representatives shall not be allowed on the day of a Statewide Council meeting.
- F. The Statewide Family Support Coordinator shall serve as a non-voting member of the Statewide Council.

ARTICLE IV - Officers

- A. Chairperson
 - 1. Nomination for the Chairperson shall take place at the April Statewide Council meeting.

2. The chairperson shall be elected annually for a term of one year at the August meeting of the Statewide Council.
3. The Chairperson may serve consecutive terms.
4. The duties of the chair shall be to:
 - a) Preside at all the meetings of the Council;
 - b) Represent and be a spokesperson for the Statewide Council on such committees, task forces, etc., as determined by the Statewide Council.
 - c) Appoint ad hoc committees
 - d) Sign approved correspondence on behalf of the Statewide council
 - e) Discuss excessive absences with membership when such occasions arise.
 - f) Develop agenda of Statewide Council meetings in collaboration with the RFSPC's and Family Support Coordinator.

B. Vice-Chairperson

1. Nominations for the Vice-Chair shall take place at the April meeting of The Statewide Council.
2. The Vice-Chairperson shall be elected annually for a term of one year at the August meeting of the Statewide Council.
3. The duties of the vice-chairperson is to preside in the absence of the chairperson at all meetings of the Council
4. Should the Chair become unable to do so, the Vice-Chair shall complete his/her term. In the event that this occurs a new vice chair shall be elected.
5. Vice -chairs may serve consecutive terms.

ARTICLE V - Committees

- A. The Chairperson of the Statewide Council shall formulate ad hoc committees based on need identified by the Statewide Council.

ARTICLE VI - Meetings, Quorums and Voting

- A. The Statewide Council shall meet a minimum of once every six months.
- B. A schedule of meetings shall be set for the year at the August meeting of the council.
- C. Special meetings may be called by the Chairperson
- D. One half of official members plus one shall constitute a quorum.
- E. Every best effort shall be made to provide information in advance on all matters requiring a vote.
- F. Any RFSPC member may attend statewide council meeting.

- G. Only official designated members shall vote.
- H. Designated members shall be permitted to submit proxy votes.
- I. The Chairperson may authorize mail, electronic and/or telephone votes on urgent matters.
- J. The Statewide Family Support Coordinator shall distribute Statewide Council meeting minutes to all Statewide Council members not later than one month after the meeting takes place.
- K. Agendas for meetings shall be received not less than two weeks prior to the meeting.

ARTICLE VII - Attendance

- A. Statewide council members are expected to attend all Statewide Council meetings.
- B. Statewide Council members are expected to notify the Statewide Coordinator when they are unable to attend a meeting.
- C. It shall be the duty of the statewide coordinator to maintain records of attendance of Statewide Council members and notify the Chairperson when a member has missed three consecutive meetings.

ARTICLE VIII - Amendments to bylaws

- A. Proposed amendments to these bylaws may be presented in writing by any member of the Council at any meeting of the council for consideration and adoption or rejection at the following meeting.
- B. Adoption of amendments to the bylaws shall require the approval of a two-thirds majority of the members present at a Statewide Council meeting at which a quorum is present.
- C. These bylaws shall be reviewed every three years and when changes in State regulation require review.



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NEW JERSEY
DEVELOPMENTAL DISABILITIES
COUNCIL
WWW.NJDDC.ORG**