

**CASE STUDY OF THE FAMILY  
SUPPORT SERVICES CONDUCTED  
BY THE UNITED CEREBRAL PALSY  
ASSOCIATION OF PHILADELPHIA**

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**INTERVIEW PROTOCOLS AND CONSENT FORMS**

## **I. BACKGROUND AND INTRODUCTION TO THE FAMILY SUPPORT PILOTS**

In 1988 the Pennsylvania Developmental Disabilities Planning Council (DDPC) funded four pilot demonstration family support programs. This report presents the findings of an evaluation of one of the four programs. This section presents an introduction to all four pilots. The remaining sections present the findings of the case study of the family support pilot conducted by the United Cerebral Palsy Association of Philadelphia. Appendices to this report and the other three evaluations are available from the DDPC.

### **A. DDPC requirements of the demonstration pilots**

As specified in the original DDPC Request for Proposals, the demonstration pilots were to target families of children who were typically unserved or underserved in Pennsylvania's constellation of services to children. Specifically, the pilots were to serve one of three groups: families with children having developmentally disabling mental illness or emotional disturbance, families with children having physical developmental disabilities with a normal range of cognition, and families with children having developmental disabilities who are adjudicated dependent or delinquent. The pilots were also required to adopt practices consonant with six DDPC guiding principles as follows:

1. Families are responsible caregivers and are the best agents for nurturing and sustaining children.
2. Families must be empowered through their participation in decisions regarding what their individualized needs are and in how those needs are met.
3. Family support programs must be flexible and able to adapt to the individual needs of families.
4. Local community resources typically used by or available to all members of a given community must be used to the extent feasible, rather than duplicating or creating another layer of specialized services.
5. Projects must characterize families and their children with disabilities from a positive point of view and promote the community integration and interdependence of people with and without disabilities.
6. Families who provide home care to children with developmental disabilities must be involved in the planning, development and administration of the family support program.

In keeping with the thrust to demonstrate innovative practices, pilots were requested to consider incorporation of the following components:

**Core services:** such services as information and referral, respite services, in-home education and parent training,

**Case consultant:** an individual to link families with local human services resources and with informal networks who is knowledgeable about interpersonal dynamics and committed to empowering and supporting the family,

**Financial assistance:** a "line of credit" available to families premised on the recognition that the care of children with disabilities go above the average costs of child-rearing and that families have the financial assistance coming as "their due" with "no strings attached."

The implicit purposes of the pilots were to demonstrate a range of solutions for meeting the needs of families with children with developmental disabilities who are typically not served or who are underserved. The pilots were also an opportunity to showcase the principles of family-centered support through flexible and individualized services. It was expected that results of the pilots would inform the next steps needed in advancing a family support agenda in Pennsylvania.

## **B. Description of the four pilots funded**

After a competitive bidding process, four proposals were selected for funding. Two targeted the needs of families with children serious mental illness or emotional disorders. Both were sponsored by local mental health associations; one in Pittsburgh and one in rural Butler County. These two projects were similar in that they employed minimal staff whose resources were devoted to advocating for and educating families rather than using a traditional social work model of case management. Other similar features were the use of parent support groups and educational forums. The projects differed in other sponsored activities and in the deployment of the cash component.

The other two projects were located in Philadelphia. One was originally sponsored by the Philadelphia County Department of Human Services but was eventually subcontracted to the United Cerebral Palsy Association of Philadelphia. This project targeted families with children with physical disabilities and health conditions who were actively served by the Department usually because the family had been accused of child neglect or abuse, or were seen as being at risk of abuse or neglect. The other Philadelphia project also targeted children with physical disabilities or medical conditions, however the families could *not* be active cases with the Department of Human Services. This project was sponsored by a private non-profit child welfare agency. Both pilots employed a more traditional casework approach with families and a monthly cash assistance component. They differed in other project activities. All four pilots employed an initial planning period and ran for approximately two years ending in the Spring of 1990. No proposal was funded targeting families with children having developmental disabilities who are adjudicated dependent or delinquent.

### **C. Methodology employed to evaluate the pilots**

Although each of the pilots was requested to undergo an internal evaluation, an independent evaluation of the funded programs was also planned. The independent evaluation was charged with answering the following questions:

- 1) What are the overall characteristics of the four pilots, their activities and the families they served?
- 2) What did the projects demonstrate in terms of whether linkages to supports assisted families to care for their children at home?
- 3) What was the experience of families and project staff regarding:
  - \* family empowerment principles
  - \* the cash component
  - \* linking families to supports, and
  - \* family satisfaction with services?
- 4) What was the impact of the project on project personnel and the service environment?
- 5) What implications for family support policy are derived from the projects?

To approach these questions the evaluation adopted a qualitative research approach. Data was gleaned through in-person and telephone interviews with a large sample of families served in each project. Consent was obtained from each family interviewed and the interviews were open ended though guided by an interview protocol. Guided interviews were also conducted with all relevant pilot staff and administrators and with a sample of members of the Parent Advisory Council. (Consent forms and interview protocols are included in this report). Relevant documents were also reviewed for each pilot. An individual evaluation team member was charged with managing the data collection for a given pilot, the data analysis, and the preparation of a single case study that describes the findings and pursuant recommendations of the evaluation. Evaluation activities occurred from December 1989 to September 1990.

## **II. PILOT DEVELOPMENT**

### **A. Agency Background**

The subject of this report is the Family Support Services operated by the United Cerebral Palsy Association (UCPA) of Philadelphia and Vicinity, with offices located at 102 East Mermaid Lane, Philadelphia. Funds for the operation of the Family Support Services (FSS) are from the Pennsylvania Developmental Disabilities Council (DDPC) under a contract with the City of Philadelphia,

Department of Human Services/Children & Youth Agency (PCCYA). In turn, UCPA operates the FSS under a contract with the City of Philadelphia. In addition to the FSS project, UCPA operates a variety of other services for people with developmental disabilities, including: Adult Services (vocational programs, rehabilitative programs, and a group mental health program); Children's Services (Homebound program, parent/child program, preschool program); Clinical Services (itinerant psychological, speech, occupational and physical therapy services); Community Recreation; Social Services; and Residential Services ("out-of-home" respite, community living arrangements, and independent living). According to the Organizational Table (9/29/88), the agency employs a total of 248 staff, and serves a total of 2379 individuals.

## **B. Project as Proposed and Budget**

This project was proposed as one of 4 pilot projects in Family Support funded by the DDPC state-wide. The UCPA project is one of two such projects that are designated to serve "families of children with physical disabilities only and/or who are considered to be 'medically fragile'."

The original application for funds was written and submitted by the Philadelphia County Department of Human Services Children and Youth Division (PCCYA), and did not mention the involvement of UCPA. That proposal requested \$305,477 in funds for FY '87-'89, and estimated that 32 percent of the funds would be expended directly on project families and their respite providers. Basic services proposed included in-home respite, a Financial Resources Bank, and systems advocacy.

## **C. Project Staff**

On the Organizational Table, the Family Support Services pilot project is listed as a part of Residential Services. The project is coordinated by the Assistant Director, of Family Support Services, who also supervises the social worker for the project. The Assistant Director is supervised by the Director of Residential Services. It is not possible to obtain a definitive count of the number of respite workers, since due to high turnover the number changes on a weekly basis. The original proposal stated that 20-40 parent-identified workers would be trained and employed. Only two of the original 26 workers were parent/family identified. At the time of the evaluation site visit only 15 respite workers were working and eight of these were parent identified.

Although a stated goal of the project is the empowerment of families, the program still hinges on the competencies of the various layers of staff. The administrative staff must see to it that the program stays on target; the social worker must help families understand their needs, and must facilitate the supports that the families want. The respite workers must be available at the appropriate times as needed by families. They must be dependable in reporting to work and in completing the tasks to which they are assigned. If any of these steps breaks down, it is the families who will suffer. A large number of the families that were



interviewed reported disruptions in one or more of the staff areas that resulted in a lower quality of service to them.

#### **D. Advisory Council**

The proposal indicated that the Parent Advisory Council (PAC) would be composed of "prospective project participants, families which have raised disabled children, and the adult disabled community." The exact number of members of the PAC is fluid. At the time of this evaluation, there were 6 members. Three of the members of the PAC were mothers who had children with disabilities who were not participants in the program, and who would not be likely to be participants in the future. The remaining members (3), were mothers of children who currently participate in the program. Three members were black, two white, and one was Hispanic. There are no men on the PAC, and there are no people who would be considered to have developmental disabilities. Meetings are held once each month, and are attended by the Assistant Director for Residential Services, and the social worker for the in-home respite program. Members of the PAC are each paid \$45 for each meeting they attend.

PAC meetings are held in a facility owned by UCP and used for out-of-home respite. The Assistant Director indicated that this facility was used because it was located close to several of the members' homes, and because it is easily reached by the public transportation network. This meeting area is not wheelchair accessible. Pilot administrators note that no member of the PAC required an accessible meeting area, and that an alternative would have been sought if needed. The main UCP offices are not located near the families, and are not easily reached by public transportation. Although the majority of the UCP main offices are accessible, the Offices relevant to the family support program are not.

As a part of this evaluation, one PAC meeting was observed. One of the women was an especially strong participant in the discussion, the others were less outspoken. The three women who are participants in the program spoke the least. Afterwards the social worker stated that they are often content "to sit and get paid to come." Pilot administrators pointed out that over time, there has been increasing participation in the PAC from parents receiving services from the program.

PAC members discussed significant implementation issues of the program. For example one decision that was made by the PAC involved the expenditure of funds from the Financial Resources Bank (see following) of a child who died. Although the family was signed up for the program, he died without ever coming home from the hospital. The family requested that \$200 of the FRB money be spent on a funeral for him. We were told that at first there was some resistance to spending the money on a child who was dead. Parents on the PAC pointed out that the money was supposed to be spent on the families, and that a funeral would be for the benefit of the family. The money was allocated, and several people cite this instance as an example of the responsiveness of the agency to individual family needs.

## **E. Project Activities**

In keeping with the proposal, and the implementation plan, the project offers three major services to the families, their children, and the community: in-home respite, financial assistance and systems advocacy.

### *1. Referral, Enrollment, and Termination*

The project has a formal relationship with Serving Children in their Own Homes (SCOH) agencies and the Department of Human Services. These agencies were referral services and has reportedly maintained involvement with referred families during and after participation in the pilot. The SCOH agencies are: Episcopal Social Services, Jewish Family Services, the SCOH Child Abuse Network, Philadelphia Society for Services to Children, and Association of Puerto Ricans on the March. Project administrators perceived their own role as being supportive to the SCOH programs.

Each family that was interviewed was asked about how they got in touch with the project. One or two were not sure, but virtually all of the others described a referral to the agency from one of the social service/child welfare agencies in the area. Most of the families indicated that they willingly accepted the referral, in fact several said that the referral came as a result of them telling a worker at the referring agency that they really needed some help or that they "just can't take it any more".

Enrollment in the program seemed quite straight forward. Families needed to meet the following eligibility criteria:

- An active case with the Department of Human Services at the time of referral (usually meaning the family has been accused of child neglect or abuse, or is seen as being at risk of abuse or neglect);
- Child has a primary diagnosis of physical and/or medical needs;
- Not currently receiving family support services from the Human Services Development Fund or the Office of Mental Retardation.

The agency can point to several instances where information about the ending of the program was communicated by phone, letter or in-person to parents. Difficulties in communicating with inner city families living in poverty are discussed at the close of this report. Nonetheless, when families were asked in the interviews six months prior to the project close how they felt about the program ending, and what their plans were for the future, several parents indicated that they had no idea that the program was ending. In fact, at the PAC meeting, one parent was quite surprised when the topic came up. She said she was totally unaware of the time-limited nature of the project. Several people seemed to assume that the project would be renewed as a matter of course.

Agency staff say they are making plans for replacement services for each of the families. Referrals have been made to the "Basic Services Unit" an entry point to mental health/mental retardation community services and other specific programs that provide services akin to those provided by the pilot and some families will be receiving continued service in this way. None of the families that were interviewed however seemed to have any idea about the status of alternative plans for them. One or two families said that now they could make it on their own. Some indicated that there would be little difference in their lives once the program ends.

At the PAC meeting, one parent suggested that the DDPC find some way to review families 6-12 months after the program ends to see how the families are doing. She suggested that this would be a good way of seeing if adequate arrangements had been made for people as well as a way to learn if any of the benefits of the program are sustained for any length of time.

## *2. In-home respite supports*

From the outset of the project, plans called for families to receive 32 hours of in-home respite each month. The initial plan was for all of the families, or as many as possible, to identify their own respite provider. That individual would be trained, paid and supervised by UCP, but would be working directly for the participating family. Families were allowed and even encouraged to identify friends, neighbors, and even family members as potential respite care providers.

Well over 50% of the families reported problems with the respite services. These problems ranged from being offered help at times or on days when it was less needed or less urgent to workers who fail to show up and never call, and going to weeks — even months without any respite at all. The administration points out that these difficulties are due to use of a "typical workforce" with typical problems (e.g., absenteeism, lateness, irresponsibility).

## *3. Financial Assistance*

UCP operated a Financial Resources Bank (FRB), and each family had an "account" with an allocation of \$100 per month. These resources were to have relatively few restrictions, and unusual requests were to be brought to the PAC. Participating families were given a "pre-evaluation" regarding the use of the FRB, which indicated a sample of identified services and items. Although the program is casually referred to as a "cash assistance program," families do not receive cash payments as such. They either go shopping with the social worker, who then pays for the purchases with an agency check, or they may make their own purchases and are reimbursed for receipts. Staff stated that it was a PAC decision not to give families cash advances in part because this practice could have jeopardized other benefits without careful intervention from the pilot program.

In general, the level of satisfaction was higher with this aspect of the program than it was with the respite services. Most families were able to look around their homes and point to material objects that they bought through the program, although there was some dissatisfaction with this service as well. Some families reported that they did not feel like the agency trusted them to "do the right thing" for their children, and the agency admits that they do not trust the families with cash. Some parents indicated that they felt pressured by the social worker to make purchases that they did not want, and others felt that they had never been given sufficient information to really use the FRB effectively.

#### *4. Systems Advocacy*

The third aspect of the project as proposed was to do systems advocacy on behalf of these families. Staff do advocate for systems change by their presence on several boards and coalitions in the area that deal with people with developmental disabilities, child abuse, etc. Most of this activity is through the agency participation in a consortium of service providing agencies known as SCOH (Serving Children in their Own Homes). The administration also reports that UCPA has been actively involved in the medical reform effort at the Federal level, the Medical Assistance Advisory Committee at the state level, and early intervention and EPSDT Task Force at the local level. However, this activity is much less visible to families than the other two pilot components. Most of the families that are served by the program are only aware of the respite and financial assistance components. The true test of the effectiveness of their systems advocacy may be the extent to which the families who are currently being served are assisted in finding alternate, comparable services when the program ends.

#### **F. Implementation Issues**

The implementation of the project must be taken in the context of the families served. On the whole this project served inner-city families beset by problems of poverty, crime-ridden neighborhoods, domestic violence, and tenuous lines of communication. The difficulties these families faced span well beyond the scope and aim of a single family support pilot. Moreover, these difficulties not only impact the family but also encumber the agency efforts to assist the families. More discussion of these matters is provided at the close of this project.

Implementation was gradual, with a few families receiving services (respite and cash support) at a time. Group 1 consisted of only five families who began the program in April of 1988. Respite services were not provided until May of 1988, when three of the families received a total of 66.5 hours of respite. By July of 1988, Group 2 was added, with 5 families, and then Group 3 in September of 1988 with an additional 5 families. A fourth group was added in December of 1988.

By March of 1989, there had been 5 case closures, and a total of 18 families were receiving services. The number of families receiving services each month reached 20, the proposed capacity by June of 1989.

The biggest problem seems to have been the recruitment and training of respite care workers, which proceeded slowly. Recruitment problems coupled with a substantial turnover rate compromised both the quality of the service, and even the ability of the agency to actually deliver any services. This problem continues in spite of efforts by the agency. The administration indicates that recruitment is complex, hampered by the nature of the job (e.g., part-time work involving a great deal of trust). Families report that recruitment of family identified workers is hampered by the facts that training is offered at limited times and testing is only in English.

Other implementation issues revolved around decisions to be made by the agency and the staff in consultation with the PAC and the DDPC. For example, decisions needed to be made regarding what kinds of expenses would be paid for or reimbursed. At issue were "regular" utility bills as opposed to "emergency payments" if there was a chance that power would be cut off. The reviewer was told that a decision was made to pay families' utility bills in cases where the power might be turned off, but not if they were "regular" bills. This position seemed to alter over time. As more families received equipment and appliances from the project, their utility bills went up and they needed more assistance to pay bills. Other decisions included the appropriateness of expenditures that benefit the whole family as opposed to just the identified child. Other examples of expenditures that were controversial at first but were later approved include:

**Household appliances.** The reviewer was told that at first there was some resistance to the purchase of household appliances which might benefit the entire family, but are not directly related to the disability of the target child, such as washers, dryers. Ultimately, these became some of the most common purchases.

**Carpeting.** One family requested new carpeting in the home due to a medical condition of the child. Again, some concerns were raised because the carpet was not exclusively for the direct benefit of the "target" child. The purchase was ultimately approved.

**Funeral service.** One family was referred to the program while the child was in the hospital. They were accepted into the program, but the child died before any respite was provided and before any of the money from the Resource Bank could be spent. The family requested \$200 to pay for a funeral. At first there was some resistance to spend money when the child was dead. Others pointed out that the funeral would benefit the entire family, and the expense was approved.

### III. EVALUATION METHODOLOGY

#### A. Overall Strategy

##### *Major activities of the review*

Material for this review was gathered through a variety of means. Site visits were conducted on February 1, 1990; April 4 and 5, 1990, and April 18, 1990. Additional information was obtained through telephone calls, as well as a review of written materials received from the project staff. (See Appendix C)

Selecting a sample of families to be interviewed encounters some difficulties as the numbers of people involved in the project depends on the perspective used. Frequently one discusses the number of "families" being served by a family support project. While this is usually sufficient, for purposes of a methodological review, this can lead to inaccuracies. In some instances, there is more than one child with a disability in a given family, and so there is a difference between the number of **eligible children** being served, and the number of **families** being served. As with many similar projects, there is also a problem with changes in the population being served over time. At the time that this evaluation began (January 1990), the FSS listed 21 families as actively receiving services. However, as of April 15, 1990, a total of 27 families had been enrolled in the program since the beginning, with a total of 30 so-called "target" children eligible for services (not counting other siblings). As of the same date, the program was serving 19 families with a total of 22 eligible children.

The files on a total of 8 families (with 8 children) had been closed since the initiation of the project. The reasons given for these closures are as follows: death of child (2 families); family moved out of area (1 family); child moved to live with neighbor who is not eligible for service (1 family); the family voluntarily ended services (1 family); and the agency discontinued services (three families).

The 19 families receiving supports at the time of the site visits were contacted by letter (see Appendix A ) and in person by the UCPA social worker, and asked to sign a release form "Permission to Conduct Interviews and Discuss Case Histories" (attached to this report). All 19 families consented to be interviewed and completed the form. Those who were interviewed were paid \$20 cash, and were asked to sign a receipt so indicating (see Appendix B).

##### *Interviews*

A wide variety of interviews and meetings were used to gather the information used in this report. A total of 14 families were interviewed regarding their experiences with the project. Most of the interviews were conducted in the family homes, but a few were conducted in the respite facility operated by UCPA. These interviews were conducted following the "Family Interview Protocol"

developed for this project. In each case, the interview was scheduled at the convenience of the individual(s) being interviewed, and was conducted in total privacy with no agency staff present.

In addition to the family interviews, a total of 6 staff were interviewed regarding various aspects of the project. These interviews were conducted using the "Pilot Program Staff Interview Protocol" developed for this project. In an effort to understand how the FSS project fits into the overall constellation of services offered by UCPA, interviews were conducted with the Executive Director, the Director and Assistant Director of Residential Services, and the staff member who coordinates staff training for the agency. Finally, interviews were conducted with members of the Parent Advisory Council (PAC). These were conducted using the "Parent Advisory Council Interview Protocol" developed for this project. These interviews were conducted in small groups, with information being collected before, during and after PAC meetings at the members' convenience.

In general, the families were open to being interviewed and seemed to be quite frank and forthcoming. In a few instances, respondents offered only single sentence responses to interview questions. Those interviews were rather short, ranging from 20-30 minutes. In other instances, the respondents were quite talkative and volunteered long, detailed responses. More than one of these interviews ran over 90 minutes.

The interviews were not tape recorded, but notes were taken during the interviews. Several families consented to have photographs taken of the child, the home, and the family.

## **B. Sampling Strategy**

The original evaluation strategy called for 40% of the recipient families to be interviewed. In order to determine which of the families would be approached first, a random sampling strategy was employed. At the time of the random assignment there were 19 families receiving services from the project. The family names were listed in alphabetical order, and beginning at the top of the list, every 5th name was selected. Families were approached in sequence (in writing and in person) and asked to volunteer to be interviewed. The response from families was quite good. Although we had intended to interview approximately 40% of the families (more if possible), when all 19 families indicated a willingness to be interviewed, a decision was made to meet with as many families as possible. A total of 19 families were interviewed, or 73.7% of the families being served at that time, and 51.9% of all the families that had ever been served by the project.

## **C. Demographics of Sample**

Interviews were conducted with the person who is the primary care provider for the child. In each instance, that person was a woman. Most were the mother of the child, however, in at least one instance, the woman being interviewed was

the grandmother (and guardian) of the child. In a few instances other people participated in the interviews (usually sisters of the child). In only 2 cases were men involved in the interviews. Both men were identified as the fathers. After one interview, the social worker pointed out to me that the man was not the father of the child who was being served, and was not married to the mother.

The project staff reviewed the names of the families that were interviewed and assured us that they represent the diversity of families served by the project. Families are black, white, and Hispanic. The majority of the families served, and the majority of the families interviewed are black. Some have only one child while others have much larger families. Two families with one Hispanic parent were categorized as "Hispanic."

Most of the families could be described as living in poverty. Among the interview sample, only two families own their homes. The balance lived in public housing provided by the City of Philadelphia, and receive public assistance. Table 1 contains the basic statistics on the program and the racial distribution of the families interviewed.

**TABLE 1  
BASIC PROGRAM STATISTICS**

**Program Participation:**

Number of families ever in the program	27 (30 children)
Number in the program as of 4/15/90	19 (22 children)

**Terminations:**

death of child	2 families
family moved out of region	1
child moved to non-qualified home	1
voluntary termination by family	1
involuntary termination by agency	3

**Interviews**

signed releases	19 families
interviews completed	14 families

**Racial distribution**

	Currently in program			Interviewed families
	Black	12		9
	Hispanic	4		2
	White	3		3



The following family profiles have been selected to offer a better understanding of the perspectives of the families, their differences, and their similarities.

## INTERVIEW 1

### Demographics:

- Single, black woman who lives in public housing.
- Five years old daughter who is non-ambulatory.
- Referred to the program by her DSS social worker about a year ago, and reported that getting started with the program was "no hassle."

### Involvement:

The FRB allotment has been used to purchase a washer and a dryer, and a refrigerator. They are now saving to purchase a new bedroom set.

### Comments:

The mother reported that she had no idea that the program was ending. She also indicated that respite services have been a problem. "We had one worker who left, two others came out to meet us, but then never showed up. I have no idea about when a worker might be coming."

The major concerns she expressed were ones that are outside of the direct scope of the project:

"I have not hooked up the appliances because I am hoping to move. I want them to find me a new place and get me out of here. I want to get out of here and start my life over. I will not be taken advantage of again. I am stronger now. That man pounded me in the face four times, I changed all the locks, I got a court order, but I still watch my back when I go out the door.

## INTERVIEW 2

- Black, single mother who is currently living with a relative.
- Five children, including a daughter with cerebral palsy,
- Referred to the program by a social worker from Jewish Family Services.

### Comments:

She too reported problems with the respite services. "The first one came for about 2 ½ months and then stopped. The second one came out to meet us, but never came back."

The mother registered several other concerns about the program, and her needs.

"They never really explained to me how the program really works. I was on WIC, but I had to move into a shelter, and I lost WIC because I did not have a refrigerator, so they disqualify you." (The evaluator asked the social worker if this was possible and was told that if the mother had asked, the agency could have used some of her FRB money to buy a small refrigerator to keep her on WIC, but "she never asked.")

"We should get a place of our own," she said.

### INTERVIEW 3

#### Demographics:

- Black, single mother.
- One child who uses a respirator.

#### Involvement:

They have used the FRB money to buy a bed, clothes, shoes, and to pay for the phone bills that are essential for the care of the child.

The family reports that they are receiving 32 hours of respite each month, and that they are quite satisfied with the service. Then asked about the possibility of an out of home placement for her daughter, this mother responded: "I'm not going to put my baby in an institution. My baby is part of my life. I know that is why she is still alive. I could never say that I can't cope."

### INTERVIEW 4

#### Demographics:

- White, single mother. She and her two children are all considered to be disabled.
- Referred to the program by a social worker in DHS because she needs a bit of help, not because she has ever abused or neglected her children. She stressed the fact that she is not like the other families in the program.

#### Comments:

She had several concerns about the program:

"It took me over a month to get a worker in the house. Then I had help from August to Thanksgiving, and then no help since then. I was told that I had a worker, but that I had no choice in her hours. We scheduled three visits. The new worker missed all three visits, no calls from the worker, and no calls from the respite worker. Now I am not sure that I can trust the worker, even if she does come back. I have people who want to help me, but they can't take off the two weeks to get trained. Now I am not sure that I can trust the worker, even if she

does come back. I just found out that I could have used my \$100 per month to hire someone who was not trained. To tell you the truth, I can train them better about my own kids. I just can't get any clear information on how it (the program) works. It's not for a lack of asking. Give me something on paper. How can this money be used?"

This mother is one who was described to the evaluator in advance as a troublemaker.

## INTERVIEW 5

### Demographics:

- Single black mother.
- Several children.
- Social worker indicated that she has been on drugs in the past and several times during home visits.

### Comments:

The mother indicated that she began with one respite worker, but this worker soon left to take on another job. The second worker came late the first time, did not show the second time, and never called and never returned.

She indicated how her family could best be helped: "I want a bigger place, a better house. Nothing is being done to help us with this. A house is the main thing, I need a house...help me get a house...I really need a house...I don't want to touch the money, just put it toward a house.

She also expressed concerns about the ease of using the service: "They need to really tell you about it, not just give you a paper to sign. They don't really explain their services. What I am saying is that I want to know."

## IV. PILOT OUTCOMES

### A. Family Experiences.

#### *1. Overall Family Satisfaction*

The opinions of the families seem to paraphrase an old nursery rhyme: "When they were good, they were very, very good, and when they were bad..." That is to say, that the families had strongly held opinions about the project, and the staff. Some were strongly positive, others strongly negative. At times it was hard to believe that we were discussing the same program and staff because the opinions differed so much from interview to interview.

One trend can be identified in the level of satisfaction from the parents. Those who were happy to get any help at all seemed quite satisfied with the program. A few people were satisfied because they were getting the amount of respite that was promised, and were pleased with their purchases. However, the families who seemed less satisfied were those who were not willing to accept anything as better than nothing. This group seemed more empowered than the former, and were critical of the way they were treated. They cited a lack of respect for their time, their privacy, and their preferences. During at least three interviews, families raised concerns about how they had been treated. In conversations with the social worker, she independently commented that several families were a "problem because they are hard to satisfy, or are picky about the time you show up at their house." Her list of "problem" families included the three that complained most in interviews.

Below are a series of quotes, each from different families, that seem to reflect their degree of satisfaction with the program.

"When I asked for help....I got it!"

"It's been good...I hope they don't close the program...it's helped a lot."

"(our worker) is really good...if they are all as good as her, they deserve to be saints"

"The program is fabulous, it should continue"

"It helps the whole family, yes it does"

"I can't really say nothing good."

"The fault is in the workers, not in the program. I am forced to deal with a person who cannot help me make effective use of my money"

"I need more help, a worker who will come more often"

"Nothing is being done to help us, I can't really say nothing good"

"Every time I go shopping, it is a head-on collision with (the staff member)"

## *2. Overall Benefits Received*

The overt purpose of the project was to provide families with two types of material benefits: in-home respite, and financial assistance. Most, but not all of the families received in-home respite services. Many did not receive services in either the quantity promised (32 hours/month) or in the quantity that the family felt was needed. Virtually everyone did receive the financial resources as promised at a rate of \$100/month. However the actual benefit realized by the families varies greatly.

### *3. Financial Assistance*

An analysis of the expenditures of the FRB indicates that expenditures tend to fall into one of several categories:

a) Basic necessities. This category includes expenditures for food, clothing, rent and utilities. It is hard to imagine how families existed without this support in the past, or how they will manage again without the support in the future. Ongoing support for such basic necessities seems to be essential for these families.

b) Household appliances. By far the most common appliances purchased were clothes washers/dryers, but other appliances including a refrigerator, vacuum and rug cleaner, were also secured. The staff have demonstrated some creativity in stretching the FRB money. By having the items purchased with the agency check, the social worker is able to use the agency tax exempt number and save the families 7% of the expense. In addition, one of the mothers works at Sears, and she qualifies for an employee discount. By using her discount and the tax exempt number she is able to stretch her FRB dollars quite a bit farther. These purchases appeal to the staff, as well as to many of the families, because they are durable and will last long after the project has ended.

c) Adaptive Equipment. The third category of expenditures is adaptive equipment related to the disability of the identified child. While the other two types of expenditures can be seen as directly benefiting the entire family, this third category represents expenditures that are targeted more directly at the child with the identified disability. These purchases include a TTY machine, and a light activator for the telephone for someone with a hearing impairment. Most of these purchases are also durable goods that can be expected to continue to benefit the individual long after the program ends.

### *4. Keeping Children at Home*

When asked about the impact of the program on possible out-of-home placements of their children, families had two types of responses. One group said that an out-of-home placement was out of the question, and that they would struggle along without support but not give up their child. These families spoke about the extent to which the program enhanced the quality of their lives and the lives of their children.

The second group indicated that the program had served as a major deterrent to an out-of-home placement. They spoke of now having the resources and patience needed to support their family member at home. Some indicated that now that they had "stabilized", that they would be able to make it on their own, while others expressed anger and fear at the scheduled termination of the program. One mother pointed out that for the first time in a long time she "had her act together, was taking care of their children and doing well. Now they (the state) want to come in and take all that away from me." These families were not

sure about what would become of their family in the absence of the current supports.

Determining the effect of supports on out-of-home placement is always difficult at best. With these families there are two reasons why it is more difficult than usual. First, many of the people interviewed seemed anxious to say the right thing, as if they would lose their benefits if they said the wrong thing. Every reasonable effort was made to assure them that they could speak freely, but one needs to question if that was always the case. On the other hand some families spoke quite frankly!

The second concern is that families might say that they would not ever place their child out of home even if they did not have the supports, but such statements imply voluntary placements. One must remember that these families have been reported for child abuse/neglect, and for some families the reports were substantiated. It is likely that in the absence of these supports, more of the children might have been removed from the homes for their protection, and the families may not be in a position to give a good estimate of the likelihood of this possibility.

The common justification for family support services is that it will reduce the need for out-of-home placements. It is likely that this program has reduced such need. However, in this particular case, a more important indicator of success may be the increased quality of life for the family, especially the child. Specifically, for families who are seen as being at risk of abusing their children, prevented abuse must be seen as a major victory. It is of course impossible to determine from two dozen families over a three year period, if the program has had any such effect. This is especially problematic since abuse/neglect (or alleged abuse/neglect) are not only criteria for enrollment into the program, but are also reasons for being removed from the program.

### *5. Family Empowerment*

This topic is another that would lead one to assume that two different projects were being discussed. Many of the parents, most of the staff, and many of the members of the PAC discuss the high level of empowerment of family decision making. They spoke of making choices, especially choices about how to spend their Financial Resource Bank allocation.

On the other hand, many parents and a few other people who were interviewed indicated concern about the level of control that the agency, especially the social worker, exerted over the families. One mother indicated that she had to shop when and where the social worker said, and at the social worker's convenience. She would have preferred to shop at another time and at another store but the social worker did not like that store and could not be available at the time that was best for the mother.

Yet another mother indicated that the social worker had an "appliance fetish", and kept pushing large expenditures for appliances, including a washer and dryer that were in violation of her lease. One family that was interviewed had a washer and dryer that were not in use because the electrical service in the apartment could not accommodate the washer and dryer along with the child's respiratory apparatus without blowing a circuit breaker. The social worker indicated that the agency did not want to pay for new electrical wiring (with the family's FRB) because the family had moved several times, and that if they moved again then that money would be "wasted". It was explained that even though the machines are not functioning now, the family will continue to own them and some day they will be functional, so that money has not been wasted.

## **B. Staff Experiences**

The staff interviewed were all proud to be a part of the program and seemed to have a sense that they were a part of an innovative project. Both the Assistant Executive Director of the agency, and the director of Residential Services indicated that they had been skeptical about the program at first. They were skeptical of the ability of families to locate and supervise respite workers, as well as their abilities to use the FRB resources responsibly. They also indicated in their interviews that they had seen accomplishments that they never expected to see. As one administrator said:

"I was skeptical at first. I had a lot of questions. There were liability questions. With someone with a trachea tube, our exposure is great. My point of view has changed--but I still think it was set up to be too expensive on a cost per unit basis. But we have learned a lot, we have increased our expectancies for the families."

Another administrator said,

"We were real skeptical. I'm amazed, I love the program. I love to see these families that I thought could not prioritize money. I thought the money would go to drugs, but it did not, they used it well. This is a real first for this agency. This is the first time that we have offered so much family direction and choice. I would give them cash now, and keep the case manager involved. They want to do what's right. I was skeptical of starting what I knew would be taken away (because the pilot would end). They have grown a lot, and even if they lose the program, they have been helped to grow — you don't take that away."

Administrators are also satisfied with one outcome of the project, that being that 24 out of 27 children remained in their own home during the project, this despite high risk conditions and implementation difficulties.

In contrast to the response of the administrators, the social worker seems relatively unchanged by the experience. She seems to be at least as distrusting of the families as she was before — maybe more so. She seems disinterested in the project, especially in comparison to her administrators. Several of the parents indicated that they had problems with her. One said "I have lost all respect for her as a professional. How did someone like that get this job?" In many of the conversations before and after parent interviews, she expressed concerns about the trustworthiness of the parents, indicating that they are "manipulative". She also made several references to "these people" and how they are lazy and uninterested in improving their lives. Her descriptions of people were a stark contrast to the hard working, concerned parents interviewed, who were doing their best to struggle against the system and their family problems.

### **C. Experience of the Parent Advisory Council Members**

Several of the PAC members expressed the fact that they had grown as a result of their participation, particularly the parents who were also participants in the program.

One member of the PAC made several cynical remarks:

The government is just paying for all of these drugs out on the street, they are a fool. What will happen when these people lose their support? I don't know what these people are going to do, we pay their utilities and everything.

When the PAC was asked to consider allowing direct cash payments to the families, one response was reportedly, "What are you crazy?" It seems clear that the non-participant members set themselves up as different from the participants ("these people"). It is hard to accept that the non-participant members of the PAC (who are in the majority) really represent the needs and interests of the participants even though some have similar circumstances. Clearly just being a parent does not mean that you are always able to see things from the participants' point of view.

## **V. DISCUSSION**

The following section provides discussion of salient issues that arose in the evaluation.

### **A. Case closures**

Program staff report that since the beginning of the project, a total of 8 families cases have been closed. One of these families moved out of the service region, and in a second case, the child moved to a new family that did not meet the



criteria of the project. A third family was said to have voluntarily terminated services from the agency. An additional 2 cases were closed following the death of the eligible child. An additional 3 families were discontinued from services by the agency. Although none of these families were interviewed, the instances which present the most concern are the three who were discontinued by the agency. The phrase that is used in the reports is that the families were "unable to adhere to guidelines set forth by the In-home Respite Care project."

### **B. The story of one family who was "terminated"**

In one case, when the child was found to have bruises, the family charged that the respite worker had abused the child. In two other instances, services to the families were terminated following incidents of neglect on the part of the family. In one particular case, the mother left the child with the respite worker for what was expected to be a few hours. Several hours later, when the mother had not returned the worker was forced to locate a neighbor who was willing to assume responsibility for the child. Ultimately, the mother was missing for 3 days. A decision was made that the agency could not serve this family. There is no doubt that this family and the 2 other families who were discontinued do present serious challenges to the agency. However, we are left with a serious question. If an agency is paid to serve families who have been reported for child abuse/neglect, then can child abuse/neglect also be a cause for discontinuing service, and if so, under what conditions? Among the factors to be considered is of course the welfare of the child who is no longer receiving services.

Although a total of 8 families have been terminated, at the time this report was being written, statistics were available on only the first 7 families that were terminated. Table 2 contains a summary of this information.

<b>Summary of services to families that were terminated.</b>			
<b>Family #</b>	<b>Hours of Respite</b>	<b>Cash Support</b>	<b>Reason</b>
1	0	\$200	death
2	192	\$862	involuntary
3	13	\$500	death
4	141.50	\$235	involuntary
5	19.25	\$200	involuntary
6	19.25	\$826	moved
7	108.50	\$612	voluntary

### **C. The role of other family members**

This project, as do several other family support projects nationally, allows families to pay family members to work with the identified child. In several cases, aunts or sisters are providing care for their relative, and are being paid as any agency employee. The issue of the role of other family members raises the same concerns in this project as can be seen in other projects nationally. On one hand, family members may already know how to meet the needs of a child who uses specialized medical equipment and they may already be sharing some of the responsibility for the care of the child. Many even forego other employment (income) in order to assist with a family member. In this light, being able to pay family members as respite workers is a major asset. On the other hand, two potentially negative situations have been raised in this program and in other programs. First, there is the question of an older sibling or other relative who suddenly becomes an "employee" of the family (usually the mother). There is some concern that family members will find it difficult to supervise other family members as employees. The second related concern is that of turning everyone in the life of the child into an employee. No one can deny the benefit of a sibling receiving a few dollars for staying home to care for a younger sibling with a disability. However, many of these children have lives that revolve around paid care givers. For some, the family is the only contact they have with people who are not paid to be with them, literally paid to touch them. The practice of paying family members to provide basic care and supervision may be removing the last unpaid contact that some children have in their lives. This is not necessarily an argument against such practices. It is only to say that there is a concern here that must be addressed with eyes open.

### **D. Communication problems**

Communication with the families is complicated by a variety of conditions and situations, as follows:

#### *Drugs*

Although only 1 or 2 of the parents seems to have any current involvement with drugs, reportedly communication with one mother is complicated by the fact that she is often on drugs when home visits are made.

#### *Unclear addresses*

Some of the families in the program move around quite a bit, changing addresses as they get evicted, choose to move, change housemates, etc. In addition, locating people is sometimes difficult because leases, utilities and phones are often in the names of other people because of previous billing problems.

### *Difficult phone communication*

From time to time, some of the families are without phones. However, even when families have phones, they can be difficult to reach. Some of the parents we tried to reach seemed to have other members of the household screen calls for them. At least one family has taken advantage of a new service offered by the local phone company called "caller ID". This is an optional phone service (available at an extra cost) that allows a phone customer to determine the number of an incoming call. When the family identifies the incoming call as being from a number (such as social services) that they would prefer to not speak to, they do not answer the phone.

### *Illiteracy*

Many of the parents have limited reading levels. They require assistance with some of the paperwork associated with the program, and the agency can not count on sending people written notices alone to convey important information.

Program staff seem to make significant efforts to keep track of the best ways to reach each of the families: whether to call, write, or stop by; the best time of day, etc.

## **E. Family Social Problems**

It should be noted that many of the families confront a myriad of problems on a daily basis. It is not possible for family support services, no matter how well delivered, to meet all of these divergent needs. The following is just a partial listing of the life-problems that were identified during the home visits and interviews.

### *Poverty*

Most of the families have income levels below the poverty line. They live in public housing that is often inadequate, and where even minor repairs require long waits. Although the family support system can offer some financial assistance and some household modifications, such a project can not be expected to elevate the families out of poverty, or make their housing substantially better. One mother was behind almost \$2,000 in rent and could not get into public housing until the rent was paid. Most of her Family Resource Bank allotment went toward eliminating the debt, without any immediate benefit to her or her child.

### *Danger*

Most of the families that were interviewed (and most of the families in the project) live in neighborhoods that others would consider dangerous. In several instances, the safety of the respite care workers has been an issue. In one instance, we learned that a mother who was receiving service had been attacked by her boy friend who attempted to strangle her. Although she had a court order barring him from her home, he was still "hanging around". The respite worker was quite upset to learn that he had attacked the mother in the past, and was uncomfortable being in the home when he might be around. On one of the days that interviews were being conducted, the social worker and the interviewer began the day in different cars. The social worker said that when they got to a neighborhood where she was willing to leave her car, they could ride in one car and go back for her car later.

### *Drugs*

In the interviews with key individuals, there was a great deal of discussion of drugs. The subject was raised by UCPA administrative staff, the social worker, respite workers, families and members of the PAC. Drugs was cited as a cause for family involvement in the program because the child was born while the mother was using drugs, the child was injured while the parents were incapacitated due to drug use, the child has been abandoned to the grandmother because of the mothers drug use, etc. One person described the neighborhoods as "typical guns and drugs" neighborhoods.

However, according to the social worker there is little evidence of day to day drug activity in the homes. The social worker indicated that only one parent is clearly involved with drugs at the current time. In contrast to this fact however, is the fact that the decision making process is continually geared towards the lowest common denominator of the drug-abusing family that will take any available money and use it to purchase drugs. This danger can not be discounted. However, there seems to be a large gap between the high level of attention this concern receives, and the low level of apparent effect of the problem.

## **F. Program Problems**

### *Mistrust*

Parents mistrust the system. The system mistrusts the parents.

### *Resource Limits*

The families have so few resources to fall back on, and the system does not have enough resources to effectively augment the family resources under the current stipulations.

### *Limited Duration*

By nature of being a pilot project, and a relatively short project the project experience was a bit like a ride on a commuter airplane. The first half of the trip is spent in reaching altitude (getting the program up and running, and approaching capacity), and then before you know it, the second half of the trip is spent in landing (preparing to phase the program out). The full-operational time was a relatively short period in the middle.

## **G. Global questions about family support that remain unanswered**

Although a great deal has been learned through this pilot project and its evaluation, there are several questions that remain unanswered:

### 1) At what point are pilot projects counterproductive?

As is evident from the comments of several parents and the social worker, there are intrinsic problems with the concept of a "pilot project". The needs of the family do not change dramatically with the end of the project, and many families have come to depend on the agency for various kinds of support. Several people seemed to assume that if the project did a good job (got a good evaluation) that of course, the project would be funded again. In fact, in pilot projects such as this, the program terminates automatically without regard for the quality of the service or the success of the project. This sends a very confusing message to the community.

### 2) Under what conditions can a family support service terminate a family's participation in the program?

Families are entitled to assistance, and should not be required to "earn" the right. However, occasionally families take actions that make it difficult if not impossible to assist them. As agencies serve more families that can be described as "difficult," they will be faced with hard decisions regarding who to serve, and who to refuse to serve.

### 3) Under what conditions should we cease to assume that parents have the best interest of their children at heart? Are there parents who cannot (should not) be given full power and autonomy?

Family support services are based on the assumption that parents will, given the opportunity and the resources, act in the best interest of their children, and that they know their family needs better than a professional can. However, occasionally families demonstrate that they are unable or unwilling to act in the best interest of their children. How should agencies determine when this is the case, and how should the agency intervene?

These questions go beyond the scope of this evaluation, but will require answers in the future.

## **H. Limitations of the program**

Perhaps the greatest limitation of the program is the one that is taken for granted; by virtue of being a pilot project, the assistance is time limited, and now that families are just accommodating to a certain way of life, and a basic level of supports, they are faced with the loss of those very supports. The impact of this must not be underestimated.

Other limitations were as follows:

**Training.** The project required extensive training for respite workers (96 hours). Although a great deal of useful information was covered in this training, it presented several problems. Many potential workers could not attend the training, or could not pass tests since English was not their primary language. Many workers are trained in information they will never use, and some parents would prefer to train their workers themselves.

**Information on Options.** Families reported that they were not informed of their options under the project. The project staff reported that families never requested many of the options available to them.

**Empowerment.** Many families indicated that they were ready for more self-determination than they were being allowed. There was also good evidence that families made decisions at least as well as the professional staff. The agency had a tendency to place restrictions on many based on fears about the few.

Even well-intentioned agencies are prone to assume a paternalistic posture with families. Even "parent" advisory groups can underestimate other parents, especially if the advisory parents are not consumers of the service in question.

Other limitations of the project include the limited resources of the project and several concerns raised by the families, e.g., the availability of the program staff, the location of the office, and insufficient information provided on the programs service opportunities.

## VI. LESSONS LEARNED

The conclusions and lessons learned from the strengths and limitations of this project are applicable at several levels: the family support services, of UCPA, other family support service, and finally, pilot projects in general as vehicles for public policy research and activism. They generate the following recommendations:

### Recommendations for Family Support

#### *Training*

- Training should be offered at times and places convenient to the trainees.
- Training needs to be offered in ways that take into account the cultural differences of trainees.
- Training for respite workers can be more specific to the children being cared for. Workers who will not be giving medications or attending to trachea tubes need much less information in these areas.
- Parents are an excellent source of information regarding their children and should play a major role in the training of their respite workers.

#### *Reliability of respite workers*

- Respite workers should report to work promptly and reliably.
- If workers cannot report as expected, they should notify both the family and their supervisor.
- Supervisors should follow-up on families who have a worker who cannot report to work.
- Families must not be left for months at a time with no respite. Every effort must be made to maintain services to families.

#### *Information on service options*

- Families must have clear access to information regarding the scope and variety of services and options that are available to them.
- Families must be provided with written materials regarding the operation of the project, and the options which are available to them. This must include specific examples of some of the more unusual types of support that are available.

- Families must also be given detailed verbal explanations of the material that they are given in writing.
- Agencies must accept the obligation of offering options to families. Agencies should even take on the responsibility of teaching families how to survive in a system that may be inherently unfair to them.

### *Empowerment*

- Policies should not be set based on the "lowest common denominator" policies must more accurately reflect the value of empowerment for families.
- Specifically, many families could be trusted with cash, would be more empowered by direct access to cash, and would be better served in the long run.

### *Time limited pilot projects*

- The DDPC should require that pilots involving direct, needed services to families (or others) should allocate some proposed funds toward obtaining continued funding for the services or otherwise providing for the adequate transition of families at the pilot's end, so that its ending is not experienced as a difficult loss.



## **INTERVIEW PROTOCOLS AND CONSENT FORM**

**PENNSYLVANIA FAMILY SUPPORT PILOT EVALUATION  
PROJECT**

***PARENT ADVISORY COUNCIL INTERVIEW PROTOCOL***

- 1) How were you invited to participate on the PAC?
- 2) What was your initial understanding/expectation of the role and function of the PAC?
- 3) What was your personal experience of belonging on a PAC?
- 4) Describe what the PAC did while you were a member.
- 5) Were your initial understandings/expectations of serving on a PAC confirmed?
- 6) If you are a parent who also received services from the program, did being on the PAC positively or negatively effect your experience receiving services?
- 7) How did the PAC function:
  - Frequency and location of meetings?
  - How were meetings conducted?
  - How were decisions reached?
  - Any special efforts to involve or include parents on the PAC? e.g., child care or transportation provided?
- 8) How did the PAC relate to the actual ongoing administration of the program? How was communication conducted between the PAC and the program?
- 9) What were the achievements of the PAC?
- 10) Do you recommend continued use of PAC in family support programs? If so, would you change to improve the functioning or the role of PAC's in family support programs?

11) Did your experience on the PAC effect of change your attitudes or ideas about:

families with children with disabilities?  
the service delivery system?  
how our laws or regulations impact families?

**EVALUATION OF THE PENNSYLVANIA DEVELOPMENTAL  
DISABILITIES PLANNING COUNCIL FAMILY SUPPORT PILOT  
PROGRAMS**

***FAMILY INTERVIEW PROTOCOL***

**TOPIC: INTRODUCTION**

- Describe your role, the purpose of the study, who pays for it, how results will be reported. Review conditions of the informed consent namely their right to refuse to answer any question. Estimate length of interview, discuss disbursement of family participation fee. Encourage family member to talk freely, to add things that come to mind.

Obtain information about family composition, nature of child's disability, nature of caretaking difficulties.

**TOPIC: SERVICES RECEIVED**

How did you find out about the program?

How did you apply for the program?

What made you decide to apply?

What did you have to do to become eligible for the program?

What was that process like? Were staff helpful in applying?

How helpful were the staff in getting you started in the program?

Did you have an opportunity to explain the ways that you could use help from the program?

Did you have any say over the kinds of services offered or the way in which they were delivered? If so, how?

What services did(do) you receive from the program?

What did you have to do to get services?

Were the services that were offered what you needed?

Were the services that were offered what you requested?

Did the services help you? Your child? How?

Any problems with the services received? How could they be improved?

Did the program help you to obtain other services that were already available elsewhere? Describe.

Did the program help you in other ways?

#### **TOPIC: INTERACTION WITH PROGRAM**

Describe the attitude of the workers or staff of the program towards you and your family.

Was the attitude any different from those that you usually encounter in agencies? If so, how?

Did you have any differences with the staff? If so, how were they resolved?

Did the program involve you in making decisions about how they could best help you? If so, how?

Did the program involve you in making decisions about how the program should run overall? If so, how?

**TOPIC: OUTCOME**

What has been the result for you of being in the program?

Did the program help you to express your and your family's needs to other agencies or persons?

What were your expectations of the program? Did the program meet your expectations?

Are there other ways that the program was or was not helpful?

What parts of the program helped the most?

What parts of the program helped the least?

Do you feel different in any way since being served by the program? If so, how

Did the program have any effect on how you are able to care for your child with a disability on a short term basis?

Any longer term or permanent change on you or on how you are able to care for your child?

What problems do you have in caring for your child with a disability that the program did not help with?

Did the program have any effect on your decision to return your child from out-of-home placement. (If appropriate)

Did the program have any effect on your decision to care for your child at home?

Did the program help to prevent you from placing your child out of the home? How?

Did the program have any effect on how your other children, family or friends feel about your child with a disability?

Would the program be helpful to other families with children with disabilities? Why?

Are there other recommendations that you would make to change or improve the program.

**EVALUATION OF THE PENNSYLVANIA DEVELOPMENTAL  
DISABILITIES PLANNING COUNCIL FAMILY SUPPORT  
PROGRAMS**

***PILOT PROGRAM STAFF INTERVIEW PROTOCOL***

**TOPIC: HISTORY OF THE PROGRAM (For administrators)**

What were the initially stated formal goals of the program?

What was the staff's understanding of the DDPC objectives of the program? (Probe for staff understandings of family-centered, family empowerment, family driven programs)

How did the program goals and the DDPC goals differ or coincide?

What was the evolution of the program services?

Did the goals of the program change over time? If so, why?

Did the program services change over time? How?

What was the experience of the staff over the course of the project?

Did staff attitudes undergo any changes?

Did staff behavior undergo any changes?

Describe any changes in agency policy and/or staff practice as a results of this project.

**TOPIC: PROGRAM PRACTICES (Ask staff for examples using actual case histories without naming the families)**

How were families identified?

How and on what basis were they determined to be eligible?



How were families needs determined?

What services were offered by the agency? (frequency, duration)

What services did the program succeed in connecting families to? How?

How was the concept "family empowerment" implemented? Was this successful, how?

To what extent were services "individualized", did service vary according to individual family need?

How did the program respond to unique or unusual family needs?

#### **TOPIC: ROLE OF FAMILIES**

What was the family's role in determining what services were given, the agency's role?

What was the family's role in the overall operation of the program?

#### **TOPIC: FAMILY AGENT (CASE MANAGER) ROLE**

What were typical duties of program staff?

What is the background, training and payscale of the family agents?

How often and on what basis did they contact families?

What were their responsibilities?

#### **TOPIC: DEMOGRAPHICS**

How many families were served?

What were the ranges of socioeconomic status of the families, races, typical composition, nature and extent of disabilities in family members?

Obtain information on typical service utilization patterns and costs.

**TOPIC: IMPACT OF PARENT ADVISORY COUNCIL**

How was the Council formed?

Describe the composition of the Council.

Describe their role in program design and implementation.

How often did they meet, under what circumstances?

Describe the interaction between the Council and the program staff.

Did the parents who comprised the Council share the philosophical goals of the program and the DDPC? How or how not?

Did the parents' attitudes undergo any changes?

**TOPIC: THE CASH COMPONENT:**

How was the cash component administered?

What were typical expenditure patterns?

To what extent did families control expenditures?

How were any legal/administrative difficulties handled? (taxes, benefits)

Were any milestones achieved in having the cash payments disregarded as income for purposes of taxation or other entitlements?

What was the families response to the cash component?

What was staff experience in administering the cash component?

**TOPIC: HOW DO STAFF EVALUATE THE PROGRAM? (Obtain concrete case examples)**

What was the impact of the program on families? Obtain examples.

Did the services offered influence a family's decision to keep a child at home, or return a child to home? How?

Did the services impact how well the family was able to care for the child? Obtain examples.

Were there any out of home placements among the families served over the course of the project? If so, why?

What are the continuing needs of families that future programs should address?

What is their experience and evaluation of the success of "family empowerment".

What is their experience and evaluation of the success of "family centered" programs.

What was the impact of the program on the staff? On the service environment?

How do they perceive family satisfaction with program services?

What were the biggest problems encountered by the program?

What were the most successful aspects of the program?

What parts of the program would you do differently, how?

## PERMISSION TO CONDUCT INTERVIEWS AND DISCUSS CASE HISTORIES

The Pennsylvania Developmental Disabilities Planning Council which funds the family empowerment pilot program of the Philadelphia Society for Services to Children has contracted the Human Services Research Institute (HSRI) to evaluate the results of this program. To conduct this evaluation HSRI is interviewing a sample of families and will be discussing the history of services of the selected families with program staff. The interviews will focus on the family's experience with the program. The information acquired during the interviews will be used to develop a report for the Council on the results of four family support programs.

When you sign this form you give specific permission for the following:

- o Program staff may give us (HSRI) your name and telephone number;
- o We may contact you to make arrangements for an in-person or telephone interview;
- o We may interview you and other family members if requested for the purpose of the evaluation.
- o Program staff may share information about the history of services to your family with us.

I give permission as described above with the following understandings:

1. All information that I or any member of my family provides will be kept strictly confidential. No one outside of the project will be able to identify me or any member of my family.
2. All information collected for this evaluation will be compiled and reported in a form that will make it impossible for any reader to identify the source of the information being discussed.
3. During the interview I or any member of my family can refuse to answer any of the questions we are asked.
4. I or any member of my family can withdraw from any further participation at any time.
5. Results of the evaluation will be eventually prepared as a report to the Council which will be disseminated widely throughout Pennsylvania.
6. Permission for the above activities is granted for the period of January to December 1990 and for purposes of the project evaluation only.
7. I will receive a \$20 payment for participating in the family interviews.

**I have reviewed this consent form and I give permission for the activities described above with the outlined understandings.**

\_\_\_\_\_  
Signature of Family Member                      Date

\_\_\_\_\_  
Signature of HSRI representative              Date

If you have questions about this form please call your program or call Marsha Ellison at HSRI (617) 876-0426.