DOCUMENT RESUME

ED 228 808 EC 151 665

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TITLE	Demonstrating Model Continua of Respite Care and Parent Training Services for Families of Persons with Developmental Disabilities. Final Report.
INSTITUTION	City Univ. of New York, N.Y. Center for Advanced Study in Education.
SPONS AGENCY	Office of Human Development Services (DHHS), Washington, D.C.
REPORT NO	CASE-24-80
PUB DATE	Dec 80
GRANT	DHHS-54-P-71303
NOTE	165p.; This project was also a cooperative endeavor with the United Cerebral Palsy Associations, Inc. (Northeastern Maine, Central Maryland, Philadelphia and Vicinity) and Retarded Infants Services.
PUB TYPE	Reference Materials - Bibliographies (131) -- Reports - Evaluative/Feasibility (142) -- Tests/Evaluation Instruments (160)
EDRS PRICE	MF01/PC07 Plus Postage.
DESCRIPTORS	College Students; Databases; Demonstration Programs; *Developmental Disabilities; *Family Life; Human Services; Information Dissemination; *Intervention; *Parent Workshops; Postsecondary Education; *Program Development; Program Effectiveness; *Respite Care; Self Care Skills; Use Studies
IDENTIFIERS	City University of New York; United Cerebral Palsy Association

ABSTRACT

A report of a project that established systems of respite care and training of parents who have developmentally disabled members in their home is presented. Attention is directed to project objectives, activities, and outcomes and to the following specific components: collection and analysis of data on factors promoting utilization and effectiveness of respite care services, technical assistance and information dissemination, and the development of university based models for parent training. The project involved the collaboration of the City University of New York and the United Cerebral Palsy Associations, Inc., as well as demonstration programs in Central Maryland, Northeastern Maine, and Philadelphia. Outcome data are presented on services used by survey respondents and their effect on family functioning, and the effectiveness of respite care workers. Additionally, parent training models are summarized, and evaluation data are provided for workshops on communication, behavior management, motor development, and feeding skills. Additional materials include: student comments on their attitudes and skills in working with parents, a family questionnaire, parent interview questions, a respite care worker questionnaire, information on workshops, lists of nine references for professionals, a list of eight references for parents and six audiovisual training materials, and a list of 19 parent training/support programs. (SEW)

Final Report

DEMONSTRATI'G MODEL CONTINUA OF RESPITE CARE AND PARENT TRAINING SERVICES FOR FAMILIES OF PERSONS WITH DEVELOPMENTAL DISABILITIES

A Project of National Significance
funded by the
Bureau of Developmental Disabilities
Office of Human Development Services
Department of Health and Human Services
Grant # 54-P-71303

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December, 1980

Acknowledgements

This project represents a cooperative endeavor between the Special Education Development Center of City University of New York and United Cerebral Palsy Associations, Inc. We wish to express our appreciation to the four direct service agencies which worked with us on this project. They are: United Cerebral Palsy of Northeastern Maine; United Cerebral Palsy of Central Maryland; United Cerebral Palsy of Philadelphia and Vicinity; and Retarded Infants Services.

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I. INTRODUCTION

A. Background and Statement of the Problem

The 1970s gave witness to a major change in the philosophical base of services to the developmentally disabled. The principle of normalization came to be accepted as a guideline and goal. Normalization refers to:

> Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible (Wolfensberger, 1972, p. 28).

Institutionalization is a non-normative means of providing human services and it is awesome in scope.

> Two million people live in institutions. There are no estimates available on annual public maintenance expenditures, but we suspect this cost easily exceeds $10 billion. According to data gathered by the U.S. Census Bureau (1963, 1973) the institutionalized population was about 1% of the entire U.S. population for 1960 and also for 1970 (Braddock, 1977, p.8).

In 1971 the President of the United States announced a national goal of reintegrating one-half of the 200,000 residents of institutions for persons with mental retardation into the community. During the nine years since that announcement federal, state and local governments have been moving toward the implementation of deinstitutionalization policies, prodded on by court decisions, advocacy group actions, and large scale exposes of institutional conditions. While the pace of deinstitutionalization efforts has been considered too slow by many advocate groups, an even stronger cry which is being heard today relates to the inadequacy of alternate community support systems. One of these alternate systems which is in dire need of further development and expansion is respite care.

The case for respite care is exquisitely made by the anonymous Westchester father who wrote the <u>New York Times</u> piece quoted below.

> Don't be too hard on Robert T. Rowe, the Brooklynite who is accused of killing his wife and three children with a baseball bat, perhaps because of the struggle involved in helping to rear one child who was blind, deaf and mute since birth 12 years ago.

> As a father of a 10½ year-old daughter, severely brain damaged from birth, I can understand how easy it is to commit such a horrible act...It doesn't take much additional stress to commit such an act when a person is under constant stress and fatigue from trying to care for a severely handicapped child, and is drained of all energy and resources.
>
> If I said to the state, "Take her, she's yours," it would cost the taxpayers $50,000 per year to put her in an institution. I don't want $50,000 or even $5,000. I would be satisfied just to get the part-time homemaker back so the wife and children can get out for a few hours (A Father, New York Times, March 28, 1978).

> Edward F. Zigler, the Yale psychologist, speaking about the Robert Rowe case...said..."There will be more cases like Rowe so long as we disdain to help such families. They need to be able to send their children to a home for a few days at a time just to get a break, and they need people to come into their own home, to play with the children and relieve the stress" (Ibid).

While only a tiny fraction of the families of severely impaired children reach the point where physical destruction results, the psychological and physical stress experienced by such families is enormous. If the deinstitutionalization movement is to succeed, it must provide for a system of family supports with respite care at its core.

The concept of respite care came into focus in the mid 70s. The impetus for this focus was the deinstitutionalization movement. More and more families of developmentally disabled individuals, rather than being advised to institutionalize their children, were urged to keep them home. Families which wanted to place their children out-of-home, often found that there were no places available. Many families which had placed their children years earlier, were told to take their now grown-up or nearly grown-up children home. Some of these families were not able to cope with the awesome responsibility of caring for a developmentally disabled individual day after day. A cry went up for expansion of community support systems. One of these community support systems is respite care. This service is not only in dire need of further expansion, but is also in dire need of a hard data-base from which to plan and guide its expansion.

> Respite care is only now being recognized as a type of service in many states. It is so new a concept that there is a great deal of variety in program models, lack of understanding as to whether

> and where it should fit into a spectrum of community-based services, and lack of recognition at the policy levels of states as to the need or desirability for guidelines and regulations. Even in those states where some sort of policy has been implemented, there has not been adequate time to see what the effect has been on the development of respite care (Provider's Management Incorporated, 1978, p. 12).

What is respite care? While there are variations in the operational aspects of the definition from agency to agency, the core of the definition of respite care is a system of temporary support(s) for families of developmentally disabled individuals, which provides the family with relief. Temporary may mean anything from an hour to three months. It may also mean periodically on a regular basis. It may be used for family emergencies, vacations and other planned activities, or relief from the day-to-day responsibility and strain of caring for a severely disabled individual. It can be provided in the client's home or in a variety of out-of-home settings.

Whatever the means used to provide respite care, the goal is always the same, namely to maximize the normalization possibilities for the developmentally disabled individual. Toward this end several basic assumptions are made:

-That normalization can usually best be achieved when the developmentally disabled individual is maintained in his/her home settings.

-That long term ongoing care of the developmentally disabled individual places an extraordinary burden on the family.

-That if families are to maintain their viability and soundness in the face of the extraordinary responsibility of caring for a developmentally disabled individual, they must be provided with a variety of supports, including respite care services.

The Center for the Development of Community Alternative Service Systems (CASS) of the University of Nebraska has delineated eight components of repite service systems: core residential programs and temporary foster care; homemaker/home health aide, visiting nurse and county/cooperative extension services; generic agency development, funding/supports, and legislation; temporary day care, companion and sitter services; personal self-advocacy and parent support groups; information referral, counseling, transportation, recreation and employment services; training of the family and the developmentally disabled person; and training of personnel to work with the family (Center for the Development of Community Alternative Service Systems, undated). While all eight components delineated above may be seen as critical to the creation and maintainance of a respite care system, it also appears important to differentiate those components which provide the family with immediate, direct relief from the care of the developmentally disabled individual, with those components that provide family relief from a long-range point of view. Many agencies currently providing respite care services make this differentiation, as do families seeking or receiving respite care. Thus, two levels of respite care system components may be conceptualized, with one level being direct respite care services and the other being programs essential to the effective functioning of respite care systems. Of the eight components identified by CASS, direct respite care services are: core residential programs and temporary foster care; homemaker/home health aide services; temporary day care, companion and sitter services.

Two services not specifically referred to in the CASS model are school and camp. The Education for All Handicapped Children Act of 1975 and The Rehabilitation Act of 1973, both of which embody a zero reject model for educational services, have provided many families of developmentally disabled children with extensive relief. Families which had been responsible for the care of severely disabled children 24 hours a day, 7 days a week, now found themselves relieved of this responsibility for 4 to 6 hours a day, 5 days a week. While the major focus of these laws is the handicapped individual, one of their extremely valuable side-effects is the respite that is provided to families while the handicapped child is in an educational program. Unfortunately, federal law does not mandate education for handicapped children from birth. Education is mandatory for 3 to 5 year olds only if consistent with state law and practice. Otherwise, it is not mandated until age 6. For some families, even three years without respite from the burden of caring for a severely disabled child is too much. The provision of educational programs for severely disabled infants, toddlers and preschoolers is therefore not only highly desirable from the point of view of the child's development, but is also an invaluable tool for preventing institutionalization and family breakdown. Currently only 13 states are mandated to provide full educational programming to handicapped children in the 3 to 5 year old range (Cohen, Semmes and Guralnick, 1979, p. 281). Thus, the 0-5 age range constitutes a period when the need for respite services is urgent. Infant and preschool program development may be seen as one method of providing families of young children with respite care.

Unfortunately, too, from a family point of view, the Education for All Handicapped Children Act of '75 does not mandate 12 months a year of educational programming for all handicapped children. Most developmentally disabled children are in school for ten months a year, as are other children. But while the two summer months are usually a time of fun and relaxation for nondisabled children and their families, the reverse is quite often true for famlies of developmentally disabled children. Without the relief provided by school; with many usual summertime activities unfeasible for reasons of transportation, health, or public attitudes; the two summer months may be intolerable. Camp, whether day camp or sleep-away, is an age appropriate, normalizing experience for school age children with developmental disabilities. It should be recognized as a valuable respite service, even though its major purpose is to provide the child with a good summer recreation program.

Perhaps the most critical need, in the area of respite care services, after improved legislative and fiscal support, is that of quality control. With the deinstitutionalization movement resulting in a drastic reduction of placement possibilties for families of developmentally disabled children, many families were overwhelmed. In the face of urgent need, respite care programs have begun burgeoning. Standards and systems for monitoring these burgeoning programs have not yet been established. Training for respite care workers varies greatly in quality and quantity. Ongoing supervision is sometimes minimal.

Attention to quality control brings into focus the whole question of the responsibilities and skills of respite care workers. In some agencies respite care workers are essentially conceived of as sitter/companions. In other agencies, respite care workers are expected to provide skilled child care while serving as models for parents. There may well be a need for both of these models. The problem is to find a systematic method for assuring that families where skilled child care is essential are matched to skilled child care workers rather than to sitters, while the more economical sitter/companion service is provided for those clients and families where skilled child care and a teaching model are not essential. Today families often receive one or another of these types of aid because the particular agency contacted only offers one of these types of service and does not sufficiently attend to the differential skill levels required. If respite care is to realize its potential as an extremely important family support service, quality controls must be built into these programs soon.

Respite care is recognized as a priority in only a few states, although it is part of one of the four priority areas identified in P.L. 95-602, The Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978. Given the fragmented nature of respite care services and their generally low status in service provision, there is a definite need for analysis, advocacy and dissemination on this subject at a national, state and local level.

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Provider's Management Incorporated. Summary of the Final Report of the Respite Care Policy Development Project. Boston: Respite Care Project, Provider's Management, Inc., October 1978.

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B. Goals and Objectives

The overall goal of this project was to demonstrate the effectiveness of flexible systems of respite care and parent training services in increasing the capabilities of families to cope with their developmentally disabled members in the home, thereby decreasing the likelihood of out-of-home placement, and enhancing prospects for successful deinstitutionalization. The major objectives of this project were:

1. To identify factors which increase the effectiveness of respite care and parent training services.
2. To demonstrate how a continuum of respite care services can be enhanced in both rural and urban settings through technical assistance.
3. To develop a university based training program for families with developmentally disabled members, as one component of a family support system.
4. To disseminate the findings, results and products of this project.

C. Results and Benefits Expected

1. A data base from which to plan more effective systems of respite care and parent training services

At the time this project was instituted little information was available about designing effective continua of respite care services. The planning of respite care programs was based on clinical impressions by agencies serving developmentally disabled individuals and their families. This project set out to collect a sizeable body of data which would shed light on such questions as:

.1 What kinds of families use respite care services?

.2 What family needs do respite care programs fulfill?

.3 How is family functioning affected by the use of respite care services?

.4 What is the relationship between use of respite care services and likelihood of long-term out-of-home placement?

.5 What factors are associated with family satisfaction with respite care services?

.6 What aspects of respite care services would families like to see improved?

2. A demonstrated model of technical assistance as a means of enhancing respite care and parent training services

Technical assistance will be demonstrated as an effective method of improving respite care and parent training services. Components of the technical assistance will include:

.1 Development of a model of a community organization approach to respite care services in a rural area.

.2 Development of a model of a direct service respite care approach in an urban area.

.3 Technical Assistance guidelines.

.4 An analysis paper on the funding of respite care programs.

.5 An initial set of systems advocacy strategies for facilitating respite care services.

3. Model university based training programs for parents of developmentally disabled children

Parent training is a sorely needed component of family support systems. Yet few attempts have been made to turn the skills of university personnel and students to the task of training parents of the developmentally disabled. This project set out to identify appropriate models of university based parent training, and to develop guidelines for the design and implementation of these programs.

4. Dissemination of findings

The findings, results and products of this project will be or have been disseminated as follows:

.1 A presentation at the 1980 AAMD conference.

.2 A presentation at the National Conference on Developmental Disabilities in Washington, D.C. in April 1980.

.3 Four regional conferences at project sites, two at the end of the first year of the project and two at the end of the second year of the project.

.4 Mailings of project products -- reports, papers, and technical assistance guidelines -- to participants at conferences at which presentations of respite care are made, to UCP affiliates, and to representatives of national organizations representing the developmentally disabled.

.5 Preparation of papers for submission to professional journals.

II. METHODOLOGY

One of the unique features of this project was the collaboration of a university - City University of New York - and a direct service agency - United Cerebral Palsy Associations, Inc. The activities involved in this project can be grouped into three major strategies: (1) Collection and analysis of data on factors which make for utilization and effectiveness of respite care services. (2) The enhancement of respite care services through technical assistance. (3) The development of university-based models for training parents of developmentally disabled individuals. The Special Education Development Center of City University of New York had primary responsibility for strategies 1 and 3, with U.C.P.A. providing input and assistance on the implementation of these strategies. U.C.P.A., Inc. had major responsibility for implementing strategy #2, with input and assistance from C.U.N.Y. staff. During Year II of the project the staffs of the two agencies worked as one team.

Four direct service agencies participated in this project. During Year I the cooperating agencies were: U.C.P.A. of Central Maryland, U.C.P.A. of Northeastern Maine, and Retarded Infants Services (N.Y.C.). During Year II of the project the cooperating agencies were U.C.P.A. of Northeastern Maine and U.C.P.A. of Philadelphia and Vicinity. Agencies were selected to represent rural and urban environments, as well as different socio-economic groups and geographic areas.

During Year I an advisory panel meeting was held in the fall and an implementation meeting in January. During Year II an advisory panel meeting was held in February. The advisory panel members are listed below:

Advisory Panel - Year I

Maine

Ruth Shook, Director
UCP of Northeastern Maine

Carolyn Garner, Parent
UCP of Northeastern Maine

Maryland

Michael Carbone, Director of New Projects
UCP of Central Maryland

Janis Ellis, Parent
UCP of Central Maryland

Philip Holmes, Director
Developmental Disabilities Council of Maryland

New York City

Rita Rosenstein, Director of Social Services
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Julia Futrell, Parent
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Ernest Weinrich, Director
Professional Services Department

Rachel Warren, Project Coordinator
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Leon Sternfeld
Medical Director

Advisory Panel, Year I:

Additional Panelists

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Developmental Disabilities Council of NYS
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John W. Conti, Director
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William Jones, Director
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Marty Thornton
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The Special Education Development Center

Shirley Cohen
Nancy Koehler
Carole Grand

A. Strategy #1: Establishing a Data Base on Respite Care

Year I Sample: Data was collected from 215 families. This sample was obtained by contacting families from the three cooperating agencies who were currently using family support services, had used them within the past three years, or had inquired about services during the past year. The breakdown of families contacted, families which signed consent forms, families which returned questionnaires, and families included in the final sample is given in Table I on the following page. It should be noted that questionnaires returned by some families had to be discarded because too many questions had gone unanswered, and that a large number of families from Retarded Infants Services were either Spanish language dominant or were headed by persons with limited educational backgrounds. This was also true of some families from UCP of Central Maryland.

Year I Instruments: Several instruments for data collection were devised by project staff in consultation with the project advisory panel, after examination of the relevant literature. These instruments were as follows:

(1) Family Characteristics Form--designed to elicit demographic information such as parental educational levels, occupations, income, type of housing, family composition, family support systems and nature of the developmentally disabled family member's impairment.

(2) Service Utilization Sheet--designed to elicit data on the number, amount and type of agency services, within the respite care continuum, were used.

(3) Service Satisfaction Form--designed to elicit parental feelings about the quality of services provided.

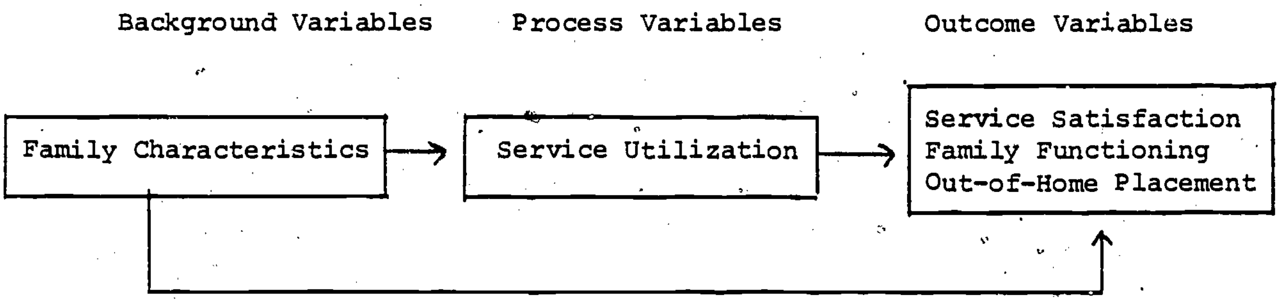
(4) Family Functioning Form--designed to elicit changes in family functioning since respite care services were initiated. This questionnaire focuses on family coping and quality of family life. The reliability of the Family Functioning Form was assessed for clients at each agency using the Kuder-Richardson formula. The resulting reliabilities were .98 for Maryland; .85 for Maine; and .84 for New York City.

Table I

Families Contacted and Sample Used in Strategy #1

Agency	Consent forms mailed	Consent forms returned	Questionnaires returned	Final sample
UCP of Northeaster Maine	215	74	61	47
UCP of Central Maryland	487	171	136	125
Retarded Infants Service	320	71	49	43
TOTAL	1,022	316	246	215

Year I Data Analysis Model: The model underlying the analysis of respite care service effectiveness is produced graphically below:



Thus family background variables were to be related to level and type of services used and to outcome variables. Service utilization was to be examined in terms of outcome variables. Correlational techniques and analysis of variance were used to compare relationships between variables, both within agencies and across agencies.

Procedure: All questionnaires were coded by agency personnel to insure confidentiality. Agency personnel completed the Service Utilization Sheets and, where necessary, helped complete the Family Characteristics Form. Service Satisfaction Forms and Family Functioning Forms were mailed by the agencies to the home, and returned directly to City University of New York. New York City families were offered help from City University personnel, including a bilingual person, in completing forms.

Obstacles Encountered During Year I: The major obstacle encountered in implementing this strategy was in formulating a "non-user" comparison group. The original plan called for a comparison of families using respite care services with a group of families not using these services, with important variables matched or controlled. Each agency kept a list of information and referral requests. It was planned that the comparison group would be formed from families on this list who had not gone on to use agency services. Unfortunately, this was not possible because very few of these families who had not gone on to use the services of the agency agreed to participate in the study. For example, whereas well over 100 such families culled from a list at Retarded Infants Services were contacted, only two completed the data collection forms. The final group of "non-users" consisted of only 33 families. Furthermore, when the protocols of these families were examined, it was found that only 13 of them were not using any services on the respite care continuum. The other 20 families were receiving these services from agencies other than those involved in the study. While comparisons were run between this group of 13 non-users and the user groups, the sample size was too small to be truly effective. Because of the absence of a non-user group, a comparison of users of different types of services was the major mode of analysis instituted.

Another limitation of the data was in the underrepresentation of families with low educational levels, and Black and Puerto Rican families. Thus while Retarded Infant Services serves a sizeable population of Black and Puerto Rican families, the questionnaires returned were largely from White families with relatively high educational achievements. This underrepresentation is undoubtedly in part a result of using written questionnaires.

Year II

During the second year of the project the strategy of examining relationships between family characteristics, service utilization, and family functioning was continued, with several changes designed to permit a more in-depth exploration of variables. However, a new research strategy was also added during Year II. This was an examination of the characteristics which make for effectiveness in respite care workers. This latter study will be reported separately at the end of this section under the heading "Respite Care Worker Effectiveness."

Year II Sample: The Year II sample consisted of 142 families as shown in Table 2 on the following page. All of the families were connected with one agency, United Cerebral Palsy of Philadelphia and Vicinity. The type of respite care provided by this agency was out-of-home placement in apartments designed for respite care use only. Respite care was provided for periods of up to two weeks at a time, with a maximum of 45 days per year allowed. (Of the 107 families interviewed who had used the respite care service only 3 had used the in-home service initiated as part of this project.) The UCP respite care program had been in operation for about 1½ years at the time the data collection began. From Table 2 it can also be seen that a control group of nonusers of respite care was obtained. The nonusers were families where the client participated in the adult care program of UCP or in the UCP preschool program.

Year II Instruments: During the second year of the project structured interviews based on a streamlined version of the Year I forms were substituted for written questionnaires. Interviews avoided the sample bias which resulted from the poor response on the part of low SES families to written questionnaires. The interview schedule contained all of the Year I items which related to outcome variables. Some additional items were added to further probe the effects of respite care utilization upon outcome variables. The Year II interview schedule is included in Appendix B.

Year II Data Analysis Model: The same data analysis model was used in Year II as was used in Year I, with family characteristics representing background variables, respite care utilization representing process variables, and satisfaction with services, changes in family functioning and likelihood of long term placement serving as outcome variables.

TABLE 2

Client Age	Respite Care Users	Nonusers	Complete Sample
0 - 5	28	9	37
6 - 17	36	0	36
18 +	43	26	69
TOTALS	107	35	142

Year II Procedure: An attempt was made to conduct the interviews face - to-face. When it bcame obvious that it would be impossible to interview 140 families in this way without greatly exceeding the time and financial boundaries of this project, telephone interviews were substituted. Approximately one-third of the sample was interviewed in person, while the remainder of the families were interviewed by telephone. Interviews were conducted by a team composed of two project staff members and three graduate special education students who had been trained in working with parents.

Factor analytic procedures were used to identify the main dimensions of the background variables, service utilization variables, and outcome measures. After these factors were extracted, the single item which best measured each factor was subjected to the following statistical tests:

1. Pearson correlation coefficients (for variables on a metric scale).
2. F - Tests or t - tests (when one variable was metric and the other was categorical).
3. Chi square procedures (for variables that were categorical).

Obstacles Encountered in Year II: The main obstacle encountered during Year II was the difficulty in arranging face-to-face interviews with parents. An attempt to get parents to come to the UCP center for interviews resulted in some parents not agreeing to come, some parents agreeing but not getting there, and some parents coming late. Next an attempt was made to go to the homes. This proved very costly in both time and travel expenses. Telephone interviews were finally decided upon as the only feasible method of reaching many families.

Respite Care Worker Effectiveness

During Year I of this project parents reported two ways of improving respite care services. One of these was to improve the skills of respite care workers. In light of this finding and the fact that the respite care worker is the crux of the program, it was decided to explore what characteristics are associated with effectiveness as a respite care worker.

Sample (Workers): One hundred seventy six respite care workers representing seven large respite care programs participated in this study. The agencies were selected to reflect the diversity of respite care programs. Thus, one of the programs was directed by a religious organization, one was a private, profit-making organization, one was a volunteer program. These agencies also represented in-home and out-of-home programs and homemaker services. The data analysis was carried out separately for an eighth agency which represented medically oriented home-health aides. The total sample is depicted in Table 3.

Instruments (Workers): A questionnaire an a behavioral rating scale were devised, both based on references in the literature and ideas solicited from respite care program directors about what variables are relevant to the effectiveness of respite care workers. The questionnaire was constructed to collect information about background variables from respite care workers, and

TABLE 3

AGENCY	NUMBER OF WORKERS IN SAMPLE
San Francisco Association for Retarded Citizens	40
UCP of Central Maryland	43
The Human Services Center (Wisconsin)	21
Home Service Association (Minnesota)	17
Archdiocese of Denver	25
UCP of Philadelphia and Vicinity	12
Upjohn Health Care Service (New York City)	18
TOTAL	176
Visiting Nurse Association of Dallas	72

to assess their perceptions of what behavioral traits are important to their job performance. The behavioral rating scale was constructed for use by respite care program supervisors in evaluating respite care workers. Both of these intruments are included in Appendix B.

Procedure (Workers): Questionnaires were sent to the agencies listed in Table 3 and were filled out by respite care workers. Respite care supervisors were then asked to rate each of the responding workers as "Outstanding," "Average," or "Below Average" (absolute rating). Supervisors were also asked to identify those who were in the top 15% of the respondents, and those workers who were in the bottom 15% of the respondents (relative rating). They were then asked to complete a behavioral rating form for each of the workers identified as falling into the top and bottom 15% of the sample.

The data was subjected to factor analysis to determine the major dimensions of the variables involved. The one item in each cluster which best represented that factor was used in ensuing analyses.

B. Strategy #2: Technical Assistance

Strategy #2 focused on the demonstration of a technical assistance model as a means of enhancing respite care programs. In carrying out this strategy two sites were employed during Year I: UCP of Northeastern Maine and UCP of Central Maryland. During Year II UCP of Northeastern Maine was retained as the rural site, while UCP of Philadelphia became the urban site. The rural site was used to demonstrate technical assistance for a community organization approach to respite care, with direct services accessed through other community agencies. The urban sites were used to demonstrate technical assistance for a direct service model.

The major techniques used in the technical assistance strategies were:

1. A survey and assessment of services within the respite care continuum provided either by the UCP affiliate or by other agencies in the community.

2. Individual Affiliate Plans drawn up after the community survey. (See Appendix C for Individual Affiliate Plan form.)

3. Periodic site visits to monitor the implementation of the Individual Affiliate Plan, advance it or modify it as needed.

Eight site visits were made to UCP of Northeastern Maine, four to UCP of Central Maryland, and five to UCP of Philadelphia and Vicinity. Community conferences on respite care were held in both Maryland and Maine at the end of Year I. Regional Technical Assistance Conferences were held in both Philadelphoa and Maine at the end of Year II. (See Appendix C for conference agenda.)

The Director of the UCPA Governmental Activities Office, worked in consultation with project staff to develop an analysis paper on respite care service financing.

The technical assistance strategy was implemented by UCPA, Inc. staff during Year I. However, during Year II the staffs of UCPA and CUNY worked together as one team, with parent training being treated as one objective of the technical assistance.

C. Strategy # 3: Parent Training

Parent training was treated in this project as one form of family support important in complementing respite care services. The focus of this strategy was university based parent training.

The first step taken in planning this strategy was a search of the available literature for models of university based parent training. During Year I two approaches were selected for implementation: workshops designed and implemented specifically for parents from one of the cooperating agencies (Retarded Infants Services) by the project staff from CUNY; involvement of graduate level special education students in working in the home. A questionairre was sent to families serviced by Retarded Infants Services to identify the preferred content and format for the training workshops. (See Appendix D.) Five training sessions of 2½ hours each were planned for Saturdays during the spring of 1979. The topics offered were communication, behavior management, moror development, advocacy, and feeding. Special education students were involved at these sessions as baby sitters and participants. Twelve of these same special education students worked in the homes of families associated with Retarded Infants Services. Each team of two students was given the following assignments: observation of parent/child interaction; interviewing of a parent; observation of the home aide (respite care worker) if there was one; direct work with the child; development of a plan for aiding the child or training the parent. The students involved in this project were all taking a course entitled "Parent Involvement in the Education of Young Handicapped Children" at Hunter College. Each student kept a log of his/her experiences and turned in a written plan at the end of the experience.

During Year II a similar approach to student involvement was implemented at the Philadelphia site. This time graduate students from the Special Education Program at Temple University were involved. All of the students were taking a course which focused on work with parents. The instructor agreed to extend his training activities to include work with parents in the home. Since many of the parents indicated that behavior management was an area of concern, this was selected the focus of the students' work in the home. An initial meeting was held at the agency so that parents and students could get to know one another and pinpoint problems to be worked on. Eleven families and nineteen students participated in this experience, with students making a minimum of four visits to a home. Students were asked to keep logs of their experiences. Parents and students were asked to evaluate the experience via a questionnaire.

In Maine during Year II a series of six workshops was designed. Again behavior management was the focus since this was an area of concern to parents. This "parent course" was taught by two faculty members from Bangor Community College. Parents were taught the basic principles of behavior management. Specific practice activities were carried out at home between sessions, and were reported on at the next workshop session. Parents were asked to evaluate the workshop series as an aid to them.

III. FINDINGS

Strategy #1, Year I: Evaluation of Respite Care Services

Characteristics of the Respondents

Maryland: Approximately 3/4 of the sample was white, with almost 1/4 black. Family income was spread out from "under 6,500" to "over $25,000," with no area of particularly heavy concentration. Most parents were high school graduates with 25% of the mothers and 35% of the fathers being college graduates. A large majority of the clients were characterized by motor disabilities, speech impairments, cognitive impairments and impairments in activities of daily living.

Maine: Ninety-four percent of the responding families were white. Most of the sample had incomes under $18,000, with a third making less than $6,500 a year. Most of the parents were high school graduates.

New York City: Seventy percent of the respondents were white, with 19% being black and 11% Spanish. A majority of families had incomes under $12,000. Thirty-nine percent of the homes had single parents.

What Kind of Services Did the Families Use?

The service most used by responding families in Maryland was the OWAR II Respite Care Service (in-home = 43; out-of-home= 11). Sizable numbers of families used the Debrey Developmental Center (N=32), a preschool program, and Camp New Horizon (N=32), a two week summer day camp.

The only service used by a sizable number of families in Maine was the Infant Development Program (N=29).

In New York City both the Home Aide Program (N=36) and the Parent Counseling Program (N=34) were heavily used.

What are the family characteristics associated with use of different forms of respite care services?

In Maryland, use of the OWAR II respite care program was associated with families which had few people to call on for help with the client in times of special need. This finding was significant at the .01 level (f = 14.59) for in-home services, and at the .05 level (f = 4.19) for out-of-home services.

The use of in-home services in Maryland was also associated with small family size (f=6.77, $p < .05$); older parents (f=10.37, $p < .01$ for father's age; f=4.00, $p < .05$ for mother's age); and parents who have fewer people to turn to for communication about the client (f=5.35, $p < .05$).

The use of out-of-home respite care in Maine* was associated with families headed by foster parents (f=5.35, $p < .01$); with larger numbers of persons (f=11.65, $p < .01$); and the presence of other disabled persons in the home (f=8.59, $p < .01$).

The use of home aides in the New York City sample was associated with severity of client impairment (f=28.9, $p < .01$), and with mothers having 24 hour a day responsibility for the client's care (f=4.2, $p < .05$).

How Is Family Functioning Affected by Service Utilization?

In completing the Family Functioning Form parents were asked to indicate whether 18 types of behavioral processes had incresed, decreased or not changed since they had begun using the agency services included in this study. Responses were coded to indicate improvement, no change, or deterioration in family functioning. The first 16 items related to a family's general coping. The last two items dealt directly with the likelihood of long term placement. Using a weight of =1 for improvements in family functioning, -1 for deterioration in family functioning, and zero for no change, the null hypothesis of no change would be represented by a combined score of zero. Using a one-tailed t-test it was found that improvement in reported family functioning was highly significant - $t = 6.46$, $p < .005$.

Which Services Were Particularly Effective in Improving Family Functioning?

The relationship between improved family functioning and use of particular services was probed using chi square procedures. Since it was not possible to establish an adequate comparison group of families not using any services, the results pertain to the relative effectiveness of each service as compared to other services.

In Maryland, the preschool program studied was significantly more effective in improving family functioning than any other single service ($p < .01$), including the OWAR|| Respite Care Programs. In Maine no single service was found to be more effective than others. In New York City parent counseling was more associated with improved family functioning than either of the other services ($p < .05$). It should be noted that the preschool and infant programs in New York City and Maine involved only a few hours per week, whereas the preschool program in Maryland was a five day, thirty hour a week program.

* While these findings are statistically significant they are to be viewed with caution as they derive from a sample of six out-of-home respite care users.

Although the comparison group of nonusers contained only 13 families, an analysis of the absolute effectiveness of services was attempted using this group. The one service which proved significantly more effective than no service was the Maryland preschool program. This finding was parallel to the results of the earlier comparison of each service against other services.

What Was the Relationship between Use of Paricular Services and Likelihood of Long Term Out-of-Home Placement?

Questions 17 and 18 on the Family Functioning Form directly addressed the question of likelihood of long term out-of-home placement. When the scores on these two items were combined it was found that out-of-home respite care in Maryland was associated with a greater likelihood that parents would place their child in long term residential care than was any other single service ($p < .05$).

This finding of greater likelihood of residential placement by users of out-of-home respite care was repeated when users were examined in relation to the comparison group of non-users ($p. < 05$).

On a scale of 1 to 4, with 1= excellent, 2=good, 3=fair, and 4=poor, 19 of the 20 services included in this study were rated as better than 2.

The one aspect of respite care services with which families were least satisfied was the time allotment. Forty-one percent of the families using the Maryland in-home service reported that the time allotment for annual respite care service was inadequate. When asked for suggestions for improving the respite care service 62% of the Maryland respondents indicated that the service could be improved by increasing the time allotted per year. It should be noted that respite care services in Maryland were available for 10 days plus 30 hours per year.

Parents using the home-aide service in New York city made the same kinds of recommendations for improvement as did the parents using respite care services in Maryland. Thirty-six percent of the parents indicated that the program aspect most in need of improvement was the time allotment. Sixty-eight percent of the families indicated that the way to improve this service was to allot more time.

The other aspect of the respite care program in Maryland which was mentioned as in need of improvement was the quality of respite care workers. This was mentioned by 23% of the respondents. This was also the only other source of dissatisfaction with services mentioned by a significant number of families (21%) receiving home-aide services in New York City.

What Kinds of Families Now Using Respite Care Services Had Formerly Placed Their Children Out-of-Home on a Long Term Basis?

The sample in this study contained sixteen families that had at one time placed their children out-of-home on a long term basis. The protocols of these respondents were examined to see if they differed significantly from families using respite care that had never placed their child on a long term basis. The family characteristics, service utilization and family functioning of these two groups were compared using F tests when the data was continuous and chi-square tests when the data was categorical. The only significant difference found between these two groups is that both mothers and fathers in the group that had placed their children had higher educational levels.

Strategy #1, Year II: Evaluation of Respite Care Services

Who Were the Respondents?

The sample of Philadelphia families using respite care services was 52% white and 46% black. A large proportion of the parents were over 35 years of age. About half of the families were headed by single parents. Most of the parents were high school graduates, but about 34% of the mothers and 20% of the fathers for whom educational levels were indicated, had not completed high school. Twenty-one percent of the families had a second disabled individual in the home. The disabled clients' main disabilities were cerebral palsy and mental retardation, with large percentages of the clients having moderate to severe problems in speech, motoric ability, cognitive problems, self-care and behavior.

How Satisfied Were the Families with Respite Care Services?

The overall rating of respite care services by families was excellent. The figures are given in Table 4. Eighty-eight percent of the families planned to continue to use respite care and 89% said they would recommend the service to others.

What Aspects of Respite Care Did the Family Find Helpful?

When asked what aspect of the respite care service was most helpful, 41% of the families answered: Having the client out of the home.

TABLE 4

Satisfaction with Respite Care Services

RATING	FREQUENCY	%
Poor	2	1.9
Fair	6	5.6
Good	35	32.7
Excellent	63	58.9
No Response	1	

What Aspects of the Respite Care Service Would Families Like to See Improved?

Forty-four percent of the families indicated that they felt a need for more time. Seventeen percent of the families indicated that they felt staff skills needed improvement.

How Do Families View In-Home in Comparison to Out-of-Home Services?

The respite care available to the families in this sample was almost exclusively out-of-home placement. When these families were asked whether they would use in-home services should they become available 58% of the same indicated that they would.

How Did Respite Care Benefit the Family?

Fifty-nine percent of the families indicated that respite care services were most helpful in improving the parents' mental health and social relationships. Nineteen percent of the families indicated that the respite care services were most helpful for the client's social/mental development. When parents were asked how they made use of the time when their child was in respite care they answered: To meet medical needs, rest and recuperate - 58; to provide service to and improve relationships with other family members - 38; to engage in personal activities like going to the library or shopping - 25; to take a vacation - 23.

When parents were asked what would have happened if they had not been able to obtain respite care services, they answered: They would have continued to manage somehow - 48; they would not have been able to cope - 29; their life would have been made much harder, more stressful - 19; they would have had to impose heavily on others - 9).

How Did Users of Respite Care Differ From Nonusers?

Families using respite care services differed from families not using these services in that they experienced greater difficulty in caring for the client (because the client is less able to care for himself or less able to communicate, and because the mother is older, and because more often there are stairs to the client's room); and more often had a second severely disabled individual in the home.

Did the Use of Respite Care Services Improve Family Functioning?

The mean responses of respite care users and nonusers of respite care services are shown in Table 5.

TABLE 5

Means for Family Functioning Items by User and Nonuser Groups

Item	Results*			
	Users	Nonusers	t	p
Number of disagreements between parents about the handicapped child	1.26	1.0	1.28	NS
Satisfaction with life	2.50	1.80	3.48	.01
Hopefullness about a good future for the family	2.41	1.71	3.56	.01
Ability to cope with a handicapped child in the home	2.39	1.77	3.13	.01
Attitude toward handicapped child	2.20	1.57	2.76	.01
Total Family Functioning	14.91	10.94	3.58	.01

* Higher means indicate improvement in family functioning.

From the table it can be seen that reported improvement in family functioning was significantly higher in the user group. The relationship between the degree of respite care service use and family functioning was determined using Pearson Correlator Coefficients. The data indicates low but significant relationships between measures of service utilization and family functioning. See Table 6. From the table it can be seen that the earlier the service was first used, the greater the number of times it was used, the longer the modal time period for use, and the longer the maximum period of use was, the greater the improvement in family functioning.

Is There an Association between Use of (Out-of-Home) Respite Care Services and Liekelihood of Long Term Placement?

When families were asked about the likelihood that they would decide to place their children permanently, a higher proportion of respite care users than non-users indicated that this was likely ($p < .009$).

When the relationship between degree of respite care use and likelihood of permanent placement was examined it was found that the longer the period of respite care service utilization was at any one time, the greater the likelihood of placement was ($p < .01$). In addition, the earlier service utilization began, the greater the number of times the service was used, and the greater the maximum service period was, the greater the frequency of thoughts about permanent placement.

However, when the associate between respite care utilization and likelihood of permanent placement was examined by client age it was found that this association was largely based on the 18+ age group. There were no significant differences between users and non-users in families where the client was under age 6. Eighty five percent of the users and 88% of the non-users said there was no possibility of placement of the child, in families where the child was under age 6. However in the 18+ age group, 47% of the non-users said there was no likelihood of placement, while only 14% of the users said this.

TABLE 6

RELATIONSHIPS BETWEEN RESPITE CARE UTILIZATION VARIABLES AND IMPROVEMENT IN FAMILY FUNCTIONING

	FAMILY FUNCTIONING	
UTILIZATION VARIABLE	PEARSON CORRELATION COEFFICIENT	P
LENGTH OF TIME SINCE FIRST USE OF RESPITE CARE	.30	.001
NUMBER OF TIMES RESPITE CARE SERVICES USED	.24	.002
MODAL LENGTH OF RESPITE CARE SERVICE PERIOD	.17	.02
MAXIMUM LENGTH OF RESPITE CARE SERVICE PERIOD	.24	.002

Strategy #1, Year II: Respite Care Worker Effectiveness

None of the factors derived from the analysis of worker characteristics differentiated between outstanding, average and below average workers, or between workers identified in the top 15% and in the bottom 15%. Neither did any of the items analyzed separately which did not load on any of the background characteristics factors.

One relationship was found, however, between worker characteristics and the trait ratings given by supervisors. Thus workers who were parents, who had a background of volunteer work, or who had worked in a field related to respite care received higher trait ratings than did workers who had only received training for a related field. See Table 7.

In regard to the rating scale used, it is interesting to note that every one of the 11 items on the rating scale significantly differentiated the top and bottom 15% of workers. See Table 8. However, these same trait ratings did not differentiate significantly between outstanding, average and below average workers.*

The above results pertain to an analysis of the data obtained from the main sample of 176 workers. The results from an analysis of 72 home health aides provides only slightly different results. One characteristic which differentiated between the top and bottom 15% of workers in this medically oriented program, which did not differentiate between workers in the main study, was marital status ($x^2 = 8.53$, $p < .04$, $c=.32$).) The home-health aides who were married were more likely to be included in the top 15% than were their unamarried colleagues. See Table 9.

Nonformal experience, the one factor which was related to worker ratings in the main study, was also significantly related to worker ratings in this study ($F=3.012$, $p < .04$). From Table 10 it can be seen that the highest trait ratings were attained by workers who were parents of disabled individuals or who had cared for a disabled family member. Differences between pairs of subgroups did not, however, attain statistical significance, probably because of the small numbers in some of the subgroups.

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* Only 10 workers out of the entire sample of 176 workers were rated by supervisors as "below average," while 81 were rated as "outstanding." Approximately equal numbers of workers were included in the top 15% (N=30) and bottom 15% (N=32).

TABLE 7

TRAIT RATINGS OF SUBGROUPS WITHIN "NONFORMAL EXPERIENCE" GATEGORY

SUBGROUP	WEIGHTED TOTAL MEAN	F RATIO	p
Volunteer work	39.33	5.212	.0009
Parenthood	39.66		
Training for a related field	27.40		
Work experience in a related field	41.00		
Personal experiences as a devalued individual	35.00		
Caring for a disabled family member	35.28		

TABLE 8

TRAIT RATINGS OF TOP AND BOTTOM 15% OF WORKERS

Worker Trait	Mean of top 15%	Mean of bottom 15%	t	p
Dependability	3.93	3.25	4.58	.01
Outlook	3.90	2.84	6.86	.01
Judgement	3.97	2.88	6.93	.01
Consideration	3.97	3.13	5.58	.01
Stability	3.93	2.75	7.59	.01
Flexibility	3.90	2.69	6.98	.01
Cooperation	3.77	3.03	3.69	.01
Client Assistance	3.97	3.22	6.17	.01
Household management	3.77	3.10	4.88	.01
Routine medical Management	3.90	2.75	4.63	.01
Supportive communication with clients	3.97	2.78	9.17	.01

TABLE 9

CROSS-TABULATION OF MARITAL STATUS AND RELATIVE RATING

Marital Status	Relative Rating	
	Top 15%	Bottom 15%
Married	22	9
Single	10	9
Widowed	5	8
Divorced or Separated	2	7

TABLE 10

MEAN TRAIT RATINGS OF SUBGROUPS WITHIN "NONFORMAL EXPERIENCE" CATEGORY

SUBGROUP	MEAN	FREQUENCY
Parent of a disabled person	40.50	2
Training for a related field	27.00	1
Work experience in a related field	30.00	5
Personal experience as a devalued individual	35.00	1
Caring for a disabled family member	39.20	20

Strategy #2: Technical Assistance

The findings of the technical assistance strategy are reported in a separate document RESPITE prepared by UCPA, Inc. and attached to this final report. Additional materials generated by this strategy are included in Appendix C.

Strategy #3: Parent Training

Parent Training Models: A summary of parent training models follows. The models represent professionally organized training programs; parent organized and/or operated programs; and programs organized around packaged materials which are self instructional to a large extent.

The largest number of parent training programs focus on parents of children from 0-5. Parent training may be offered as an ancillary service in such a program, with the major approach being direct training of the child; or, parent training may be the primary approach to the education of the child, with professionals having limited direct interaction with the child. Infant programs and home based programs typically involve maximum parent utilization in the training of the child.

Professionally organized parent training programs may be based in an agency or center; they may have both center and home based components; or they may be entirely home based. Among the professionally organized parent training programs are a small number of university based programs which function semi-independently of child programs or which cut across child programs.

Parent training programs which are organized and/or staffed primarily by parents are few in number. They are differentiated by the high level of parent involvement and by the use of parents as trainers of other parents and children, rather than only as recipients of training and trainers of their own children.

Parent training programs organized around packaged materials which are largely self-instructional are also few in number, although many of the professionally organized programs have developed materials which are used in their programs. Packaged training programs can be particularly valuable to rural families which do not have access to educational programs for their children or themselves.

A large number of parent training models were developed as part of the network of early childhood demonstration projects funded by the Bureau of Education for the Handicapped, U. S. Office of Education.

Examples of various types of parent training programs are listed below.

I. Training Parents to Be the Young Child's Primary Teacher

Example #1.1: The Parent-Infant Project of the Nisonger Center, Ohio State University, Columbus, Ohio.

This program is an infant education program in which parents and children come to a center once a week. Parents must agree to implement at home the program worked out for the child at the center. One hour of center time per week is spent in developing an individualized program for the child; one hour in a parent group meeting.

Example #1.2: P.E.E.R.S. (Parents Are Effective Early Education Resources) of the Philadelphia Association for Retarded Citizens and of Special People in the Northeast, Philadelphia, Pennsylvania.

This program is an infant education program in which parents come to a center weekly for formal training, and in which a teacher visits the home monthly to guide parents in implementing prescriptions for the child.

Example #1.3: The Portage Project of the Cooperative Educational Service Agency 12, Portage, Wisconsin.

This is a home visiting program for children from birth-6 which is particularly appropriate for rural areas. Each home is visited once a week, with parents committing themselves to working with the child daily on individual prescriptions. Written guides for parents and home visitors facilitate replication of this model.

Example #1.4: Baby Buggy, Macomb 0-3 Regional Project,
College of Education, Western Illinois University,
Macomb, Illinois.

This home-based infant program features a mobile van which is used as an educational demonstration center. Thus it is particularly relevant for rural families. Prescribed tasks are assigned for parents to work on daily with their children.

Example #1.5: Regional Intervention Program (RIP)
Nashville, Tennessee.

This largely parent staffed program serves children under age 5 through a preschool program. Parents are trained through modules including observation and supervised teaching activities. Each parent makes a commitment to participate in five mornings of training a week for as long as necessary, and to give six months of service to the preschool program after training is completed. Parents are used as trainers of other parents.

II. Parent Training as a Corollary of Individualized Child Programs

Example #2.1: Parent Education Program of the Center on Human
Development, University of Oregon,
Eugene, Oregon.

This center-based model is part of a preschool program for multiply handicapped children. It trains parents through parent-teacher meetings; home teaching skill development meetings; weekly small group meetings; weekly or monthly education meetings; and use of parents as volunteer aides in the classroom. Behavior management, skill development and advocacy are stressed.

[Another preschool program with a similar parent training model is the PEECH (Precise Early Education of Children with Handicaps) program of Champaigne, Illinois.]

Example #2.2: Teaching Research Behavioral Clinic of the Teaching
Research Infant and Child Center,
Monmouth, Oregon.

In this program the parent comes to the center for individual training sessions, at first weekly, then bi-weekly and then monthly. The child may be placed temporarily in the clinic's prescriptive program or admitted into the preschool. The parents are trained in implementing the remediation sequences detailed in the Teaching Research Infant and Child Center Master Instructional Curriculum.

III. Parent Training as a General Supplement to and Support for Educational Programs

Example #3.1: Parent Involvement Center, Albuquerque Public Schools
and University of New Mexico,
Albuquerque, New Mexico.

This center serves parents of handicapped children from preschool through secondary school by: implementing established parent training programs; training parents as volunteers; operating a resource library for parents. It also trains professionals to work with parents.

Example #3.2: Project Train, University of Hartford,
Hartford, Connecticut.

This project implements a mini-course of five sessions designed to involve parents of handicapped children in the educational process. Special education teachers from public school programs serve as the parent trainers/instructors.

Example #3.3: Weekend College, Department of Special Education,
Winthrop College,
Rock Hill, South Carolina

Parents attend Friday evening course meetings at the college as part of teams including teachers, aides and students. Monthly meetings are held at program sites, e.g., Headstart centers, day care centers and public schools.

Example #3.4: Parent Education Project, School of Education,
University of Louisville,
Louisville, Kentucky.

This program encompasses a four week summer training program; parent training workshops; and parent training courses offered as part of the continuing education program.

Example #3.5: PACER Center (Parent Advocacy Coalition for Educational Rights), Minneapolis, Minnesota.

This parent organized program is designed to inform parents of the handicapped about their rights and to teach them how to work with the school to develop appropriate programs for their children. The major training vehicle is workshops. Project staff members are mostly parents.

IV. Parent Training as Part of a Family Support Service

Example #4.1: Cooperative Extension Project for the Handicapped Exceptional Child Center, Utah State University, Logan, Utah.

In this program, which is particularly appropriate for rural areas, field workers of the cooperative extension project of Utah State University aid families of the handicapped to obtain appropriate packaged instructional materials; to obtain access to 4-H programs and to other community programs for their children; and to obtain consultive services from professionals. This program disseminates a parent newsletter, operates a parent resource library and has a toll-free telephone consultation service.

Example #4.2: Pilot Parents, Omaha, Nebraska.

This is a parent-to-parent support network, in which each family agrees to serve as a pilot parent for one year. Parents are given seven week training sessions twice yearly and attend monthly meetings. Pilot parents are matched to other families to provide emotional support and information through telephone contacts and visits.

V. Programs Revolving Around Packaged Training Materials

All of the packaged materials listed in this section should be used with some form of supervision and support. However, they can be used independently to a large extent if supervision is not available.

Example #5.1: Castro, G. CAMS: Curriculum and monitoring system: An early intervention program for the handicapped child. (1 cassette filmstrip kit, manual, 5 programs: 1. Receptive Language; 2. Expressive Language; 3. Motor Development; 4. Self-Help; 5. Social-Emotional.) New York: Walker & Co. $98.50 (Individual items sold separately.)

Example #5.2: Exceptional Child Center. Parent training program. (7 slide carousel trays, 1 monitor's manual, 10 participant's manuals, 5 audio cassettes) 4 units: 1. Behavior; 2. Cues; 3. Reinforcement; 4. Programming and Recording. Exceptional Child Center, Outreach and Development Division, Utah State University, Logan, Utah 84322. Purchase $350.00.

Example #5.3: Project MORE: "Myself"--Daily living skills. (1 cassette, certificates and 13 booklets: 1. How to Do More (manual); 2. Eating; 3. Brushing Your Teeth; 4. Blowing Your Nose; 5. Washing Your Hands; 6. Taking Care of Your Complexion; 7. Washing Your Hair; 8. Using Deodorant; 9. Using a Sanitary Napkin; 10. Rolling Your Hair; 11. Taking Care of Eyeglasses; 12. Showering; 13. Shaving) Northbrook, Illinois: Hubbard, 1979.

Example #5.4: Texas Institute for Rehabilitation and Research. Parental skills program--handicapped children. (10 Core-program units and 5 Handicap units, soft cover materials, set of slides and cassette tapes.) Houston, Texas: Interaction, Inc., 1979. $500.00.
(Texts, workbooks and tapes available at individual prices.)

The preceding analysis of parent training models highlights the following facts: Most parent training programs are part of early education programs; universities are very active in the design and direction of model early education programs with parent training components; universities are not very much involved with parent training apart from these early education programs.

One problem highlighted by this analysis is that of funding. Most of the parent training programs described were funded by project monies from the Bureau of Education for the Handicapped (BEH).* Lack of a long-term funding source is undoubtedly a major reason why so few parent training programs exist outside of BEH model programs, and a major reason for the limited involvement of universities in parent training apart from these funded projects.

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* Now the Office of Special Education

Implementation of a University Based Training Model: The university based training model implemented had two components: training workshops, and the involvement of special education students in working with parents and clients in the home.

Workshop series were implemented in New York City during Year I and in Maine during Year II. During Year I five areas of training were requested. One workshop was designed to address each of these priority areas: Communication, behavior management, advocacy, motor development, and feeding. Another reason for having a different focus for each workshop was that most parents indicated they could not attend a series of sessions. Five Saturday afternoon workshops were implemented. Each lasted two-and-a-half hours. The elements build into each workshop were:

- The availability of coffee and cookies at the start of each session
- A materials display
- A presentation of theory
- Interaction between group leader and participants
- Activities for participants
- Demonstrations with developmentally disabled children from participating families
- Suggestions for home activities
- Written guides for home use
- Availability of a bilingual person for translation
- Availability of child care for hte disabled child at the training sessions

Attendance at the workshops was as follows:

Session	Families	Professional Staff	Students	Home Aides
COMMUNICATION	8	4	4	1
ADVOCACY	5	1	2	0
BEHAVIOR MODIFICATION	10	0	1	0
MOTOR DEVELOPMENT	6	0	1	0
FEEDING	10	14	1	1

Compilations of evaluations of the workshops follow. The evaluations were strongly positive. An attempt was made to get follow-up data several weeks later to determine whether the workshops had in any way changed parental behavior or feelings. Unfortunately only a handful of parents responded so that no conclusions could be drawn.

EVALUATION

Workshop: COMMUNICATION: Improving understanding and speech

May 5, 1979

	(Check One) YES	NO	No Response
1. Did you find this workshop interesting?	8		
2. Was this workshop informative?	6	2	
3. Were any of the ideas presented new to you?	6	2	

If YES, name a few:

- .Presenting the objects while explaining what they are. (Presentar los objectos haciendo saber que es.)
- .Helping child pay better attention and focus.
- .Putting words in simple form for understanding.
- .Picture Board.
- .Idea of teaching names. Clarified how retarded children need simplicity.
- .Keeping to one object like pointing to a apple for awhile.

	YES	NO	No Response
4. Did this workshop give you any ideas on:			
(a) How to help your child learn to understand the names of common objects?	5	3	
(b) How to help your child learn to understand simple directions?	6	2	
5. Do you think you will use some of the ideas from the workshop?	8		

- .How to get her to eat with a spoon herself. (Como logiargue coma por su propia mano.)
- .I plan to talk more and use names of things and describe what is going on and what we're doing.
- .Letting my sister use her sense of feeling.
- .Talk to your child even if she is deaf.
- .Be more specific. Don't use multisyllabic words as much. Worry more about speech development.
- .I will read to my child more.
- .I knew all about the ideas spoken here today.
- .We have been using them.

	YES	NO	No Response
6. Have you learned some ways of encouraging your child to communicate with you?	7		1

7. This workshop was (check one):

2 very useful; 6 useful; ____ not useful

COMMENT

The instructors were informative, pleasant and patient. They seemed to be kind, concerned human beings with a lot of information to offer. I enjoyed watching the actual work Jackie did with the children. Thank you.

EVALUATION

Workshop: ADVOCACY

May 12, 1979

	(CHECK ONE)		
	Yes	No	No Response
1. Did you learn more about ways you could be more involved in your child's education?	5		
2. Do you now understand what an IEP (Individualized Education Program) is and how it is prepared?	5		
3. Was the discussion of the role of the COH (Committee on the Handicapped) informative?	5		
4. Did the information on your child's legal rights answer any of your questions?	5		
5. Did the range of take-home materials look interesting to you?	5		

6. This workshop was (check one):

very useful 5 useful ____ not useful ____

COMMENTS

- Yes, it answered a lot of questions that would be helpful in the future.
- I think this workshop was very informative, interesting and helpful. I think I learned a lot of facts and information in this short amount of time.
- Learning more about the rights for our childrens.

EVALUATION

Workshop: Behavior Management
Developing good behavior and changing problem behavior

May 19, 1979

	(Check One)	
	YES	NO
1. Did you learn new ways to manage your child's behavior at home?	8	2
2. Do you think you can now identify one of your child's specific behaviors in order to work on improving it?	10	
3. Did the workshop make you aware of the many ways your child's behavior can be reinforced?	10	
4. Do you feel you know some ways that you can begin to bring about improvement in your child's behavior?	10	
5. Did the workshop increase your knowledge of the methods you can use to teach your child a simple skill?	9	1
6. Do you understand how to break down a task into its simplest steps?	10	
Do you think you can now teach these steps?	10	
7. Was the videotape informative?	9	1

COMMENT

- I really enjoyed the workshop and felt I learned quite a bit.

EVALUATION

Workshop: MOTOR DEVELOPMENT: Activities for large and small muscles

June 2, 1979

	(check one) YES	NO	No Response
1. Did you find this workshop interesting?	6		
2. Was this workshop informative?	6		
3. Were any of the ideas presented new to you?	5	1	

If YES, name a few:

- .Different ways to make motor coordination fun. How it can be developed with such simple techniques.
- .Different exercises for coordination.
- .Use of various objects to enable child to function and how to use them.
- .The scooter and the bubbles

4. Did this workshop increase your knowledge on how to improve your child's

	YES	NO	No Response
(a) balance?	5		1
(b) large muscle development?	4		2
(c) awareness of his body?	4	1	1
(d) small muscle development?	5		1

	YES	NO
5. Were the suggestions for materials that you can use at home with your child helpful?	6	
6. Do you think you will use some of the suggested games with your child at home?	6	

7. This workshop was (check one):

6 very useful; ____ useful; ____ not useful

COMMENT

I don't know much about physical therapy and was told somethings that is helpful.

(Write any comments on the reverse side of this paper.)

THE SPECIAL EDUCATION DEVELOPMENT CENTER
Hunter College of the City University of New York
440 East 26th Street - Room 715
New York, New York 10010
(212) 481-4323

EVALUATION

Workshop: Feeding Skills June 5, 1979

	YES	NO	(check one)
1. Did you find this workshop interesting?	10		
2. Was this workshop informative:	10		

3. Do you feel that you can use these basic feeding techniques demonstrated today:	YES	NO	NOT APPLICABLE	No Response
(a) spoon feeding	7	1	1	1
(b) manual jaw control	5	2	2	1
(c) drinking from a cup	7		1	2
(d) independent spoon-feeding	5		3	2
(e) independent cup drinking	5		3	2

4. Did this workshop increase your knowledge on how to develop:	YES	NO	NOT APPLICABLE	No Response
(a) swallowing & lip closure	7		2	1
(b) tongue control	6		2	2
(c) biting & chewing	7		2	1
5. Were the suggestions for materials that you can use at home with your child helpful?	8	1	1	
6. Do you think you will use some of the suggested feeding methods with your child at home?	9		1	

7. This workshop was (check one):

6 very useful; 4 useful; ____ not useful

.Child has problems involving breathing and swallowing, and on a special diet;technique useful in this.

(Write any comments on the reverse side of this paper.)

In spite of efforts made to tailor the training program to the needs of the families at one agency, only a small number of families - about 20% of the families invited - participated in the program. Moreover, parent attendance at any one training session never exceeded 10, about 10% of the number of families contacted even though almost three times this number indicated that they would participate in each session. Follow-up telephone calls were made to parents who had indicated that they would attend particular workshops but who didn't. Reasons given for non-participation included illness of the disabled child, illness of another child, other types of family emergencies, lack of a caretaker for the non-disabled children, and transportation problems.

During Year II training workshops were implemented in a rural site to determine whether the same parameters of workshop planning were appropriate and to determine whether the same problem of limited attendance would occur within this very different setting. This time parents expressed an interest in a workshop series focusing on behavior management. A six session workshop series was implemented over a two month period, taught by two faculty members from Bangor Community College. There were 16 participants, including several teacher/parent teams. What occurred, however, is that attendance dwindled from session to session, so that by the sixth session only five participants were present. This took place in spite of the fact that parents reported the workshops to be quite valuable.

The second aspect of the university based training model implemented - student involvement in the home - was implemented during Year I in New York City and during Year II in Philadelphia. During Year I 12 students participated. Although the plan called for students to work in the home one full day a week for eight weeks, this turned out not to be possible. Thus while some students worked for eight days others worked for only 4 to 6 days. Some of the reasons for this disparity were: (1) Mother and disabled child live with grandmother and aunt. Mother's sister does not want students in the home. (2) Mother in hospital emergency room when students show up at the home. (3) Mother unwilling to have students present until after 11 A.M. although appointment was for 9 A.M. and children are awake.

A summary of student responses to this experience follows.

THE SPECIAL EDUCATION DEVELOPMENT CENTER
Hunter College of the City University of New York
440 East 26th Street - Room 715
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(212) 481-4323

An evaluation is needed of your home visits to a family with a handicapped child. Please answer the questions below as specifically as possible. Thank you.

Did your participation in this program contribute to:

1. your understanding of parents of developmentally disabled children? Yes 9 No 1
Explain:

2. your attitude toward working with parents of developmentally disabled children? Yes 8 No 2
Explain:

3. your skills in working with parents of developmentally disabled children? Yes 7 No 3
Explain:

4. your understanding of the role of the paraprofessional as a family support? Yes 3 No 1 Not applicable 6
Explain:

Student Comments

Question #1

- I think I am more sensitive to parent's complex emotional feelings.
- It helped by seeing what goes on in the home and exactly what the mother's job entails having a disabled child.
- I saw how isolated a mother of a severely MH baby can be socially, physically, etc., during the day due to the inability to find an appropriate babysitter.
- In the course we covered the area of insights into parents feelings and attitudes very thoroughly. When I got to this home I was very aware of the parents view.
- My experience with above-mentioned parents has been rather limited before my participation in this special project. Actual field-work with parents reinforced my classroom activities.
- Yes, through interview and discussion I gained a greater understanding.
- An encounter with any new parents of a handicapped child is always a learning experience.
- I had the opportunity to interact with different members of the family I was working with, therefore was able to understand them much more than I was able to before this experience.
- Going into the home of a handicapped child gave me insight, understanding and compassion to the many concerns the parent of a handicapped child may have.
- I was able to gain insights into the everyday problems facing the parent.

Student Comments

Question #2

- Yes, I think I am more accepting of parents negative feelings considering their situation. I used to tolerate such negativity less.
- You have to be understanding, and most important be a listener and a friend. One shouldn't form a judgement on a parent from working with the child. Give the parent a chance.
- Better understanding of how difficult it is to implement educational goals at home.
- After being in the home and getting a view of the everyday life of the parents I feel that my perspective has been broadened. Many times I found my view of parents was very narrow minded.
- I enjoyed my experience. I feel I was very helpful and along with this, felt needed. I really had no pre-conceived attitudes toward parents, except that of having the idea of chronic sadness.
- I viewed my attitudes as positive prior to this class.
- Have worked with a considerable number of parents of handicapped children before participation in the program. My attitude has been established prior to participation in program
- Definitely, because I used to blame parents of handicapped children a lot for one thing or another, but now I know what it is like to have a handicapped child. I can understand them better.
- My attitude also encompassed understanding and compassion toward the parent. The experience gave me a more "real" sense of what it's like to have a handicapped child.
- I feel that I have become even more empathetic to parents needs now that I have been placed in their position, even though it was for a short time.

Student Comments

Question #3

- Yes, I found I had to alter my techniques at times due to input from the parent.
- I learned that you have to sit back a lot and let the parents build up a confidence in you. Once this rapport is acquired one can work easier with a parent.
- Offered complete respite care to mother.
- The position that we were in, as a student, kept us in the background most of the time. Although we were allowed to speak and give suggestions, we felt very nebulous most of the time. I don't feel that it contributed to my skills.
- I carried out (3) different assessments, throughout my stay with the family. I and my partner had free reign to carry out these assessments.
- My in-home experiences truly benefitted me in learning to interact with the parents.
- Again working with any new parents and their child always adds to your existing skills.
- I think these home visits were greatly helpful to me regarding the following skills: ability to interview, as I had the opportunity to interview a parent of a HC, ability to make recommendations to a parent regarding his HC, and also ability to interact with the whole family structure of a HC.
- It helped teach me skills in talking with the parent of the child, and in making professional recommendations for the child.

Student Comments

Question #4

- I found a strong emotional support given by the aide in my situation.

- The home aide became a friend and a support for the mother. The respite care gave the mother a chance to relax, and accomplish things that she had to get done.

- We were placed in a home where the home aide and the mother had an excellent working relationship! We saw a good example of that role. She was helpful and supportive to the mother and was very sensitive to the mother's feelings.

- My experience with a home aide was rather negative so I was not afforded a clear understanding of the role.

Students also kept logs of their experiences. The benefits to students and parents are highlighted in these records, as the excerpts below illustrate.

> In the four sessions which we spent with D., we were able to gain many insights into problems with which the parents of multihandicapped children must contend.... We found it difficult and at times depressing to be shut in with a handicapped child. At the same time we realized that there were two of us there to take turns caring for D. and we had each other to talk to. Mrs. M. has neither someone to help her with D. or someone to talk to .... We became aware of how lonely and isolated this mother must feel, remaining indoors with a handicapped child who is unable to speak or care for herself .... The only regret we have is that this service cannot be continued on a regular basis.

> The first time we saw the home aide feed A., I became extemely upset inside. A. was slumped in her chair, head tilted back all the way and turned to the side.... The home aide mentioned that A. did not want to eat and removed her from the highchair. A. has a tongue thrust and is unable to close her lips to retain the food in her mouth.... The next time, we talked to the home aide about the proper seating position for A. during mealtime. We positioned A. so that her hips were flexed 90° and she therefore had more head and trunk control. We suggested that the home aide present the food in midline to A. There are lots of other things that were needed but we decided that there had been a start.

> Today, was our last day with D. family. Ms. D. gave us each a plant to show her appreciation for our work with C. It was really touching.... The Committee on the Handicapped had finally come to a decision about placement in a school program for September. The teachers had come to meet with the family. They asked Ms. D. if there were any particular areas whe would like to see worked on in the fall, This fit right into our special project. We first explained to her the importance of attending. We tried to impress upon her that her input would be just as valid as that of the professionals. We gave her a list of recommendations based on our assessments and observations.

The home placements created additional work for agency staff and some stress when misunderstandings arose over placements. However, the agency responded most enthusiastically to the work of the students when very favorable reports from parents began coming in. After the project was completed the agency asked some of the students to continue to work in the homes on a paid basis.

During Year II a more directed approach was taken to how the students were to work in the homes. Since behavior management seemed to be a primary concern of parents, students were directed to work on one aspect of this task with the parents. An initial orientation meeting was called for all the parents who had indicated an interest in participating in the project. Many of the parents failed to show up. Students later implemented two additional group workshops for parents on behavior management. Each student made four visits to a home to work on one or two specific behaviors which parents wanted to change. Students kept logs of their experiences. Parents and students completed evaluation forms. The instructor wrote a brief review of the experience. Excerpts from a student log illustrating the benefits of this project follow:

> The experience of dealing with the parent/teacher relationship directly in the home environment was extremely beneficial. It gave us the opportunity to directly implement the knowledge obtained from our textbooks' readings into workable behavior management programs for parents. Through our participation in this program, we refined many of our "teaching" skills and found them to apply to the family unit as well as to the classroom. We gained a greater insight and understanding of what the parents of a developmentally disabled child go through day in and day out - the joys, the frustrations and the concerns.

A compilation of responses from 10 parents follows.

1. Were the students' home visits of any value to you and/or your family? YES 10

   In what way(s)?

   - It gave me new hope where I was ready to give up. I had toyed with the idea of giving my son up because of his behavior changes. J. and C. gave me a fresh look at trying to help him.
   - My son knows if he does something wrong and I don't like it, he will be punished.
   - Learning about new ways of dealing with behavior problems was very helpful.
   - I'm having more patience with her.
   - It made me feel that I was not alone with my problems. That there was somenne to help and guide me and most of all that there is people who care.
   - for his participating with children like him. So he could be easy to handle at home.
   - It helped me find different ways to handle my son's inability to brush his teeth.
   - Not to use force.

2. Did the students' home visits in any way change your behavior or the behavior of other family members toward your handicapped child? YES 5, NO 4, NO RESPONSE 1

   In what way(s)?

   - They showed me how to make charts and how to encourage him to do more for himself. Things he hadn't done, he began to do.
   - I have learned to be more strict.
   - We have always understood his needs.
   - By trying to solve the problem and having some one to talk to.
   - Brain is doing better in school and at home (Smile).
   - They have more time to self & other family member.

3. Do you feel more competent in managing your child's behavior at home? YES 8 , NO 2

Explain:

-Where I had automatically done for him, things he should have been doing for himself because of his reliance on me to do so, I now have more patience and work with him more. He is now doing chores for himself that normal children automatically do and he's enjoying it.

-Sometimes it works and sometimes it doesn't.

-Yes, the booklet received is very helpful.

-By understanding her problem and taking steps to cure her problem.

-Have tried different approaches, but none of them seem to help.

-I think it's good for him to get out and resond to other kids like him.

-I know of other approaches in handling the problem.

-Needing to be bathed and combing hair and other needs for a woman.

Additional comments on the value of this experience:

-Although this was only a short study, it was very helpful to me and to my son, J. He'll be 18 next month and he refused to do a lot of personal things for himself although he once did them. By having the students come in seemed to reach a part of him that he was turning off. Perhaps a new face or faces that truly seemed interested in him, did it, but I'm truly grateful something did. It's a good program.

-Three visits is too few, their should be at least five.

-They realy is a big health.

-This experience has been very healthful for family member, Who learned how to handle L. more mainerble.

4. Check the skills you learned through the students' visits:

6 (a) targeting specific behaviors
3 (b) charting behavior
4 (c) selecting and applying reinforcement
6 (d) breaking a task down into its simplest steps
7 (e) beginning a program to change behavior

A compilation of feedback from 13 students follows. (See Appendix D for the instructor's informal feedback.)

1. Did your participation in this program contribute to:
   (a) your understanding of parents of developmentally disabled children? YES 13
   In what way(s)?

- observing a life style different than ones in which I had previously come into contact. The hardships that poverty and poor living conditions create for a single parent.
- After working with Mrs. B I was better able to understand her reasons for frustration and apathy. Both her daughters are in their 30s. Mrs. B has had to care for and support them all their lifes. After 30 years of this she has grown tired.
- Yes, because I feel the parents are very involved emotionally with their child and the difficulties the child has to deal with. It became apparent that the family has a lot of pressures placed upon them by society and need to be understood, listened to, and supported by people, especially in the field of special education.
- Just by talking with the parents, I became aware of how they felt about their child and things were brought to my attention--things that I had never realized or thought about before.
- I feel that a lot of the parents need emotional and moral support: in a lot of ways, the parent in our case, was interested in knowing if we felt the relationship she had with her kids was a good one.
- I feel more empathetic towards their anxieties and responsibilities. Parents have tried to train their developmentally disabled children over the years and are open to our suggestions.
- By going into the home I was able to see how this parent lived and how his daughter acted, first hand. I found the home visit much more informative than getting information by narrative. It also enabled me to see the father interact with his daughter.
- It was an excellent experience for working with parents of exceptional children. It provided an opportunity to better understand the situation from one other than the classroom.
- I had experience with parents through my employment experience but this participation in this program brought out insights I had not considered before, such as the parents' guilt about having a mentally retarded child, their frustration because they are not always able to help their children, and their lack of awareness of services that are available to them, etc. The parents' extreme fear about what will happen to their children when they die.
- Expecially in regards to difficulties they experience with various service delivery systems.
- Being actually in the home environment contributed to the inner dynamics of the family realtionships.
- They want the <u>best</u> for their child.

1. Did your participation in this program contribute to:
   (b) your <u>attitude</u> -toward working with parents of developmentally disabled children?

<u>In what way(s)?</u> YES 13

-These visits furthered an already begun process of reevaluating just how realistic my expectations of parent's ability and motivation to be involved in their child's education helped me touch base with reality and not form generalizations based on vague ideals.

-I was able to see the difficult situation of having grown handicapped children. I can understand Mrs. B's reasons for being tired of trying. But, I still feel that there is great hope, and needed change regarding her daughters and their capabilities and behaviors.

-I feel my attitude toward working with parents changed in a great many ways. By getting to visit the parents in their home and know them I understood how difficult it is for them to attend meetings and other such activities schools want participation from parents. Whereas before this project (being a teacher) I thought it was a lack of interest on the parent's part. But being a parent is a very tough and full time job. I feel if more teachers had the chance to see the parents side there would be a better understanding and more communication between the two and therefore the child would benefit.

-The parents I worked with were very receptive and friendly and I enjoyed talking with them.

-I began to see some of the problems that these parents have with school systems and teachers, as well as home problems they were having.

-I feel that as a "parent-trainer" I have a lot to learn from the parents' sharing about their experiences. I must respect them (and I do) for their trial and error methods of handling their problems.

-I have a stronger attitude towards the importance of working cooperatively with parents. I also got a better understanding of how difficult it can be for a parent to deal daily with a disabled child and of how many different ideas they've already tried.

-Better able to empathize.

-I have always enjoyed and learned from working with parents in the institution where I work. This experience made me more empathetic to their needs, whereas my main focus before was on the children.

-I was able to identify more with the parents' basic needs and frustrations instead of seeing them through the eyes of the child.

-More sympathetic to overwhelming problems.

1. Did your participation in this program contribute to:
   (c) your skills in working with parents of developmentally disabled children?
In what way(s)?

YES 13

- These visits helped me gain more experience in terms of exposing me to one more situation in which I'd never been before.
- I learned how to present and represent the same information in several ways in order to make my point clear and understandable. I also learned the importance of establishing a firm foundation (of skills and understanding of the exact problems) before trying to change behaviors.
- Yes, at first I was a bit nervous but by working with the parents my skills improved because I saw the need they had in explanations of different ways of dealing with behaviors, and because of their interest it was easy to explain because they put me at ease.
- Just the fact that we all sat down and talked and discussed their child helped me to understand their problems.
- I became more sensitive and empathetic to the problems of the parent, and began to see the parents' side of a situation, through exercising active listening and discussion.
- some practical techniques of parents work, e.g., parents leave undesirable scene for some time to block it out. Quite effective in enabling them to retain their sanity.
- I feel more comfortable applying my skills as I was able to get practical experience.
- In some ways it made me more aware of other factors that are experienced by the family other than the ones contributed by the exceptional child.
- Through this experience I realize more of the restraints parents have when receiving training such as lack of transportation or someone to care for the children while the parents are away. In the future skills I teach to parents will consider these real problems.
- This was a first experience for me and sensitized me to the needs of parents.
- We both helped each other. The parents had a basic understanding, and I had skills that they could share.
- The need to specify specific observable, measureable behaviors that are a problem.

2. Do you think that as a result of your visits, the parents are better able to manage their child's behavior? YES 9 , MAYBE 1 , NO 3

In what way(s)?

-Parent already had as much information available to her as I would have been able to obtain for her.

-Due to the input that our family is receiving from several agencies and our visits, I feel that they (she) is better able to manage her daughters. What needs to be worked on is her attitude towards change. Without the desire to change behaviors, the skills are useless.

-A little, I feel mostly that just having someone to talk to about their daughter was our biggest contribution however. We did show several techniques to use with their daughter and stressed positive reinforcement.

-I'm not sure whether they are better able to manage their child's behavior, but I think that they were presented with methods to use if they wanted to.

-I believe that they can see the positive things which they can do to encourage appropriate behavior, where they may not have thought of a systematic way to reward appropriate behavior previously.

-They get a clearer picture of the rationale of the antecedents--behavior--consequences pattern in behavior modification. This set of parents does not have any behavior problems from their child--however suggestions re: improving self-help care were well-taken.

-The problem in my family's situation needed more cooperation from the regular service agencies to be effective. Three visits did not seem adequate to solve their problems.

-I provided the knowledge for the mother to interact more effectively with her children, but she did not feel strongly enough about the problem to be consistent in the application of the program.

-The parent I talked to decided to put her adult sister in a group home because of her age and the adult retarded sister's increases in behavioral problems. I hope I was able to confort her in this decision.

-We offered a viable alternative to punishment.

-Not in 3 visits perhaps; but the parents were able to relax and discuss their fears, their frustrations, and their needs to a third party.

-Discussed information in the book, "Systematic Parent Training."

3. Do you think that your visits were helpful to the family's overall functioning? In what way(s)?

YES 9 , NO 4

-Three short visits did little to change patterns of interaction which had been established over time.

-Our family seemed to enjoy our visits. They always welcomed us into their home and allowed us to stay as long as we wanted to. Our visits gave the daughters something to look forward to. We were always given their fullest attention while visiting.

-Yes, I feel they understand their daughter a little more now and have more patience with her. They seemed very pleased with our visits and this made us very happy.

-I think so because the parents always seemed happy just to talk with us.

-Yes. We helped inform the parent of the way in which special education works in the school; made her more aware of her rights as a parent, and suggested options (like a parent advocacy group) to help her deal with the school system.

-In a small way I feel I was able to give some emotional support to the father.

-Socially and emotionally I think I provided some outlet for the mother which was sorely needed.

-Although the parent I called did not permit me to visit her I feel that through our numerous telephone calls I was able to make her aware of organizations that provided services for the mentally retarded, comfort her by just listening to her and providing suggestions to help her with her adult mentally retarded sister.

-We didn't touch upon many areas of concern.

-Not in 3 visits perhaps; but the parents sere able to relax and discuss their fears, their frustrations, and their needs to a third party.

-Gave information concerning agencies to be contacted.

Additional comments on the value of this experience:

-The idea is good and of value. Unfortunately I think the parents don't stand to gain as much from the experience as the student. I think the administration and follow-up by local agencies (UCP of Philadelphia) could be better organized. I think if the project covered an entire year instead of one semester that it would be more valuable and provide more continuity for all involved.

-We enjoyed this experience very much.

-I also feel that our interest in her and her children helped give her "moral" support, and confidence.

-It was a fantastic eye-opener to deal with actual parents than in just reading about them in case histories. The project should definitely be included for future classes.

Strategy #4: Dissemination

The following dissemination strategies were implemented:

1. A presentation at the 1980 AAMD Conference in San Francisco.
2. A presentation at the National Conference on Developmental Disabilities in Washington D.C. in April 1980.
3. Four regional dissemination conferences at project sites, two at the end of Year I and two at the end of Year II.
4. Mailings of products (draft of Technical Assistance Handbook, Analysis paper and/or reference list) to approximately 80 persons.
5. A technical assistance handbook has been prepared. (This handbook will go through one more revision before being disseminated. See enclosure with attached letter.)

The following dissemination activities are still in process:

1. Correspondance with approximately 80 individuals on a mailing list to inform them of the cost of final products. (The Final Report and Technical Assistance Guidelines will be disseminated at cost.)
2. Sections of the final report dealing with strategy #1, a data base for planning respite care services, and strategy #3, parent training, will be prepared as separate guidelines for dissemination.

3. Preparation of two articles for professional journals, one reporting the research results, the other the parent training findings.

These activities will all be completed by March 1981.

IV. SUMMARY AND DISCUSSION OF FINDINGS

What value does respite care have? How does it effect families? What is its relationship to deinstitutionalization and normalization? How can it be made more valuable? These are the questions which this project attempted to answer. The results obtained are summarized below:

1. Respite care users differ from families not using respite care in that they:
    a) Are more likely to have a second severely disabled individual in the home.
    b) Are more likely to have disabled family members (clients) whose care is very burdensome.
    c) Are more likely to lack a network of persons outside the home to call on for help with the client during times of special need.
2. Respite care improves family functioning, as perceived and reported by parents. Families report that their satisfaction with life, hopefulness about the future and ability to cope with a disabled child in the home improved with the use of respite care services.
3. Families are generally quite satisfied with the respite care services they receive. The aspect of respite care service which is most often perceived by parents as needing improvement is the time allotted per family for respite care. Another aspect of respite care programs which about 20% of users see as needing improvement is the quality of respite care workers.
4. When given a choice of in-home and out-of-home respite care services, a majority of families are likely to make use of in-home services. On the other hand, having the client out-of-home for a period of time appears to be an extremely important part of the service for about 40% of the families using it. It appears that in-home services are more likely to be used by small families with few people to communicate with about the client; while out-of-home services are more likely to be used by large families, families with another severely disabled individual in the home, and families where the client is severely and multiply impaired.
5. Respite care appears to help families by improving the mental health and social relationships of the parents. Parents used the time allowed them by respite care services primarily to meet medical needs,

rest, recuperate and improve their relationships with other family members. To a lesser extent they used this time to engage in personal activities and take a vacation.

6. If respite care services had not been available some of the families now using these services,perhaps as many as 25% of families, would not have been able to cope with the disabled client in the home. Another group of families would have experienced severe stress, which may well have required the provision of other family support services.

7. There is an association between use of out-of-home respite care services and likelihood of long term placement. However, this association is largely accounted for by families with clients over age 18. It probably also reflects a selection factor at work, namely that it is families which are more severely burdened by the care of the disabled client that are more likely to use out-of-home respite care to begin with.

8. When the value of respite care services is compared to that of other family support services, time factors appear to play a critical role. Thus a 30 hour a week preschool program may be more effective in improving family functioning than a respite care program is because the preschool program provides the primary caregiver with more actual respite than does a respite care program.

9. Some families in which the primary caretaker has twenty-four hour a day responsibility for a handicapped child may require regular, on-going in-home services. Whether the worker providing such service is called a respite care worker, a homemaker or a home aide, the primary purpose of this service is to provide the parent with respite so that she/he may continue to cope with the handicapped child in the home.

10. The association between out-of-home respite care and likelihood of long term placement in families with older clients should be viewed as appropriate to the development of the disabled client and the family, in light of the normalization principle. Group homes and other community residential facilities are probably at least as appropriate for many developmentally disabled adults as is continued residence in the parental home. Moreover, out-of-home respite care allows families to test the appropriateness of this alternative and to adapt to it in stages. Thus, it probably plays a very valuable role for the family and client which is considering this option.

Another set of questions posed in this study dealt with the effectiveness of respite care workers. Specifically, the study sought to identify characteristics of effective respite care workers which might be used to guide recruitment, hiring and training procedures. Basically, this study was unable to identify any factors which were clearly associated with job effectiveness. None of the factors which appeared logically to be related to job effectiveness, or which were reported by program directors to be so associated, proved to differentiate very effective workers from average or below average workers. However, it does appear that experience -- as a parent, as a volunteer with disabled clients, as a worker in a field related to respite care, or as a person who cared for a disabled family member -- is more associated with effectivenss as a respite care worker than is formal training (education) in an area related to respite care.

One tool developed in this study which may prove to be of value in screening potential respite care workers is an 11 item rating scale, since on each of these 11 items workers identified as being in the top 15% in terms of effectiveness had significantly higher ratings than did workers in the bottom 15%. However, further research with this instrument would be needed to establish its value as a screening device.

Still another set of questions raised by this study pertained to the potential involvement of universities in training parents of developmentally disabled clients, with training serving as an adjunct to respite care in a family support system. One model of such training was a series of workshops prepared and implemented by university personnel. Although care was taken to incorporate features identified as essential to the success of parent training efforts, including parental input into the content and format of the training, only a relatively small proportion of the invited families participated in the workshops. Moreover, a good number of parents who indicated that they would come, did not do so, or came to a couple of workshop sessions and then dropped out. It would appear that many parents find themselves too burdened to take the time to participate in training workshops.

In view of the small numbers of parents who do participate, and the temporary or sporatic nature of the participation, university based parent training programs which are on-going in nature and which are not intricately interwoven with child services, do not appear to be a very strong approach to family support. The most successful parent training programs are part and parcel of handicapped child education programs. Another problem in establishing university based parent training programs is clearly financial. Most of the parent training programs reported in the literature were funded by the Bureau of Education for the Handicapped (now the Office of Special Education) as part of an early children model demonstration centers network. There does not appear to be a viable permanent or long-term funding source available to universities in supporting parent training programs.

On the other hand, universities do have a major resource in their students. Many universities conduct graduate programs in special education and have recently begun to recognize the importance of training these students to work with parents. Graduate special education students can be involved in aiding parents of handicapped children through parent training in the home. One obvious technique for implementing this goal is to include work with a family as part of the requirements in courses about parent involvement. Another approach is to allow students who have already demonstrated competence in teaching handicapped children to meet practicum requirement by working with parents. Whenever feasible, students can "be apprenticed to" home teachers for this practicum.

The great advantage of this approach is its home base. The danger of this approach is that insensitive or unskilled students will act in ways that are contraindicated. The success of this approach requires that students be carefully selected, closely supervised, and work in ways congruent with the goals established by the service system.

V. CONCLUSIONS, POLICY IMPLICATIONS AND RECOMMENDATIONS

1. Respite care should be made available to all families of developmentally disabled clients who want such service.

2. The time dimensions of respite care programs should be generous enough to allow for rest and recuperation as well as family emergencies. (The 10 days plus 30 hours allotment in central Maryland appeared to be too low an allotment for many families.)

3. Both in-home and out-of-home respite programs should be available. While a majority of families appear to prefer in-home services, the out-of-home aspect of respite care appears to be of central importance to a sizeable group of families. Since in-home services are less expensive, the provision of out-of-home services only is unsound fiscally as well as programmatically.

4. The respite function of programs not primarily designed for this purpose or labeled as respite care must be recognized so that these programs, (e.g., preschool, summer camp, day care) will be utilized to help meet long term respite care needs.

5. The need in some families for regular, on-going relief over a long period of time must be recognized and met. This need may be particularly common in families with developmentally disabled children below school age where one parent has 24 hour a day responsibility for the child's care.

6. Respite care programs should not be allowed to spring up in isolation from other family support services. To allow this to happen will undoubtedly mean that respite care would be used to meet needs more appropriately met by other family support services. This would put further, unnecessary strain on the limited resources available for respite care. There is a very real danger also that out-of-home respite care places will be taken over by what appeared to be temporary clients who stay well beyond defined time limits because the parents refuse to take them home.

7. More attention needs to be given to the selection and training of respite care workers. Further research should be carried out to develop a valid and practical screening device which might be used in place of the usual letters of recommendation which applicants submit. More time and funds should be allotted to on-going training.

8. In many states long term funding for respite care programs appears to be problematic, with restrictions hindering the development of needed programs. Federal funding sources for out-of-home residential programs often require that they be based in medical facilities, or that they be made available only to families with very limited incomes. However, there are potential funding sources which are untapped in some states.

These include monies set aside to finance alternatives to institutional placement, and Title IV -B Child Welfare Services monies. While federal funds appear to be catalytic in initiating many respite care programs, state funds are needed to provide stable funding. Some states are already providing such funding. Other states need to move in this direction.

Respite care appears to be a family support service critical to the success of deinstitutional efforts and the maintenance of family functioning. This is particularly true in the case of families where the care of the developmentally disabled individual in the home is extremely burdensome. Respite care programs, both in-home and out-of-home, need to be established in all states so that they are available to all families which need them, if deinstitutionalization efforts are to succeed in both qualitative and quantitative ways.

Appendix A: Year I Data Collection Forms

(Strategy # 1)

Family Characteristics Form

Complete one Family Characteristics Form for each client. Much of the information can be obtained by checking client files and therefore can be done by clerical staff. However, some questions can only be answered by the professional staff who have worked with the families involved and who can contact the families themselves if needed. Provide as much accurate information as possible. Please add any comments you feel are needed to clarify your responses.

Agency: ____________________

(1) Client Identification: First Name ____________ Last Initial ______

(2) Date of Birth: Month ________ Year ________

(3) Male _____ Female _____

(4) Caucasian _____

Black _____

Spanish Surname _____

Oriental _____

Other _____

(5) Urban _____

Suburban _____

Rural _____

(6) Family Income

Under $6,500 _____

6,500-12,000 _____

12,000-18,500 _____

18,500-25,000 _____

Over $25,000 _____

(7) Age of parents:

	Mother	Father
Under 18	______	______
18 - 24	______	______
25 - 35	______	______
35 - 50	______	______
Over 50	______	______

(8) Parental occupation:

	(Primary Job)	Full Time	Part Time (Give number of hours)
Mother	______________________________	______	______
Father	______________________________	______	______

If a parent holds a second job, indicate which parent and state the position.

______________________________	______	______
______________________________	______	______

(9) Educational level of parents: (Check highest level completed.)

	Mother	Father
Elementary	______	______
Junior High	______	______
High School	______	______
Trade School	______	______
College or above	______	______

(10) State the primary language spoken in the home ______________________________

(11) If parent(s) were not born in one of the 50 states, state number of years of residence in the U.S.

Mother ________ Father ________

(12) (A) Is family receiving economic assistance? Yes _____ No _____

(B) If (Yes), what type of assistance? ______________________________________

(13) (A) Total number of people residing in household (including client)________

(B) Number of other adults over 18 in home (excluding client)________

(C) Number of children below 18 in home (excluding client)________

0-4____ 5-12____ 13-18____

(D) Check ALL those who reside in household:

Mother____	Father____	Grandmother____
Foster Mother____	Foster Father____	Grandfather____

(14) Primary disability:

Cerebral Palsy________

Mental Retardation________

Other(Identify)________________________

If multiply handicapped, list additional disabilities________________

____

(For questions 15 through 19, check one category for each impairment.)

	NONE	MILD	MODERATE	SEVERE
Severity of Motoric Impairment?		Can walk with aids. Fairly good head and arm control. ____	Uses wheelchair but has fairly good head and arm control. or Can walk with difficulty but also has poor head and arm control. ____	Poor head and arm control and uses wheelchair. ____
(16) Severity of Speech Impairment?		Speech adequate to make self understood. ____	Some understandable speech but limited in quantity and understandable only to those who have spent some time with client. ____	No understandable speech ____
(17) Severity of Cognitive Retardation?		Understands environment as well as average client of his/her age. ____	Some understanding of environment but at much lower level than average client of same age. ____	Little understanding of what is happening around him/her. ____

	NONE	MILD	MODERATE	SEVERE
(18) Severity of Functional Impairment (ADL Skills)		Can toilet, dress and feed self close to appropriate age level. ____	Can do at least 2 of the following with help: toilet, feed or dress self. ____	No self-toileting, dressing or feeding; or only 1 of these with help. ____
(19) Severity of Behavioral Problems		Occasionally (less than 20% of the time): ____	Sometimes (between 20% and 40% of the time): exhibits bizarre mannerisms and socially inappropriate behavior; damages or destroys objects; physically assaults others or self. ____	Often (more than 40% of the time): ____

(20) (A) Is there any other person(s) who is disabled living in the house?

Yes_____ No_____

(B) If (Yes), please indicate:

Relationship to client	Type of disability	Severity of impairment (mild, moderate, severe)	No. of mos. or years disability present

(21) List those household members who take major responsibility for the care of the client and note the total number of hours per day that the client is in their care.

Relationship to client	Hours per day
____	____
____	____
____	____

(22) Does anyone outside the home, other than Agency Home Workers, regularly share in the client's care? Yes_____ No_____

If (Yes), list here and give:

Relationship to client	Hours per week
____	____
____	____
____	____

(23) How many hours per day does the client spend out of the home in an educational or a community program not offered by your agency? ____________

(Describe.)

(24) Does the family make use of any other neighborhood agencies or programs which offer:

(a) direct service to the client? Yes_____ No_____

(b) support service to the family? Yes_____ No_____

If so, describe.

(25) How important a role does religious affiliation play in the family's life?

none_____ minimal_____ moderate_____ strong_____

(26) To what extent are there other family members, relatives, friends, or neighbors that can be called on when:

(a) the family is in special need of help with the client

none_____ some_____ many_____

(b) parents themselves need to communicate with someone

none_____ some_____ many_____

(27) Complete the following:

(A) Number of rooms in client's home__________

(B) Number of persons sharing the client's bedroom?__________

(C) How many flights of stairs does the client have to climb to get into the house and/or his/her bedroom?______________

(28) Has this client ever resided in a residential setting other than on a temporary basis? Yes______ No_________

(A) At what age and for how long?______________________________

(B) Indicate the type of setting:

state institution__________

halfway house or community group home__________

other(please indicate)______________________________

Client ______________________
(First name, last initial)

INDIVIDUAL CLIEN[illegible]LY UTILIZATION SHEET

(Complete information requested only if service is appropriate for client/family.)

Service	(✓) Service is appropriate to this client/family	(✓) Service is currently used	(✓) Service was utilized but discontinued	Amount of time service used-- # hours			Duration of time service used	(✓) Level of utilization of service			If service utilization was discontinued or reduced, list possible reasons.	Indicate any factor that may have prevented the use of this service (e.g. travel time, travel cost, availability of transportation, cost of service, lack of openings).
				Daily	Weekly	Monthly		Minimal	Moderate	Maximal		
Pre-School Class												
Infant Development Program												
Camp CaPella (Day Camp)												
Camp CaPella (Residential Camp)												
The Homemaker Service of the Counseling Center												
Home Service Program												
The Levinson Center												

Family Questionnaire

Part A: Family Functioning

Agency United Cerebral Palsy of Central Maryland, Inc.

Child's Name ______________________ (first) ______________________ (first initial of last name)

This form is being completed by Mother_____, Father_____, Both_____, Other_____(please describe relationship to child.)

On the following page there are statements to be completed by checking one of three choices. These choices are: "increased," "not changed," and "decreased." They refer to what has happened in your family since you began to use any of the services listed below. (If your family has not used any of the services, then these words refer to changes in your family that have occurred during the last three years.)

Please answer all questions as best you can, except those that clearly don't apply to your family. If you don't answer a question, please note why next to the question.

If you have two children who are receiving any of the listed services, answer two copies of this form; one in relation to each child.

- Delrey Development Center
- Arbutus Development Center (Adult unit)
- OWARII
  - Homemaker Service (e.g. Quality Care)
- OWARII
  - Respite Care Workers
- OWARII
  - St. Vincent's Child Care Center
  - Mt. Washington Hospital
  - Hyattsville Manor Nursing Home
  - Colton-Manor Nursing Home
  - Rosewood State Hospital
- The Place
- Wheelchair Basketball & Sports Program
- Bowling Program
- Scout Programs
- Camp New Horizon
- Club Ridge

NOTE: Several questions on this form were adapted from:

Pless, I. B., & Satterwhite, B. A measure of family function and it's application. Soc. Sci. & Med., 1973, 7, 613-621.

Since services began:	increased	not changed	decreased
1. Your family's happiness has			
2. Disagreements between you and your husband about your handicapped child have			
3. Your feelings of affection toward your handicapped child have			
4. The times when your handicapped child is upset or unhappy have			
5. The help and support which family members give each other have			
6. The adjustment of your <u>non</u>-handicapped child(ren) in school and with friends has			
7. The problems between your <u>non</u>-handicapped child(ren) and your handicapped child have			
8. Cooperation in the care of your handicapped child between all persons living in the home has			
9. The confidence you have in your ability to care for your handicapped child has			
10. Your satisfaction with your life has			
11. The number of activities your family shares together has			
12. The need for emotional or psychological support for yourself or your husband(wife) has			
13. Your hopefulness about a good future for your handicapped child has			
14. Your hopefulness about your own future has			
15. The quality of your relationship to your <u>non</u>-handicapped child(ren) has			
16. The overall ability of your family to cope with having a handicapped child in the home has			
17. The number of times you have seriously thought about out-of-home placement for your handicapped child has			
18. The likelihood that your family will decide to place your handicapped child in a permanent out-of-home residence has			

*If you answered "increased" to #18, please explain your answer.

Family Questionnaire

Part A: Family Functioning

Agency Retarded Infants Services, Inc.

Child's Name ______________ (first) ______________ (first initial of last name)

This form is being completed by Mother____, Father____, Both____,

Other____(please describe relationship to child.)

On the following page there are statements to be completed by checking one of three choices. These choices are: "increased," "not changed," and "decreased." They refer to what has happened in your family since you began to use any of the services listed below. (If your family has not used any of the services, then these words refer to changes in your family that have occurred during the last three years.)

Please answer all questions as best you can, except those that clearly don't apply to your family. If you don't answer a question, please note why next to the question.

If you have two children who are receiving any of the listed services, answer two copies of this form; one in relation to each child.

Home Aide (Family) Service
First Hope
Counselling

NOTE:

Several questions on this form were adapted from:
Pless, I. B., & Satterwhite, B. A measure of family function and it's application. Soc. Sci. & Med., 1973, 7, 613-621.

Family Questionnaire

Part A: Family Functioning

Agency United Cerebral Palsy of Northeastern Maine, Inc.

Child's Name ______________________ (first) ______________________ (first initial of last name)

This form is being completed by Mother_____, Father_____, Both_____,

Other_____(please describe relationship to child.)

On the following page there are statements to be completed by checking one of three choices. These choices are: "increased," "not changed," and "decreased." They refer to what has happened in your family since you began to use any of the services listed below. (If your family has not used any of the services, then these words refer to changes in your family that have occurred during the last three years.)

Please answer all questions as best you can, except those that clearly don't apply to your family. If you don't answer a question, please note why next to the question.

If you have two children who are receiving any of the listed services, answer two copies of this form; one in relation to each child.

- Pre-School Class
- Infant Development Program
- Camp CaPella (Day Camp)
- Camp CaPella (Residential Camp)
- The Homemaker Service of the Counseling Center
- Home Service Program
- The Levinson Center

NOTE:

Several questions on this form were adapted from:
Pless, I. B., & Satterwhite, B. A measure of family function and it's application. Soc. Sci. & Med., 1973, 7, 613-621.

Part B: Satisfaction With Service

Service:

Child's Name____________________ (first) ____________________ (first initial of last name)

1. Do you feel that this service was helpful to you and/or your family? YES_____ NO_____

   Briefly describe some of the reasons for your answer.

2. Did your child benefit as a result of using this service? YES_____ NO_____

   Briefly describe any changes you have noted.

3. What aspects of this service were most helpful to you?

4. In what ways could this service have helped you more?

5. What aspects of this service are most in need of improvement?

6. Do you plan to continue to use this service?

NO_____ PROBABLY_____ YES_____

7. Would you recommend this service to other families?

NO_____ PROBABLY_____ YES_____

8. If you had not received this service, what would have happened to your family?

9. Is there another type of service that would have met your needs better?

YES_____ NO_____

If YES, describe briefly.

Additional Comments:

Check the appropriate rating for each question. Omit any that do not apply to this particular service.

How satisfied are you with:	very unsatisfied	generally unsatisfied	generally satisfied	very satisfied
the number of hours that the service is available each week	____	____	____	____
the total amount of time that the service is available per year	____	____	____	____
the time of day or week when the service is offered	____	____	____	____
transportation (to and from service)	____	____	____	____
cost of service to family	____	____	____	____
the staff:				
ability to deal with special needs of child	____	____	____	____
ability to relate to child	____	____	____	____
ability to relate to parents	____	____	____	____
the facilities:				
physical (sleeping, eating, toileting)	____	____	____	____
recreational	____	____	____	____
support services to parents:				
counselling	____	____	____	____
advice & referral	____	____	____	____
parent groups	____	____	____	____

	poor	fair	good	excellent
Please rate the overall value of this service to your family.	____	____	____	____

Appendix B: Year II Data Collection Forms

(Strategy # 1)

Parent Interview Relationship to child________ I.D. #______

Interviewer's Initials________

Child's Name________ (first) ____ (first initial of last name) Age____

A. SERVICE UTILIZATION

1. Which UCP services are you or your child currently using?

Infant Program____
Children's Developmental Program____
Adult Services____
(personal & work, independent living skills, workshop employment)
Other________

Respite Care Service:
In-Home ____
Out-of-Home ____
Independent Living____
Recreation____
(Bowling, Crusaders, Rays)

2. In the past year did you use any UCP service that you are not presently using? YES____ NO____

(If YES, which one?)________ Period Used:________

Other services used (not UCP)________

FOR RESPITE CARE PROGRAM USERS ONLY (IN-HOME, OUT-OF-HOME, BOTH)

	Out-of-home	In-home
3. When did you begin using this respite care service?	____	____
4. When was the last time you used this respite care service?	____	____
5. How many times have you used this respite care service during the past year?	____	____
how many days (or hours) each time?	____	____

6. How did you hear about this respite care program?________

7. Do you know about any other respite care programs that might be available to you? YES____ NO____

(If YES, which one[s]?)________

Have you ever used another respite service? YES____ NO____

When?________

For how long?________

8. Do you have any unmet needs for relief? (Needs not satisfied by the respite care services used.) YES____ NO____

What is the nature of this need?________

How could this need be met?________

9. (FOR FAMILIES WITH CHILDREN UNDER 6 WHO ARE NOT IN PRESCHOOL OR INFANT PROGRAM)

Why is your child not in a preschool or infant program?

10. (FOR FAMILIES WITH CHILDREN OVER AGE 18 WHO ARE NOT IN A DAY PROGRAM)

Why is your son/daughter not in a day program or workshop?

Additional Questions for Special Conditions

FOR FAMILIES USING OUT-OF-HOME RESPITE CARE ONLY

11. If an in-home service were made available, in addition to the out-of-home service, would you consider using it?

YES_____ NO_____ WHY______________________________
(under what circumstances)

12. If an in-home service were established, what kind of a respite care worker would you need? (babysitter/companion, a home health aide, a homemaker)

13. Are there any other conditions essential to your willingness to use in-home services?
(meeting the worker before hand, qualities of the respite care worker, e.g., training, experience, age, sex)

FOR FAMILIES USING IN-HOME RESPITE CARE ONLY

14. Why haven't you used the out-of-home service?

15. Are there any circumstances under which you would use it?

FOR FAMILIES NOT USING RESPITE CARE SERVICES

16. Do you have any unmet needs for relief?
YES_____ NO_____

What is the nature of this need?______________________________

How could this need be met?______________________________

17. Do you know about UCP's respite care program? YES_____ NO_____
(If YES, why haven't you made use of it?) ______________________________

18. Do you know about any other respite care program that might be available to you? YES_____ NO_____
(If YES, which one(s)?)______________________________
(If YES, why haven't you used it?)

19. Has your child ever lived out of the home for more than a month?

YES________ NO________

(a) If YES, at what age____________

(b) For how long________________

(c) How many such placements_____________

(d) What type of residence________________

(e) When you made this placement, did you think of it as
permanent________________ or temporary_____________________

(f) What was the reason for this out-of-home placement____________________
____

FOR FAMILIES THAT HAD AT ONE TIME PLACED THEIR
CHILDREN OUT-OF-HOME FOR MORE THAN A MONTH

20. Did you know about respite care before you took your child home?
YES______ NO______

(If YES, did this influence your decision to take him/her home?) YES___ NO___

(If YES, explain.)

21. If respite care services had been available before you placed your child, do you think it would have made any difference in your decision to place him/her? YES______ NO______

How?____________________________________

B. FAMILY CHARACTERISTICS

1. Child's date of birth: Month____________ Year____________

2. Male_____ Female_____

3. Caucasian_____ Black_____ Spanish(born in Spanish speaking country)_____
Oriental_____ Other_______________

4. What is your age (mother) Under 18___ 18-24___ 25-34___ 35-50___ Over 50___
Age of spouse (father) Under 18___ 18-24___ 25-34___ 35-50___ Over 50___

5. What is your marital status?
married___ single___ divorced___ widowed___ other__________

6. What is your occupation?____________________________________
Are you employed? YES_____ NO_____ full time_____ part time_____

7. What is your spouse's occupation____________________________________
Is he/she employed? YES_____ NO_____ full time_____ part time_____

8. What was the highest school level you completed? elementary_____
jr. high_____ high school_____ trade school_____ college or above_____

9. What was the highest school level your spouse completed? elementary_____
jr. high_____ high school_____ trade school_____ college or above_____

10. Were both parents born in one of the 50 states? YES_____ NO_____
(If NOT, how many years has he/she resided in the U.S.?)
mother_____ father_____

11. Is your family receiving any economic assistance? YES_____ NO_____
(If YES, what type of assistance?)____________________________________

12. How many people live in your home?____________
Besides your handicapped child, how many are:
children under 6_____ children 6-18_____ adults over 18_____

13. What is your child's primary disability?
cerebral palsy_____ mental retardation_____ other(specify)______________
If multiply handicapped, list additional disabilities.

	None	Mild	Moderate	Severe
14. Does your child have a motor problem?				
15. Does your child have any speech problem?				
16. Does your child have problems in understanding?				
17. Does your child have any problems in feeding, dressing, toileting?				
18. Does your child have behavior problems?				

19. Is there any other person(s) who is disabled living in your house? YES___ NO___
(If YES:

Relationship to handicapped child?	Type of disability?	Severity of disability?	How long disability present?

20. How much time each day (or week) is your child out of your home and not in your care? hours per day_____ hours per week_____

21. Of the time your child <u>is</u> home, do you have any help from other family members for caring for him/her? YES_____ NO_____
(If YES, how much?) a lot_____ some_____ very little_____

22. How much help do you get from people outside your home in taking care of your child? hours per day_____ hours per week_____

Describe type of help:

paid babysitter_____ agency provided homemaker or respite care worker_____

relative_____ other_____

23. Are there other relatives, friends, or neighbors that can be called on when:

(a) The family is in special need of help with the child? YES_____ NO_____

Describe who they are and what kind of help they give:

(b) You (and your husband/wife) need to communicate with someone about your handicapped child? YES_____ NO_____

Describe who they are:

QUESTION 24 ONLY IF CHILD HAS PHYSICAL DISABILITY

24. Are there any steps that have to be climbed to get into your home? YES_____ NO_____ HOW MANY_____

Are there any steps that have to be climbed to get to your child's bedroom? YES_____ NO_____ HOW MANY_____

C. SATISFACTION WITH RESPITE CARE SERVICE

1. Do you plan to continue to use respite care services? YES_____ NO_____
MAYBE(explain)____

2. Why haven't you used it more?

3. Did you need this service for more time than it was available?
YES_____ NO_____ MAYBE(explain)____

4. Do you feel this service was helpful to you and your family? YES_____ NO_____

5. What aspects of this service were most helpful to you?

6. What aspects of this service are in need of improvement?

7. Would you recommend this service to another family? YES_____ NO_____

HOW SATISFIED ARE YOU WITH:	very satisfied	somewhat satisfied	somewhat unsatisfied	very unsatisfied
8. The total amount of time that the service is available?				
9. What your child does while he/she is there?				
10. the facilities: (sleeping, eating, toileting				
HOW SATISFIED ARE YOU WITH THE STAFF'S ABILITY TO: 11. relate to child?				
12. deal with special needs of child?				
13. relate to parents?				
14. deal with emergencies?				

15. Now please rate the overall value of this service to your family:
poor_____ fair_____ good_____ excellent_____

16. Apart from the respite care service, do you feel a need for additional help in learning to deal effectively with your child's needs? YES_____ NO_____
(If YES, explain)

17. (For families that have used both in-home and out-of-home respite care)
Which type of respite care do you prefer?____________________ WHY____________________

D. FAMILY FUNCTIONING

1. When your child was in respite care, how did you use the time? (vacation, medical needs, service to other family members, personal activities, rest)

2. If you had not received this service, what would you have done? (If this service had not been available, how would your family have been affected?)

SINCE YOU BEGAN USING RESPITE CARE:	Yes	No	How increased	decreased
3. Has the number of disagreements between you and your husband about your handicapped child changed?				
4. Has your satisfaction with life changed?				
5. Has your hopefulness about a good future for your family changed?				
6. Has the overall ability of your family to cope with having a handicapped child in the home changed?				
7. Has knowing that the service is available affected your attitude toward your child?				
8. Has the number of times you have seriously thought about out-of-home placement for your child changed?				
9. Has your feeling toward your handicapped child changed?				

10. What is the likelihood that your family will decide to place your handicapped child in a permanent out-of-home residence?

none_____ very little_____ possible_____ great_____

The City University of New York is currently studying the characteristics of people who provide respite services to developmentally disabled clients. In order to obtain this information, agencies in different parts of the country are cooperating by asking their workers to fill out the enclosed questionnaire.

We would greatly appreciate it if you would complete the attached questionnaire. The identity of each worker will be kept confidential.

Name of Agency____

Worker: ________________ ________________ ________
(first name) (middle name) (first 2 letters of last name)

RESPITE CARE WORKER QUESTIONNAIRE

NOTE: In this questionnaire the term respite care will be used to mean temporary care of children or adults who are disabled so as to provide relief for their families as well as service to the clients.

1. AGE: 18-21_____ 36-45_____ SEX: male_____ female_____
22-25_____ 46-55_____
26-35_____ 56 and over_____

2. MARITAL STATUS: married_____ single_____ widowed_____ divorced_____
number of children_____

3. What is the highest level of school you completed?

elementary school_____
junior high school_____
high school_____
vocational or business school_____
junior college_____
college or university_____
other(describe)________________

4. If you attended a school after high school, what was your major area of study?

5. During your last year of school, what kind of work did you plan or want to do after finishing your education?

6. In what kind(s) of settings have you been a respite care worker?

client's home_____
out-of-home respite care center_____
your own home_____
residential center_____

7. How many years were there between your completion of school and the beginning of your work as a respite care worker?

less than 1 year_____
1-3 years_____
4-5 years_____
6-9 years_____
10-15 years_____
more than 15 years_____

8. List the kinds of work you did between your completion of school and the beginning of your work as a respite care worker.

Type of work	Number of years

9. If you did volunteer work before becoming a respite care worker, describe this volunteer work.

Type of work	Number of years

10. Do you have a disabled (handicapped) person in your immediate family (i.e., your mother, father, sister, brother, husband, or child)? YES_____ NO_____

If YES, what is the relationship?_____

11. Did you have close contact with a disabled (handicapped) relative or friend during your childhood or adulthood? YES_____ NO_____

If YES, please describe the handicap, the relationship and how it affected you.

12. When you first took this job, did you think of it as something you wanted to do permanently or did you consider it temporary work until you could get another kind of job?

permanent_____ temporary_____

13. For how long have you been a respite care worker?

less than one year_____
1-3 years_____
4-5 years_____
6-9 years_____
10-15 years_____
more than 15 years_____

14. Are you going to school now? YES_____ NO_____

If YES, what is the purpose? (Check the appropriate line(s))

(a) to get a degree_____
(b) to improve my skills in this field and/or to qualify for a promotion_____
(c) to get another type of job in the field_____
(d) to work in another field_____

15. For how much longer do you expect to be a respite care worker?

less than 2 years_____
2-5 years_____
more than 5 years_____

16. What kind of training did you have before you were hired that helped you as a respite care worker, e.g., a community college course in recreation, a special education course on the severely retarded.

17. What kind of training did you receive when you were hired as a respite care worker?

Type of Training	Number of days
individual orientation________	____
lectures and workshops________	____
observation of another worker on the job________	____

18. Have you had the Red Cross Standard First Aid Course? YES___ NO___ YEAR________

19. What kinds of experiences other than formal training or education have you had that you feel helped you become a good respite care worker?

20. Describe your current position. (Check as many as you need to.)

full time_____
part time_____

regular hours_____
on call_____

days_____
evenings_____
overnight_____
weekends_____

21. What kind of settings do you currently work in?

client's home_____
out-of-home respite care center_____
your own home_____
residential center_____

22. Describe the clients you work with.

Major disability
mentally retarded_____
physically handicapped_____
emotionally disturbed_____
multiply handicapped_____

Client Age
0-5 years_____
6-12 years_____
13 years and over_____

23. Are there any kinds of clients that you feel you cannot work with well?

YES_____ NO_____

If YES, which ones?

mentally retarded_____
physically handicapped_____
emotionally disturbed_____
multiply handicapped_____
other(please describe)______________________________

0-5 years_____
6-12 years_____
13 years and over_____

24. What behavioral characteristics do you think make for an effective respite care worker?

(Please rate the importance of the behavioral characteristics listed below.)

Behavioral Characteristics	very important	of some importance	not important
1. Exhibits dependability (punctuality, low absenteeism, carrying out of responsibilities).			
2. Displays a positive outlook, pleasant mood and sense of humor.			
3. Exercises good judgment (common sense).			
4. Demonstrates throughtful consideration and warmth toward client (affection, empathy, concern, good commuication).			
Demonstrates emotional stability and control in relation to clients (does not become overinvolved; ability to maintain objectivity).			
6. Can move into new situations with ease (flexibility, adaptability, resourcefulness).			
7. Works well with co-workers, supervisors and other team members.			
8. Demonstrates skill in assisting clients with self-help skills and other activities of daily living.			
9. Displays skill in management of household (food preparation, housekeeping).			
10. Manages medical routines effectively.			
11. Communicates supportively with parents and other family members.			

BEHAVIORAL CHARACTERISTICS RATING FORM

Name of Worker: ________________ ________________ ________________
(first name) (middle name) (first 2 letters of last name)

Rating: Top 15%_____ Bottom 15%_____

Please rate the frequency with which the worker named above exhibits the following behavioral characteristics.

Behavioral Characteristics	Frequency			
	Almost always	Often	Sometimes	Seldom
1. Exhibits dependability (punctuality, low absenteeism, carrying out of responsibilities).				
2. Displays a positive outlook, pleasant mood and sense of humor.				
3. Exercises good judgment (common sense).				
4. Demonstrates throughtful consideration and warmth toward client (affection, empathy, concern, good commuication).				
5. Demonstrates emotional stability and control in relation to clients (does not become overinvolved; ability to maintain objectivity).				
6. Can move into new situations with ease (flexibility, adaptability, resourcefulness).				
7. Works well with co-workers, supervisors and other team members.				
8. Demonstrates skill in assisting clients with self-help skills and other activities of daily living.				
9. Displays skill in management of household (food preparation, housekeeping).				
10. Manages medical routines effectively.				
11. Communicates supportively with parents and other family members.				

(THIS FORM TO BE COMPLETED BY ADMINISTRATIVE OR SUPERVISORY PERSONNEL.)

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UNITED CEREBRAL PALSY ASSOCIATION
of PHILADELPHIA AND VICINITY

A WORKSHOP EXPLORING
"THE CONCEPT OF RESPITE CARE"

SEPTEMBER 1980

Made possible through United Cerebral Palsy Associations
and the City University of New York Special Education
Development Center as part of a Project funded by the
Federal Developmental Disabilities Office

"THE CONCEPT OF RESPITE CARE"

SCHEDULE

MONDAY - September 8, 1980

8:30 - 9:15	Registration
9:15 - 9:30	Welcome *Willis A. Dibble, Jr.*
9:30 - 10:00	Project Description *Rachel Warren*
10:00 - 10:30	Parent Panel *Clara Holgate Kovacs* *Marjorie Jett-El* *Pat Thornton*
10:30 - 10:45	Break
10:45 - 11:45	Research Discussion *Shirley Cohen, PhD*
11:45 - 1:00	LUNCH
1:00 - 2:30	Federal, State and Local Perspectives on Respite Care Panel Discussion *Edythe Ballard* *Arthur Geisler* *E. Clarke Ross*
2:30 - 3:00	Presentation of a Rural Respite Care Model *Ruth Shook*
3:00 - 3:15	Break
3:15 - 5:00	Presentation of an Urban Respite Care Model *Ralph Mann* *Kay Weiss*

"THE CONCEPT OF RESPITE CARE"

SCHEDULE

TUESDAY - September 9, 1980

Technical Assistance Sessions

9:00 - 10:00	Staff Recruitment and Training
10:00 - 11:00	Miscellaneous Issues (ie; Committee Involvement Summer/Day/Long Term Respite Overlap and Coordination of Similar Systems Sexuality Considerations)
11:00 - 12:00	Pre Placement Responsibilities/ Maintenance of Routine
12:00 - 1:00	LUNCH
1:00 - 2:30	Family Support and Training
2:30 - 3:30	Policies and Procedures relevant to Respite Care

Appendix C: Materials for Strategy # 2

UNITED CEREBRAL PALSY ASSOCIATION, INC.
66 EAST 34th STREET
NEW YORK, N. Y. 10016

CONSULTANT TRAINING WORKSHOP: RESPITE CARE

SEPTEMBER 10, 1980

PURPOSE:

To enable individuals to be a resource to local affiliates in establishing and upgrading the quality of respite care programs.

OBJECTIVES:

1. To expand participants knowledge of respite care:
   - history
   - models
   - concepts
2. To expand participants skills in consulting with local staffs about respite care programs.
3. To expand participants knowledge of potential funding sources and procedures.
4. To expand participants knowledge of parent training models and significant dimensions of parent training programs.

UNITED CEREBRAL PALSY ASSOCIATION, INC.
66 East 34th Street
New York, N. Y. 10016

AGENDA

WEDNESDAY September 10, 1980

	Coffee and Danish	
8:45 - 9:00	Introduction, purpose	Rachel Warren
9:00 - 9:30	Knowledge Base - History - Models - Concepts	Rachel Warren
9:30 - 10:00	Funding	Clarke Ross
10:00 - 10:15	Questions	
10:15 - 10:30	Break	
10:30 - 11:15	Parent Training	Nancy Koehler
11:15 - 11:30	Questions	
11:30 - 11:45	Snack Break	
11:45 - 12:15	Parent Counseling/Support	Margaret Schilling
12:15 - 12:45	Consultation Process	Rachel Warren
12:45 - 1:15	Questions	
1:15 - 2:00	Informal Resource Review	

RDW:hd
8/25/80

RESPITE CARE WORKSHOP
September 8, 9, 1980

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REQUEST FOR INFORMATION

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Request for Information (cont'd)

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Synopsis of In-Home Respite Care

Pilot Project

UCP of Philadelphia and Vicinity

For the past year, a national grant has made available a limited amount of money for UCPA of Philadelphia to provide In-Home Respite Care in addition to its Out-Of Home service.

In accordance with the established priorities for service, seventeen(17) clients were served on twenty-eight(28) separate occasions. Of the 17 clients, thirteen have a physical disability. Of those 13, eight(8) did not have a diagnosis of mental retardation.

Eight of the seventeen used the hourly service, three used the overnight(PM,sleepover,AM) and six used the round the clock(24 HRS) service. The range of usage was from one to four times, with the clients being repeat users numbering five.

The twenty-eight occurences of service ranged from four hours to three weeks. Of these, five were emergencies and twenty-three were pre-planned.

Major benefits seen by UCPA of adding this service to its existing model are the increased flexibility to serve larger numbers, especially during high demand periods such as week-ends; the ability to serve clients for shorter periods over extended crises; and the ability to serve the mentally alert/physically disabled client-something that is an impossibility in the categorically funded Out-of-Home model.

NAME	AGE	DISABILITY	LENGTH OF RESPITE	REASON FOR RESPITE
CYNTHIA H.	29	Cerebral Palsy - Fractured back	9:00 a.m. -1:00 p.m.	Client fractured back and has a newborn baby, Needed help with lifting & chores until other assistance was found.
FELIPE C.	3	Severly involved Cerebral Palsy, seizure disorder, gastrostomy	4 Sunday evenings 6:00 p.m.-10:00 p.m.	Mother wanted to attend church services- had never been away from the home prior to Respite.
KATHY & PATTY O'NEIL		Severely involved, Cerebral Palsy, non-ambulatory	3 full days from 10:00 a.m. -10:00 p.m.	Mother needed Respite to attend outings with a social group.
DARREN B.	19	Profound mental retardation	1 Saturday from 5:00 o.m. -10:00 p.m.	Single parent with Darren and four other siblings.
DAVID B.	38	Moderate mental retardation with Cerebral Palsy	3 weeks of service by male attendant, 5 hours per day (broken up)	David had an operation to improve ambulation, Unfortunately, his condition worsened along with his attitude and mother couldn't lift him to bathe or transfer to and from bed.
ROSEMARIE K.	23	Severe Mental retardation	1 evening 7:30 - 11:00	Parents have a family event and there was no space in or out of home respite for Rosie
GOLAN H.	12	Cerebral Palsy non-ambulatory	7:00 - 12:00 on a Saturday evening	Parents attending a wedding in family

FAMILY CONSTELLATION	ALTERNATIVE SUPPORTIVE SERV.	B.S.U. AFFILIATE
Single parent and newborn	NONE	NONE
Single parent with Felope and 2 year old daughter	None	COHMAR
Single parent with Patty and Kathy	NONE	NONE
Single parent	Attends Hill School	Einstein
Single parent with David and four other siblings	Out of home respite prior to operation through U.C.P.A.	Northeast
Mother and father	Out of home respite Vocational habilitation day program	Northeast
Mother and father and nine year old sister	Attends Widner School	None

FAMILY CONSTELLATION	ALTERNATE SUPPORTIVE SERVICE	B. J.
Only child, lives with Mother, father deceased	U.C.P.A. workshop and Partial Hospitalization Program	Catchment Area #4
Single parent with Horace and one brother	U.C.P.A. boy scouts	Catchment Area #4
Mother, father, Marc, and three other siblings	Kencrest preschool Developmental for Autistic	COHMAR
Husband and Nancy	None	None
Foster mother and Marcellus	Marshall School	Northeast
Mother and Sonia	U.C.P.A.	Northwest
Mother and father	None	Catchment Area #20
Mother and father	U.C.P.A. day program	COHMAR
Foster mother	U.C.P.A. day program	Northeast

MEMOIRS OF RESPITE CARE PROJECT

I quite readily agreed to participation by our affiliate in the Respite Care Project. The concept of "respite care" was certainly not new to me, but we did not have a program that I perceived as having the primary purpose of respite care, nor had any of us at this affiliate been directly associated with a full-blown primary service respite care program. I wanted to know more about this area of program and was intrigued by the idea of being part of a broad multi-faceted project as this one would be. Our affiliate has been part of other United Cerebral Palsy projects and those experiences have been very positive ones, with, of course, responsibilities on our part but many benefits resulting from the participation. I felt a good way to learn more about respite care was by becoming actively involved in this project. I was not disappointed!

During the first year of the project, I had trouble "getting into it" - moving beyond the global definition of respite care that had been adopted in the grant and into the actual activities of the project. Pre-school, camp and home-based infant program - these I perceived as direct child services with camp being the only one with an identified respite component. However, for purposes of the project, the others were treated as respite services, also.

The above comments are not to be interpreted to mean that the project did not take shape and progress as planned. The grant as written provided the framework for the development of project activities and as with any good plan, there was room for movement - movement in directions that were appropriate for us in our geographic area, with our service program and with current fiscal limitations, for modification and/or adjustment of goals and objectives without losing sight of the main goal of the project.

Early in the project, it was apparent that a community organization model was indeed the best model to be considered for our affiliate. There were not sufficient monetary resources from the grant, the community, the state government or any other known agent to set up a new service - that of in-home or out-of-home direct respite care for families of developmentally disabled persons that would be an exemplary program. Broader utilization of existing services, enrichment provided as feasible, support and encouragement of parent activities, developing community awareness of what respite care is and why it should be part of the service delivery continuum, developing a mechanism for continuing to work for more respite services through the inter-agency Respite Care Committee (this committee placed a heavy emphasis on parents' needs and parent involvement) - these were all part of the first year's accomplishments and they continued to grow and develop through the second grant year.

The mix of research and direct service that the project provided for was not always compatible. These participants in each of these two areas - research and direct service - appeared to accept and appreciate the need for the other and their endeavors in their respective jobs, however, the mechanics of securing data for research purposes were not always understood or approved by direct caregivers. This data collection process was sometimes interpreted as an invasion of client privacy. On the other hand, the client concern that was often manifested by caregivers at the expense of research efforts was sometimes interpreted as being overprotectiveness and unreasonable thwarting of legitimate research work.

The project staff was excellent. Their individual skills and experiences provided a basis for contributions to both affiliate staff and Board members that were invaluable. The project itself was one that afforded an opportunity for staff and Board members to work as a team, sharing ideas and utilizing the expertise of the project staff and consultants together with their own abilities and knowledge to develop these ideas. One of the decided and obvious benefits to all of us at UCP of Northeastern Maine was the personal and professional associations provided during the two-year period of the project.

The second year of the project was more self-directed. We had a better understanding of what this project was about, what our responsibilities were and how we could benefit from the experience. Site visits were anticipated with pleasure and structured to provide a mix of site team-affiliate staff-affiliate Board-community people.

Would I do it again? Yes!

Regrets - that the project happened during a time that our affiliate was faced with unusual budget difficulties and reorganization following the transfer of all school-age children to public schools and terminating UCP's special education classes for school-age children. Staff energies were not always up to meeting project expectations. Frustrations on all sides resulted.

I am happy to say that our Respite Care Committee will continue to meet and work. The members know there are no easy solutions to meeting the respite needs of our families. They have made a commitment to do something and I believe they will. Adopting the community organization model means an on-going process by the affiliate and committee to search out interested and concerned community representatives to join our ranks. This should prevent the group and its work from becoming static and unproductive. It promises to continue to be an exciting project.

Ruth Shook
United Cerebral Palsy of Northeastern Maine

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United Cerebral Palsy of Northeastern Maine.

WORKSHOP

EXPLORING RESPITE CARE
Existing and Future Models Appropriate for Persons with Developmental Disabilities.

September 15-16, 1980

Airport Hilton Inn
Bangor, Maine

This Conference is made possible through United Cerebral Palsy Associations, Inc. and the City University of New York Special Education Development Center as part of a Developmental Disabilities Project of National Significance.

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Workshop Schedule

Monday - September 15, 1980

International Room

9:00 - 9:30	Registration and Coffee
9:30 - 9:45	Welcome Gerry Palmer
9:45 - 10:00	Overall Strategies of the Project Rachel Warren
10:00 - 10:45	Respite Care - Need or Luxury ? Margaret Schilling, M.S.W.
10:45 - 11:15	Respite Care - Word from Washington E. Clarke Ross
11:15 - 12:00	Research Discussion Nancy Koehler
12:00 - 1:00	Lunch in Cabinet Room B
1:00 - 2:30	Panel - Models of Respite Care Rachel Warren, Facilitator
	Philadelphia Model Marjorie Jett-El
	Kalamazoo Model Nancy Koehler
	Bangor Model Carolyn Garner Ruth Shook

2:30 - 3:30 **Models of Parent Training**

Philadelphia Model
  Nancy Koehler

Bangor Model
  Sally Healey

3:30 - 4:00 Summary
  Marty Thornton

Social Evening - To be announced

Tuesday - September 16, 1980

9:00 - 12:00 Discussion and Consultation

Rachel Warren
Margaret Schilling
Marjorie Jett-El
Representatives from Bangor Project

Summary
  Frank Setter

Individua[illegible]filiate Plan

UCP of Northeastern Maine
Year 2

Major Year 2 Activities:

Respite Care Committee
Parent Support Groups

Advocacy
Community Organization

Social/Recreational
Training: Parent/Personnel

Consumer Programs
A. RESPITE CARE COMMITTEE

Recommendations:	Follow-up:			
	Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
Respite Care Committee will define UCP role in relation to Respite Services	(See attached minutes of November 14). Role is one of coordination and community organization.	Complete		
	Job description prepared and will submit to CETA Lifte for funding by December 30, 1979.	Report results to Rachel Warren by April 1, 1980.		
Respite Care Committee will invite adults with cerebral palsy to join the Respite Care Comm. and the Social/Recreation Committee.	Contact has been made with adult with a disability for Respite Committee.	Complete		
	New board member who is a consumer will be placed on Social/ Recreation Committee	Report persons name by April, 1980.		

A. Respite Care Committee (continued)

Recommendations:	Follow-up:			
	Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
Consider other representatives for Respite Committee	Parent utilizing Levinson Center will be invited.	Complete		
	Parents Anonymous representative attended 11-14 meeting.	Complete		

I. Consumer Programs (continued)

B. PARENT SUPPORT GROUPS

Recommendations:	Follow-up:			
	Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
Begin planning next years Parent Statewide Meeting by Parents & Friends	Budget to be submitted by 12-79; UCP will support in some way.	UCP will contribute from the respite care budget $500. Support will be enlisted for Fall Regional Conference.		
UCP develop Parent Groups based on needs arising and identified in programs	Determine co-leaders and support resource person for social worker.	Complete. Support will be for supervision rather than group work.		
-Toddlers	Begin group of parents of toddlers on Thursday.	Will begin February 14 or 28.		
-School Program	Eliminate as need .			
-Millinockett -Dover-Foxcroft		Dover Foxeroft will be assumed as part of the pre-school site visit project.		

II. Advocacy

Recommendations:	Follow-up: Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
Determine role and functioning of the P & A System in Maine. Develop close linkages.	Dean Crocker of P & A System to be contacted for reporting on 2-12-80.	Report made - see interview.		
	Discuss mutual linkages with P & A System regarding respite services.	See interview,		
Define advocacy issues and strategies relative to respite care.	→	→		
Assign advocacy responsibilities	→	→	→	

II. Community Organization

A. INFORMATION/REFERRAL

Recommendations:	Follow-up:			
	Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
Define the respite care continuum existing in Bangor. Establish the continuum as part of an information/referral system.	Meet with Human Services, Information and Referral Services to pursue including respite care continuum as part of their system.	Interview Complete -Have information in 1980 MB & Health Directory. -Meet Harold Farmer for State I & R.		
Have a few families use various respite services and document experiences of a few families using respite service.		(Omit as recommendations)		
Define gaps in respite care continuum.		(Omit as recommendations)		
Input identified gaps to advocacy committee.		(Omit as recommendations)		

B. RESPTIE CONTINUUM

Recommendations:	Follow-up:			
	Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
1. The Counseling Center: Homemaker/Home Health Aides				
-Secure names of families having used HHHAS	→	Only one family identified.		
-Discuss experience of using services with staff of HHHAS and families.	→	Bob Dalecki will present staff development for UCP.		
-Follow through with 2 or 3 families to review experiences with services	→	A memo will be sent to families regarding service availability and way to utilize.		
	Follow-up with field testing of National Curriculum.			
2. County Extension Service	Have UCP staff present orientation to outreach workers	Complete		

B. RESPITE CONTINUUM (continued)

Recommendations:	Follow-up:			
	Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
	Prepare package of sitter brochures & infomation for extension.			
	Pursue method of input to babysitting curriculum at the Y.	Complete course for members of Y only.		
3. City and State Visiting Nurses				
4. Out-of-home respite (hospitals, group homes, nursing homes, etc.)	List out-of-home respite continuum.			
	Incorporate list as part of I & R.			
5. Sitter/Companion Services				
-Determine input into St. Joseph's companion sitter service	Bob Dalecki will prepare report.			
-YWCA/EXTENSION	Discuss sitting for children with special needs with extension. Team member should meet with YWCA to review their coordination and referral role for sitters.	-Members only		
6. BMR		Obtain copy of report. If appropriate send support letters.		
		Spread the word of respite care in formal way, newsletter, speakers		

IV. SOCIAL/RECREATION

Recommendations:	Follow-up:			
	Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
Explore year around socio-recreational possibilities.	John Martin will explore federal, state funding. Meetings to be held with relevant local, state agencies (adult ed, Y, extension, city/state parks, camps)	Investigate water safety staff from other agencies. Consider criteria for camp - # days - other camps		
Define plans for use of new camp building from May-November.	→	Consider 5th camp day for parent recreational activity.		
Hire camp director early	→			
Hire additional male counselors	→			
Address transportation concerns regarding camp	Regional planning effort underway. Will report.			
		Contact horticulture specialist for shrubs. Follow-up State Ed Department & Brewer Schools.		

V. TRAINING: Parents and Personnel

Recommendations:	Follow-up:			
	Site Visit 5	Site Visit 6	Site Visit 7	Site Visit 8
Implement parent training.	Subcommittee appointed to identify and prioritize training needs. Determine training, times, location. Explore other methods of parent training and student involvement (i.e. U of Maine, Orono)			
Conduct staff development	Determine needs, parameters and the way it relates to respite. Are there similarities with parent training needs (NDT, early intervention)			

Appendix D: Materials for Strategy # 3

The Special Education Development Center
Hunter College at CUNY, 440 East 26th Street, Room 715
New York, New York 10010
(212) 481-4323

Selected Parent Training Materials*

I. Materials For Professionals to Use With Parents

Baker, B. L., Brightman, A. J., Heifetz, L. J., & Murphy, D. M. Steps to independence: A skills training series for children with special needs. 1. Training Guide, 2. Behavior Problems, 3. Early Self-Help Skills, 4. Intermediate Self-Help Skills, 5. Advanced Self-Help Skills. Champaign, Ill.: Research Press, 1976.

Castro, G. CAMS: Curriculum and monitoring system: An early intervention program for the handicapped child. (1 cassette filmstrip kit, manual, 5 programs: 1. Receptive Language, 2. Expressive Language, 3. Motor Development, 4. Self-Help, 5. Social-Emotional.) New York: Walker & Co. $98.50 (Individual items sold separately.)

Exceptional Child Center. Parent training program. (7 slide carousel trays, 1 monitor's manual, 10 participant's manuals, 5 audio cassettes) 4 units: 1. Behavior, 2. Cues, 3. Reinforcement, 4. Programming and Recording. Exceptional Child Center, Outreach and Development Division, Utah State University, Logan, Utah 84322. Purchase $350.00.

Fredericks, H. D., Baldwin, V. L., Grove, D. N., & Moore, W. G. Toilet training the handicapped child. Monmouth, Oregon: Instructional Development Corporation, 1975.

Herst, J., Wolfe, S., Jorgensen, G., & Pallan, S. SEED--Sewall early education developmental activities for young children, birth - 3 years. Denver: Sewall Rehabilitation Center, 1973.

Marshall-Poweshick Joint County Department of Special Education. Parent discussion manual. (12 group sessions to stimulate discussions about preschool skills. Home activities and games included.) Marshalltown, Iowa: Area Education Agency 6, 1975.

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*Prices are provided for items costing $25.00 or more.

Project MORE: "Myself"--Daily living skills. (1 cassette, certificates and 13 booklets: 1. How to Do More (manual), 2. Eating, 3. Brushing Your Teeth, 4. Blowing Your Nose, 5. Washing Your Hands, 6. Taking Care of Your Complexion, 7. Washing Your Hair, 8. Using Deodorant, 9. Using a Sanitary Napkin, 10. Rolling Your Hair, 11. Taking Care of Eyeglasses, 12. Showering, 13. Shaving) Northbrook, Illinois: Hubbard, 1979.

Rossett, A. Parenting and the exceptional child. (To stimulate open-ended discussion and provide the basis for individual counseling--42 pages that can be used to make transparencies.) Arlington, Virginia: ERIC Document Reproduction Service, 1975.

Texas Institute for Rehabilitation and Research. Parental skills program--handicapped children. (10 Core-program units and 5 Handicap units, soft cover materials, set of slides and cassette tapes.) Houston, Texas: Interaction, Inc., 1979. $500.00

(Texts, workbooks and tapes available at individual prices.)

II. Materials For Parents

Bluma, S. M., Shearer, M., Frohman, A., & Hilliard, J. M. A parent's guide to early education. Portage, Wisconsin: Portage Project Cooperative Educational Service Agency 12, 1976.

Exceptional Child Center. Language packages. 1. A Language Program for Naming Common Objects, 2. Improving Speaking Skills, 3. Teaching the Retention of Important Oral Phrases and Numbers, 4. Emergency Telephone Skills. Exceptional Child Center, Outreach and Development Division, Utah State University, Logan, Utah 84322.

Exceptional Child Center. *Self-help and basic living skills I.* (11 booklets: 1. *Parent Guide to Packages*, 2. *Eating and Drinking*, 3. *Play Skills*, 4. *Toilet-Training* (short-term), 5. *Toilet-Training* (long-term), 6. *Matching Sizes, Shapes, and Colors*, 7. *Balanced Nutrition & Exercise*, 8. *Improving Speaking Skills*, 9. *Naming Common Objects*, 10. *Motor Development I*, 11. *Motor Development II*) Exceptional Child Center, Outreach and Development Division, Utah State University, Logan, Utah 84322. $38.00 (Individual items sold separately.)

Hanson, M. J. *Teaching your Down's Syndrome infant: A guide for parents*. Eugene, Oregon: Center on Human Development, University of Oregon, 1977.

Hofmeister, A. M., & Hofmeister, J. *Training for independence.* 1. *A program for teaching the understanding of functional words and phrases*. 2. *A program for teaching independent use of zippers, buttons, shoes and socks*. Niles, Illinois: Developmental Learning Materials, 1977.

Karnes, M. B. *Learning language at home*. (3-5 year level). Reston, Virginia: The Council for Exceptional Children, 1977. (Box of 200 sequenced color coded cards with skill activities.)

Karnes, M. B. *Karnes early language activities*. (18-36 month level). Champaign, Illinois: Generators of Educational Materials, 1975.

Wood, J. M. Ed. *Infant stimulation curriculum*. Columbus, Ohio: The Nisonger Center, 1976.
(color-coded cards with easy-to-understand instructions.)

III. Audiovisual Materials for Training Parents*

CYNTHIA DRESSES HERSELF
color - 10 minutes - 1970
Learning principles necessary for teaching specific dressing behaviors.
Exceptional Child Research Program, Monmouth, Oregon 97361

KIRSTEN LEARNS TO EAT
color - 11 minutes - 1969
Techniques that can be used in teaching a physically handicapped child to eat independently.
Exceptional Child Research Program, Monmouth, Oregon 97361

PARENTAL RIGHTS AND ROLES UNDER 94-142*
slide/tape
Chapel Hill Training Outreach Project, Lincoln Center, Chapel Hill, N.C. 27514 $25.00

PARENTING HANDICAPPED CHILDREN: EARLIEST EXPERIENCES
109 slides/22 minute cassette - 1976
Materials Distribution, Rehabilitation Research and Training Center in Mental Retardation, 2nd floor, Clinical Services Building, University of Oregon, Eugene, Oregon 97403
Purchase: $85.00

THE RIP EXPANSION PROJECT:*
1. Parents Helping Parents Helping Children: A Model for Early Intervention.
2. The Support Just Flows.
3. Using Skills Effectively: A Compentency-Based Training Program

3 slide/tape kits - 1978
The RIP Expansion Project, 2400 White Avenue, Nashville, TN

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*The starred items listed have not been reviewed but from the descriptive literature they appear to be valuable.

THE RIP PROJECT:*
1. <u>That's What It's All About</u>.
2. <u>Toddler Management</u>.
3. <u>Individual Tutoring</u>.
4. <u>Language Classroom</u>.

four 16 mm films - 1972
National Audiovisual Center, Washington, DC 20409

SARA HAS DOWN'S SYNDROME
color - 16 minutes - 1974
Her family discusses their feelings about six year old Sara who has Down's Syndrome.
EDC Distribution Center, 39 Chapel Street, Newton, MA 02160

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*The starred items listed have not been reviewed but from the descriptive literature they appear to be valuable.

The Special Education Development Center, Hunter College at CUNY
440 East 26th Street, Room 715, New York, NY 10010

A SELECTED LIST OF PARENT TRAINING/SUPPORT PROGRAMS

Baby Buggy
Macomb 0-3 Regional Project
College of Education
27 Horrobin Hall
Western Illinois University
Macomb, IL 61455

Cooperative Extension Project for the Handicapped (CEPH)
Exceptional Child Center (801) 752-4100
Utah State University Ext 7753
Logan, UT 84322

FACT
(Family and Child Training Program)
1020 William Street (310) 338-9212
Iowa City, IA 52240

Kendall County Special Education Cooperative
Early Childhood Program
Bingam Administration Center
South Hale Street
Plano, IL 60545

The Nisonger Center
Parent-Infant Project
Ohio State University (614) 422-9670
1580 Cannon Drive
Columbus, OH 43210

PACER Center, Inc.
4701 Chicago Avenue, So. (612) 827-2966
Minneapolis, MN 55407

Parent Education Program
Center on Human Development
University of Oregon (503) 686-3591
901 East 18th Street
Eugene, OR 97403

Parent Education Project
School of Education
University of Louisville
Louisville, Kentucky

Parent Involvement Center
1700 Pennsylvania N.E. (505) 292-0101
Alburquerque, NM 87110

PEECH(Precise Early Education of Children with Handicaps)
403 East Healey (217) 333-4891
Champaign, IL 61820

PEERS(Parents are Effective Early Education Resources)
Philadelphia ARC
1211 Chestnut Street (215) LO-7-3750
Philadelphia, PA 19107

Pilot Parents
3212 Dodge Street (402) 348-9220
Omaha, NB 68131

Portage Project
Cooperative Educational Service Agency
412 East Slifer Street (608) 742-5342
Portage, WI 53901

Project P.A.C.E.(Parent Action in Childhood Education)
c/o Area Residential Care, Inc.
2909 Kaufmann Avenue (310) 556-7560
Dubuque, IA 52001

Project Train:
A Model Minicourse of Parental Involvement
in the Special Education Process
University of Hartford
Hartford, Connecticut

Respite Care Co-op Program
Family & Childrens Services
1608 Lake Street (616) 344-0101
Kalamazoo, MI 49001

R.I.P.
Regional Intervention Program
2400 White Avenue (615) 269-5671
Nashville, TN 37204

Teaching Research Behavioral Clinic
Teaching Research Infant & Child Center
345 N. Monmouth (503) 838-1220
Monmouth, OR 97361 Ext 401

Week-End College
Department of Special Education
Winthrop College (803) 323-2151
Rock Hill, SC 29733

Retarded Infants Services, Inc.
386 Park Avenue South, New York, N. Y. 10016 Tel: (212) 889-5464

Families of handicapped children often ask for help in learning to better care for their handicapped children. Retarded Infants Services is working with The Special Education Development Center at Hunter College in planning a series of training sessions for families known to our Agency. Your family can help us plan training meetings which will meet your needs by answering this form.

Name(s) of handicapped child(ren) ______________________________ Age ____
(First, last)

______________________________ Age ____
(First, last)

Parent(s) or Guardians(s) ______________________________
(First, last)

____
(First, last)

Address ______________________________
#street city zip code

Phone Number ______________________

If anyone other than you and/or your husband (such as grandparent, brother, sister or neighbor) cares for your handicapped child(ren) and would like to attend these meetings, have them answer in the boxes marked "Other."

Look over the list of possible training areas. There are separate boxes for the choices of each individual. Each person should put a #1 in the box next to the training she or he wants most. Write #2 for the next most important area. Numbering should be continued for all the training areas that anyone is interested in.

After training areas are numbered, be sure to check off the skill levels that apply to your child(ren). If you have particular problems that are not listed in a specific skill area and that you would like help with, please briefly describe them next to the blank line provided for each area. Under the training area labeled "Other," please list any additional areas of concern that you may be interested in.

TRAINING AREAS

	Mother	Father	Other	
FEEDING	☐	☐	☐	______ (Describe relationship to child)

_____spoon feeding; drinking from a cup

_____self feeding

_____nutrition and health

_____

	M	F	O
DRESSING	☐	☐	☐

_____putting on and removing clothing

_____zippering, buttoning, buckling and tying

_____

	M	F	O
TOILETING	☐	☐	☐

_____beginning toilet training

_____improving toileting habits

_____

	M	F	O
PERSONAL HYGIENE	☐	☐	☐

_____bathing--grooming

_____teenage health problems

_____

TRAINING AREAS

	M	F	O
COMMUNICATION	☐	☐	☐

_____improving understanding

_____developing and improving speech

_____

	M	F	O
LEARNING SKILLS	☐	☐	☐

_____thinking and memory

_____pre-reading

_____arithmetic in the home

_____

	M	F	O
MOTOR DEVELOPMENT	☐	☐	☐

_____large muscle(sitting, walking, throwing a ball)

_____small muscle(reaching, grasping, handling objects)

_____

	M	F	O
BEHAVIOR MANAGEMENT	☐	☐	☐

_____developing good discipline

_____changing problem behavior

_____dealing with sleeping problems

_____home learning skills(manners, helping around the home)

_____

TRAINING AREAS

ADVOCACY M ☐ F ☐ O ☐

_____ knowing your rights in dealing with the system (education, medical, etc.)

_____ where to get information about services

_____ evaluating the effectiveness of services

_____

OTHER AREAS M ☐ F ☐ O ☐

Some family members may choose to attend one training session, and others more than one. In order to plan these sessions, we would like each person to indicate their two most convenient times of the week. Look over the choices and fill in the times that are best.

Weekdays (Mon to Fri)

Mornings

Afternoons

1-3

3-5

Evenings

7-9

Weekends

Saturday Morning

Saturday Afternoon

Sunday Afternoon

	Day of Week	Time of Day
Mother		
First choice (1)	______	______
Second choice (2)	______	______
Father		
First choice (1)	______	______
Second choice (2)	______	______
Other (describe relationship to child)		
First choice (1)	______	______
Second choice (2)	______	______

Parent Training Questionnaire

Name(s) of handicapped client(s):

____ age____
(first) (last)

____ age____
(first) (last)

Names of parents or guardians:

____

____

Address:________________________________
(street)

____
(city, state, zip code)

____
(phone number)

1. Would you be interested in participating in training sessions for parents of developmentally disabled children: YES____ NO____

2. What topics would interest you most? (check one or more)

   Toilet Training ____
   Feeding ____
   Communication ____
   Behavior Management ____
   Personal Hygiene (dressing, grooming) ____
   Advocacy ____

   If there are any other areas that would interest you, please list below:

3. How often would you want these training sessions to be held? (check one)

   once a week ____ once every two weeks ____ once a month ____
   two to four times a year ____

4. Would you be able to make your own arrangements for the care of your child so that you could attend these sessions? YES____ NO____ MAYBE____(please explain)

5. If the training sessions were held at the UCP center or a local college, would you be able to arrange your own transportation? YES____ NO____ MAYBE____(please explain).

6. Which time schedule would you prefer?

   1½-2 hour sessions____ half-day (3-3½ hours) sessions____
   all day (6-7 hours) sessions____

Additional Comments:

1H

TEMPLE UNIVERSITY
COLLEGE OF EDUCATION
PHILADELPHIA, PENNSYLVANIA 19122

DEPARTMENT OF SPECIAL EDUCATION
EARLY CHILDHOOD HANDICAPPED
EDUCATION OF THE HEARING IMPAIRED
EDUCATION OF THE VISUALLY IMPAIRED
MILDLY HANDICAPPED
SEVERELY AND PROFOUNDLY IMPAIRED

August 15, 1980

Ms. Nancy Koeheler
Special Education Development Center
Hunter College
440 East 26th Street
New York, New York 10010

Dear Nancy,

This letter is to share some of my views on the parent training program conducted in co-operation with the United Cerebral Palsy Association of Philadelphia and the grant to Hunter College.

The students were assigned to a parent in co-operation with UCPA. An initial orientation meeting was held for initial parent-student contact and an review of the program services. Many of the parents failed to attend this meeting although attempts were made to schedule it at a time convenient for them. Students who failed to meet the parent they were to work with at this meeting contacted them by phone and arranged an initial meeting. Students were then assigned to co-operatively assist the family in an area of behavior management. Students reports have been forwarded to the agency.

The parent training experience was, I feel, a very positive experience for the graduate students involved. Advantages included:

1. Direct contact with the parent of a handicapped child;
2. Exposure the realities of programming in a home environment;
3. In many cases, success in producing change;
4. The opportunity to discuss home training experiences in a coursework setting (Spec. Ed. 581). This forum allowed students to share successes, failures, and discuss alternative approaches.

For most students there were no major difficulties in contacting parents or arranging mutually agreeable times for home visits. The major difficulty many students faced was having the parents understand the exact nature of the program and its objectives. While UCPA staff reported this had been done for all parents, students reported they felt the parents only poorly understood the nature and direction of the program.

Needed components of a model like this would be as follows:

1. Clear information to parents on nature, focus and expected outcomes of project
2. Students who are sophisticated in behavior management strategies
3. An initial group meeting where students and parents can meet for the first time.
4. A forum for students to share ideas, experiences and concerns
5. An agency follow-up program for parents so they aren't left high and dry when student involvement ends.

For a first time attempt, I feel, the project was very worthwhile. Both student needs and parents needs were considered and it was a valuable outlet for parent concerns. As you have seen from some of the student reports, it was an exposure for some of the students on how the service delivery system often ignores parent needs. The project helped some parents address their important concerns about their handicapped child.

Sincerely,

Terry D. Meddock, Ph.D.
Associate Professor
Special Education

TDM:cbm