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ABSTRACT

A study of Newfoundland's and Labrador's Direct Home Services Program (DHSP) for families of developmentally delayed infants and preschool-age children evaluated current efforts and obtained data for use in the development of strategies for future interventions. The study had six purposes: (1) to examine parents' early experiences pertaining to the detection of their child's problem, awareness of and access to early intervention services, and contact with support groups; (2) to analyze parental perceptions and satisfaction regarding the early intervention program, including perceptions about the intervention worker's competence and professional skills; (3) to appraise parental expectations about the child's future and the relationship between these expectations and the perceived severity of the child's handicap or delay; (4) to obtain a measure of parent-child interactive play, both in terms of variety of activities and the frequency with which interactive play occurred; (5) to ascertain the program's effectiveness relative to the child's developmental progress; and (6) to examine the role that family ecological variables played in the intervention process. Findings are discussed. Nearly 50 references are cited. A questionnaire and fact sheet are appended. (RH)

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EARLY INTERVENTION WITH DEVELOPMENTALLY DELAYED INFANTS AND PRESCHOOL CHILDREN IN NEWFOUNDLAND AND LABRADOR

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We are grateful also to all responding parents for the time they took to share with us their perceptions about the intervention programme. Finally, our appreciation goes to all the children who, together with their families, are teaching us how to develop and implement more effective intervention programmes.

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CHAPTER I: INTRODUCTION AND BACKGROUND TO THE STUDY

Intervening early in the lives of children who are developmentally disabled or at risk for developmental and functional delays has become a significant feature of educational and social service delivery systems throughout North America and other parts of the world. The prominence that early intervention work has attained since the 1960s in North America is perhaps the result of a number of interrelated factors. Significant shifts in societal attitudes towards handicapped persons, coupled with new and increasingly expanding knowledge about the impact of early experience and environments on the developmental potential of handicapped children, led to a critical appraisal of traditional approaches to care and education. Mounting scientific evidence on the potential deleterious effects of institutionalization resulted in increasing commitment on the part of governments and agencies to support home- and community-based programmes. The impact of, and lessons from, nation-wide early intervention efforts, such as Project Head Start for culturally and environmentally disadvantaged preschool children in the United States, served as a major impetus for early intervention work with handicapped and at-risk children and their families.

In Canada, the value of early intervention work with developmentally disabled or delayed children and their families has received widespread recognition. Across the country, intervention programmes employing a wide range of models and specific techniques exist under the aegis of governmental as well as nongovernmental agencies. A recent national survey by Kendall, Brynelsen, and La Pierre (1985) found as many as 50 infant development programmes in Ontario alone. British Columbia, Quebec, Saskatchewan, and Alberta had 27, 20, 15, and 12 programmes, respectively. New Brunswick had 3 programmes, while Nova Scotia and Manitoba had 4 each. Newfoundland and Prince Edward Island had one programme each. However, Newfoundland appears to have the only centralized and publicly funded intervention programme with a mandate to serve an entire province. According to the Kendall et al. (1985) survey, governmental funding of intervention programmes is available in all provinces except Nova Scotia.

Also noteworthy is the degree of attention that the field of early intervention has received from researchers in Canada. Some of the early demonstration projects in Canada were begun in the mid- to late 1970s by Kysela and his associates at the University of Alberta (see Kysela, 1978; Kysela, Daly, Doxsey-Whitfield, Hillyard, McDonald, & McDonald, 1979; Kysela, Hillyard, McDonald, & Ahlston-Taylor, 1981). University-affiliated and community-based programmes and research projects (both programme based evaluations and experimental efficacy studies) have been, and continue to be, carried out in several parts of the country (e.g., Barrera, Lounsbury, Toal, Miron, & Darling, 1984; Barrera & Rosenbaum, 1986, Kysela, 1984; Piper & Pless, 1980; Watkinson & Wall, 1978). Early intervention has also been the subject of several thesis and dissertation studies in Canadian universities (e.g., Barros, 1981; Girolametto, 1986, McDonald, 1980; Marfo, 1981; Tannock, 1985).

As with all social service programmes, the increasing public support for early intervention continues to raise questions about efficacy (see Dunst, 1985; Marfo & Kysela, 1985; Simeonsson, Cooper, & Scheiner, 1982 for more extensive reviews and discussions of this subject) and accountability (see Bagnato & Neisworth, 1980; Simeonsson & Weigerink, 1975). The benefits of early intervention services are increasingly being recognized as going beyond the target child. In addition to arresting developmental decline or enhancing developmental functioning in the children involved, benefits are seen to accrue to parents -- in the form of psychological support and knowledge in techniques of care and parenting -- and to society at large -- in the form of potentially significant reductions in the numbers of children that might otherwise require, in later life, extensive special services involving massive public expenditures.

However, it is now a widespread view that the justification for public support of intervention services should rest on empirical evidence that these universally accepted goals are attainable. In fact, as the early intervention movement has evolved, it has become imperative that interventionists demonstrate accountability by building into their service delivery models systematic evaluations designed not only to provide evidence of effectiveness and goal attainment but also ongoing feedback for the purpose of further refining their programmes for enhanced efficiency.

Such evaluations should target the broad goals of intervention and not just child developmental gains, as is traditionally the case (see Marfo & Kysela, 1985 for further comments). Parents and family environments are important child developmental variables that serve as critical mediators between the intervention programme and the child (Marfo & Kysela, 1985; Sheehan & Keogh, 1981); consequently, a comprehensive evaluation of any intervention programme should include measures of what changes occur in parents and in the child's overall family ecology. This view is consistent with some of the trends currently occurring in the early intervention field.

The early intervention movement in North America and elsewhere is going through important transitions; while the underlying philosophy of intervention remains unchanged, there is increasing recognition of the need to broaden goals and to target more than the child-parent dyad. The work of ecological theorists (e.g., Bronfenbrenner, 1979; Cochran & Brassard, 1979) and adherents of social systems theory (e.g., Dunst & Trivette, in press; Dunst, Trivette, & Cross, 1986) is exerting a great deal of influence on the early intervention movement, forcing interventionists no' only to reappraise their methods, but also to redefine their target populations.

Over the past few years the administrators and staff of the Direct Home Services Programme have felt the need, based on their own field experiences and on emerging trends in the literature, to explore new directions for serving families more effectively. It has become increasingly clear that thorough analyses of parental attributes and family ecological variables that impinge on the intervention process are necessary if the intervention model itself is to be adapted to better serve the needs of individual families. The present study was designed not only to evaluate current efforts but also to provide concrete data upon which to base future strategies for working with families.

Consequently, the study had the following six-fold purpose:

1. to examine parents' early experiences pertaining to the detection of the child's problem, awareness about and access to early intervention services. and contact with support groups;
2. to analyze parental perceptions about, and satisfaction with, the early intervention program -- including perceptions about the intervention worker's competence and professional skills;
3. to appraise parental expectations about the child's future, and to examine the relationship between such expectations and the perceived severity of the child's handicap or delay;
4. to obtain a measure of parent-child interactive play, both in terms of variety of activities and the frequency with which interactive play occurs;
5. to ascertain the program's effectiveness relative to child developmental progress; and
6. to examine the role that family ecological variables play in the intervention process -- paying attention to parental, family ecological, and intervention variables that appear to be associated with (1) child developmental progress and (2) parental satisfaction with intervention.

The methods and instruments used to address the above goals are described in subsequent sections of the report. To place both the methods and results in a proper perspective, a fairly elaborate description of the Direct Home Services Programme is provided prior to those sections.

A Note on Choice of Terminology

Clinically, the children in this study may more appropriately be classified broadly under the two umbrella labels "developmentally disabled" and "developmentally delayed." The former terminology covers children with chronic disabilities which result from mental and/or physical impairment and manifest themselves in substantial functional limitations in such areas as academic skills, communication (including receptive and expressive language), social skills, mobility, self-care, and capacity for independent living. Children with such conditions as Down syndrome, cerebral palsy, autism, and spina bifida are among the recognized subgroups covered by the developmental disabilities label (Bernheimer & Keogh, 1986). In the Direct Home Services Programme, these children are considered for intervention if concurrent mental deficit is identified.

The term "developmentally delayed", on the other hand, is used to describe children who manifest signs of slow development and language/communication problems, but who exhibit no clear signs of associated physical or biological impairments. Thus, the aetiology of their developmental delay is largely unknown (Bernheimer & Keogh, 1986). A significant proportion of the children in the Direct Home Services Programme is made up this category of children.

In this report, however, the term "developmentally delayed" is used generically to describe the entire population of children served by the intervention programme.

CHAPTER II: THE INTERVENTION PROGRAMME

Introduction and Programme Philosophy

The Direct Home Services Programme (DHSP) is a home-based early intervention programme for families of developmentally delayed infants and preschool-age children operated under the aegis of the Division of Mental Retardation Services, Newfoundland and Labrador Department of Social Services. The programme is an adapted version of the original Portage Project model described by Shearer and Shearer (1976), and was initiated in this Province in 1975 (Browne, Corbett, Gallant, & Thompson, 1985).

Since its inception, DHSP has grown in status from a small-scale pilot project to a permanently funded programme which currently serves close to 300 developmentally delayed young children and their families on a regular basis. Professional home teachers, called Child Management Specialists (CMS), make weekly home visits (a visit lasts for a duration ranging from 1 to 1.5 hours). Each CMS has a maximum caseload of 13 children, and the purpose of the home visits is to teach parents appropriate and effective ways of stimulating and promoting the development of their children.

DHSP's working philosophy is based on several primary assumptions of early intervention and on the Department of Social Services' mandate to provide community-based as opposed to institution-based services to developmentally delayed individuals. These assumptions include the following:

1. Intervention services should be initiated as early as possible to have maximum effect on the child's development.
2. Parents are the primary and most influential teachers of their children; hence intervention services should include an emphasis on enhancing parenting skills.
3. The home is the most natural setting to observe, interact, and effectively change parent/child behaviours.
4. Effective intervention with families requires: (a) accurate assessment of the child's current developmental strengths and needs; (b) intensive skill teaching; and (c) constant communication between teacher and parent, coupled with strong regard for parental input.
5. An individual with developmental delay has the basic human right to live within a family unit and to have full access to services in his/her own community.

The programme has become widely accepted throughout the Province as an important support to families of developmentally delayed children and a valuable asset to the deinstitutionalization process in the Province (Browne & Gallant, 1982; Hickey, 1982; Kappel et al. 1981). To illustrate the latter, Browne and Gallant (1982) have reported that the DHSP has contributed greatly to the prevention of admissions to institutional settings, noting that there have been no admissions of children under 12 years of age to Provincial institutions for individuals with developmental delay over the past ten-year period.

The movement away from institutionalization may in part be reflective of the increasing impact DHSP has made on the lives of families with developmentally disabled children in Newfoundland and Labrador. Not only has the programme taken on the role of teaching parents effective methods of managing and enhancing the development of their children at home, but it has also strongly encouraged families to identify, seek out, and support the development of progressive community-based services for developmentally delayed individuals.

Overview of the DHSP Model

Referral:

Referrals for service are received by programme staff from any concerned source, but are most frequently initiated by medical and social services professionals and agencies. Referral data are generally submitted on the DHSP Referral Form and may be supplemented by medical reports, telephone contacts, or other forms of inter-agency information sharing.

Prior to the initiation of a referral, the referring agent is requested to discuss the Direct Home Services Programme with the respective family and to obtain permission for referral. If this important procedure has been followed, the initial contact by DHSP staff should not come as a surprise or shock to the family. DHSP field staff and supervisory personnel frequently engage in communication with the various service providers throughout the Province to ensure increased awareness of the program. Referral forms and DHSP brochures are frequently distributed to professionals in the health, social services, and education fields across the Province. Major referral agents are strongly urged to refer children as soon as a handicapping condition is identified or potential developmental delay is suspected.

Initial Contacts With the Family:

Following receipt of a referral, the respective CMS (the home teacher) makes initial contact with the family by telephone or in person, if the family does not have a telephone. This contact occurs within one month of the date of referral, and is made to confirm receipt of the referral, further explain the purpose of the program, and provide a full outline of the DHSP delivery model; it also allows the CMS the opportunity to arrange the date and time for the first home visit.

Because the initial home visit is also designed to satisfy the program's screening requirements, during the visit the CMS gathers background data for the DHSP Fact Sheet and determines specifics regarding a child's developmental delay by administering the Alpern-Boll Developmental Profile (Alpern & Boll, 1972). A family is deemed eligible for the programme if the following criteria are met:

1. The child is between birth and seven years of age and not attending a public school program.
2. The child displays significant developmental delay in one or more of the following developmental domains: cognition, communication, socialization, self-help, and motor. A significant delay for programme purposes is operationalized as a minimum of one year delay in one or more of the above areas or a 6-month delay in two or more domains, as determined by the Alpern-Boll Developmental Profile.
3. The family agrees to receive programme services on a regular weekly

schedule and indicates willingness to participate in and follow through on prescribed weekly assignments.

A family meeting the above eligibility requirements is considered for active programme status immediately, and is provided regular service as soon as a vacancy in the caseload of the respective CMS becomes available. Depending on the number of active and wait-listed cases for the geographic area concerned, a family may be started on weekly intervention the following week or wait-listed until a vacancy is available.

First Regular Home Visit and Curriculum Planning

The first regular home visit lays the foundation for curriculum planning and the course for home teaching. During this visit the CMS and parents discuss the strengths and needs of the child, pinpoint short and long-term curriculum goals, and plan for the initiation of skill teaching sessions. If the family had been wait-listed for service over a three-month period, the Alpern-Boll is administered again to obtain updated scores on the child's development.

The Portage Guide to Early Education is implemented next. The Portage Guide is a curriculum checklist containing hierarchies of developmental skills -- from infancy to age 6 -- in the following developmental domains: cognition, language, motor, socialization, and self-help. The CMS -- with input from the parents -- examines each section of the Portage Guide, noting the skills acquired or not acquired by the child and pinpointing those beginning to emerge in the child's developmental repertoire. For teaching purposes, the emerging skills are of utmost importance to the CMS; it is from these that the CMS and parents select 3 to 5 skills to be taught during the next home visit.

In concluding the first regular home visit, the CMS requests the parent to complete the DHSP Parent Priority and Reward Survey forms. The former taps the parents' preferences for behaviours to be taught, increased, or decreased, while the latter addresses the child's likes and dislikes for reinforcement purposes. Information from both forms has proved useful for successful identification and implementation of target skills.

Depending on the nature of the child's developmental delay or parental preferences, informative literature in the form of articles and books are lent to the family and discussed during subsequent home visits.

Second Regular Home Visit

Regular skill teaching is generally initiated during the second regular home visit. On the basis of the 3 to 5 skills selected during the previous visit, the CMS test-runs each skill with the child for purposes of identifying the level and method for effective teaching. Since the DHSP teaching model emphasizes weekly success on assigned tasks, the CMS pays special attention to individualizing each targetted skill to meet the child's needs as well as the rate and style of learning.

Once the CMS obtains sufficient information for the identified skills, each target assignment is recorded on a target sheet. A target sheet must include a comprehensive behavioural objective, a detailed teaching prescription, and full instructions for charting purposes. The completed target sheet is then read out loud with the parents. The CMS next demonstrates a target with the child based on the information written on the target sheet. Baseline data on the task is recorded as the child performs the prescribed activity. The parent is then given the opportunity to model the same. Corrective feedback is provided by the CMS during each trial of the activity.

The same steps are repeated for each assigned skill. Positive reinforcement to both the child and the parents are given high priority throughout the entire teaching session. Following the completion of skill teaching, the parents are asked to practise teaching each of the assigned targets for a specified number of trials each day until the following week's home visit.

Subsequent Regular Home Visits

At the start of the third and all subsequent regular visits, the CMS begins the session by testing the previous week's assignments with the child. If the skill has been successfully acquired, credit is given. If the criterion for success is not met, the assignment is modified either by simplifying the task or by changing the reinforcement component. If the parents had not practised the assignments, the reasons and possible solutions are explored.

In preparation for the next home visit, 3 to 5 new or revised targets are identified and the skill teaching model is repeated for each target skill. Regular home visits for skill teaching are continued until services are deemed to be no longer necessary.

In addition to skill teaching, the CMS may assist the parents to identify and secure other important support services for their child -- e.g., preschool, speech therapy, physiotherapy, etc. If a child is receiving other specialized services, the CMS requests written permission from the parents to communicate with the other professionals/agencies regarding the child's progress.

Graduation

Graduation from DHSP may occur as a result of one or more of the following conditions:

1. Parents demonstrate independence with appropriate curriculum planning and skill teaching; or
2. A child's developmental delay is no longer considered significant to warrant continuation of regular intervention services; or
3. A child commences a public school program; or
4. A child reaches 7 years of age.

Official graduation is initiated by administering the Alpern-Boll Developmental Profile. Outcome scores are shared with the parents and a list of activities for the parents to implement with the child is left with the family. The CMS also offers follow-up services to the parents. If parents agree to participate, follow-up activities include the implementation of 4 home visits over a two-year period. These visits take place 3, 6, 12, and 24 months after graduation, respectively. Follow-up visits allow the CMS to recheck the child's developmental progress periodically (the Alpern-Boll is administered at each visit), and parents get the opportunity to discuss any concerns they may have regarding their child's development. Data from follow-up assessments are routinely included in DHSP evaluations.

Group-Based Parent Training Course

Periodically, a parent training course is offered by DHSP staff. Parents wait-listed for service are considered ideal candidates for this service; however, active parents are also invited to participate. The training course is designed to teach parents the basic skills needed to start home-based skill teaching -- from selecting a skill to recording the child's progress on that skill. Lecture topics include motivation, reinforcement, discipline, skill teaching, task analysis, the principle of social role valorization, and integration. The course makes use of videotapes, films, and resource persons.

Programme Administration

Staffing Model

DHSP is headquartered in the Provincial capital of St. John's from where the programming and teaching activities of field staff in 19 districts across the province are monitored. The administrative structure of DHSP consists of a Provincial Coordinator, an Assistant Coordinator, one Clerk II, and 21 Child Management specialists.

In certain districts within the province which have high waiting lists and/or where current or projected caseloads do not warrant the use of a full-time staff person, part-time Child Management Specialists are utilized. These positions are not permanent in status, and are developed and maintained in direct response to specific caseload demands.

The DHSP staffing model also includes the position of Early Intervention Worker (EIW). The EIW is a paraprofessional position used in relatively isolated or remote communities where weekly visits by a CMS are improbable. These temporary staff work under the close supervision of a full-time CMS, and function specifically as an extension of the CMS to support families in the completion of skill teaching activities. A full-time CMS carries a maximum caseload of 13 children, while a part-time CMS and an EIW carry a maximum of 4 cases each. The distribution of field staff across the province is presented in Table 1.

The utilization of the above-named positions enables the programme to provide in-home support to families throughout the province, regardless of geographic location. The staffing pattern adopted in the province reflects an alteration to the original Portage Programme model, in response to specific geographic and caseload demands of the province. Currently, DHSP has the capacity to provide early intervention services to approximately 300 infants and pre-school children.

Staff Qualifications

The position of Provincial Coordinator is the only non-union management position within DHSP. The position requires an individual with a master's or doctoral degree in developmental psychology or a related field, and a dynamic background in the human services field.

The position is under the supervision of the Assistant Director of the Division of Mental Reatardation Services, but requires considerable independent judgement and initiative.

The position of Assistant Provincial Coordinator is unionized but has supervisory status. The position requires a master's level degree in psychology or a related field, and considerable experience in the human services field. The Assistant Coordinator receives supervision from the Coordinator, but the two work as a team to monitor and supervise the programming and teaching activities of field staff.

The position of CMS, both full- and par -time, is filled by individuals with a bachelor's degree in psychology or related fields who have experience in case management or implementation of skill teaching programmes.

The EIW position requires an individual with a minimum of 2 years university preparation -- with coursework in psychology education, early intervention -- or a related human service field and considerable experience in working with children. Effort is made to recruit from the local community so as to ensure relative staff permanency.

Staff Training and Supervision

Prior to assuming the full role of CMS or EIW, individual candidates undergo extensive training under the direction of the Coordinator and Assistant Coordinator at the programme headquarters in St. John's. The minimum training periods for CMSs and EIWs are 4 weeks and 2 weeks, respectively. The standard DHSP training course involves a combination of lectures, audio-visual aids, and practical home-based experience. The major components of the training are as as follows:

1. Orientation lectures on the Department of Social Services, the Division of Mental Retardation Services, the Direct Home Services Programme, and other support programmes for individuals with developmental delay;
2. Visits to service agencies for young children with specified handicaps (e.g., Children's Rehabilitation Center);
3. Audio-visual materials and lectures on behaviour modification;
4. Lectures and workshops on writing behavioural objectives, task analysis, and precision teaching;
5. A range of home visits, with trainee participation in home programming increasing over the course of training;
6. Lectures on working with families and other professionals;
7. Lectures on social role valourization, integration, and educational mainstreaming; and
8. Weekly required and recommended readings.

Following successful completion of training, field staff are given a one- to two-week supervised field placement orientation in their respective work sites by either the Coordinator or the Assistant Coordinator. Subsequent supervised visits, lasting from 3 to 5 days in length, are made every four months. During these visits, the supervisor reviews all in-office data, accompanies the worker on regular home visits to observe the implementation of services, and provides constructive feedback to the worker. An annual performance evaluation on each field worker, done over 5 full working days, is completed by the Coordinator. The Coordinator and Assistant Coordinator also make required weekly telephone contacts with each staff person to provide programming consultation.

Other forms of staff supervision and consultation are provided during specialized workshops and monthly programme case conferences. Supervisory personnel attempt to organize at least one formal training workshop each year for all programme staff. Such events usually cover major themes like integration, working with the severely involved, etc., and typically take place over a whole week. Staff are also encouraged and supported to attend field-related workshops which are often offered within the Province by other human service agencies.

The CMS position is often a professionally isolated and lonely line of work. Management recognizes this as a critical issue and perceives a great need for staff cohesiveness and support. The monthly case conference, held regionally, provides one tool for achieving such support and cohesiveness. The Department of Social Services provides services on a regional basis. Each of the 21 CMS positions falls under 1 of 5 designated regions. On the average, 5 CMSs are located in each region (see Figure 1). Each regional group of CMSs meet for a full day, once a month, at the most centrally convenient district office. The purpose of the meetings is to discuss individual problem cases, share success stories, and discuss strategies for skill teaching. The Coordinator and/or Assistant Coordinator make it a point to attend at least three of each region's case conference meetings every year.

Table 1. Geographic Distribution of DHSP Staff

	Child Management Specialist		
District	Full-Time	Part-Time	E.I.W
St. John's West	2		
St. John's Centre	1		
St. John's East	2	2	
Whitbourne	1		
Marystown	1		
Harbour Grace	2		
Clarenville	1		
Harbour Breton	1		
Grand Falls	1		
Gander	1	1	
Springdale	1		
Baie Verte	1		
Deer Lake	1		
Corner Brook	1		
St. Anthony		1	
Stephenville	1		
Piccadilly	1		1
Goose Bay	2		3
Labrador City		1	
TOTAL NUMBER OF STAFF	21	4	5

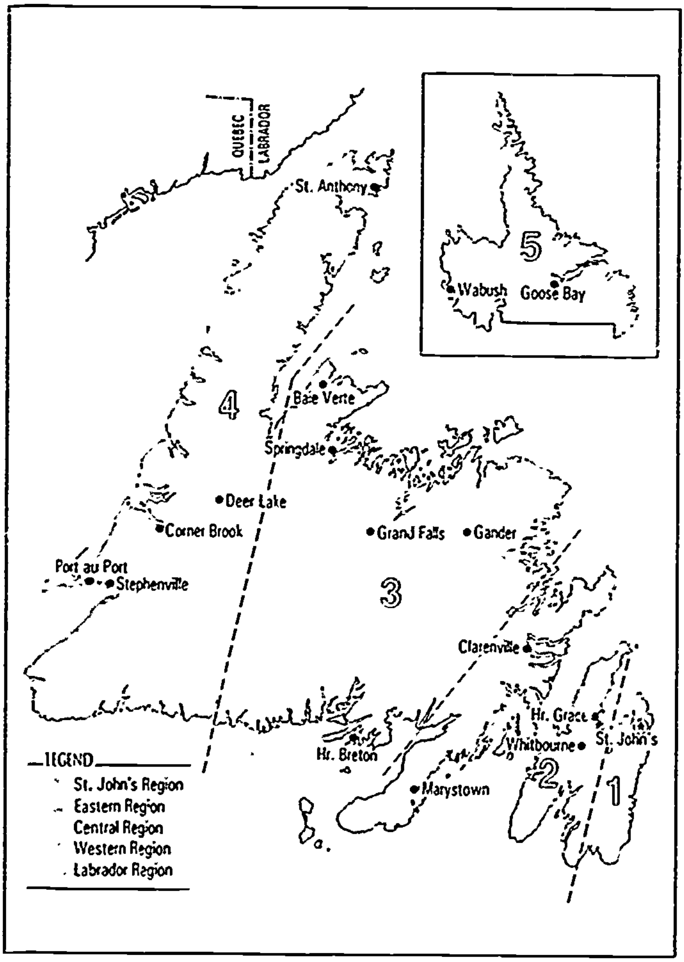

Figure 1. Centres From Where Early Intervention Services are Delivered Across the Province by Child Management Specialists and Early Intervention Workers.

CHAPTER III: METHOD

Subjects

The subjects in this study were families of developmentally delayed infants and preschool children who were recipients of early intervention services through the Direct Home Services Programme (DHSP). A total of 280 families were contacted and requested to participate in the study. Of this number, 263 families completed and returned at least some of our instruments, yielding a return rate of 94%. However, 63 returns (24%) were deemed too incomplete to be included in data analyses. The 200 families included in the analyses consisted of 132 active participants (66%) and 66 graduated recipients (33%). The programme status of 2 families could not be readily determined from available records.

The final study sample included 138 married, 20 single, and 9 divorced or separated parents. Information on marital status was not disclosed by 33 of the parents. Additional information on family and child characteristics are presented in Tables 2 and 3. Four dimensions of family demography -- age, educational background, family income, and size of community of residence -- are presented in Table 2. Reported incomes were relatively low, with as much as 56.5 % of the sample earning below $15,000.00 a year. These income levels should, however, be viewed in relation to the relatively rural nature of the sample, and to the reported educational backgrounds (as much as 76.2 of mothers and 63.3% of fathers had only up to high school education). A third factor is worth bearing in mind: for a variety of reasons, reported incomes in survey studies of this nature tend to be lower than actual incomes.

Table 2. Family Demographic Characteristics

MEAN AGES IN YEARS

	Mean	Std. Dev.	Range
Mothers (n=150)	31.8	7.2	20-58
Fathers (n=137)	34.8	7.7	20-61

EDUCATION

	% of Mothers (n=163)	% of Fathers (=149)
Grade school	29.4	27.5
High school	47.2	35.8
Vocational training	14.7	22.8
University: undergraduate	6.1	9.4
University: post graduate	2.5	4.7

FAMILY INCOME (Thousands of dollars)*	(n=154)
10 or less	37.0%
10 - 15	19.5%
15 - 25	22.7%
25 - 40	13.6%
Above 40	7.1%

SIZE OF COMMUNITY BY POPULATION (Thousands)	(n=158)
Up to 5	64.6%
5 to 15	16.5%
15 to 30	4.4%
30 to 125	14.6%

*Data received from Newfoundland Statistics Agency indicate that the mean and median census family incomes for the Province in 1986 were $27,687.00 and $23,756.00, respectively.

Table 3. Breakdown of Children by Clinical Label*

Label	%Occurrence
Mental handicap/developmental delay of unspecified origin	69.5
Down syndrome	11.7
Cerebral palsy	7.1
Spina bifida	5.1
Hydrocephalus	1.5
Multihandicapped with visual impairment	1.0
Multihandicapped with visual and hearing impairment	1.0
Tuberous sclerosis	1.0
Cre du chat	0.5
Hypoglycemia	0.5
18Q syndrome	0.5

*Based on information retrieved from DHSP records. Information was available for 177 of the 200 children in this study.

At the time of data collection the mean chronological age of the children was 58.9 months (SD-21.4; range-11-165 months). The sex ratio for the children was 59% boys and 41% girls. Table 3 presents information pertaining to the variety of conditions associated with delay among the children. For the vast majority of children, the clinical label available from programme records was developmental delay (DD) of unspecified origin. Of the more defined and specific conditions, Down syndrome (23 cases), cerebral palsy (14 cases), and spina bifida (10 cases) were the most prevalent in the sample.

Design

The subjects in the study constituted a large single group of families receiving similar early intervention services. Consequently programme effectiveness and the determinants of such effectiveness were examined through correlational and descriptive analyses. In the absence of experimental manipulation regression techniques were used to isolate critical variables in intervention.

Instruments and Procedures

The main instrument employed in this study for evaluating the intervention programme was a Parent Evaluation Questionnaire (PEQ) (Appendix A) designed specifically to evaluate the Direct Home Services Programme (DHSP) from the perspective of participating parents. The PEQ had 5 sections. Section 'A' dealt with questions pertaining to when and how parents became aware of their child's handicap, the extent to which they were satisfied with information provided them about their child's problem, how they became aware of DHSP, and what support groups -- if any -- they were in touch with. Section 'B' requested information on parents' initial and current impressions of DHSP and their satisfaction with the overall gains made by their child and with the methods of intervention. Section 'C' asked for parents' rating of the intervention worker in 8 areas pertaining to competence, sensitivity to family and child needs, attitude, and regard for parental input. Section 'D' asked parents to indicate how much knowledge and specific skills they felt they had gained from their participation in the programme. They were asked also to rate their satisfaction with (1) the amount and quality of attention the programme paid to each of the five developmental/skill domains and (2) their child's progress in each of the domains. The final section of the PEQ dealt with questions pertaining to whether parents had ever participated in a group-based parent training workshop, whether they would be interested in such a workshop, and whether they would recommend DHSP to other parents with developmentally delayed children. Attached to the PEQ was a cover sheet requesting child and family demographic information. On this sheet also parents were asked to rate their child's functional level on a 4-point scale: mild, moderate, severe, and profound.

The PEQ was mailed to all parents with a stamped return envelope. An accompanying letter from the DHSP coordinator requested parents to assist in evaluating the effectivness of the programme to enable programme staff to provide the best possible service to its clients. Parents were requested to be as frank in their responses as possible; they were assured of the highest level of confidentiality, by stressing that no child or family names would be used in storing information and that all responses to the questionnaire would be analyzed only at the level of the entire group of participating parents.

Three weeks after mailing the PEQ, several other instruments were sent to parents through the intervention workers: the Child Expectations Scale, originally developed by Dunst and his associates at the Western Carolina Center and revised by our research team; the Family Resource Scale (Leet & Dunst, 1985); the Parent-Child Play Scale (Dunst, 1986); and the Home Screening Questionnaire (Coons, Gay, Fandal, Ker, & Frankenburg, 1981). On these other instruments, Child Management Specialists were instructed to provide assistance to parents who needed help. They could, however, not assist parents with the actual selection of responses to items. Each of the instruments is described briefly below.

Child Expectations Scale (CES): The CES is a 10-item multiple-choice scale designed to assess expectations that parents hold regarding the future of their handicapped children in the domains of schooling, physical and financial independence, socialization and community involvement, and living and working environments. Within-item response alternatives are ordered from low to high expectations.

Family Resources Scale (FRS): The FRS assesses the adequacy of a variety of resources available to households with young chilren. The original instrument (Leet & Dunst, 1985) contained 30 items rank-ordered from the most to least basic. To render the scale appropriate for use with our Newfoundland sample, 10 of the original items considered socially and culturally inappropriate or too sensitive to elicit reasonably accurate responses were dropped, resulting in a 20-item scale. However, the original most-to-least basic order was preserved.

Resources covered by the abridged version of the instrument included the following: social assistance; special child welfare allowance; dependable transportation; time to get enough sleep or rest; time to be by self; time for family to be together; time to be with children; time to be with spouse or close friend; access to a telephone; babysitting or day care for children; money to buy special equipment or supplies for children, someone to talk to; time to socialize; time to keep in shape and look nice; money to buy things for self; money for family entertainment; money to save; and vacation. Mothers rated the adequacy of each of those resources, except those considered not applicable to their situation.

The FRS is based on the conceptual premise that the adequacy of resources necessary to meet basic needs would bear a direct relationship not only to family well-being but also to parental commitment to early intervention-related activities (Leet & Dunst, 1985). Reliability and validity data on the FRS have been reported in Leet and Dunst (1985).

Parent-Child Play Scale (PCP): The relationship between parent-child interaction and the development of competence in children is extensively documented in the developmental literature (see Kysela & Marfo, 1983; Marfo, 1987, for reviews). In recent years, researchers have sought to understand how a child's handicapping condition affects the parent-child interaction process and the extent to which the resulting patterns of interaction in turn influence the development of competence in the handicapped child (see Marfo, 1983, for a synthesis of theory and research on this topic). We utilized Dunst's (1986) Parent-Child Play Scale to examine the nature of parent-child play interactions.

Designed to measure both the variety and frequency of interactive games that parents engage in with their preschool-age children, the PCP consists of 24 developmentally ordered items (ranging from about 2 to 48 months), falling into 6 equal categories: responsive games (e.g., blowing raspberries, tickling games, and gymnastic games, such as bouncing child on bed); lap games (e.g., playing peek-a-boo or pat-a-cake, getting child to give hugs and kisses); mastery play (e.g., playing catch or rolling ball back and forth, and finger games like "itsy-bitsy spider"); pretend play (e.g., make belief games, pretend phone conversations, and playing puppets with child); verbal play (getting child to sing songs or repeat numbers/alphabets, naming pictures and people, etc.); and discovery play (e.g., coloring together with crayons and markers, pasting pictures and stamps). Reliability and validity data on the PCP have been reported in Dunst (1986).

Home Screening Questionnaire (HSQ): The quality of the child's early environment has long been acknowledged as a critical factor in development (e.g., Bloom, 1964; Calwell, 1967; Wachs & Gruen, 1982). The need to include assessments of the child's home environment in implementing and evaluating intervention programmes has been recognized for many years, although very few tools exist for this purpose.

Developed for use by health professionals and educators directly involved in promoting child health and development, the HSQ measures the quality of children's home environment. It was designed along the lines of the more well-known Home Observation for Measurement of the Environment (HOME) Inventory (Caldwell & Bradley, 1978), using a questionnaire format. Unlike the HOME, the HSQ is completed directly by the parent. A variety of response formats is employed: multiple choice; fill-in-the blank; and "yes/no" options. Two separate forms are available for use with children 0-3 and 3-6 years old, respectively, each with a toy checklist at the end of the instrument. Because the HSQ is essentially meant for screening purposes each of the two scales has a cut-off score for identifying children with environmentally suspect backgrounds.

Items on the HSQ cover a wide range of factors that have the potential to influence child development: availability of materials like books and toys; how often the child is read to; extent of parental involvement in child's play; the amount of time child spends with adults other than the primary caregiver; opportunities to interact with other children; opportunities for exploration both within and outside the home; verbal stimulation in a variety of contexts; and exposure to experiences such as outing (e.g., going shopping with parents or other adults), television, pets, and a variety of household items.

Developmental data: Longitudinal developmental data from Alpern-Boll assessments of all children were retrieved from programme records. Two sets of scores were used in this study: scores from entry point assessment and from the last assesssment prior to this study.

Data Reduction

In addition to analyzing individual items on the PEQ, we derived the following composite scores from item clusters to enable us examine three themes related to parental evaluation of the intervention program: parental rating of the intervention worker; parental perceived knowledge gain; and parental satisfaction with the programme and with child progress.

Index of Parental Rating of Intervention Worker: A composite score ranging from a minimum of 8 to a maximum of 40 was computed for the 8 items in this section of the PEQ by assigning weights of 1, 2, 3, 4, and 5, respecectively, to the response options inadequate, poor, fair, good, and excellent. Thus, a higher composite score signified stronger regard for the worker's competencies.

Index of Parental Perceived Knowledge Gain: A composite score ranging from 16 to 80 was derived in the same manner as described above for the 16 items in this section of the PEQ. The 5-point response range went from "gained nothing" to "now an expert."

Index of Parental Satisfaction with Programme: Twelve items pertaining to parental satisfaction with elements of the programme and with progress made by the child in the five developmental/skill domains served as the basis for a composite score derived in a manner similar to the other indices. The index had a minimum and maximum of 12 and 60, respectively, and was based on a response rating going from "extremely dissatisfied" to "extremely satisfied."

A composite measure of parents' expectations about their child's future (regarding schooling, physical and financial independence, and living and vocational environments) was derived from 9 items on the Child Expectations Scale that had hierarchically ordered responses. Weights were applied in a manner that resulted in higher scores for parents with higher expectations. Possible scores ranged from a minimum of 9 to a maximum of 37.

The 5 response options to each of the 20 items on the Family Resources Scale (FRS), ranging from "not at all helpful" to "extremely helpful" were assigned weights from zero to 4, respectively, yielding a minimum composite score of zero and a maximum of 80.

The Home Screening Questionnaire was scored using the standard instructions set out in the manual (Coon et al., 1981). The total possible score for the 0-3 and 3-6 scales were 43 and 56 respectively.

Finally, two types of child developmental indices were computed from Alpern-Boll Scores: The Developmental Delay Severity Index (DDSI) and the index of Relative Developmental Gain (RDG). DDSI was based on the entry level Alpern-Boll scores and was computed as the difference between developmental age and chronological age divided by chronological age. RDG was based on both the entry level and latest developmental age scores, and was computed by subtracting the developmental age at programme entry from the current developmental age and dividing the result by the number of months between the two assessments (i.e. the amount of time in intervention). This manner of computing developmental gain is similar to the Intervention Efficiency Index (IEI) as suggested by Bagnato and Neisworth (1980). The preferred term in this report is RDG rather than IEI because the notion of an intervention efficiency index connotes that developmental gain results directly from the intervention process whereas RDG does not.

Both the DDSI and the RDG were computed for the separate developmental domains as well as for overall development; however, only overall scores were utilized in the analyses reported.

CHAPTER IV: RESULTS AND DISCUSSION

As stated in the introduction, the objectives of this study were: 1) to examine parents' early experiences pertaining to (a) detection of their child's problem, (b) awareness about, and access to, early intervention services, and (c) contact with support groups; 2) to analyze parental perceptions about, and satisfaction with, the early intervention program; 3) to appraise parental expectations about the child's future; 4) to examine parent-child interaction in relation to child developmental characteristics; 5) to ascertain the program's effectiveness relative to child developmental progress; and 6) to examine the role family ecological variables play in the intervention process -- identifying which parental, family ecological, and intervention variables are associated with the child's developmental progress. The results of the study are presented in sections corresponding to the above objectives.

Early Experiences

Parents were asked to indicate how they became aware of their child's problem, how old the child was at the time of detection, how they became aware of DHSP, and what support groups they had contacts with. The responses obtained to these questions were examined along with information retrieved from programme records about the age at which the child entered the intervention program. The date of the first developmental assessment was taken as the entry date, although in many cases formal admission may have occurred up to two months later.

Table 4. How Parents Became Aware of Child's Problem and Intervention Program

Informant re: Child's Problem	% Respondents (n=132)	Informant re: Program	% Respondents (n=172)
Family doctor	81.1	Family doctor	28.5
Public health nurse	9.1	Public health nurse	16.9
Social worker	7.6	Social worker	26.7
Speech pathologist	1.5	Speech pathologist	1.7
Parent/relative/friend	0.8	Parent/relative/friend	11.1
		Children's Rehab Center	8.1
		Psychologist	1.7
		OT/PT	1.2
		Can. Nat. Inst for Blind	1.2
		School/school board	1.2
		Parent groups/voluntary org.	1.2
		Behavior Management Services	0.6
		Exon House residential prog.	0.6
		DHSP personnel or brochure	0.6

Responses on how the child's problem and the intervention programme became known to parents were available from 132 and 172 parents, respectively (Table 4). Eighty-one percent of responding parents found out about their child's handicap or delay from their family doctor, while 16.7% of parents were first informed by public health nurses and social workers. Of 170 parents responding to the question as to whether they were satisfied with the information provided them at the time of detection, as many as 52 (31%) indicated that they were not satisfied.

Comments by these parents were summarized to obtain some insight into the basis for dissatisfaction. The most dominant comment (made by 20 parents) was that the professionals involved were either unclear or reluctant to be open in disclosing the child's handicap.

Four respondents indicated that they were given incorrect information, including misdiagnosis of the child's problem. Two mothers were told too soon after delivery to be prepared for the traumatic news, while two found it inappropriate to be told in the absence of their husbands. Other comments made by at least 2 to 4 respondents included the following: "staff denied that there was a problem"; "I didn't know where to get help"; "I was told by telephone"; and "the doctor was unsupportive."

The emotions that parents go through following diagnosis or confirmation of the child's handicap have been documented extensively in the literature (e.g., Klaus & Kennell, 1976; Legeay & Keogh, 1966; Matheny & Vernick, 1968; Taichert, 1975; Wolfensberger, 1967). The need for medical and other human service professionals dealing with these parents to show sensitivity and support -- while being informative at the same time -- is a common theme that runs through much of this literature (see also Howard, 1982; Huang & Heifetz, 1984).

While training programmes for medical and other human service professionals are increasingly addressing this issue, early intervention programmes can play an important role by forging stronger ties with professionals and agencies that deal with parents during this critical period. Such interdisciplinary ties should seek to raise awareness about the psychological needs of parents and about the existence of community services, such as the early intervention program, to which parents can turn for support.

Parental awareness about DHSP came through a wide variety of sources. As shown in Table 4, while most parents found out about the programme through family doctors (28.5%), social workers (26.7%), and public health nurses (16.9%), the long list of other sources (including family members, relatives, and friends) is an indication that the programme is widely known in communities across the province.

One of the popular assumptions upon which early intervention with handicapped and at-risk children is premised is that the earlier the child is identified and targeted for intervention services the better the outlook for ameliorating deficits or arresting decline in functioning. Thus, one good test of programme adequacy and efficiency is to examine the time lag between identification and programme entry. All except 3 children entered the programme prior to age 6. In fact, as Table 5 shows, 62.1% of the children were admitted to the programme before or by their third birthday. However, Table 5 reveals also that while as much as 65% of children were detected in the first year of life, only 22% entered the programme in their first year.

Table 5. Breakdown of Ages at Which Parents Became Formally Aware of Child's Problem and Ages at Which Child Entered Intervention Program

Age at Detection	% of Children (n=162)	Age at Entry	% of Children (n=198)
Birth to age 1 year	65.4	Birth to age 1 year	22.0
Age 1 to 2 years	19.8	Age 1 to 2 years	23.5
Age 2 to 3 years	8.6	Age 2 to 3 years	16.0
Age 3 to 4 years	4.3	Age 3 to 4 years	17.0
Age 4 years and above	1.9	Age 4 to 5 years	15.5
		Age 5 to 6 years	4.5
		Age 6 and above	1.5

It is impossible to tell from these data exactly what factors are responsible for the delay in accessing intervention services. It is conceivable that this lag may be accounted for, partially, by the time that parents spend "shopping" for potential solutions. Alternatively, part of this lag was time that parents spent waiting for referral to the intervention program. It is possible that although many diagnosing physicians may be aware of the existence of early developmental intervention programmes, some physicians may decide not to make a referral immediately after diagnosis -- preferring instead to give parents enough time to get ready psychologically for such a service.

At any rate, the reason for this time lag between identification and programme entry is certainly one area that programme staff need to address. If the potential gains of intervention are to be maximized for children and families requiring programming, it is important that programme entry occurs soon after the child's problem has been identified.

Table 6. Contact With Support Groups

Support Type	%Yes	%No
Association for the Mentally Retarded (n-176)	10.8	89.2
Formal parent support groups (n-176)	13.6	86.4
Other specialized groups (e.g., Spina Bifida Association) (n-174)	9.8	90.2
Other parents (informal) (n-176)	18.6	81.3

Finally, we examined the extent of contact that parents have with several types of formal and informal support groups. The results showed a very low level of parental involvement with support groups (Table 6). Across the four categories of support groups presented, less than 20% of parents reported contact. Within-categories comparison shows that parents made relatively more contacts with other parents of handicapped children informally than they did with formal support groups.

Parental Perceptions About the Intervention Programme

Table 7 summarizes parental responses to two questions pertaining to initial and current impressions about DHSP. While 29.1% of parents were uncertain about the programme prior to their involvement, only 9.6% remained uncertain after participating in it. Twenty percent more parents expressed extreme satisfaction or satisfaction with the programme after participating in it for varying lengths of time.

Table 7. Parents' Initial and Current Impressions About DHSP

	Percentage of Parents by Impression Rating				
	Extremely Impressed	Impressed	Not Sure	Unimpressed	Extremely Unimpressed
Initial (n=172)	20.3	47.3	29.1	1.7	1.2
Current (n=167)	37.7	49.7	9.6	1.2	1.8

Generally, parents rated the programme very positively. In fact, 98.8% of parents indicated that they would recommend the programme to other parents of developmentally delayed children. The summaries presented in Table 8 depict a very high level of satisfaction with programme components and with child progress. In all developmental domains (social, self-help, academic, language, and physical), over 82% of parents expressed satisfaction or extreme satisfaction with the quality of programming. Satisfaction with children's progress in these domains was not as uniform, however. While 85 to 88 percent of parents were satisfied or extremely satisfied with progress in the social, self-help, and physical developmental domains, only 75 to 78 percent showed similar levels of satisfaction with their children's progress in academic and language skills.

Examination of parents' comments and suggestions revealed insights on the basis for the high positive rating of the program. Many parents were pleased with the programme not only because of the benefits to their children but also because the programme enabled them to cope better as parents of developmentally delayed children. There were many others who saw the program's value solely in relation to the gains their children had made. Suggestions centered mainly on the need for more staff and more visits. Several parents felt that they needed more visits per week, while others felt the need to hire more workers to reduce the waiting period between initial screening and the commencement of intervention. Concern was also expressed about lengthy waiting periods caused by the loss of workers.

Table 8. Parents' Satisfaction With Programme and Child Progress

Item	Percentage of Respondents by Satisfaction Rating				
	Extremely Satisfied	Satisfied	Not Sure	Dissatisfied	Extremely Dissatisfied
Quality of Programme Component (n=166):					
Social	27.3	58.3	9.1	2.2	2.4
Self-help	30.5	55.5	7.9	3.0	3.0
Academic	24.1	58.4	12.7	3.0	1.8
Language	30.7	56.0	9.6	2.4	1.2
Physical	38.0	52.4	6.6	1.8	1.2
Methods for behavior change	28.2	57.7	12.3	1.8	-
Progress in Developmental Domains (n=160):					
Social	33.1	52.5	7.5	5.0	1.9
Self-help	31.9	55.0	5.6	6.3	1.3
Academic	22.0	52.8	17.8	6.9	0.6
Language	30.4	47.5	14.6	7.6	-
Physical	36.7	51.3	8.2	3.2	0.6
Overall gains	30.4	59.6	8.2	1.8	-

Table 9. Parents' Ratings of the Intervention Worker

	% of Respondents by Satisfaction Rating (n=170)				
Worker Attribute/Skill	Excellent	Good	Fair	Poor	Inadequate
Ability in explaining child's program	62.9	31.8	5.3	-	-
Sensitivity to your needs as parent	53.8	39.1	6.5	-	0.6
Knowledge and skills about management	56.8	36.7	6.5	-	-
Relationship with your child	63.7	28.6	6.5	1.2	-
Ability to deal with questions and problems	58.2	37.6	3.5	0.6	-
Welcoming your opinions and input	59.4	36.5	3.5	0.6	-
Using or acting on your suggestions and input	52.4	39.3	6.5	0.6	1.2
Attitude toward you during visit	74.0	23.1	1.8	-	1.2

Table 10. Parents' Rating of Knowledge Gained From Participation in Programme

	% of Respondents by Satisfaction Rating (n=170)				
Knowledge/Skill Area	Now an Expert	Gained a Lot	Gained Some	Gained a Little	Gained Nothing
Assessment and evaluation of your child	5.3	55.9	33.5	4.7	0.6
Knowledge of your child's abilities and needs	16.5	57.6	20.6	3.5	1.8
Behavior management techniques for children	7.2	45.5	34.1	9.0	4.2
Skills for coping with your child	8.3	52.4	26.2	11.3	1.8
Recording of your child's progress at home	15.8	56.1	21.1	6.4	0.6
Selection of appropriate toys and books for child	19.3	49.1	18.7	7.0	5.8
Knowledge of social development	9.6	50.6	24.7	10.8	4.2
Knowledge of self-help skills development	10.8	56.3	18.6	9.0	5.4
Knowledge of academic skills development	9.2	50.3	27.6	9.2	3.7
Knowledge of language development	12.2	45.1	27.4	11.0	4.3
Knowledge of motor development	9.8	54.3	22.6	9.1	4.3
Knowledge of preschool placement options	10.9	35.8	25.5	10.9	16.8
Knowledge of school placement options	5.9	37.5	26.3	14.5	15.8
Knowledge about parental rights	10.5	38.3	27.2	12.3	11.7
Knowledge about normalization and integration	7.0	38.0	27.8	14.6	12.7
Knowledge of other relevant community services	6.4	33.1	23.6	17.2	19.7

Parental satisfaction with programming and child progress was coupled with an extremely high and uniform rating of intervention workers in all 8 dimensions of worker attributes (see Table 9). The percentage of parents rating the workers as good or excellent ranged from 92 to 97.

Responses to items pertaining to parental preceived knowledge gain (Table 10) showed much greater variability, compared to the satisfaction and worker ratings. Two observations are worth noting about the knowledge gain data. First, far more parents chose responses on the negative end of the scale than was the case with satisfaction and worker ratings. Second, parents reported greater knowledge gain on items relating to the child's abilities and needs, actual skill development, and immediate programme activities (e.g., record keeping, selection of toys, and assessment and evaluation) than on broader and relatively more remote and less immediate issues like preschool and school placement, parental rights, and normalization and integration. Overall, parents reported the least knowledge gain with regard to the existence and accessing of other relevant community resources.

Although the primary parent training model adopted by DHSP is one-to-one home-based training involving the Child Management Specialist and the parent, programme staff also make an effort to provide occasional workshops for groups of parents. The principal target group for these workshops are waiting-list parents, but active programme parents are also invited to attend. The analysis showed that so far only 11% of parents had attended a group-based parent training workshop. Of the 151 parents indicating they had not attended a workshop, 76% expressed an interest in attending such a workshop in the future.

Parental Expectations Regarding the Child's Future

In examining the expectations that parents held about their child's future, we were interested not merely in knowing what these expectations were but also in ascertaining what relationships such expectations bore with parental perceptions of the severity of the child's developmental delay. Two independent indices of severity were utilized in this study: a parental rating on a 4-point scale ranging from mild (1) to profound (4); and an index computed from Alpern-Boll scores (with severity increasing as the index approached 1.0). We tested the cross-validity of both indices by examining the intercorrelations among the parental rating, the Alpern-Boll index, and current developmental age (also based on Alpern-Boll measures).

As Table 11 reveals, the three indicators of developmental status were strongly intercorrelated, suggesting that the parental ratings were reasonably valid. Parental rating of severity of delay correlated .37 ($p < .001$) with the Alpern-Boll Index of severity and -.38 ($p < .001$) with current developmental age. Having established the validity of the parental ratings, we examined parental expectations relative to the child's perceived level of functioning under three themes: expectations regarding schooling and independence (Table 12); expectations regarding physical care and socialization (Table 13); and expectations regarding future living and working environments (Table 14).

Table 11. Intercorrelations Among Indices of Severity of Handicap, Current Developmental Age, and Relative Developmental Gain (RDG)

	PSR	A-BSI	DA	RDG
Parental Severity Rating (PSR)	-	.37***	.39***	.28***
Alpern-Boll Severity Index (A-BSI)		-	.45***	.35***
Current Developmental Age (DA)			-	.64***

* p<.05 ** p<.01 *** p<.001
Undelined correlation coefficients are negative.
Valid sample sizes ranged from 146 to 188

In all three theme areas, a clear trend toward higher expectations for less severely delayed children is observable. For example, while parents of children rated as profoundly delayed did not expect any more than special class placement for their children, higher educational hopes were held by parents of children with severe, moderate, and mild delays; in fact as much as 41% of parents of severely delayed, 57% of moderately delayed, and 79% of mildly delayed children expected their children to have up to high school, vocational, or college education. While parents of profoundly delayed children expected their children to be totally or highly dependent -- physically and financially -- significantly increasing degrees of independence were expected by parents of severely, moderately, and mildly delayed children.

Table 12. Expectations Regarding Schooling and Independence

Item and Responses	Mild (n=48)	Moderate (n=72)	Severe (n=17)	Profound (n=4)
	% of Parents Choosing a Response Within Levels			
How far do you expect ... to go in school?				
No schooling	0.0	0.0	5.9	25.0
TMR class	0.0	11.1	35.2	50.0
Special ed. class	4.2	16.7	5.9	25.0
Regular grade 1-6	6.3	12.5	5.9	0.0
Junior high school	10.4	2.8	5.9	0.0
High school	27.1	26.4	29.4	0.0
Vocational	14.6	6.9	0.0	0.0
College	37.5	23.6	11.8	0.0
How independent, financially, do you expect ... to be as an adult?				
Always entirely dependent	6.3	16.4	37.5	100.0
Contribute toward own support	25.0	28.8	12.5	0.0
Become self-supporting	68.8	53.4	50.0	0.0
How independent do you think ... will become in planning and managing his/her own affairs?				
Will need constant supervision	0.0	6.9	31.3	80.0
Will need someone to make plans and day-to-day decisions for him/her	2.1	18.1	18.8	20.0
Will need help and advice in making major decisions	45.8	31.9	25.0	0.0
Will be able to take responsibility for his/her own affairs	52.1	41.7	25.0	0.0

Table 13. Expectations Regarding Physical Care and Socialization

Item and Responses	% of Parents Choosing a Response Within Levels Mild (n=49)	 Moderate (n=71)	 Severe (n=17)	 Profound (n=5)
How well doy you think ... will be able to care for himself/herself physically?				
Will need care all day long	4.1	8.3	17.6	80.0
Will need some help every day	4.1	16.7	41.2	20.0
Will need help only in unusual situations	22.4	36.1	17.6	0.0
Will be entirely self-sufficient	69.4	37.5	23.5	0.0
How active do you expect ... to be in the community?				
Unable to join in community activities	0.0	9.9	17.6	100.0
Able to join but no active role	28.6	28.2	35.3	0.0
Able to join and be an active member	61.2	52.1	29.4	0.0
Be able to leadership roles	8.2	9.9	17.6	0.0
How much will ... be involved in informal social relationships?				
Relate only to people within family	0.0	4.1	11.8	60.0
Relate with relatives/family friends	4.2	13.7	29.4	40.0
Will make friends of his/her own	95.8	82.2	58.8	0.0

Table 14. Expectations Regarding Living and Working Environments

Item and Responses	% of Parents Choosing a Response Within Levels			
	Mild (n=49)	Moderate (n=71)	Severe (n=17)	Profound (n=5)
Where do you think ... will live as a teenager?				
In an institution	0.0	0.0	0.0	0.0
In a group home	0.0	2.8	5.9	0.0
With his/her own family	100.0	97.2	94.1	100.0
Where do you think ... will live as an adult?				
In an institution	0.0	0.0	0.0	0.0
With family members	14.3	38.0	43.8	100.0
In small supervised group home	4.1	2.8	6.3	0.0
In his/her own apartment independently	81.6	59.2	50.0	0.0
In which of the following environment do you think ... will work as an adult?*				
Prevocational training center	0.0	7.5	23.1	50.0
Sheltered workshop	0.0	13.4	23.1	50.0
Supervised employment	52.2	43.3	15.4	0.0
Competitive employment	47.8	35.8	38.5	0.0

*Three of the 5 parents rating their children as profoundly handicapped and 4 of the 17 rating their children as severely handicapped did not respond to this item.

Table 15. Correlations Between Child Developmental Characteristics[1] and Individual Child Expectations Items

	Severity of Handicap Rating[2]		Develop. Age	Knowledge
	Parent (n=141)	Alpern-Boll (n=175)	(Current) (n=167)	Gain (n=99)
Parental Expectations Regarding:				
Schooling	.45***	.34***	.40***	.23*
Financial independence	.33**	.30**	.37***	NS
Independence in physical care	.47***	.39***	.51***	.20*
Managing and planning other affairs	.46***	.36**	.53***	.21*
Community involvement	.33***	.29**	.41***	NS
Informal social relationships	.48***	.40***	.36***	.44***
Teenage living environment	NS	NS	NS	NS
Adult age living environment	.35**	.35***	.49***	NS
Adult age work environment	.36**	.25**	.41***	NS
Composite child expectation index	.49***	.40***	.51***	.30**

* p<.05   ** p<.01   *** p<.001

[1] Parental knowledge gain was included in the matrix to examine the relationship between knowledge gained from participation in intervention and expectations about the child's future.

[2] The greater the numerical value of the rating/index, the more severe the child's delay.

A potential influence of the deinstitutionalization and normalization movements on this population of parents emerges clearly from our analyses. Regardless of the perceived severity of delay, institutional settings were not considered a living arrangement option for any of the children at any age. Almost all parents expected their children to live with their own family during the teenage years. All parents of profoundly delayed children expected their children to continue to live with them into adulthood, while 50% of severely delayed, 59% of moderately delayed, and 82% of mildly delayed children were expected to live in their own home or apartment during adulthood. In fact, even supervised group homes were not considered significantly as an alternative living arrangement during the teenage years or adulthood. Of 142 responding parents, only 2% expected their children to live in group homes in their teens. The corresponding figure for adulthood was 3.5%. It should be cautioned, however, that the extent to which these results reflect parental knowledge and understanding of the group homes concept cannot be ascertained or even inferred from the study.

Trends similar to those found in relation to schooling and independence were observed with regard to work environments as well. Expectations moved away from prevocational and sheltered workshops toward supervised or competitive employment with increased perceived level of functioning. The correlational patterns displayed in Table 15 confirm the trends described above. With the exception of teenage living environment, expectations tended to be higher with increased perceived level of functioning. Varying degrees of relationships were also found between parental reported knowledge gain and several expectation items. Parents who reported greater knowledge gain from participation in the intervention programme tended to express higher expectations regarding their child's schooling, physical care, planning and management of nonfinancial affairs, and informal social relationships. The composite child expectation score also correlated significantly with parental knowledge gain, suggesting that on the whole parents reporting more knowledge benefits from intervention held higher expectations.

Parent-Child Play Interactions

Both the variety and frequency of play activities that parents engaged their children in were examined in relation to: 1) child developmental age; and 2) child developmental progress. As shown in Table 16, significant correlations were found between child developmental age and all play interaction types, except responsive play. Thus, unlike all other play types, the variety and frequency of responsive games did not vary as a function of level of child developmental functioning. The only negative correlation was that involving lap games. These results suggested that parents engaged in more lap games with developmentally younger children, while engaging in more mastery, pretend, verbal, and discovery games with developmentally older children. When total scale scores w e considered, however, child developmental age correlated significantly with variety but not with frequency of play activities.

Table 16. Correlations Between Parent-Child Play and Child Developmental Characteristics

	Responsive		Lap Games		Mastery		Pretend		Verbal		Discovery		Full Scale	
	Var.	Freq.	Var.	Freq.	Var.	Freq.	Var.	Freq.	Var.	Freq.	Var.	Freq.	Var.	Freq.
DA	NS	NS	NS	.27***	.17*	NS	.14*	.17*	.19**	.46***	.33***	.29***	.26***	NS
RDG	NS	NS	NS	.19**	.16*	.13*	.19**	.23**	.22**	.27***	.32***	.32***	.19**	NS

DA-Developmental Age; RDG-Relative Developmental Gain; Var.-Variety; Freq.-Frequency.

Sample sizes for coefficients involving DA and RDG were 167 and 161, respectively.

Underlined coefficients are negative.

Similar correlational patterns were found between parent-child play and child developmental progress. Generally, greater variety and higher frequency of mastery, pretend, verbal, and discovery games were associated with greater developmental gain, while a higher frequency of lap games was associated with lower developmental gains. Again, when total scale scores were considered, only variety of play activities was correlated significantly with developmental gain.

Three conclusions can be drawn from these results. First, child developmental characteristics influence parent-child play interactions and vice versa. Second, it appears that what varies more reliably as a function of child developmental characteristics is the variety of play activities that parents engage their children in and not how frequently games are played. Finally, as an extension of the second conclusion, the dimension of parent-child play interaction that may be associated with the enhancement of developmental competence in developmentally delayed children appears to be quality and not quantity of interactions.

Child Developmental Progress

While developmental progress varied markedly among the children, the average developmental gain was remarkably high. The mean relative developmental gain of .83 (SD-.67) suggests that on the average the rate of progress made by children in the programme was 83% of normal rate of development (see Table 17). In examining the relationship between amount of time spent in intervention and amount of developmental gain achieved, however, we found a significant negative correlation between the two ($r=-.42$, $p<.001$; see Table 21).

This finding could be interpreted in several ways, but caution must be exercised in so doing. While the negative correlation seemingly suggests poorer outcomes for longer-term recipients, such an interpretation is perhaps simplistic and misleading. A more reasonable interpretation appears to be that developmental gain is greater at the earlier stages of involvement than it is at later stages. Interpreted this way, the finding appears to be consistent with what one would theoretically expect. That is, there is more room to demonstrate the impact of intervention in the absence of prior programming than there is once intervention has started and has begun to increase developmental competence. To further illustrate this point, let us consider the goal of intervention, relative to the child's development. Essentially, the goal is to close the gap between the current level of development and the potential level of developmental competence under maximum environmental and experiential input.

If we called this gap the *zone of maximum potential developmental gain (MPG)*, we will theoretically expect this zone to diminish as intervention progresses. If environmental and experiential input in the form of therapeutic developmental intervention has a potentially powerful influence on the development of young handicapped children, and if such intervention does actually result in a significant reduction in MPG when first introduced, then subsequent progress is bound to be relatively minimal. Such a scenario does not suggest a diminishing effect of intervention, rather it reflects a ceiling effect on the gain index.

From a programming perspective, it is conceivable also that the intervention activities and strategies are best suited to younger and beginning recepients, such that the intervention becomes less responsive to the developmental needs of children beyond either a certain level of developmental competence or a certain level of involvement with programming. Thus, there may be a need to critically examine programme content and instructional strategies to ascertain the extent to which they remain developmentally appropriate, challenging, or enhancing for the entire range of ages covered.

From a measurement perspective, it is appropriate to argue that this finding underscores the superficiality of length of involvement as a process measure. Intensity of involvement or commitment to carrying out intervention activities on the part of parents will undoubtedly be a more appropriate and reliable process measure than a duration index. Such a measure may take one or more of the following forms: (1) actual number of hours spent in programming over a given period; (2) intervention workers' ratings of parental commitment to the program; or (3) some kind of index of demonstrated parental competence in carrying out intervention activities.

Relationships Between Family Ecology and Intervention Outcomes

The correlational data reported in this section were based on composite scores derived for each of the three dimensions of parental rating of the intervention programme and for the four family ecology scales: child expectation; family resources; quality of the home environment, and parent-child play interactions. Family income and mother's education were categorical variables, each with 5 levels. Scores for all family ecological variables -- except income and education -- are summarized in Table 17, while child developmental characteristics and related intervention variables are summarized in Table 18.

Table 19 reveals significant intercorrelations among the parental intervention variables. Parents who reported greater knowledge gain rated the intervention worker more positively and expressed greater satisfaction with the program, while parents who expressed greater satisfaction tended to rate the intervention worker more strongly.

Table 17. Means, Standard Deviations, and Ranges of Composite Parental and Family Ecological Variables

Variable	Mean	SD	Range
Intervention Variables:			
Parental rating of intervention worker	36.2	4.1	18-40
Parental perceived knowledge gain	55.1	12.0	16-80
Parental satisfaction with programme	49.5	6.3	29-60
Family Ecological Variables:			
Child expectation	28.7	7.1	9-37
Family resources	59.6	14.0	5-87
Quality of home environment	35.3	8.3	13-49
Parent-child play: Variety	17.0	5.2	3-45
Parent-child play: Frequency	34.9	12.8	6-68

Table 18. Developmental Characteristics of the Children
(All Scores Expressed in Months)[a]

Variable	Mean	SD
Chronological Age at programme entry	30.4	18.9
Developmental Age at programme entry[b]	18.5	14.3
Developmental Delay Severity Index[c]	0.37	0.29
Current Chronological Age	58.9	21.4
Current Developmental Age[b]	32.0	17.7
Months spent in intervention	21.5	15.6
Relative Developmental Gain[d]	0.83	0.67

[a] Valid sample sizes ranged from 182 to 199 for variables in this table.
[b] Composite index extracted from all five Alpern-Boll subscales.
[c] Derived from Alpern-Boll scores at entry into programme.
[d] Overall gain in development divided by months in programme.

Table 19. Intercorrelations Among Three Intervention Variables

Variable	Knowledge Gain	Rating of Worker Ability	Satisfaction With program
Knowledge gain	-	.33***	.33***
Rating of intervention worker		-	.43***

*** p<.001; Valid sample sizes ranged from 95 to 134

Intercorrelations among the family ecological variables are reported in Table 20. Quality of the home environment correlated significantly with family resources, family income, parent-child play, and maternal educational background. Family income also correlated strongly with family resources and maternal education but not with parent-child play. Finally, parental expectations about the child's future correlated significantly with family resources and parent-child play.

Table 20. Correlations Among Family Ecological and Socio-economic Variables

	Family Resources	Family Income	Mother's Education	P-C Play (Variety)	P-C Play (Frequency)
Home Environment	.46 ***	.27 **	.24 **	.42 ***	.36 ***
Parental Expectation	.14 *	NS	NS	.37 ***	.25 ***
Family Income	.43 ***	-	.43 ***	NS	NS

* p<.05; ** p<.01 *** p<.001
Valid n's for correlational analyses ranged from 140 to 173.

Having ascertained the interrelationships among the intervention and family ecological variables, the extent to which elements of these two sets of variables were related to child developmental characteristics and to length of participation in intervention (Table 21) was also examined. The strongest positive correlations were observed between quality of the home environment and expectations about the child's future -- on one hand -- and the child's current level of developmental functioning on the other hand. These correlations could be interpreted in at least two ways: (1) parents of higher functioning children had higher expectations about the future and provided their child with a more enriched environment; or (2) parents who provided their children with a more enriched environment and held higher expectations about their child's future had children who were higher functioning developmentally.

The results showed also that parents of higher functioning children reported greater satisfaction with intervention, as shown by the significant negative correlations between severity of delay and the other variables. Thus, the more severely delayed the child was, the lower the degree of satisfaction the parent expressed with the intervention program. Also, parents of more severely delayed children reported less knowledge gain, had lower expectations for their child's future, and provided the child with less enriched environment.

Table 21. Relationship Between Child Developmental
Characteristics and Quality of Home Environment,
Parental Expectations for Child, and Three Intervention Variables

	Home Environment	Expectations	Time in Programme	Knowledge Gain	Satisfaction
Current Developmental Level (Alpern-Boll)	.53 ***	.42 ***		.18 *	.37 ***
Severity of Delay/Handicap	.30 ***	.29 ***		.21 *	.29 ***
Relative Developmental Gain	.31 ***	.37 ***	.42 ***		.20 *

* p<.05; ** p<.01 *** p<.001
Valid n's for correlational analyses ranged from 107 to 182.
All negative correlations are underlined

Child developmental gain correlated positively with quality of the home environment, expectations for the child's future, and parental satisfaction with the program. Thus, children from more enriched environments and children whose parents held higher expectations for their future and engaged them in a greater variety of interactive games (see Table 16) showed greater developmental gains. The parents of such children expressed greater satisfaction with the intervention program.

The finding that parents of more severely delayed children expressed less satisfaction with the intervention and reported less knowledge gain has profound implications for intervention work. It underscores the differential value of early intervention to different client groups. First, the finding suggests that perceptions or judgements about the value of intervention are sometimes mediated more significantly by the developmental characteristics of the target child than by qualities of the intervention programme. What constitutes significant change or improvement in the target child depends to a large extent on what the parent expects from the programme, relative to the child's developmental needs. More intensive effort, sustained over a reasonably long period of time, is required to make small amounts of conspicuous change in the more severely delayed child. Thus, it is possible for an early intervention delivery system to have all the elements of quality programming -- including excellent staff and various other supports -- and yet be perceived by some clients (particularly families of more profoundly delayed children) as being only minimally effective or supportive.

Programme developers and implementers need to be aware of these dynamics, if they are not to give up easily when they receive "mixed reviews" from some of their clients. Of course some of the "mixed reviews" sometimes stem from overoptimism and unrealistic expectations projected by interventionists themselves. Raising parental expectations beyond what can be deemed realistic can be counterproductive. If parents expect intervention to serve a curative function, then parents of more severely delayed children are likely to be more disappointed and less satisfied even in the face of progress on the part of their children. The importance of the need to provide parents with realistic information about the goals and potential effects of intervention cannot be overemphasized.

<u>Quality of the home environment:</u> Given the strong correlation between the quality of the home environment and child developmental progress, we utilized the risk status cut-off points on both the 0-3 years and 3-6 years scales of the Home Screening Questionnaire to examine what proportion of our sample of children came from home environments that could be potentially deprived. Because the HSQ was standardized only on children from birth to 6, we did not include any children older than 6 in this stage of the analysis. Of 25 children in the 0-3 years range whose parents completed the HSQ, 14 (56%) had suspect scores. The suspect rate was even higher in the 3-6 years range. Of 107 3- to 6-year-old children whose parents completed the scale, as many as 72 (67.3%) had suspect scores. Thus, as much as 65% of children in the 0-6-year range scored in the suspect range in terms of the quality of their home environment.

The HSQ was validated using an American sample, and therefore caution should, as a matter of course, be exercised in interpreting these results. However, the HSQ was also standardized on low income families, a characteristic that is shared by a large proportion of the families in this study. These results then call for a closer look at what emphasis, if any, the Direct Home Services Programme places on the importance of the child's overall environment and what strategies may be adopted to assist families provide quality home environments for their young handicapped children.

Predicting Child Developmental Gain, Parental Satisfaction, Parent-Child Play, and Parental Expectations

Table 22 summarizes relevant results of several separate regression analyses performed to predict child developmental gain, parental satisfaction, variety and frequency of parent-child play, quality of the child's home environment, and parental expectations. In addition to reporting multiple correlation coefficients for each prediction, Table 22 also includes zero-order correlation coefficients between each of the five dependent variables and all independent variables included in each prediction.

To isolate programme or family ecological variables that appeared to be most critical to the developmental progress of children in intervention, a stepwise multiple regression analysis was run to predict developmental progress (defined as the ratio of months gained on the Alpern-Boll Developmental Profile to number of months spent in intervention). Thirteen variables were entered into the analysis: (1) child developmental characteristics (developmental progress, developmental age at entry into intervention, and age at detection); (2) intervention factors (time spent in intervention, parental knowledge gain, and parental satisfaction with programme); and (3) family ecological factors (quality of the home environment, expectations about child's future, maternal education, family income, family resources, frequency of parent-child play, and variety of parent-child play).

The best predictors of child developmental progress were the child's level of development at the time of entering intervention, and parental expectations about the child's future (R-.69. These two variables explained 45% of the variance[1].

A second stepwise regression analysis was run to ascertain what factor(s) were most critical in determining parental satisfaction with the intervention program. Twelve variables were included in the analysis: parental satisfaction; parental knowledge gain; parental rating of worker competence; time spent in intervention; parental expectations, quality of the home environment; maternal education, family resources; family income; and the child's current level of development, level of development at entry into intervention, and developmental progress. The child's current level of development and parental rating of the intervention worker were the best predictors of parents' satisfaction with the intervention programme (R-.52). The two variables explained 25% of the variance.

A third regression analysis was performed to ascertain variables that would be most predictive of (1) variety of play activities parents engaged their children in, and (2) the frequency with which parent-child interactive play occurred. In addition to these interaction variables, 8 other factors were included in each of the two separate runs: the child's current developmental age; time spent in intervention; parental knowledge gain; satisfaction with intervention; quality of the home environment; parental expectations; family resources; family income; and maternal education.

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[1] All estimates of the amount of variance explained by the predictor variables are based on an adjusted R^2.

Table 22. Zero-order Correlations Between Independent and Dependent Variables and Corresponding Multiple Rs for Regression Analyses

# Independent Variables	Dependent Variables Dev. Prog	Satis-faction	Play (Var)	Play (Freq)	Home Environ	Expecta-tion
1 DA: Entry Level	.55***	.19*			.37***	.33***
2 DA: Current		.37***	.26***	NS	.32***	.51***
3 Detection Age	.24***				NS	NS
4 Developmental Progress	--	.20**				.42***
5 Time Spent in Programme	.42***	NS	NS	.17*	NS	NS
6 Knowledge Gain	NS	.33**	.37***	.42***	.42***	.30**
7 Worker Rating		.43***				
8 Satisfaction	.20*	--	.30***	.29**	.17*	.46***
9 Home Environment	.31***	.17*	.42***	.36***	--	.33***
10 Expectations	.42***	.46***	.37***	.25***	.33***	--
11 Mother's Education	NS	.15*	NS	NS	.24**	NS
12 Income	NS	NS	NS	NS	.27**	.21**
13 Family Resources	NS	NS	.24**	.22**	.46***	NS
14 Parent-Child Play: Var	.19**		--		.42***	.37***
15 Parent-Child Play: Freq	NS			--	.36***	.25***
BEST PREDICTORS	1/5	7/2	10	6	2/11/10/13	2/14
MULTIPLE R	.69	.52	.46	.38	.82	.74
VARIANCE (ADJUSTED R^2)	44.8%	24.5%	19.6 %	12.8%	64.9%	52.7%

Underlined correlations are negative.

Parental expectations regarding the child's future emerged as the best predictor of the variety of play activities that parents engaged their children in (*R*=.46), while parental knowledge gain emerged as the single best predictor of how frequently parents and their children engaged in play (*R*=.38). These predictions were relatively weak, however, since they accounted for only 20% and 13% of the variance respectively.

We also examined factors that were most predictive of the quality of the child's home environment. All the 15 variables mentioned in the preceding analyses, except child developmental progress and parental rating of the worker, were entered into the analysis. The four best predictors -- in order of significance -- were the child's current level of development, maternal education, parental expectations, and family resources.(*R*=.82). These variables explained quite a substantial proportion of the variance (65%).

Because the analyses depicted parental expectations as an important determinant of several of the variables examined in this study (child developmental progress, variety of parent-child interactive play, and quality of the home environment), we performed an additional stepwise regression analysis in search of the predictors of parental expectations. Expectations and all the other variables, except parental rating of the intervention worker, were included in the analysis.

Two variables emerged as the best predictors of parental expectations regarding the child's future: the child's current level of development and the variety of play activities that parent engaged the child in (R=.74). The two variables together explained 53% of the variance.

These results show clearly that parental expectations regarding the future of their developmentally delayed children exercise a powerful influence on the nature and quality of the parent-child interaction process, shape the nature and quality of the home environment to which the child is exposed, and -- consequently--determine how much progress the child makes in the development of competence.

The finding that parental expectations and parent-child interaction are predictive of each other is noteworthy; it underscores the view that relationships among the broader ecological variables which impinge on child development are cyclical rather than unidirectional in nature. In this case, the evidence suggests that while parents' expectations about their children's future lead them to interact in specific ways, the knowledge that parents acquire about the child's competencies during the course of interaction may form the basis for maintaining or revising expectations.

It is significant to note also that although parental knowledge gain did not correlate significantly with child developmental progress, it correlated very significantly with several major family ecological variables -- parental expectations, quality of the home environment, and variety and frequency of parent-child interactions--one of which (parental expectations) predicted child developmental progress. In fact, knowledge gain predicted the frequency of parent-child interaction. It does appear from these results, then, that the intervention process may impact the child's development via its strong influence on family ecology (in particular, by influencing parental expectations and parent child interaction). If this interpretation is valid, then one of the implications of this research is that an intervention process that targets family ecology more directly--rather than via the "parent as teacher' paradigm -- is likely to produce even better results.

In fact, other aspects of the results obtained in this study reinfornce the need for an approach to intervention that focusses broadly on the entire family ecology. First, this study has revealed that as much as 65% of children six years or younger may be exposed to environments that may be cognitively and socio-emotionally less enriching. Second, the regression analyses have shown that the best predictors of quality environment are the child's developmental competence, maternal education, parental expectations, and family resources. A close examination of the family resources scale shows that the family resources index is -- to some extent -- also a measure of overall family psychological well-being. Parents reporting greater perceived adequacy of those resources are less likely to be stressed by the task of bringing up a developmentally delayed child. If such parents hold reasonably high expectations about their child's future and have a relatively strong educational background, their children are more likely to show greater developmental gain.

From there results, it appears the challenge is to evolve methods and strategies of intervention aimed at enriching the overall family environment to which the child is exposed. Among critical areas to address are: helping parents cope with the stresses of rearing a developmentally delayed child, by promoting family well-being and increasing accessibility to resources; promoting developmentally enhancing dyadic and polyadic interactions; helping parents identify and/or choose developmentally appropriate activities and toys; providing supports such as respite care; and other strategies that generally serve to strengthen the family as a system and context for enhancing child development.

These comments and proposals do not in any way diminish the perceived value of the present intervention model, however. In fact, not only was satisfaction with the programme very high, but satisfaction was based -- in part -- on attributes of the programme. Both the zero-order correlational patterns and the regression results showed that satisfaction with the intervention programme was largely associated with child and programme variables. Nonprogramme variables, such as parental education, family income, and family resources did not correlate significantly with satisfaction. Although one family ecological variable -- parental expectations -- correlated significantly with satisfaction ($r=.43$, $p<.001$), the variables that were most predictive of satisfaction with the intervention programme were the child's current level of development and parental rating of the intervention worker.

CHAPTER V: SUMMARY AND RECOMMENDATIONS

The results presented in the preceding chapter provide several significant insights about the early intervention process and issues related to it. In this concluding chapter, we summarize the major themes emerging from the study and offer specific recommendations when findings are deemed to have significant implications for policy, improved programming, and future research on the programme.

The summary is organized under the following four headings: (1) programme accessibility, identification, and support systems; (2) parental perceptions about the intervention programme and expectations about children's future; (3) child developmental progress; and (4) determinants or correlates of selected child and parental variables.

Following the summary, recommendations are offered under the following four headings: (1) recommendations on policy issues; (2) recommendations regarding programme extensions/improvements; (3) recommendations on enhancing early referral and programme entry; and (4) recommendations regarding future research on the intervention programme.

Summary

Programme Accessibility, Identification, and Support Systems

1. The Direct Home Services Programme is fairly widely known in communities, agencies, and institutions across the Province, as indicated by the broad range of referral sources.

2. While some parents were officially informed for the first time about their child's problem by public health nurses and social workers (16.7% of cases), family doctors and other physicians remain the primary professionals communicating the child's handicap or delay to parents (81.1% of cases).

3. A sizeable proportion of the sample of parents (31%) reported that they were not satisfied with the information they were provided at the time their child's handicap or delay was communicated to them. The most frequently expressed concern was that professionals were either unclear or reluctant to be open in disclosing the child's problem.

4. Most children in the study (93.8%) were admitted to the intervention programme prior to age 3 years. This, indeed, is an indication that DHSP has successfully carried out its mandate to intervene early in the lives of its clients. However, there is a significant delay in accessing early intervention services for many children identified as having a delay in their first year of life. As much as 65% of children were identified in the first year, but only 22% of all children in intervention entered the programme prior their first birth day.

5. There is a very low level of parental involvement with formal and informal support groups.

Parental Perceptions About Intervention and Expectations About Child's Future.

1. On the whole, parents rated the intervention programme very positively. Almost all parents found the programme so valuable

that they would recommend it to other families with similar needs.

2. Child Management Specialists (the home teachers) were rated very positively on all eight attributes probed: ability in explaining the child's programme; sensitivity to the needs of parents; knowledge and skills regarding child management; relationship and rapport with children; ability to deal with parents' questions and problems; regard and receptiveness to parental opinions and input; acting on parental suggestions and input; and attitude toward parents.

3. Parents expressed strong satisfaction with the quality of programming in all five developmental domains. Satisfaction with child progress in the domains was also high; however, parents appeared to be less satisfied with progress made in the academic and language domains than they were in the three other domains. This, perhaps, is a reflection of the importance that parents attach to language/communication and cognitive skills.

4. Parents were not as unanimous in their perceptions about knowledge gain as they were in their satisfaction and worker competence ratings. On the whole, parents reported that they gained more knowledge in areas related directly with programming (e.g. recording, assessment and evaluation, behaviour management techniques) and children's abilities/development than they did on broader and relatively less immediate issues like preschool and school placement, parental rights, integration, and social role valourization. Parents reported the least knowledge gain with

regard to the existence and accessing of other relevant community services.

5. Parents' expectations about their children's future were strongly related to their perception of the children's level of functioning. Higher expectations regarding school placement, physical and financial independence, and vocational placement were expressed for relatively higher functioning children.

6. A potential impact of the deinstitutionalization and social role valourization movements was apparent from the pattern of parental expectations observed in this study. Regardless of how parents perceived the severity of their child's handicap, institutional settings and supervised group homes were not deemed to be living arrangement options for either teenage or adulthood.

7. Significant intercorrelations were found among the three indices reflecting parental perceptions about the intervention programme. Parents reporting greater knowledge gain rated the home teacher more positively and expressed greater satisfaction with the programme as a whole.

8. With the exception of knowledge gain the parental perception variables and parental expectations were all significantly related to child developmental progress. Thus, children who made greater developmental gains were those whose parents expressed greater satisfaction with the intervention, rated the home teacher more positively, and held higher expectations about their child's future.

Child Developmental Progress

1. The children in this study were found to progress at the remarkable rate of 83% of normal rate of development during the time they were in intervention, assuming the normal rate of development to be one month of developmental age per calendar month. Wide variations were observed, however.

2. Child developmental progress was found to be strongly related to the quality of the child's home environment and to the expectations that parents held about the child's future.

3. Further analysis to categorize children by risk status, showed that as much as 65% of children in the birth to 6-year range may be exposed to developmentally less optimal environments and experiences. This situation may be explained, in part, by the large number of low-income families in the sample. In fact, both family resources and family income correlated positively with the quality of the child's home environment.

4. A signficant negative correlation was found between relative developmental gain and amount of time spent in intervention. This was interpreted as suggesting that the earlier stages of intervention were associated with greater gains than were later stages, with the implication that current intervention activities and strategies may be best suited for the earlier stages of the intervention process.

5. Parent-child play interactions influence, and are influenced by, child developmental characteristics. However, the aspect of the parent-child interaction process that correlated significantly

with child developmental characteristics was variety -- and not frequency -- of play activities. Thus, the dimension of parent-child interaction that may be associated with the enhancement of developmental competence in children appears to be quality of interaction, not how often interaction occurs.

Determinants of Selected Child and Parental Variables

1. The best predictors of child developmental progress in the sample studied were the child's level of development at the time of entering intervention and parental expectations about the child's future. Thus, children who were relatively higher functioning at the time of entering intervention and who had parents with higher expectations made greater developmental gains.
2. The best predictors of parental satisfaction with the intervention process and with child progress were parental rating of the intervention worker and the child's current level of development. That is, parents were most likely to express extreme satisfaction with the programme if they perceived the worker as being highly competent and had children who were relatively high functioning.
3. Parents who were more likely to expose their children to a greater variety of interactive games and activities were those who held higher expectations regarding their child's future.
4. Parents were most likely to engage in frequent interactions with their child if they reported greater knowledge gain from the intervention programme.

5. Parental expectations about the child's future were, in turn, predicted by two variables: the child's current level of development and the variety of parent-child interactive play. Thus, parents who had higher functioning children and who exposed these children to a greater variety of interactive play were more likely to express higher expectations.

6. The variables that most likely determined what the quality of the child's home environment would be were the child's current level of development, maternal education, parental expectations, and family resources.

7. On the whole, the results of the study revealed family ecology--in particular, parental expectations, parent-child interaction, and quality of the home environment -- as critical mediator variables between the intervention process and its impact on the child. One implication of this finding is that interventions which target broader family ecological variables more directly are likely to produce even better results.

Recommendations

Recommendations on policy issues

1. The finding that as much as 65% of children in the birth to 6-year range may be exposed to developmentally less optimal environments and experiences -- coupled with the large number of families reporting significantly below average incomes -- calls for policy initiatives towards providing more material assistance

to families in need of such support. Some consideration should be given to the allocation of funds to establish an auxiliary toy and educational material lending/ support service. Such a service would (1) provide information and counselling to parents on children's developmental needs, (2) provide advice on the choice of age-appropriate materials for stimulating children's development, and (3) actually lend materials out to families who cannot easily afford to acquire them.

2. Consistent with the foregoing, it is recommended also that the Direct Home Services Programme adopt formally a more "General Service Plan" approach to service delivery. Such a structure would allow for the consideration of broader child and family needs beyond those of specific skill teaching.

3. In view of the large numbers of families that currently have to wait for extensive periods of time before getting into the programme, consideration should be given to staff expansions, including more use of part-time Child Management Specialists and Early Intervention Workers across the Province.

4. The parent training component of the programme should be reoriented to place greater emphasis on preparing parents to become independent of the programme as quickly as possible. This will ensure higher turnover in caseloads and result, ultimately, in significant reductions in waiting periods and waiting lists. More importantly, however, such a policy makes sense philosophically; intervention with families should foster independence and initiative on the part of parents so that

developmentally delayed children are not deprived of the opportunity to grow up in a normal, undisrupted family milieu.

5. There is a need, within the Division of Mental Retardation Services, to acknowledge that parental expectations regarding alternatives to residential placements do not indicate a favourable acceptance of group homes. Consequently, the development of other less restrictive environments (e.g., foster care and cooperative living) should be emphasized both in the short and long term.

Recommendations regarding programme extensions/improvement

1. The results of this study underscored the central role of broad family ecological factors in the intervention process. There is the need to extend the focus of intervention beyond skill teaching to target the broader family ecological context more directly. Specifically efforts should be made, in the short term, towards expanding the programme in the following two directions:
    a. Intervening more directly to improve the overall quality of the child's home environment. In particular, parents should be provided direction and assistance in providing a wide range of developmentally appropriate materials and developmentally enriching experiences to their children.
    b. Providing supports that will reduce the pressures and stresses associated with care of developmentally delayed children and thereby increase the probability that parents would enjoy their children and provide them with

quality stimulation.

c. Promoting developmentally enhancing interactions between parents and the child and between the child and the family at large. Strategies for increasing parents' awareness of the child's role in communication and interaction should be emhasized, alongside techniques that parents can use to reduce parental dominance and increase greater balance in interaction.

These recommendations are consistent with trends alreay occuring in the early intervention field, and literature and other relevant resources necessary for DHSP to make this shift are available across North America.

2. One of the speculations made on the basis of the significant negative correlation between length of participation and developmental gain was that intervention tasks may become less developmentally challenging as children spend more time in the programme. It is recommended that a critical appraisal of the skill teaching curriculum be undertaken to ensure that children continue to benefit from the programme during the entire period of their involvement. It may indeed be productive to employ a developmental framework to examine the adequacy of the curriculum.

3. Depending upon the nature and degree of the child's problem, families of developmentally delayed children will need to access a variety of other programmes and services beside the developmental intervention programme -- e.g., speech-language

therapy, audiological services, physiotherapy. There is evidence to suggest that families do not always utilize all the available services that they require, partly because of lack of knowledge about the existence and/or relevance of such services. The finding that parents reported the least amount of knowledge gain in relation to "knowledge of other relevant community services" does not imply necessarily that parents are not aware of or not accessing other services to the extent that they should. Nevertheless, it suggests the need for DHSP to pay greater attention to this aspect of the intervention programme.

4. It is recommended also that DHSP staff encourage the formation and active functioning of parent groups to provide (a) a support base for parents who would need such support, and (b) a forum for the discussion and sharing of ideas and concerns. Parent support groups, when effectively organized, can help parents deal with secondary psychological problems associated with the parenting of developmentally delayed children. A large number of parents expressed interest in occasional group-based workshops. Organized parent groups can serve as the context for such workshops, providing input on issues and concerns that may be addressed in workshop presentations.

Recommendations on enhancing early referral and programme entry

1. There is the need for DHSP staff to work towards stronger ties with other human service professionals and agencies that deal with parents during the critical period of diagnosis and

identification. Among the perspectives to share with these other professionals is the need for sensitivity and professional support when communicating diagnosis to parents. Such interdisciplinary networks with other professionals should also provide avenues for promoting early referral, sharing referral and other information, and educating potential clients about the intervention programme.

2. DHSP should intensify its efforts to ensure that children with developmental delays are enrolled in the intervention programme as soon as they are identified and referred.
3. Since the attainment of early enrollment for all qualified children is influenced by the availability of resources -- such as funding and personnel -- it is recommended that DHSP establish a mechanism for projecting future expansions in service needs so that adequate advance planning and preparations, including budgetary requests and personnel training, can be put in place to ensure prompt service to <u>all</u> children who qualify.

<u>Recommendations regarding future DHSP evaluative research</u>

1. In future DHSP evaluations studies, effort should be made to either retrieve relevant information on time/age of referral or include questionnaire/interview items designed specifically to obtain an index of wait time between referral and admission into programme. In addition to this more basic information, the research should seek to identify factors associated with delays in accessing the intervention programme. These two sets of

information would help plan effective strategies for promoting early programme entry.

2. Future studies should replace (or perhaps add to) the "duration of intervention" measure with a more intuitively valid measure, such as (a) actual number of hours spent by parents in programming activity per week, (b) a rating of the degree of commitment shown by each parent to the intervention process; or (c) some objective measure of demonstrated parental competence in carrying out intervention.

3. Procedures for assessing how we [illegible] parents may be coping with the demands of the intervention programme should also be included in future studies. Such data are necessary, if interventionists are to avoid situations whereby the intervention process itself becomes an additional source of stress for parents of the developmentally delayed child.

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APPENDIX A:

DIRECT HOME SERVICES PROGRAMME PARENT EVALUATION FACT SHEET

FACT SHEET

1. BIOGRAPHICAL INFORMATION

A. CHILD

1. Identification # ______
2. D.O.B. ______
3. Sex: ______

B. OTHER FAMILY MEMBERS

1. Total # of children: ______
2. # living at home now: ______
3. Age and sex of those living at home:

______

C. MOTHER

1. Age: ______
2. Educational Level: Check one

☐ Grade school
☐ High school
☐ Vocational training
☐ University
☐ Post graduate

3. Occupation: ______

D. FATHER

1. Age: ______
2. Educational Level: Check one

☐ Grade school
☐ High school
☐ Vocational training
☐ University
☐ Post graduate

3. Occupation: ______

2. GENERAL INFORMATION

(a) The size of your community is:

☐ 5,000 or less
☐ 5,000 to 15,000
☐ 15,000 to 30,000
☐ Over 30,000

(b) Your family income is:

☐ less than $10,000
☐ $10,000 to $15,000
☐ $15,000 to $25,000
☐ $25,000 to $40,000
☐ Over $40,000

(c) Marital status:

☐ Single parent: ____ ☐ Married: ____ ☐ Divorced/Separated: ____

3. HOW WOULD YOU RATE YOUR CHILD'S DEVELOPMENTAL LEVEL?

☐ Mildly delayed ☐ Moderately delayed ☐ Severely delayed ☐ Profoundly delayed

APPENDIX B:

PARENT EVALUATION QUESTIONNAIRE

DIRECT HOME SERVICES PROGRAMME

PARENT EVALUATION QUESTIONNAIRE

ID CODE:__________

INTRODUCTION

Please answer the following questions to give us your feedback about the Direct Home Services Programme. The questions are designed to give us an indication of how our programme works across the Province, and, as such, all answers will be analyzed for the whole group. Individual identities will not be disclosed in presenting results.

Please answer all questions as honestly as you can. Feel free to make additional comments wherever you find it necessary to do so.

After completing the evaluation, we ask that you please return it by mail to the provincial office of the Direct Home Services Programme in the self-addressed envelope provided.

SECTION A

1. How did you become aware of your child's developmental problem?

____

____

____

2. How old was your child when you found out about the problem? __________

3. Were you satisfied with the way in which you were informed about your child's problem(s)?

[ ] Yes [ ] No

Comments: ____

____

____

4. How did you become aware of the Direct Home Services Programme? Who informed you?

____

____

____

5. Do you have any contact with any of the following groups? If so, indicate how often.

	Yes	No	How often?
1. Association for Mentally Retarded/Community Living	___	___	________
2. Parent support groups	___	___	________
3. Other specialized groups (e.g., Spina Bifida Assoc)	___	___	________
4. Other parents of delayed children (informally)	___	___	________

SECTION B

1. What were your initial impressions about the Direct Home Services Programme?

☐ Extremely Impressed ☐ Impressed ☐ Not Sure ☐ Unimpressed
☐ Extremely Unimpressed

Comments: ________

____

____

2. What are your current impressions about the Direct Home Services Programme?

☐ Extremely Impressed ☐ Impressed ☐ Not Sure ☐ Unimpressed
☐ Extremely Unimpressed

Comments: ________

____

____

3. How satisfied are you with the gains made by your child in this programme (new behaviours or skills learned)?

☐ Extremely Satisfied ☐ Satisfied ☐ Not Sure ☐ Dissatisfied
☐ Extremely Dissatisfied

What do you consider to be the most important gains made by your child? ________

____

____

If your child has not made any gains in the programme, why do you think this is so? ________

____

4. How satisfied are you with the methods used to change your child's behaviour?

☐ Extremely Satisfied ☐ Satisfied ☐ Not Sure ☐ Dissatisfied
☐ Extremely Dissatisfied

Comments: ____

____

5. How satisfied are you with the <u>quality of programme attention</u> paid to each of the following developmental areas? (Please check one response for each area)

		Extremely Satisfied	Satisfied	Not Sure	Dissatisfied	Extremely Dissatisfied
A.	Socialization: the ability to play and interact with others	______	______	______	______	______
B.	Self-help: toileting, eating, dressing, etc.	______	______	______	______	______
C.	Academic: problem solving and thinking skills	______	______	______	______	______
D.	Language: what the child says and understands.	______	______	______	______	______
E.	Motor: crawling, walking, running, etc. Small and large muscle coordination	______	______	______	______	______

6. How satisfied are you with your child's <u>actual progress</u> in each of the following areas? (Please check one response for each area)

		Extremely Satisfied	Satisfied	Not Sure	Dissatisfied	Extremely Dissatisfied
A.	Socialization: the ability to play and interact with others	______	______	______	______	______
B.	Self-help: toileting, eating, dressing, etc.	______	______	______	______	______
C.	Academic: problem solving and thinking skills	______	______	______	______	______
D.	Language: what the child says and understands.	______	______	______	______	______
E.	Motor: crawling, walking, running, etc. Small and large muscle coordination	______	______	______	______	______

SECTION C

Please rate your Child Management Specialist (the intervention worker) on each of the following factors. Please note that the ratings will not be seen as a reflection on any one Child Management Specialist. Instead, the ratings will give us an idea of how effectively our staff are performing as a group across the province.

	Excellent	Good	Fair	Poor	Inadequate
1. Ability in explaining your child's programme to you.	______	____	____	___	______
2. Appears sensitive to your needs as child's parent.	______	____	____	___	______
3. Seems knowledgeable and skillful with regard to child management	______	____	____	___	______
4. Has built a good relationship with your child.	______	____	____	___	______
5. Ability to deal with problems and/ or questions that you want help with.	______	____	____	___	______
6. Welcomes your opinions and input into the child's overall programme.	______	____	____	___	______
7. Uses or acts on your suggestions and input.	______	____	____	___	______
8. Attitude towards you during visits.	______	____	____	___	______

Comments: ____

____

____

Continued on next page

SECTION D

1. The following are some things parents might gain from a service such as the Direct Home Services Programme. How much knowledge do you feel you have gained about each of the following? (Please check one response for each statement)

	Now an Expert	Gained a Lot	Gained Some	Gained a Little	Gained Nothing
a. Assessment and evaluation of your child	____	____	____	____	____
b. Knowledge of your child's abilities and needs	____	____	____	____	____
c. Behaviour management techniques	____	____	____	____	____
d. Skills for coping with child's problem	____	____	____	____	____
e. Recording of your child's progress at home	____	____	____	____	____
f. Appropriate selection of toys and books for your child	____	____	____	____	____
g. Knowledge of child development:					
- Social development	____	____	____	____	____
- Self-help skill development	____	____	____	____	____
- Academic skill development	____	____	____	____	____
- Language development	____	____	____	____	____
- Motor development	____	____	____	____	____
h. Options for pre-school placement	____	____	____	____	____
i. Options for school placement	____	____	____	____	____
j. Parental rights	____	____	____	____	____
k. Principles of social role valourization and integration	____	____	____	____	____
l. Availability of other community resources to support your child's needs	____	____	____	____	____

2. Are there any other topics not included in question 1 above that you feel should have been explained by the Child Management Specialist?

[ ] Yes [ ] No

If yes, please specify: ________________________________

SECTION E

1. Have you ever participated in a parent training course?

   ☐ Yes Please specify: ______________________________

   ☐ No

2. Would you be interested in participating in a parent training course offered by the Direct Home Services Programme in your area?

   ☐ Yes ☐ No

3. Would you recommend the Direct Home Services Programme to other parents with similar needs?

   ☐ Yes ☐ No

4. Finally, please rate the service to show how satisfied you are with the programme as a whole.

   ☐ Extremely Satisfied ☐ Satisfied ☐ Not Sure ☐ Dissatisfied
   ☐ Extremely Dissatisfied

5. Please add any comments or suggestions you would like to make: