DOCUMENT RESUME

ED 323 678 EC 232 103

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TITLE	Project Continuity: A Handicapped Children's Early Education Project. Final Report, October 1, 1986 to September 30, 1989.
INSTITUTION	Nebraska Univ. Medical Center, Omaha. Meyer Children's Rehabilitation Inst.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC. Handicapped Children's Early Education Program.
PUB DATE	Mar 90
GRANT	G008630275888
NOTE	130p.
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC06 Plus Postage.
DESCRIPTORS	Agency Cooperation; Child Development; *Congenital Impairments; *Diseases; *Early Intervention; Evaluation Methods; Family Programs; Infants; *Nursing; Quality Control; *Special Health Problems; Toddlers; Transitional Programs
IDENTIFIERS	*Project Continuity NE

ABSTRACT

The final report describes Project Continuity, a federally funded effort to provide continuity of care for handicapped infants with chronic illness or complex medical needs while in the acute care setting and to facilitate transition of the infant into the home environment. Goals were accomplished within the context of a family-centered intervention model. The project provided habilitative, educational, nursing and medical care in various settings to 42 infants and toddlers with such diagnoses as congenital heart condition, gastrointestinal anomalies, genetic disorders, and muscular skeletal problems. Major project components included: (1) support for primary care nurses for incorporation of developmental strategies in nursing care plans for the hospitalized infants; (2) developmental assessment and intervention; and (3) case coordination. Quality assurance procedures required identifying national or local standards and monitoring the case coordination and nursing. Ten appendixes present such information as: the condition classification system, an Individualized Family Service Plan, the roles and sequence of activities for the case coordination process, a product dissemination flyer, and a workshop flyer. Contains 19 references. (DB)

The Project Continuity Model

Final Report

Department of Special Education
Meyer Rehabilitation Institute
University Hospital
University of Nebraska Medical Center

FINAL REPORT

PROJECT CONTINUITY

OCTOBER 1, 1986 to SEPTEMBER 30, 1989

A Handicapped Children's Early Education Project

Funded by Office of Special Education Rehabilitation Services
Project #G00863027588

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March 1990

Project Continuity - Abstract

Project Continuity, a federally funded Handicapped Children's Early Education Program (HCEEP) model demonstration project, was a joint project implemented collaboratively with the University of Nebraska Hospital (UNH) and Meyer Rehabilitation Institute (MRI). Continuity of care was identified as a priority service need for handicapped infants with chronic illness and their families who were faced with long term or frequent hospitalizations. This priority emerged as an outgrowth of previous work by project staff in an early identification and referral project. The primary goal of Project Continuity was to develop and validate a model designed to: (1) provide continuity of care for the handicapped infant with chronic illness or complex medical needs while in the acute care setting, and (2) facilitate transition of the infant into the home community. Supportive services were provided to the family to facilitate coordination of care among local community agencies. These goals were accomplished in a context of a family-centered intervention model in which the family played an integral role in the planning and implementation of their child's care plan. The enactment of PL 99-457 during the course of the project validated these goals which encompased the principles of family-center care. This project provided habilitative, educational, nursing and medical care which was integrated with respect to care needed across life settings, i.e., hospital, home and educational/therapy programs. Major components of this project included: (1) support for primary care nurses for incorporation of developmental strategies in nursing care plans for the hospitalized infant; (2) developmental assessment and intervention, and (3) case coordination.

Project Continuity served 42 infants and toddlers who were diagnosed as disabled and who had chronic illnesses which resulted in frequent or prolonged hospitalizations. Infants in this population represented a wide range of medical diagnoses including congenital heart condition, gastrointestinal anomalies, genetic disorders, muscular skeletal problems and renal disease. Eighty three percent of the infants were eligible and were enrolled in early intervention programs through their local communities. This project served a wide geographic area as UNH is a tertiary care center. Fifty seven percent of the children's families resided in Nebraska.

Assessment, intervention and case coordination services provided by Project Continuity encompassed the principles of family-centered care (Shelton, Jeppson & Johnson, 1987). Central to the philosophy and work of the project was respecting and supporting the families' priorities and perceptions. A continuum of services was available to families through Project Continuity ranging from assessment to referral for financial support for respite care. Case coordination procedures were developed to ensure continuity of developmental and health care routines for infants who have to accommodate to multiple transitions between hospital and home. A team comprised of speech occupational and physical therapists supported the primary care project positions of nurse specialist, child life coordinator, special educator and social worker. Staff roles permitted team members to work with families, hospital staff and personnel from other agencies to facilitate case coordination efforts.

Quality Assurance (QA) was adopted as a model for monitoring and assessing case coordination and nursing outcomes. QA procedures required identifying national or local standards (outcomes, indicators and criteria). Monitoring of the case coordination and nursing QA standards was completed over two time periods. In addition, a job analysis of the case coordination functions was completed as well as a detailed job description of the knowledge, skills and abilities required in case coordination. The dimensions and time data from this job analysis were coordinated with task logs kept by the staff in order to estimate the cost of case coordination and its component parts.

TABLE OF CONTENTS

TABLE OF CONTENTS

(continued)

Appendices

LIST OF TABLES

LIST OF FIGURES

PROJECT CONTINUITY STAFF
(Name, Role and Year)

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OVERVIEW

Purpose

Project Continuity was a joint project implemented collaboratively with University of Nebraska Hospital and Meyer Rehabilitation Institute. The primary purpose of Project Continuity was to develop and validate a model designed to provide continuity of care for the handicapped infants who had chronic illness or complex medical needs while the child was in the acute care setting and to support transition of the infant into the home environment. Supportive services were provided to the family to facilitate coordination of care among local community agencies. These goals were accomplished in the context of family-centered intervention in which the family played an integral role in the planning and implementation of their infant's care plan. The primary goal of this project was to provide habilitative, educational, nursing and medical care which was integrated with respect to care needed across life settings, i.e., hospital, home and educational/therapy programs. The project's objectives to accomplish this overall goal were to:

1. Develop curriculum implementation strategies to be incorporated into nursing care plans for hospitalized chronically ill infants by adapting published developmental intervention curricula and training primary care nurses in their use.
2. Develop, refine and document procedures for ensuring continuity of care for chronically ill, severely handicapped infants and toddlers across settings in which the child lives and in conjunction with agencies involved in the child's overall care and habilitation.
3. Establish and implement an evaluation procedure utilizing an interdisciplinary team for the purpose of assisting in the implementation of the Individualized Family Service Plan (IFSP) and monitoring child progress.
4. Develop and implement a program of supportive services for parents and other family members, i.e., siblings and grandparents, as appropriate.

5. Develop and implement a project management plan which included documentation and monitoring of timelines of staff activities, resource allocation by objective, project outcomes in relation to children, staff and parents; cost effectiveness, and the advisory committee membership and activities.
6. Develop and implement an evaluation design that included a formative and summative evaluation of all major project components.
7. Develop and implement a plan for demonstration and dissemination of project findings and products.

Setting

Services were provided through Project Continuity at the University of Nebraska Hospital (UNH) from December 1986 through September 1989. Referrals were received from two locations including the Pediatric Intensive Care Unit and the Infant/Toddler Pediatric Unit. UNH is a regional tertiary care center located in one of two major urban cities in eastern Nebraska. Nebraska is primarily a rural state that can be characterized as sparsely populated and widely dispersed. In addition, UNH as a liver transplant center draws patients nationally. Of the 42 children and families served by this project, only 24 were residents of Nebraska. The remaining 18 represented a wide geographic area. (Additional children and families were enrolled in the project once continuation funds were solidified. See continuation section for further information.) The geographic dispersement of the families is illustrated in Figures 1 & 2.

Figure 1
Geographic Location of Families Served in Project Continuity

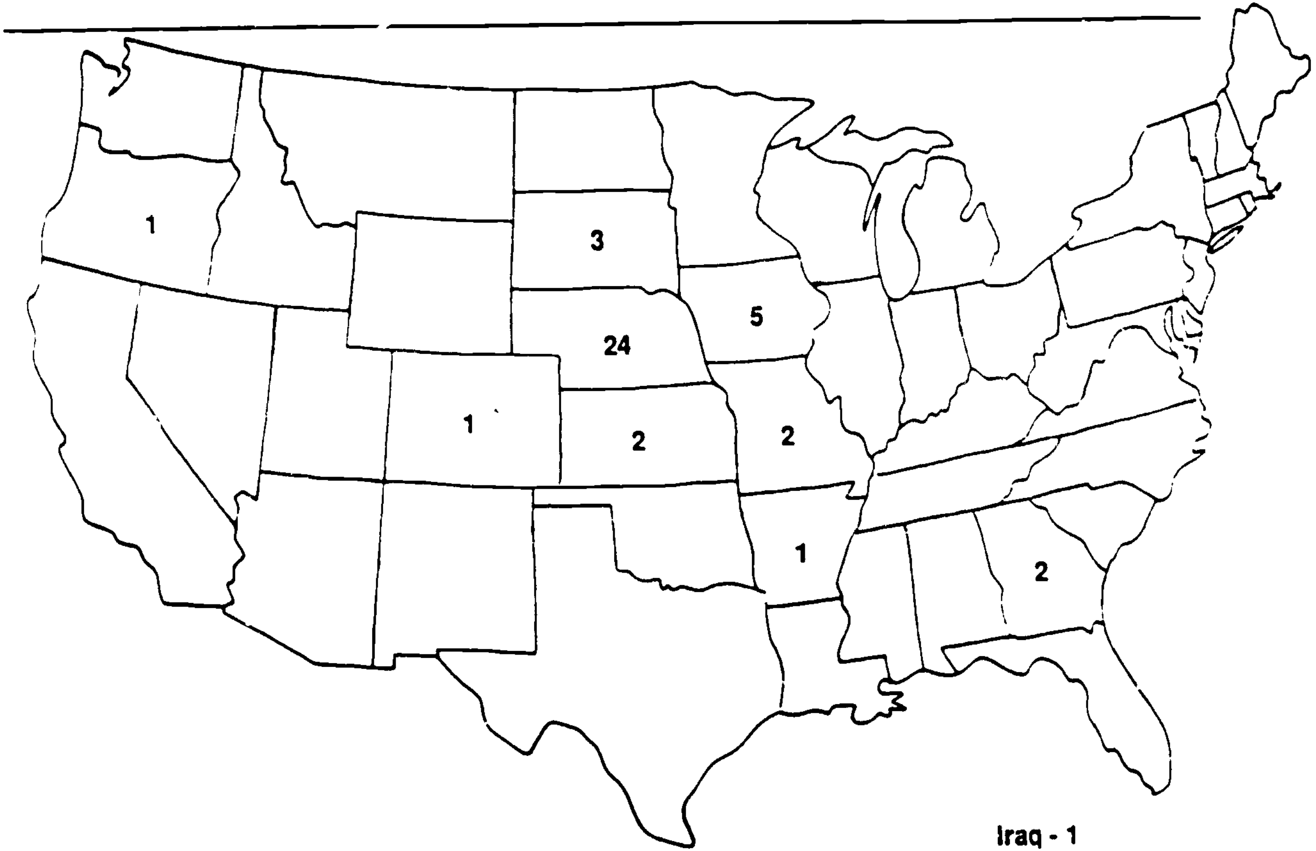
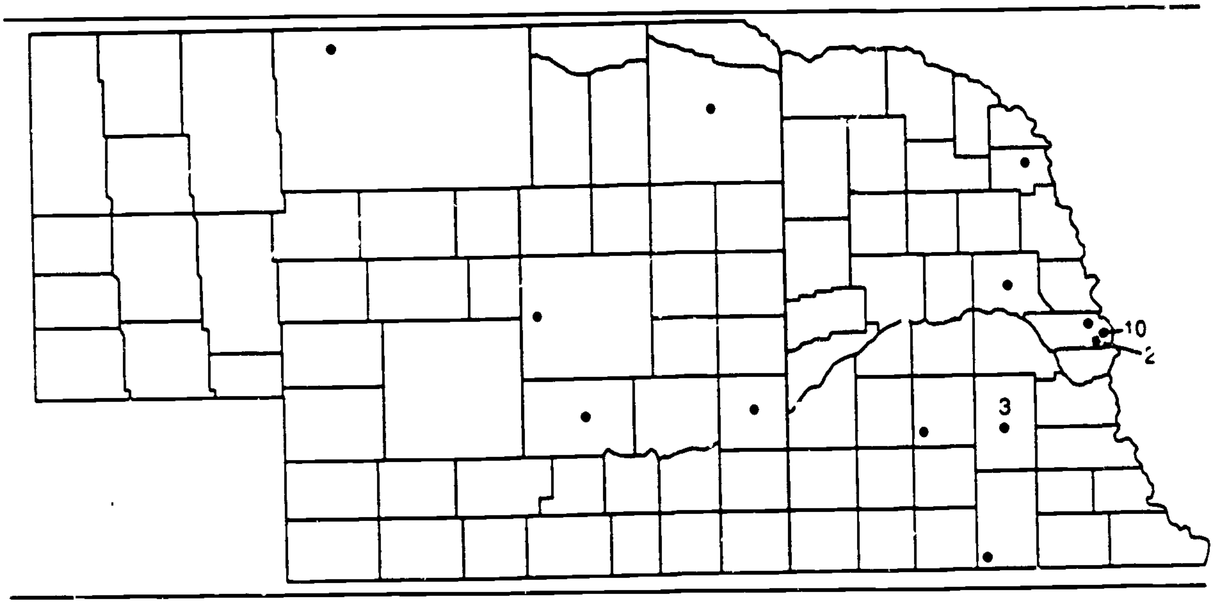


Figure 2
Geographic Location of Families Served in Nebraska



Population Characteristics

Infants who were suspected to be delayed or handicapped and who were long-term or frequently hospitalized were eligible for services through this project. Long-term hospitalization was defined as a hospital stay over two weeks. Frequent hospitalization was defined as anticipation of four or more hospitalizations during a one year period. From December 1986 through September 1989, Project Continuity served 42 infants/toddlers, birth through 2 years of age, who met this criteria. The annual average number and length of hospitalizations are summarized in Table 1. These data suggest that the average number of days hospitalized and the average number of hospitalization per year was consistent over each year. The pattern of individual infant's hospitalization is summarized in Table 2. These data suggest that the highest average number of days infants are hospitalized are during the first six months after entry into the project. Overall, there is a general decrease in both the number of infants hospitalized over time in the project as well as the average days spend in the hospital. The only exception is during the 18-24 month period post entry in which four infants averaged 50 days.

Table 1
Average Number of Days Hospitalized & Frequency of Hospitalizations Per Year

Year	Average Days of Hospitalization	Range of Individual Hospitalization	Average # of Hospitalizations	Range of Individual's # of Hospitalizations	# of Infants
1987	65	8-267	3	1-8	11
1988	58	5-260	2.8	1-12	24
1989 (Prorated)	68	2-179	2.3	1-6	14

Table 2
Average Monthly Hospitalization Stays in 6 Month Increments From Entry into Project

Period after Entry to Project Continuity	# of Infants Hospitalized	Range of days Hospitalized	Average # of days Hospitalized per child during the 6 month period
First 6 months	38	3 - 182	60
Second 6 months	21	1 - 92	23
Third 6 months	11	3 - 132	29
Fourth 6 months	4	9 - 84	50
Fifth 6 months	2	2 - 3	3
Sixth 6 months	1	---	2

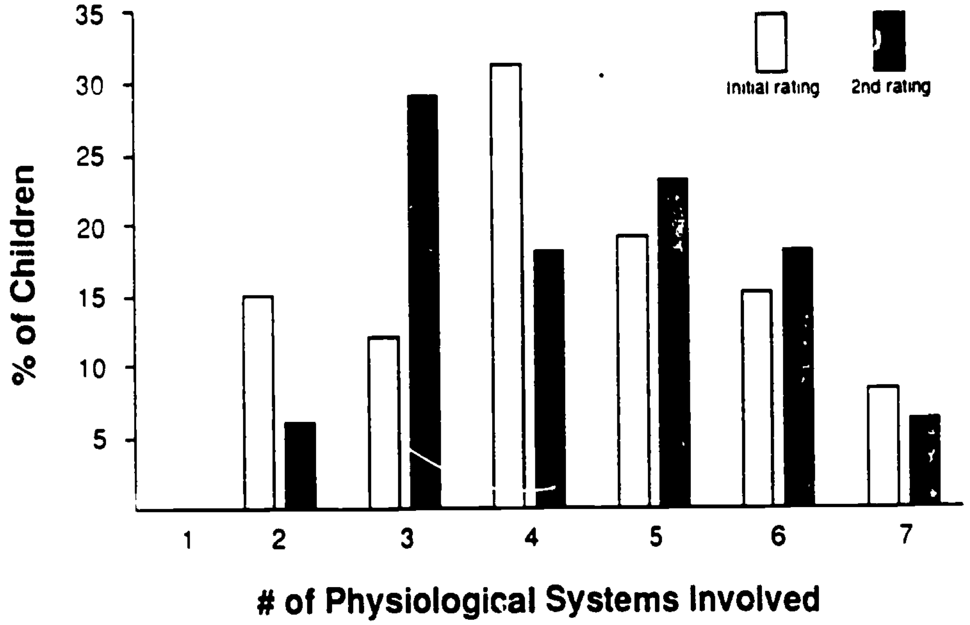
The medical diagnoses, gender and mean age of the infants at the time of entry into Project Continuity are presented in Table 3. Appendix A includes the classification system for determining primary diagnosis. For descriptive purposes, a primary diagnosis was identified. However, all infants in this project had multiple health care problems that affected more than one physiologic system. A series of health measures developed by the project co-director (Robinson) was administered by the project nurse specialist at the time of enrollment and on a quarterly basis thereafter (see Appendix B for sample protocols). Using these tools, data on the severity of illness was obtained for each infant enrolled in the project. The severity of illness tool specifically examined the degree of involvement of the systems, including cardiac, neurological, gastrointestinal, musculoskeletal, genital/urinary and metabolic/endocrine. Infants ranged from having two to seven systems affected when first referred to the project (see Table 4). Changes from the initial to quarterly evaluation indicate that 53% of the infants showed an increase of systems involved; 24% of the infants showed a decrease of systems affected. These data reflect the complexity of the health status of this population.

Table 3
Medical Diagnosis, Gender & Mean Age at the Time of Entry into the Program

Diagnosis	Frequency	Gender M	Gender F	Mean Age at Referral*
Gastrointestinal	16	10	6	10.9
Congenital	15	8	7	11.9
Cardiac	4	2	2	13.4
Renal	3	3	2	6.4
Musculoskeletal	2	1	1	10.0
Pulmonary	2	0	2	6.3
TOTAL	42	23	19	9.8

*Reported in Months

Table 4
Distribution of the Number of Physiological Systems Involved



Thirty-three children (83%) were enrolled in early intervention programs through their local communities, 19 received services through their local school districts in Nebraska and 14 received early intervention programs outside of Nebraska. Fourteen children (34%) died during the course of the project.

INTEGRATION OF EDUCATIONAL SERVICES IN A HEALTH CARE SETTING

Collaborative efforts between Project Continuity staff and the nursing staff of the University of Nebraska Hospital's pediatric units have a history of working with medically fragile infants and toddlers. Previously they spent three years working cooperatively on Early Referral and Follow-up (Robinson, 1987), a federal demonstration project, the purpose of which was to design and integrate educational and therapeutic early intervention practices into nursing care. As educators entering the hospital environment during the Early Referral Project, staff were initially met with uncertainty by some and perceived as a threat by others. This experience was instrumental in gaining entry into the hospital setting. Recommendations as a result of this project led to the change of relationship of the hospital nursing division and specialized University Affiliated Program to a jointly administered project, rather than the Early Referral Project relationship of an education program as a guest in the hospital setting. This change in relationship was seen as a key element to the success of Project Continuity. Staff were hired from each setting to jointly administer and implement the Project's objectives. As a resul , information was shared, roles negotiated and hospital staff involved in all aspects of the project development. Grant staff solicited input not only from hospital administration, but also from on-line staff in the development of the model. This relationship was purposefully negotiated in order to accomplish shared ownership of the project and its integration into the hospital unit at all levels, to avoid the project being perceived as a separate entity. The primary role of the grant staff was to facilitate broadening existing procedures and activities to include a greater developmental perspective in care plans, consistent with trends in nursing practice today. This approach allowed for a shared commitment to the ideal of integrated and consistent family-centered care.

Support to Staff

A principle objective of Project Continuity was to integrate developmental interventions into existing nursing procedures and routines in the infant/ toddler units of the hospital. Nursing administration and on-line staff expressed an interest in expanding the primary nurse's role in developmental intervention in the hospital setting. A plan was established and implemented to accomplish this objective based on a needs assessment completed with the nurses. Results of the initial needs assessment indicated a strong interest in learning more about assessment and intervention strategies. To accomplish this objective and implement the plan, several strategies were utilized including a series of in-service training programs, ongoing consultation from team members with the primary care nurses on individual patients, development of a videotape series for use on the unit, and distribution of printed materials. Developmental information has been condensed and integrated into the unit's orientation for new staff. Three program times were offered for the inservice with a total attendance of 23 nurses, representing 77% of the staff. Results of an evaluation of satisfaction of the inservices indicated that the mean rating for the program overall was 5.77 on a 7-point Likert scale with a rating of 1 as low and 7 as high.

In addition, national speakers provided additional educational opportunities for nursing staff as well as other hospital personnel. Shirley Kramer, a parent of handicapped twins from Minnesota, spoke to nurses on her experiences in coordinating care for her children in the hospital and at home. Patricia Pierce, RN, PhD, from the College of Nursing, University of Florida, consulted with the nursing staff on case coordination and efforts to establish a home-based nursing support system to families with chronically ill children in rural parts of Florida.

Summary

In summary, the key elements to the successful integration of educational services within an already existing medical setting are the joint development of the plan, ongoing communication and the identification of benefits to patients and to the health care community. In addition, a nursing unit's acceptance of an educational program is influenced by such factors as: 1) the level of inconvenience the staff senses with perceived new demands from project implementation versus perceived benefits from new educational opportunities and service to families and 2) the impact of encroachment on previously existing hospital staff roles compared with the project benefits. Maintaining line of communication despite real or perceived rejection of the project is an overall key to a successful program. Nursing adminstrations commitment to continue the effort was a critical element to Project Continuity's success.

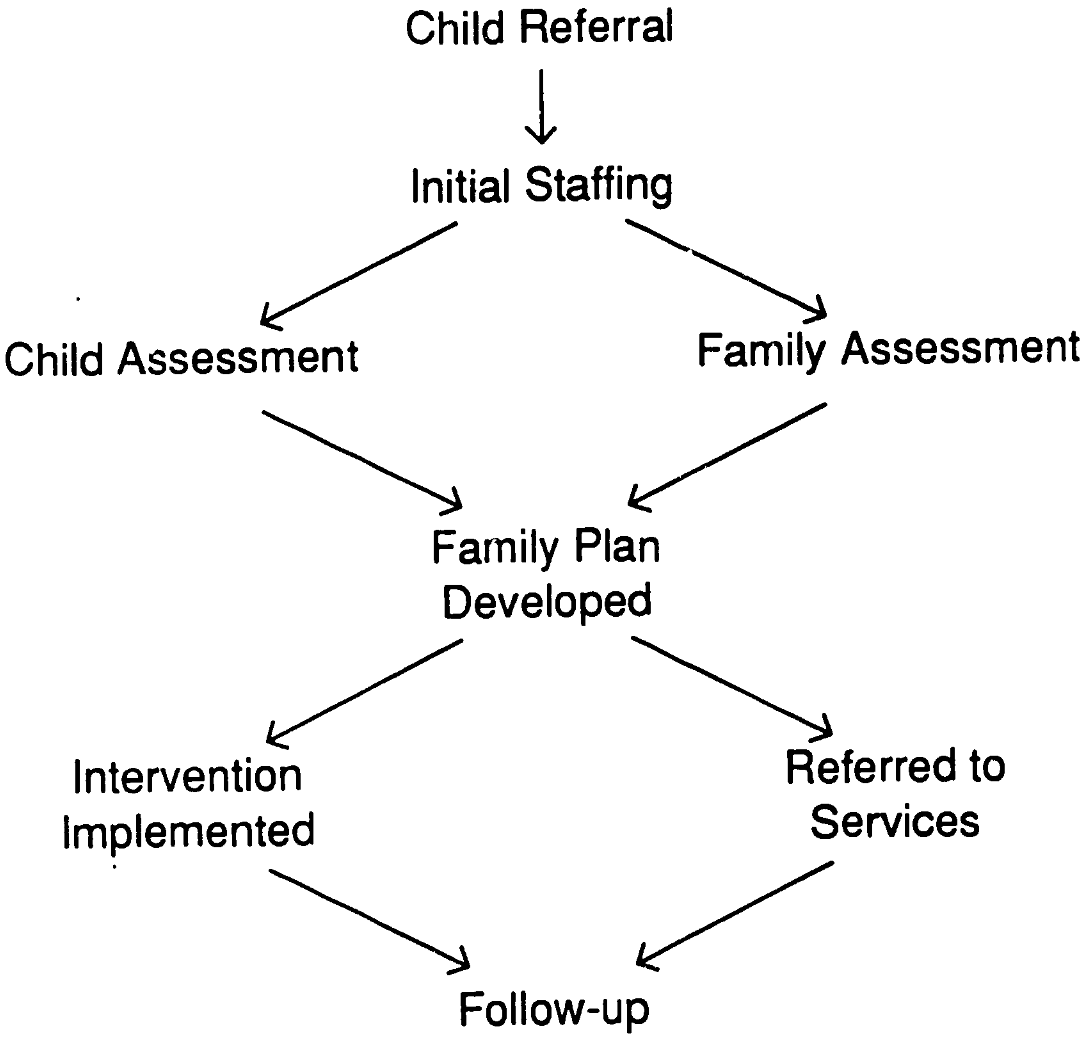
PROJECT CONTINUITY SERVICE MODEL

Introduction

Project Continuity was a service model that demonstrated the principles of family-centered care that families are the key element in a child's health, growth and development. Central to the philosophy and work of Project Continuity was respecting and supporting the families priorities and perceptions. Families played an integral role in the services to their infant. A continuum of services ranging from assessment to follow-up was made available to families.

In this section, the services provided to children and families in Project Continuity are reviewed. The temporal sequences of services provided as part of Project Continuity is presented in Figure 3. Once a child was referred to the project, the family and attending physician were contacted to determine interest in enrolling in the project. An initial staffing was then scheduled with the core team, including the family, nurse specialist, child life coordinator, social worker, special educator and primary nurse. The purpose of the initial meeting was to introduce the family to the project, identify any immediate needs of the family, and develop a family and a child assessment plan. This plan was then implemented and assessments were completed. Following the completion of the assessments, the information was discussed with the family and an intervention plan was established, including referrals to outside agencies. Follow up services were provided to all children and families regardless if the children were hospitalized or in the home setting. These services continued until the child was discharged from the project. The following is a description of each component in the sequence of services just described.

Figure 3.
Schematic Representation of Sequence of Project Continuity Services

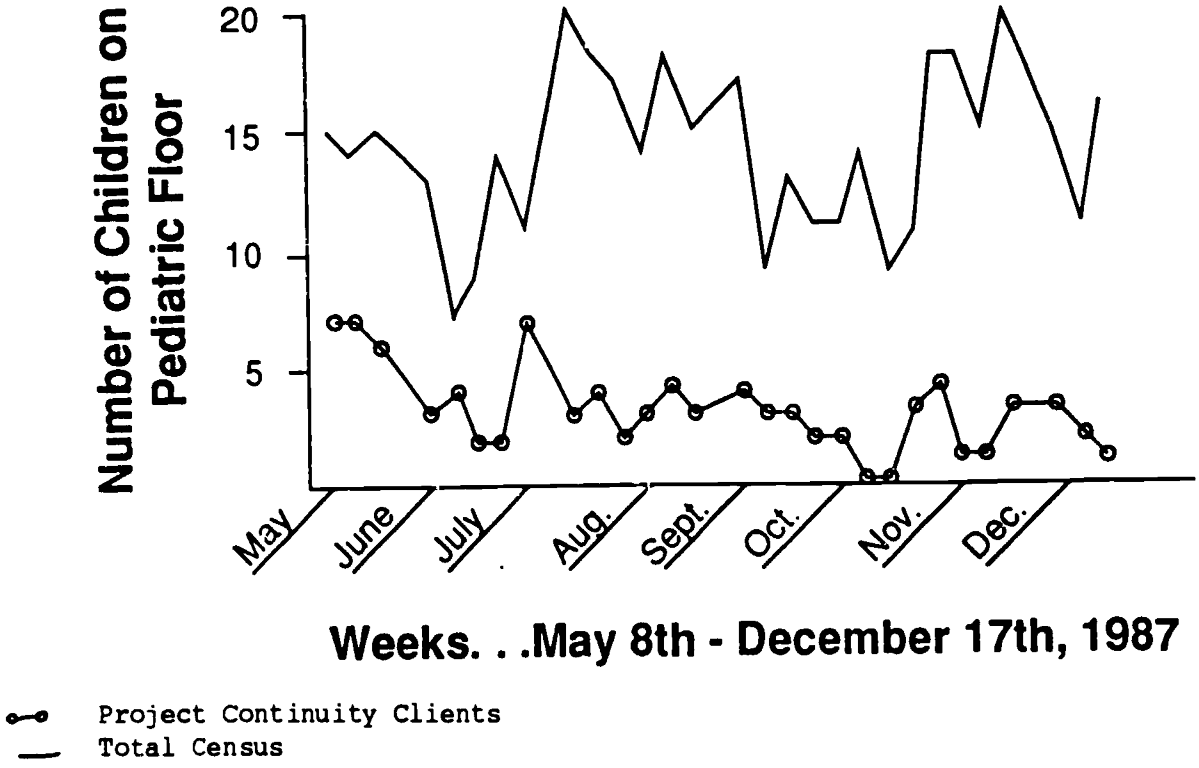


Project Continuity Services

Referral to Project Continuity

During year one, the primary care nurses reviewed the admissions to the pediatric unit with project staff at a weekly discharge planning meeting, which became the primary source for referrals. In addition to identifying children, the meeting served as an excellent mechanism for informing nurses about the role of project staff. Primary care nurses, as part of this process, were initially a primary referral source to Project Continuity. Referrals were also made by physicians, specialty nurses and hospital social workers. In Figure 4, the number of children hospitalized on the infant/toddler pediatric unit of UNH is presented by categories of total census and by number of Project Continuity children.

Figure 4.
Total Pediatric Unit Census (0-3) & Number of Project Continuity Clients



During years 2 and 3 nursing staff no longer held weekly discharge planning meetings. As a result project staff instituted a procedure in which they reviewed the census for the infant/toddler unit and pediatric intensive care unit to determine potential candidates for the project. Once children were identified through these procedures, the attending physician for the individual child was contacted by one of the project staff and his/her approval obtained prior to contacting the family.

Initial Staffing

After receiving the primary physician approval for referral, project staff contacted the parents to explain the project and to obtain their written consent for participation. An initial meeting was scheduled with the family and the core team of the project, which included the primary nurse. The purpose of the initial staffing was to acquaint the family with service options through Project Continuity and to discuss the families priorities for their child and family. Family members were present during most of the initial staffings. Family absences from initial staffings were largely due to their inability to be in Omaha at the time of the meeting. For those families, the same process was accomplished through a telephone conversation with the case coordinator. Assessment of the family and child was then arranged and planned based on the outcome of the initial staffing. The goal of the project was to individualize both the program content and the enrollment and intervention process for each family according to their needs and strengths. During the initial staffing, a case coordinator was assigned. This assignment frequently was based on the primary needs of the child and family. Family choice was also a determining factor. For example a child with complex medical problems may be assigned to the nurse specialist as the case coordinator.

Assessment Process

Child Assessment Procedures

An interdisciplinary team, including a parent/infant educator, physical and occupational therapist, and speech pathologist, provided initial and follow-up evaluations as needed for the purpose of assisting in the implementation of goals identified in the Individualized Family Service Plan (IFSP) goals and for monitoring the child's progress. Families were an integral part of this process. Family's questions and priorities guided the type of assessments completed. During the actual assessment, family members were present if possible and actively participated in the evaluation by answering questions, illustrating parent-child interaction and assisting in assessment procedures as appropriate. For example the parent may have demonstrated an interactional game that their infant enjoys to illustrate how their child responds in a social interaction and communicates to them.

Standardized norm-referenced and criterion-referenced assessments and parent interviews were utilized for evaluating the child's progress and for program planning. The Vineland Adaptive Behavior Scales frequently were used to monitor the child developmental progress because the instrument could be completed by telephone interviews. Such flexibility was desirable because many of the infants identified in the project lived a distance from UNH, making it difficult to participate in direct testing on a frequent basis after discharge from the hospital. The evaluations completed on each child were individualized based on his/her needs and medical condition at the time of testing. Table 5 describes the assessment tools used in this evaluation process. Ongoing assessment information was also obtained from behavioral observation conducted by nursing and child life staff. Overall, assessment of medically fragile infants posed unique problems which are elaborated in the section on assessment issues.

Table 5
Tools for Assessment of Child Progress & Program Planning

Assessment Tools	DOMAINS ASSESSED Cognitive	Social/ Emotional	Communication	Motor	Adaptive
Bayley Scales of Infant Development Bayley, N. (1969) Bayley Scales of Infant Developmental Manual. NY: The Psychology Corp.	X	X	X	X	
Ordinal Scales of Psychological Development Uzgiris, I. & Hunt, J. (1975) Assessment in Infancy: Ordinal Scales of Psychological Development. Urbana, IL: University of Illinois Press.	X				
Peabody Developmental Motor Scales & Activity Cards Folio, M.R. & Sewell, R.R. (1983) Peabody Developmental Motor Scales & Activity Cards, Allen, TX: Developmental Learning Materials (DLM).				X	
Sequenced Inventory of Communication Development Hedrick, D., Prather, E., & Tobin, A. (1984) Sequenced Inventory of Communication Development: Revised edition. Seattle, WA: University of Washington Press.			X		
Vineland Adaptive Behavior Scales Sparrow, S., Balla, D. & Cicchetti, V. (1984) Vineland Adaptive Behavior Scales, Circle Pines, MN: American Guidance Service (AGS).		X	X	X	X

Coordination with community. To facilitate continuity of developmental care, Project Continuity staff contacted local teachers and therapists to assess whether there was an Individual Education Plan (IEP) for the child If the child had been thoroughly evaluated by his/her local school district, assessments and IEP's were not duplicated during hospitalization. Rather, permission was obtained for release of the information from the local school district to Project Continuity. A large number (91%) of the infants initially identified by Project Continuity had not received any previous evaluation or services in the home community. This finding is not surprising in view of the mean age at referral of 9.5 months. During the course of the infant's hospitalization, the interdisciplinary team staff were available for continuing consultation to the family and primary nurses. The evaluation process including staffings with health care, community service, project staff and family to integrate evaluation findings and develop intervention plans. Such staffings, while costly in time, were seen as a valuable mechanism for coordinating services and providing consultation services to the family.

Assessment issues. Some infants, when initially referred to the project were very ill and formal assessment was not appropriate. Informal observations were made with the philosophy of making as minimal intrusion to the medical routines as possible. In addition to developmental issues, the infant's response pattern to daily care and treatments was noted.

Special precautions needed to be considered when evaluating these medically fragile infants to assure that no harm occurred as a result of the evaluator's interaction with the infant. Specifically, the infant's state at the time of the assessment and physiological response to the interaction was constantly monitored. Assessment was terminated when there was evidence of loss of state regulation or physiological disequilibrium such as changes in color, muscle tone, vital signs, oxygen saturation and/or behavioral signs that indicated the infant was stressed. Capacity for interaction was a concern especially for those infants with sensory problems or for those who responded to stimulus overload by withdrawal. With very sick infants, assessments were confined to observation, family and nursing staff input. Once stability improved, more extensive probing was instituted to assist in the developmental interventions provided by staff at UNH and to provide baseline data for discharge planning. Among the developmental priorities for assessment related to intervention for the very ill child were parent/infant interaction, soothing techniques, and physical management to prevent deformity.

Developmental outcomes. The infants served in this project represented a broad range of developmental abilities. Initial assessments indicated that 9% of infants demonstrated cognitive or motor delays of at least one standard deviation below normal, while 61% of the total population showed delays of two or more standard deviations below normal.

The medical condition of these infants greatly influenced their performance on any assessment tool, thus decreasing the validity of assessment for predictive purposes with this population. Several infants who were evaluated over time, demonstrated significant changes in development that would not be typical in the normal population. These examples are outlined in Table 6. These case samples further illustrated the need to view any assessment of this population of medically ill infants with caution and to not consider any results as predictive of future performance.

Table 6
Case Illustrations of Developmental Abilities Across Time
Comparison of Standard Scores on the Mental Scale of the Bayley Scales of Infant Development

Case	Point 1	Point 2	Point 3	Point 4
A	58	84	--	--
B	86	67	--	--
C	86	99	82	78
D	50	64	--	--
E	111	96	87	114

Family Assessment

An individualized program of supportive services for families was developed for each Project Continuity family. The family plan was generated through a needs assessment process. The family needs assessment process was flexible allowing parent choice in the mechanism for the assessment. Parents were able to chose either to have a discussion with the case coordinator about their priorities and needs or offered the opportunity to complete a formal needs assessment, e.g., the Family Needs Survey (Bailey & Simeonsson, 1985). The Family Needs Survey was given to parents to complete individually and was then reviewed with the family's case coordinator. In some instances, the tool was administered orally to those parents who did not read English. Of the 42 families served in Project Continuity, 32 parents (24 mothers and 8 fathers) completed a formal needs assessment. Table 7 summarizes the needs of families as scored on the Family Needs Survey. The most cited need by both mothers and fathers related to information about their child's services, either presently or in the future. Overall, mothers identified more areas of need for support than did fathers. These results were consistent with previous work by Bailey and Simeonsson (in press).

Family resource and counseling needs were also assessed through a formal psychosocial assessment interview with parents that was administered by the project social worker and through informal ongoing interviews and phone conversations with parents.

Table 7
Family Needs Survey

FNS Items on Which at Least 30% of Mothers or Fathers Indicated a Definite Need for Help

Mothers		Fathers	
Item	**%**	**Item**	**%**
(5) I need more information on the services that are presently available for my child.	74	(6) I need more information about the services that my child might receive in the future.	67
(14) I need reading material about other parents who have a child similar to mine.	70	(5) I need more information on the services that are presently available for my child.	44
(6) I need more information about the services that my child might receive in the future.	61	(23) I need help locating babysitters or respite care providers who are willing & able to care for my child.	44
(26) I need more help in paying for expenses such as food, housing, medical care, clothing, or transportation.	52	(26) I need more help in paying for expenses such as food, housing, medical care, clothing, or transportation.	33
(3) I need more information about how to teach my child.	43	(3) I need more information about how to teach my child.	33
(1) I need more information about my child/s condition or disability.	39		
(7) I need more information about how children grow and develop.	39		
(23) I need help locating babysitters or respite care providers who are willing & able to care for my child.	35		
(12) I would like to meet more regularly with a counselor (psychologist, social worker, psychiatrist) to talk about problems.	30		
(15) I need to have more time for myself.	30		
(31) I need more help paying for toys that my child needs.	30		

Health Assessment

A health assessment of the infant was a crucial aspect of the assessment process for the infants and toddlers served by Project Continuity. It was felt that individualized services could be provided most effectively if the team was knowledgeable of the child's diagnoses and health status. Upon acceptance to the project, a medical history was written by the project nurse so the staff might have a better understanding of the child's and family's past medical experiences. The health measures described previously were used as part of the process. This information on the infant's health management problems, as well as mortality risks were all assumed to be factors influencing family stress and the support services needed. As diagnoses were identified, professional literature pertaining to the condition was collected for any team member interested in additional information to access. Throughout every hospitalization, the child's current health status was monitored primarily through chart review and regular consultation with primary and specialty nurses. This information was communicated to the other team members so they could plan their daily interventions accordingly.

An effort was also made to assess the parents' knowledge and understanding of their child's diagnosis and treatment needs. At three month intervals, the project nurse interviewed the parent or primary caretaker asking him/her to state the child's diagnosis or present symptoms as he/she understood them. The parent was then requested to identify the management needs of the child. The interviewer could provide prompts if the parent was having difficulty identifying them. These data were then used to describe the parent's: (1) understanding of the child's diagnosis and symptoms, (2) understanding of the treatment implication, and (3) level of confidence in meeting the child's needs. Each area was rated using a seven point Likert scale with 1 indicating a rating of minimal comprehension and 7 indicating a rating of extensive.

It was noted that several parents interviewed scored high in understanding and confidence in providing prescribed treatment, but, for various reasons, were not in agreement with the treatment plan. Recommendations for future research might include a measurement of the parents' understanding of their child's diagnosis and treatment against their level of confidence in providing care compared to their compliance with the prescribed treatment.

Development and Implementation of an Integrated Service Plan

The integrated service plan developed and implemented by the family, project staff and designated others was an outcome of the child, family and health assessments. This process was for the majority of families in this project initiated in the hospital, but the plan which remains consistent, transcends environments. As the child moves across settings, e.g., hospital, home and community, ideally the location of the service providers change, not the plan. This process, in conjunction with effective case coordination, was what promoted and facilitated continuity of care. This integrated plan was developed through a process of collaborative goal setting between professional staff and family. See Appendix C for sample of a family plan.

The following is a discussion of the two primary components of the integrated service plan, child-centered and family-centered intervention.

Child-centered Intervention

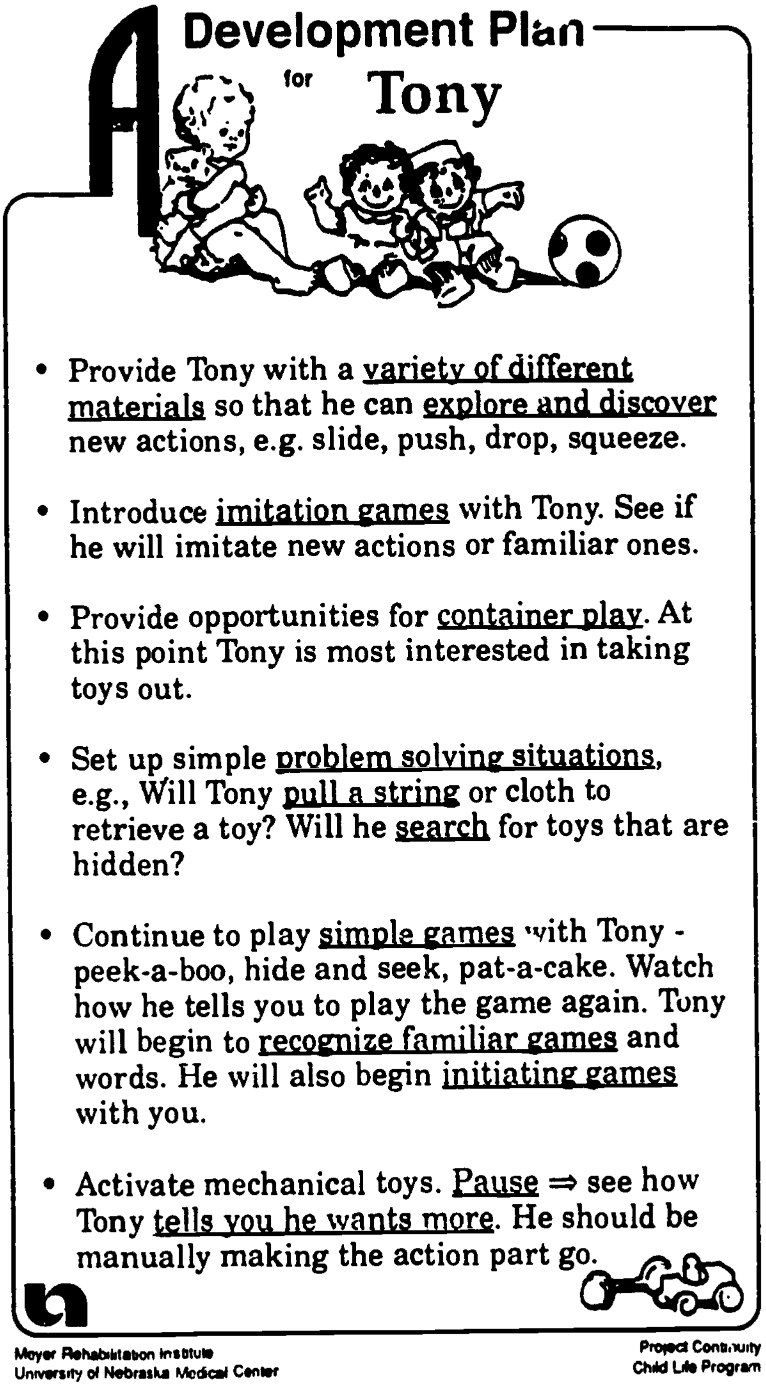
A major concern of professionals working with the hospitalized infant is the potential disruption to the child's development. Project Continuity's goal was to assist primary care nurses in providing a consistent environment for these infants that would facilitate their learning and maximize their potential. For the project to be most successful, it was decided that primary nurses needed to assume a larger role in providing developmental intervention, not as a separate activity, but rather as part of the nursing care plan. Since case identification and referral were the first steps in this process, nursing administration decided that it was important for nurses to assume responsibility for developmental screening on the pediatric unit. Outcomes of an informal needs assessment indicated that primary care nursing staff needed information both on assessment and developmental intervention for handicapped infants, if their role was to be expanded effectively. Project staff introduced nurses to a developmental screening tool, the Home Monitoring Questionnaire (Bricker & Squires, 1986), used on admission to screen children who might be delayed and potentially eligible for the project, and to alert nurses to age appropriate developmental landmarks for children 3 years and under. This did not prove to be an effective mechanism for referrals. The process was cumbersome and nurses were not able to complete the screening during the child's first days in the hospital. Project and nursing staff investigated alternative approaches. As a result, the Developmental Intervention for Care Planning and Family Education was developed as a quick method for nurses to informally observe the developmental characteristics of infants, (see Appendix D). This tool also outlined care plan interventions which could be individualized by the nurse for the child's nursing care plan. This format was readily accepted and was effectively administered by the nursing staff. Monthly monitoring of its use on the pediatric floor indicated that observations were made and documented in the chart for 80% of the census. The UNH Department of Nursing is in the process of computerizing the nursing care plans. The intervention strategies on this tool are being incorporated into this database under the Standard of Care, altered growth and development. Developmental standards have become an institutionalized aspect of the nursing quality assurance of UNH.

On the pediatric units at University of Nebraska Hospital, Project Continuity established and implemented educational recommendations and consultation to the child's primary care team, for incorporation into the child's care plan while hospitalized. Instruction and explanation about this plan, written by the parent/infant educator and child life staff with input from other team members as appropriate, was provided to the parent and primary care staff. Resource materials were provided including printed materials, e.g., Age Appropriate Kardex (St. Michael Hospital, 1985), a developmental activity flip chart and instructional videotapes.

Information on educational recommendations and ongoing progress was available in many formats. The detailed description of goals and objectives was outlined in the Individualized Family Service Plan and kept in the University Hospital charts. Ongoing progress was documented in the progress note in the hospital as well as on a developmental intervention sheet incorporated as a new hospital form (see Appendix E for a sample form). In addition a developmental plan was posted at bedside (see Figure 5).

During the child's hospitalization, the parent/infant educator and child life coordinator were available to provide direct instruction through a model of parent-mediated intervention. Instructional techniques used with parents included joint problem solving, modeling, verbal instruction, and requests for a return demonstration by the parents. Emphasis was placed on incorporating

Figure 5.
Sample Developmental Plan



A Development Plan for Tony

- Provide Tony with a variety of different materials so that he can explore and discover new actions, e.g. slide, push, drop, squeeze.
- Introduce imitation games with Tony. See if he will imitate new actions or familiar ones.
- Provide opportunities for container play. At this point Tony is most interested in taking toys out.
- Set up simple problem solving situations, e.g., Will Tony pull a string or cloth to retrieve a toy? Will he search for toys that are hidden?
- Continue to play simple games with Tony - peek-a-boo, hide and seek, pat-a-cake. Watch how he tells you to play the game again. Tony will begin to recognize familiar games and words. He will also begin initiating games with you.
- Activate mechanical toys. Pause ⇒ see how Tony tells you he wants more. He should be manually making the action part go.

Meyer Rehabilitation Institute
University of Nebraska Medical Center

Project Continuity
Child Life Program

developmental activities into daily care in nursing care routines as well as during play times.

When a parent could not stay with the child, a foster-grandparent was assigned. The foster-grandparent was briefed on the child's developmental plan for intervention. Direct intervention by project staff with the hospitalized child was also part of the intervention plan. Such direct intervention was specifically prioritized when family members could not be with their child during periods of hospitalization.

Family-centered intervention

For families facing long-term and often repeated hospitalizations of their infants, life was "in limbo." Work and everyday routines had not only been upset by the birth or diagnosis of a special child, but time away in the hospital postponed "getting on with daily life." Repeatedly parents said if their child could just have a month at home without rehospitalization, their family could begin to get on the right track.

Through informal, day-to-day interactions with parents by nursing and project staff and through the more formal avenues of staffings, counseling and weekly parent coffees, a dynamic approach for support and intervention evolved. For many families, day-to-day and sometimes hourly changes in their child's health status was both emotionally and physically draining. In an effort to meet the parents each day while they were on this roller coaster, the Project Core Team was in constant contact with one another and the family. Along with primary nursing staff, team members were identified as a major support for the parent. The call would go out if there was a crisis or special procedure imminent. This emotional support along with the continuity of the project case coordinator following the child and family from the pediatric intensive care unit (PICU) to the pediatric floor and back to PICU was greatly appreciated.

Project staff encouraged families to respect themselves as an integral part of the service team for their child. When parents displayed apprehension in addressing certain issues with health care professionals, written information, verbal support and redirection of questions were offered. Parents' needs and questions were addressed on a one-to-one basis with staff, during inpatient care conferences and in liaison with outside agencies. Care routines usually reserved for nursing staff were brokered with parents so that vital tasks were not taken away and the parental role usurped. Parents learned to change dressings, suction tracheostomies, and check blood pressure in addition to normal batheing or dressing routines. These tasks were constantly monitored, allowing the parent to learn in the way most beneficial to him or her, e.g., written materials, direct or videotape instruction.

Supportive counseling was provided as needed to families by social work and child life personnel with referrals made to community family therapists when appropriate. Staff worked with local communities to find community resources that would provide support once the child was discharged from the hospital. Supportive counseling was utilized, especially around issues of loss, grief, marital and family stress, sibling concerns and financial concerns. In the community, resources such as Pilot Parents, grief support groups and private therapists were utilized. In rural Nebraska such resources were sometimes difficult to access, therefore Project Continuity staff were prepared to provide ongoing consultation after discharge.

To facilitate home-to-hospital and hospital-to-home transitions, videotaping was initiated of the child at play and during special tasks. This became a chronicle not only for growth and development and improvements in the child's medical condition, but also for a reliable teaching resource for parents. To further bridge the gap between home and hospital, Project Continuity staff also instant snap shots, events journals, and videotapes to chronicle the child's life in the hospital. These materials were shared with family members who were not able to be with the infant during the hospital stay. A sibling intervention program was incorporated into the project's support to families, as siblings of chronically ill children may often be ignored (Craft, 1986). The intervention program sought to educate, provide play therapy outlets and support brothers and sisters. Parents were advised of usual sibling concerns and misconceptions, and the child life staff helped parents create a scenario of the ill child's hospitalization or condition. In this way, the well sibling had an honest explanation, dissolving his fantasies and building trust with parents. Support to siblings was provided to 95% of families with other children.

Additionally, parents were provided respite opportunities by project staff. They were encouraged to go shopping, enjoy lunch away from the hospital, or return home for several days while a primary nurse, child life staff or designated others provided consistent care.

Project staff also followed up on birthdays with the families of infants who were outpatient and celebrated with parents as new babies arrived. And most sadly, as children became terminal and died, project staff sat at bedside, held hands, cried and attended funerals. Bereavement follow-up revealed one of our most precious gifts to parents was the videotape taken of their child.

Referral and Follow-up

Once a child was discharged from the hospital, Project Continuity staff worked with the primary care nurse to assist in continuity of care as the child and family made the transition into the local community. Referrals to appropriate agencies, including health care, family support and educational services, were made prior to discharge with release of information signed by parents. These agencies were notified of the impending plans and updated information was provided to them about the needs of the child and family. Consultation to community agencies was provided on request. Many community-based interventionists were not prepared to work with the child who was chronically ill and would have questions regarding issues related to a child's chronic illness. The child's progress was monitored by quarterly follow-up contacts between the case coordinator and the family and identified agency staff to review the child's progress and enrollment in specific programs. Child progress was documented and copies of reports were sent to community agencies and hospital staff, with parent approval. These liaison activities were important because they provided primary nurses updated information that could assist them in the child's transition back to the hospital if he/she was rehospitalized. It also facilitated communication between agencies by providing updated information. Case coordination for this population is often complex due to the number of different agencies involved and the wide geographic area served. Initially a major effort was to increase staff knowledge of local and regional resources and to gain a better understanding of state agencies program and funding alternatives.

In some cases the case coordinator continued to facilitate communication among representatives of multiple agencies after early intervention services were in place. Such involvement frequently occurred if the family had not identified a case coordinator in their community to assume the responsibilities and assist the family in overall case coordination. Frequently as families became more secure with accessing systems and agencies, they began to take on more of the case coordination functions

Case Coordination System

To ensure continuity of services, the development of a case coordination system was essential. Case coordination was the glue which held the service model and family together. The purpose of case coordination was to facilitate communication among service components and the family. This process of case coordination was much more complex for families with medically fragile children, as they needed to work with multiple systems and locate resources not only in their own community, but across settings. The Project Continuity case coordination process was guided by several major assumptions about the role of case coordination as it relates to families. The first assumption was based on the premise that case coordination services were provided not simply to the child but to the family. The infant's disability impacts the entire family system, therefore support for the entire family was important, not just child-centered intervention. Secondly, families should be allowed to decide on their level of involvement throughout the entire service process, including their participation in the case coordination process. Finally, families should be supported so that they could increase their capacity to identify and obtain needed services.

A major effort of Project Continuity was to develop and document procedures for ensuring continuity in developmental and health care routines for children who must accommodate to multiple transitions between hospital and home. A core team consisting of a child life coordinator, parent/infant educator, social worker and nurse specialist was responsible for the development and implementation of a case coordination system. In this project, case coordinators were assigned depending on the child and family needs and family preference. This format for determining the case coordinator was in accordance with the guidelines outlined in P.L. 99-457, which states "The IFSP shall contain the name of the case coordinator from the profession most immediately relevant to the infant or toddlers or family needs who will be responsible for the implementation of the plan incoordination with other agencies or persons." p. S.2294-6 (Education of the Handicapped Act Amendments of 1986, 1986).

In this model each case coordinator brought to the role his/her own professional specialty; however, additional skills were needed including: knowledge of accessing services; effective communication skills, including listening, bargaining and mediation; and understanding of family dynamics. Case coordinators met weekly to discuss cases, brainstorm solutions to problems, and share resources. A case coordination package has been developed that outlines the role and sequence of activities that are part of the case coordination process (see Appendix F). The role of the case coordinator was analyzed and detailed. Information on the specific functions of the case coordinator can be found in the evaluation findings.

PROBLEMS IN DESIGN & IMPLEMENTATION OF PROJECT

Having described the service model, it is instructive to understand the difficulties of the design and implementation of the project that were instrumental in the evolution of the current procedures. In reflecting upon the development of the project over the past three years, four key areas emerge as having that had the most change over the course of the project: (1) integration of the project within the health care setting, (2) development of assessment procedures, (3) refinement of a case coordination process, and (4) development of an effective evaluation component. The following is a brief discussion of major problems and resolutions that were implemented and attributed to the overall success of the project.

Integration into Health Care Setting

Integration of the project within the health care setting provided unique challenges for both project and nursing staff. Project staff, new to the hospital setting, needed to learn medical terminology, health care procedures, e.g., infection control, and unique aspects of assessing and providing intervention to chronically ill children. Establishment of project roles that complement existing hospital staff was essential, so that there was not encroachment of existing hospital roles. The initial conceptualization of the pediatric unit nursing staff role greatly changed over the course of the project. Initial goals envisioned that nursing staff would assume responsibility for the case coordination role as defined by the project. Due to factors such as time constraints and nursing shortages, this goal was modified. Nursing staff continued to have an active role in case coordination, but did not assume the primary role.

The other primary goal in this area was to provide support to nurses in the incorporation of developmental activities in their nursing care plans and interventions with the child. Inservices, provision of print materials and consultation were the primary technical assistance provided. The continuing change in nursing staff presented problems in this area. As a result many of the training experiences were institutionalized. Videotapes of the inservices presented and self-instructional packages are now available as part of the nursing orientation. In addition, many adaptations of ways to involve nurses in screening children and incorporating information into the care plans were changed. As seen by the results in this report, a mechanism has finally been found that is being utilized successfully by nursing staff.

Assessment Procedures

Assessment procedures typically used by project staff with infants with handicaps needed to be modified for the chronically ill infant. Experience with this group of children showed much more variability and less validity in test results than in other populations. Results of testing needed to be viewed with caution due to the medical history of these infants and their condition at the time of testing. Staff needed to be flexible in scheduling the assessments, as it was difficult to find times that the infant was in an alert state. Many infants also would tire very quickly so assessments frequently were conducted over several sessions. Often informal developmental observations were initially completed, with formal assessment being postponed until the infant's health status had stabilized.

Case Coordination

Case coordination also was an evolving process throughout the three years. One area of significant change occurred in the procedures for family assessments. Initially family assessments included tools typically used in research, e.g. evaluating stress, coping strategies and family functioning. Family assessments now are completed to identify ways staff can support the family. Both formal tools or informal interviews are used to assist the family in identifying those supports. In addition, the philosophy of the project shifted over the course of the three years from a parent involvement model to a family-centered model. The last aspect of case coordination involved familiarity of resources. Initially staff had limited familiarity with resources available for families. The advantage of having an interdisciplinary team for the case coordination process involved mutual sharing of resources so an individual's knowledge of resources increased over the time period.

Evaluation

Evaluation of a model such as Project Continuity is not simple and cannot follow the traditions of a true experiment. As a result, data were primarily descriptive and focused more on formative issues such as the development of the case coordination process rather than collection of summative data. As will be described in the next section, quality assurance procedures were used for the summative evaluation method as it is a common evaluation method in health care settings.

EVALUATION FINDINGS

Project evaluation focused on the case coordination and nursing components. A majority of the evaluation questions were related to these two components, as they were new service areas with which project staff h limited experience and for which there was limited information nationally. Fewer evaluation questions addressed the project service model (described in the previous section). Those evaluation efforts are integrated within that discussion.

Case Coordination Component

A major difficulty in evaluating the impact of this type of demonstration project was that there are no standards or criteria for assessment of family needs or of individualized case coordination services. Furthermore, case coordination involves professional behaviors which are not easily observed and family outcomes which are private events with potentially different interpretations. Procedures were borrowed from social and industrial psychology and from the quality assurance tradition in medicine to overcome these difficulties. It was the application of these procedures which have been useful to the project in an exciting blend of qualitative and quantitative methods to what are by tradition, private professional interactions. The areas of job description, service monitoring, outcome assessment and cost benefit analysis are discussed below.

Critique of Case Coordination Process

The Projects' case coordination process was critiqued in a day-long seminar by a group of 17 persons not associated with the project who represented a variety of state agencies and professions (e.g., the state medical director of Social Services, teachers, psychologists) and parents of medically-complex handicapped children. The critique accrued 21 months after the inception of the project at a point in which the case coordination model was deemed stable. This was completed as one component of the formative evaluation of the development of the case coordination process.

An external facilitator was brought in, and the participants worked in a variety of small group settings. Participants identified family needs and resources using the Family Needs Assessment (Bailey & Simeonsson, 1985);

reviewed and critiqued four case histories which staff felt represented the range of cases served; and summarized the constraints to service as being in five areas, i.e., home health care, respite, mental health, educational system, and social service. Sixteen recommendations were developed for facilitating case management, many of which may serve as goals for the state P.L. 99-457 Interagency Coordinating Council, which was well-represented among the participants (see Appendix G). Thus, specific needs and resources relevant to the four cases presented, as well as generic recommendations useful to other groups resulted from the project staff inviting criticism from other professionals and parents with relevant expertise. The staff was able to do this because they expected that their own skills, knowledge, perseverance, and creativity in brokering solutions across agencies as family advocates, represented new efforts which would be appreciated by others.

Analysis of Case Coordination Functions

A detailed job description including the knowledge, skills and abilities required in case coordination was developed after 18 months of staff experience in providing case coordination services. The service model was deemed to be stable at this time with appropriate in and out-patient referral processes. Two industrial psychology graduate students and their supervisors contracted to perform an independent job analysis using the tools developed in that field (Furst, D. & Suh, Y., University of Nebraska - Omaha, 1988). Based on observations and interviews with the four case coordinators, they defined a case coordinator's job function as "... to ensure that comprehensive care, including emotional, psychological, spiritual, physical and developmental aspects, have been provided for the patient... also act in an advocacy capacity and provide emotional support for the parents and siblings of the hospitalized infant or toddler." The job analysis described the job setting, a seven dimension structure of critical tasks, the actual and percentage time per task dimension, and the knowledge (K), skills (S), and abilities (A), (KSA) needed to function as a case coordinator, as well as the importance and sequence of the development of each of the KSAs. Lists of 51 knowledges (K), 59 abilities (A), and 8 skills (S) were developed by the job analysts from the data collected during the KSA interview. Case coordinators ratings of the KSAs on a five point Likert scale indicated average ratings of all the KSAs were greater than or equal to 3 (about medium importance) on the importance scale. A description of the KSAs are located in Appendix H.

The seven critical task functions identified through this process of job analysis included: 1) assisting in determining child eligibility for the project; 2) identifying and arranging necessary evaluations; 3) coordinating the IFSP process; 4) assisting the family in obtaining necessary services through a referral process; 5) maintaining follow-up contact; 6) exchanging information; and 7) determining case discharge. Table 8 illustrates the percentage of time spent on each function as determined by the job analysis.

This analysis suggested that exchange of information between project staff, families, hospital and agency staff would require the highest percentage of time (39%). Ongoing monitoring of family and child status, e.g., maintaining contact with the family during hospitalization and providing emotional support to family, and maintaining follow-up contact were also rated high in time efforts, that is 20% and 17% respectively. All three of these functions were related to the need to have ongoing communication links between all parties which requires a large amount of time. Activities reflected in the other case coordination activities were rated to take less time (10% or under) and were more related to administrative account keeping or referrals to outside agencies that required less coordination time.

Table 8
Functions of Case Coordination

# TASKS	% TIME	FUNCTION
16	5	Determine participation in Project Continuity.
6	6	Identify and arrange the necessary evaluations.
9	39	Exchange information.
6	10	Make referrals to outside agencies.
18	20	Monitor case status.
9	17	Maintain follow-up contact.
4	3	Determine case discharge.

Quality Assurance

Quality assurance (QA) was adopted as a model for monitoring and assessing case coordination outcomes. This procedure required identifying standards (outcomes), indicators, and criteria using either national (as in hospital accreditation) or local standards. A series of meetings was held to train the case coordination staff in developing QA procedures, resulting in their writing four standards. Three were monitored by external evaluators and one required internal review. The four outcomes, indicators, and evaluation processes and criteria are listed in Table 9. For example, one standard was "that parents are able to demonstrate knowledge of and are comfortable with their level of knowledge about each discipline involved with their child." This standard included specific behavioral criteria (i.e., 80% of the parents will be able to...).

Monitoring of the case coordination quality assurance was completed at the end of each of two time periods during the course of the project period, January 1987 - May 1988 and June 1988 - June 1989. The results of these QA reviews are summarized in Table 10.

Recommended Services Received

The first outcome evaluated was the level at which recommended services, both "in" and "out" patient, were received on a timely basis. This information was obtained from an internal review of the written case records. Of the 30 families reviewed through May of 1988, 90% of the families received 63.4% of the recommended services within a three month period. The other 10% received services at a lower rate. Primary reasons documented for families not receiving the services within this time limit included no documentation of date when family received services, child's health had not stabilized, and family determined services were no longer necessary. Results from the quality assurance done in June 1989, indicated improvement in this area. At that time 90% received 84.8% of the recommended services within three months, which approaches the original set criterion of 90%. In reviewing the data, the significant difference between the two assessments may be related to better record keeping rather than an improved rate in receiving services. When the initial data were recalculated counting those services received where an explicit date was not recorded, the rate increased to 77%.

Table 9
Case Coordination Quality Assurance Standards

Outcomes	Evaluation Process	Criteria
1. The child and family will receive appropriate recommended services both in and out patient. Recommended services are specified by the staffing team including the parents.	1. Case coordinators will review staffing and progress note reports and identify for each family a list of recommended services. Families will be interviewed by a person outside of the project following the family measure format asking parents what they are receiving. If case coordinators have identified services that parents did not report they were receiving they would be asked about those recommendations.	1. 90% of families will receive 90% services recommended within 3 months.
2. Parents are able to demonstrate knowledge of and are comfortable with their level of knowledge about each discipline involved with their child.	2. As parents are being interviewed on #1 after they list recommended services they will be asked what the purpose of those services include. The adequacy of their understanding will be determined by using the model of the nursing rating. Project Continuity staff will review parent's answers and rate them on a one to five scale.	2. 80% of parents will be able to list and describe services provided.
3. Parents are integral in planning for the child and family service plan.	3. a. Case coordinators will review all staffing meetings and determine the percentage of parents participating in them.	3. a. 75% of families will participate in Project Continuity's staffings.
	b. Parents will be interviewed with respect to the question "Are you listened to?" and "Are you respected by professionals in the area of medicine, education and health care?" How important is it that you are listened to and your opinions respected.	b. 75% families are satisfied with the level of control in their child's care.
4. The project will broker solutions with agencies with which have referral services, creating solutions where necessary.	4. Case managers collectively review files to identify cases where a needed service was refused or unavailable. The case will be followed to see if the service was provided after the case manager persevered or reconstructed the case. The method by which success was achieved will identify (ie., medicaid waiver, information scarcity overcome, detective work, precedent setting, etc.)	4. Count number of such cases and hope to be successful on more than 50% of such incidents.

Table 10
Case Coordination Quality Assurance Summary

Outcome	Criteria	Time period I	Time period II
The child and family receive appropriate recommended services both in and out patient. Recommended services are specified by the staffing team including the parents.	90% of families will receive 90% services recommended within 3 months.	63.4%	84.8%
Parents are able to demonstrate knowledge of and are comfortable with their level of knowledge about each discipline involved with their child.	80% of parents will be able to list.	85%	N/A
	Describe services provided.	55%	N/A
Parents are integral in planning for the child and family service plan.	75% of families will participate in Project Continuity's staffings.	60%	100%
The project will broker solutions with agencies for services not readily available, creating solutions where necessary.	Count number of such cases and hope to be successful on more than 50% of such incidents.	88%	50%

Parents' Knowledge/Comfort of Services

The second outcome measured was the level of parents' knowledge and degree of comfort with their knowledge about each discipline involved with their child. This measured the family's understanding of services provided by the Project as well as by other hospital staff and community agencies. This information was collected by surveying 18 families through telephone interviews with a graduate student who was not involved with the project and was only collected during one time period. Of the 30 families in the project, 12 were not included for a variety of reasons, e.g., their child's recent death (3), could not access by phone (no phone - 5, unlisted - 1, foreign - 1), and other (2). Results of the QA review indicated that 85% of the families were able to list the services that they were receiving. The mean number of services was 3.3, the mode was 4, and the range was 1-4. Fifty-five percent clearly understood the major purposes of each of their services, 36% had some difficulty understanding half or more of the services and 9% clearly did not understand the services that were being provided to their child. Parents' ability to list services was above the set criterion (80%), but their understanding was below criterion. This suggest that professionals need to improve their efforts to communicate not just what services they are providing, but also the purposes and reasons underlying the services.

Parent Involvement

The third outcome was related to parents being integral in the planning for their child and the family service plan. This information was obtained through an internal review of written case records. Of the 25 children for whom staffings were held through May 1988, a parent(s) attended 15 (60%). Of the 32 staffings held (some children had one or more staffing), a parent(s) was present at 16 (50%). These ratings were less than the 75% criterion. Of the 11 new children in the project from June 1988, staffings were held for eight of them and a parent(s) attended eight of them (100%). This rate was above the 75% criterion. Formal staffings were not held for three children as their parents were not staying in the Omaha area during the child's hospitalization and visited infrequently. Parents in these circumstances were contacted individually by the case coordinator and information obtained from the family was shared with the core team. These differences may also reflect a change in the procedures of Project Continuity with respect to the staffing process. Initially staffings were held after assessments were completed as a mechanisms for summarizing assessment data and planning intervention. Staff then decided to change the process. As a result, an initial staffing was held prior to assessments to identify parent priorities from the start.

Service Brokering

The fourth outcome assessed was the number of cases in which project staff were able to "broker" solutions with agencies where existing services were not available. This outcome was monitored by having project staff identify any situations in which services were not available and then, identify the outcome of attempts at brokering, whether it was successful or not. The results of the first wave QA indicate that eight cases were identified and solutions were successfully found for seven (88%) of the incidents. This was above the 50% criterion that had been established. Of the four families where services were brokered through June 1989, the second wave QA, solutions were successfully found for two (50%). This was at the criterion set. The need to broker solutions crossed a variety of circumstances. Some examples include access to respite programs, transportation funding, provision of family supports, and nursing care. Solutions typically involved creative funding solutions with other agencies, interagency care conferences to identify nursing services, and work with social services to identify funding resources for family members to stay in the Omaha area during their child's hospitalization. Cases in which staff were not successful in finding alternatives typically involved rural areas where staff were not available to deliver services, e.g., occupational therapy, educational program or trained respite providers. For example, one family in rural Kansas was referred for educational services. Those services were only available in a neighboring community, 60 miles away. The mother who was single, worked during the day and did not have anyone who could drive her child to the service program. Physical therapy services were located in her community, but no alternate solution for an educational program could be identified.

Parental Satisfaction

Parental satisfaction of services was evaluated as part of the case coordination QA survey described earlier. Sixteen of the 18 families who were interviewed had evaluations completed on their children. A 100% of those 16 families reported that the results of the evaluation done by the project staff were explained in an understandable fashion. The two children who did not have evaluations completed had died. Satisfaction with case coordination activities was rated by families on a 4 point Likert scale, with 4 being "helpful in many problem areas" and 1 being "not at all helpful". Overall parents evaluated case coordination by the project case coordinators as "helpful in many problem areas" (83%) with the remainder of the families rating these services as "helpful in several problem areas" which was a 3 on the Likert scale. Overall project case coordination services were highly valued by families as is indicated by one families response, "Project staff provided a lot of support and was always available when needed.

Time Cost Analysis

The costs of case coordination were a major interest of project staff and administration and also have broad implications for states beginning to implement PL 99-457. These costs may be specific to the medically complex infant. There are some general trends that would be consistent for families with medically complex children who move between the hospital and community settings and where a significant percent of the children are identified with developmental delays early in life. In order to evaluate the costs of case coordination activities, time data was collected through completion of a weekly log by each case coordinator during a selected eight month period. The case coordinators documented their time related to each case coordination function on each child and family contacted during the week. During this time frame children were referred, as well as discharged from the project. Thus, the total days in the project for each child/family varied. In order to translate this information into a cost figure, personnel costs for each case coordinator were calculated on an hourly basis, including salary and benefits and factoring in vacation time. Overhead and administrative costs, including support personnel, were not included into this cost figure.

Time Costs Related to Case Coordination Functions

Case coordination costs can be evaluated across several dimensions. Initial cost analysis examined time and cost factors related to each of the project's defined case coordination functions. These case coordination functions from the job analysis have been combined with task logs kept by the staff in computer accessible files in order to estimate the costs of case management and its component parts. The coordination costs are analyzed in Table 11 based on the seven case coordination functions described in Table 8.

Table 11
Annual Projected Time & Cost Figures by Case Coordination Function

Category	Total Time (hours)	Total Cost (dollars)	% of Total Hours	% of expected hours from job analysis
Determine Eligibility	56.0	997.67	5.6	5
Identify & Arrange Evaluations	49.0	881.94	5.0	6
Monitor Case Status	443.0	7,957.35	45.0	20
Make Referrals to Outside Agencies	51.0	923.06	5.2	10
Exchange Information	194.0	3,415.55	19.7	39
Maintain Follow-up Contact	187.0	3,439.74	19.0	17
Determine Case Discharge	5.0	76.19	.5	3
TOTAL	985.0	17,691.50	100%	100

This table represents the prorated annual project costs for the case coordination activities of this project, which includes four part-time coordinators. As anticipated in the job analysis, the functions that would require the most time included monitoring case status, exchanging information and maintaining follow-up. Monitoring the case status, which involved ongoing monitoring of the child's and family's situation while the child was hospitalized, composed the largest percent of staff time (45%). Once children returned to the community setting, less coordination time was spent in activities in this category. The average monthly personnel costs for case coordination per month were $1,474.29, or 82 hours of coordination services provided. During each of the eight months in the sample period the number of active cases ranged from 18-21, with the total number of children and families seen being 31. The number of children hospitalized on any day ranged from 1-6 infants.

In analyzing each of the four case coordinator's time in relation to specific functions, there are similar percentages of time spent across case coordinators with the exceptions of the categories of identifying and arranging evaluations, monitoring case studies and maintaining follow-up contact (see Table 12). The nurse specialist expended the highest percentage of time in monitoring and maintaining follow-up contact. This is a reflection of the nurse's case load. She was assigned families whose children were more complex medically and she spent accordingly, larger amounts of time in the hospital. These children frequently would require more contact following discharge, due to the multiple services necessary to support the family in the community, e.g., home health services, equipment vendors, educational services. The other major time difference between case coordinators was in the area of identifying and arranging evaluations. The parent-infant educator spend a larger amount of time carrying out this activity, as she had primary responsibility for coordinating the interdisciplinary team's assessments of children enrolled in the project.

Table 12
Time & Cost Figures by Case Coordination Function by Case Coordinator: Total Costs for 8 Month Time Collection Period

Category	Social Worker		Nurse Specialist		Parent/Infant Educator		Child Life Specialist	
	Total Time*	Total Cost**	Total Time*	Total Cost**	Total Time*	Total Cost**	Total Time*	Total Cost**
Determine Eligibility	8.25	141.32	18.50	348.91	4.50	83.34	5.75	91.54
Identify & Arrange Evaluations	6.25	107.06	7.50	141.45	15.75	291.69	3.00	47.76
Monitor Case Studies	19.75	338.32	151.75	2,862.01	53.25	986.19	70.25	1,118.38
Make Referrals to Outside Agencies	1.00	17.13	15.75	297.05	11.75	217.61	5.25	83.58
Exchange Information	20.00	342.60	27.50	518.65	45.50	859.66	36.00	573.12
Maintain Follow-up Contact	6.50	111.35	83.00	1,565.38	21.25	393.55	14.00	222.88
Determine Case Discharge	.75	12.85	.50	9.43	.25	4.63	1.50	23.88

* Total Time in hours
** Total Cost in dollars

Time Costs Related to Diagnosis

The data were analyzed to determine if case coordination cost varied with medical diagnosis. An average cost per month per child was calculated for each diagnostic category. This figure is based on the actual months the child was in the sample. These results, summarized in Table 13, indicate that overall, the average monthly case coordination costs for children with gastrointestinal problems was at least twice as high as children with other identified medical diagnoses. These cost differences may be a reflection of the different patterns of hospitalizations based on diagnosis. The majority of children seen in this project with gastrointestinal problems had liver disease and were recipients of liver transplants. Their hospital course ranged from 2 to 6 months or more. Once discharged from the hospital there was less likelihood of rehospitalization. Therefore, the case coordination costs would be high for that intense period of hospitalization. Children with other diagnoses show more variability in their patterns of hospitalization. For example there may be shorter hospital stays, e.g., one month, but perhaps a higher frequency of rehospitalizations. The overall cost of coordination would be less for children with this type of hospitalization pattern, as there is less overall monitoring of their status by project staff when the children are in the community setting. As indicated in Table 13 there is a wide range of hours for each diagnosis demonstrating the great variability of time costs spent based on the individual child.

Table 13
Average Monthly Time/Cost Analysis by Child by Diagnosis

Diagnosis	Range of Average Time per Month/ per Child (hours)	Average Time per Month/ per Child (hours)	Range of Costs per Month/ per Child (dollars)	Average Cost per Month/ per Child (dollars)	# of Children During 8 Month of Cost Monitoring	Average # of Months Served During 8 Months
Gastrointestinal	.26-36.0	8.49	4.15-647.18	162.44	12	4.02
Cardiac	.20-8	4.13	3.61-153.18	76.59	4	6.25
Congenital	.22-73.75	3.97	3.65-196.92	549.77	12	5.27
Renal	.21-6.96	2.75	3.41-125.86	49.92	2	6.50
Muscular Skeletal	---	.44	---	7.54	1	8.00

Time Costs Related to Family Variables

Time cost data were also analyzed based on the complexity of the family situation. A definition of a complex family situations was derived by case coordinators and included such variables as financial concerns, family problems, and lack of identified resources. A typical family who was identified as complex is illustrated in the following scenario. The Jackson's had six children, with their youngest hospitalized. The family decided that the mother would stay with the hospitalized child while the father stayed at home with the five siblings. The family lived at a great distance from the University of Nebraska Hospital. Father became unemployed during the course of the child's hospitalization. Two siblings were having problems adjusting to their separation from their mother. Financial concerns became paramount. This definition was then applied post hoc by the case coordinator and families were categorized into two possible groups, non-complex or complex situations. Staff are currently working on a more articulated definition that can be used by others.

Family situations that were categorized as complex fall into two groups. In the first group these factors were significant only during the child's hospitalization, so that they were temporary. Once the child was discharged, these situations were no longer problematic, e.g., separation from siblings.

The other group of families continued to deal with multiple family issues even after the child was discharged from the hospital. The data, based on months in the project, suggests that the case coordination costs were significantly higher for families who were categorized as encountering complex situations. This information is summarized in Table 14. As indicated in this table there is a wide range of hours/costs spend based on the individual child and family. This can be attributed to the timing of cost data collection. For example, one family may have encountered multiple family issues early during their enrollment in Project Continuity, but during the time of the cost analysis, the family situation had improved. Likewise, a family who was not identified as encountering complex family situations may have increased coordination costs due to their child just entering the Project or being rehospitalized at the time of cost data collection.

Table 14
Average Monthly Time/Cost Analysis by Child by Family Variables

Diagnosis	Range of Average Time per Month/ per Child (hours)	Average Time per Month/ per Child (hours)	Range of Costs per Month/ per Child (dollars)	Average Cost per Month/ per Child (dollars)	# of Children During 8 Month of Cost Monitoring	Average # of Months Served During 8 Months
Complex	.26-15.09	6.26	4.15-641.18	117.66	16	5.31
Non-Complex	.21-19.00	3.62	4.63-353.16	63.86	15	4.78

Time Costs Related to Age of the Child

Comparisons of time based on the age of the infant is summarized in Table 15. These results showed that young infants (12 months & under) had a much higher average time spent per child (6.42) as compared to the older age group (13-27 months). Data has been based on months in project. A Pearson Product correlation was used to determine the relation between the age of the infant at entry into the project and the times spent on case coordination activities. Results indicate that the r= -.26 (p= .08); the older the child the less time spent. The result is marginally nonsignificant but the reader should note that the N is low and the data is very variable.

No significant differences was noted in the average months served by either age group during the time data collection. An analysis of the distribution of age as related to diagnosis as reported in Table 16 was completed to see if there were any relationships between these two factors. This information suggests that there are similar distributions of children with congenital and gastrointestinal problems across age groups. However, a larger percentage of children entered the project under twelve months of age who had renal and muscular skeletal problems, with older children entering who had cardiac problems. Based on these distribution analyses, neither the distribution of average time or diagnostic categories does not reveal any clear pattern to explain the reasons younger children and their families accrue higher case coordination costs.

Table 15
Comparisons of Case Coordination Average Month Time/Costs Associated with Age at Entry to Project Continuity

Age at Entry (months)	# of Children	Average Monthly Time per Child	Average # of Months Served During 8 Months
Birth - 12 months	22	6.42	5.42
13 - 27 months	9	1.48	4.67

Table 16
Distribution of Children at Entry Age in Project as Related to Diagnostic Category

Diagnostic Months Category	# of Infants	Age in Months Birth to 12	# of Infants	Age in 13 to 27
Gastrointestinal	9	41	3	34
Congenital	8	37	4	44
Cardiac	2	10	2	22
Renal	2	10	0	--
Muscular Skeletal	1	1	0	--
TOTAL	22	100	9	100

Case Illustrations of Time Cost Analysis

Three cases have been selected to illustrate the time cost analysis.

Amy, who had gastrointestinal problems, was six months old at the time of referral into the project. She was referred to the project two months after the time data collection was initiated, resulting in a total of six months cost data, and was hospitalized throughout that period. The average monthly time spent in case coordination activities for these six months for Amy and her family was 15.09 hours per month. The average cost per month was $275.00.

Andy was referred to the project when he was 22 months old and had cardiac problems. He was also in the project for six of the eight months that time data was collected. In contrast to Amy, Andy's hospitalization pattern could be characterized as frequent short admissions (i.e., six hospitalizations during the six month period). His overall monthly average of case coordination activities for these six months was 7.0 hours. The time cost figure per month was $125.86.

A third child, Roger, who was eight months at the time of referral also had gastrointestinal problems. He was only in the project for two weeks of the time cost data collection. His prorated monthly average of time spent on case coordination activities for two weeks was 19.0 hours, with a total cost of $353.16.

These three cases illustrate the variability of time cost based on such factors as length of stay in the hospital, diagnostic category, and time of referral to the project. It also illustrates the greater costs associated with the earlier periods in the project (see Table 2) when children experience more hospitalization then they do later in the project and initial case coordination functions of planning and implementing the initial IFSP take place.

Nursing Component

Nursing Quality Assurance

Quality Assurance was adopted as a model for monitoring and assessing nursing care outcomes. Four outcomes, indicators, evaluation processes and criteria were identified and are listed in Table 17. For example, one standard was that "upon admission, each child will be screened for developmental level." This standard further specified behavioral criteria (e.g., '0% of all patients [birth to 2 years] admitted will be screened according to a specified protocol.) A review of a random selection of charts of in-patients on the infant/toddler unit was completed during August 1988. Chart reviews were completed by the Quality Assurance Committee on the infant/toddler floor. A total of six charts were reviewed. This process was then repeated in January 1990. The overall QA standard was "that patients development was evaluated and they received age appropriate interventions during hospitalization to maintain current level of development and encourage further development." The results of that QA evaluation are summarized in Table 18.

Table 17
Nursing Quality Assurance Standards

Outcomes	Process	Criteria
1. Upon admission, each child (ages 0-2) will be screened for developmental level.	1. The primary nurse is responsible for selection, administration, scoring and documentation of the developmental screening tool within 24 hours of admission.	1. 90% of all patients admitted (0-2 years) will be screened according to protocol.
2. Children who score below the norm on the developmental screening tool will be referred to Project Continuity for further evaluation.	2. The primary nurse will refer the child according to established protocol.	2. 100% of all children identified as needing further evaluation will be referred according to protocol.
3. Each child will receive individualized developmental interventions incorporated in the daily care activities.	3. Primary nurses will use the resources available to enhance their knowledge of developmental assessment and intervention. (Inservices, video tapes, learning packets, individualized consultations.)	3. All new employees will review the developmental orientation material in the first 6 weeks of employment. Documented on checklist. All employees will show documentation of have reviewed the developmental video tapes at the time of their annual evaluation.
	Primary nurse will incorporate developmental intervention in daily care activities.	Nursing care plans will reflect at least one developmental intervention. Evaluation of developmental progress will be documented in the patient record.
4. Parents will be taught appropriate developmental intervention for their child and participate in the evaluation of those interventions.	4. The primary nurse, in consultation with Child Life and/or Project Continuity Staff, will provide the parent with individualized intervention techniques to assist the child in reaching his/her developmental goals.	4. 90% of all children will have documentation of some developmental instruction on their teaching plan or developmental progress form.

Table 18
Nursing QA: Percentage of Developmental Assessments & Intervention Documented in Nursing Care Plans

	1988	1990
The child, between age 4 months & 24 months had a developmental assessment tool completed by the family within 24 hours of admission 80% of the time.	13%	80%
The assessment tool was scored 80% of the time.	13%	80%
Based on results of assessment tool, the child was referred for further evaluation as evidenced by documentation in the chart 90% of the time.	40%	80%
The Nursing Care Plan reflected at least one intervention related to development 90% of the time.	50%	N/A
On-going assessment of development is documented in the chart 90% of the time.	88%	N/A

These results indicate that the screening process that was instituted in 1988 was not working as intended. Use of the Infant Home Monitoring Questionnaire was then re-evaluated, and it was determined that the process was too cumbersome to be implemented in the pediatric unit. As a result, the Developmental Intervention for Care Planning and Family Education tool, discussed previously, was developed and implemented. As noted in Table 18, a dramatic increase in assessment occurred following these changes in assessment procedures.

Even though in 1988 assessment was only being completed in 13% of the cases reviewed, nursing staff were referring for further evaluation 40% of the time, based on either results on the screening or their informal observations. When this was reassessed in 1990, the results indicated that referrals were being made based primarily on the assessment findings.

Although the number of developmental interventions documented in the nursing care plan in 1988 was still below the target criterion, improvements have been shown compared to the baseline data obtained prior to the initiation of the project (Robinson, 1987). This earlier review of care plans indicated that the number of charts that had documented developmental activities was 30% or below. This information is summarized in Table 19. Although the developmental intervention was not mentioned in the nursing care plans, the ongoing assessment and monitoring of development was documented in the chart in nursing progress notes slightly below the criteria of 90%.

Table 19
Percentage of Care Plans (CP) with Developmental Activities (DEV. ACT.) on the Infant/Toddler Unit

Year	Percent with Developmental Activities
1986	33
1988	50

These quality assurance procedures developed by the project for the pediatric unit have been modified and continue to be a primary means of evaluation. In November 1988, the hospital was visited by the Joint Commission for Accreditation of Hospital Organizations (JCAHO) for an accreditation visit. The nurse surveyor, while visiting the infant/toddler unit, asked for the method by which children received developmental screening and how this was then carried forward to developmental interventions. Because of the influence of project efforts, the pediatric unit scored very well in this area. The JCAHO has in the 1990 standards for accreditation (Joint Commission on Accreditation of Health Care Organizations, 1989), developed new standards for facilities that treat children and adolescents. These standards emphasize a greater requirement for developmental assessment and interventions. The work on the project has greatly facilitated meeting the new standards.

Role of the Nurse in Case Coordination

Initial expectations of the grant staff were that there would be an increasing role of primary nursing in assuming the case coordinator role as this project has defined it. During the three year project, primary care nurses continued to play an active role in planning the case coordination activities but did not assume the primary role as coordinators. One of the constraints to their assuming this role was their limited time. Unless nurses were provided with more time, they would not be able to assume the coordination role, particularly with the expectations of coordinating care for children who are already discharged. With the growing nursing shortages, it was decided that nurses would assume a supportive role to the project case coordinators and that case coordination as defined by this project would not be a the role of primary care nurses. The emphasis of the project then focused on developing mechanisms by which the primary care nurse, as the health care coordinator during hospitalization, could facilitate and maintain good lines of communication. The nursing department is a recipient of a Robert Wood Johnson grant to help strengthen hospital nursing, including their role as a case manager. The work of the project will be helpful in determining the role of the staff nurse as a future case manager.

DISSEMINATION

During the second and third years of Project Continuity, staff efforts expanded to include dissemination activities. These efforts were targeted at providing information on a service delivery model for hospitalized chronically ill infants. Components included presentations on the case coordination model, increasing the nursing role in assessment and intervention, and developmental assessment and intervention with this population of infants. Targeted audiences included health care professionals, case coordinators, educators, child life specialists, social workers and parents. Dissemination activities could be categorized into three primary areas including: product development; workshops; and publications. The following is a description of each one of these components.

Product Development

Case Coordination Manual

A case coordination manual was designed to provide professionals a guide to case coordination for infants with chronic illness and their families. It described the case coordination process through vignettes and discussion of related issues based upon the Project Continuity Model.

Videotape Series

A three-part videotape series has been developed entitled Learning through Play. These videotapes were targeted for use with primary care nurses on pediatric units as well as parents, with the intent to increase their awareness of developmental activities that can be incorporated into nursing care or home routines. Useful suggestions were presented for interacting with medically fragile and at-risk children, birth-12 months. Strategies, based on the Uzgiris-Hunt interpretation of Piagetian sensorimotor development (Uzgiris & Hunt, 1975, Meyer Rehabilitation Institute, 1985), illustrated ways to create and respond to opportunities that facilitate learning across a variety of settings in the home or hospital. Illustrations are based on work of Project Continuity.

Developmental Intervention Form

The Developmental Intervention for Care Planning and Family Education form is designed for professionals responsible for implementing care plan interventions appropriate for young children. The checklist, prepared by an interdisciplinary team from UNH, identified appropriate interactions with children at ages birth through 24 months.

Distribution of Product Material

Initial dissemination of these products occurred at a poster session at the International Early Childhood Conference on Children with Special Needs in Minneapolis, Minnesota in October 1989 (see Appendix I). Plans are being made to do a national mailing to advertise these materials in the winter of 1990.

Workshops

Statewide Workshops

A conference entitled "The Medically Complex Child: What Do We Do?" was supported by Meyer Rehabilitation Institute through Project Continuity and First Start, a grant from the Governor's Planning Council on Developmental Disabilities, Nebraska Department of Health; the Nebraska Department of Education, Special Education Office; and Educational Service Unit #3 (see Appendix J for workshop brochure). The purpose of this conference was to identify issues, barriers and strategies for responding to the needs of families with children who are medically complex. The conference was designed for parents and professionals in health, education and social services who were in policy-making or leadership positions for the development and implementation of programs for families with children who are medically complex. National, regional and local speakers addressed 79 persons who participated in the day-long workshop. A summary of information regarding the participants is presented in Table 20.

Table 20
Disciplines of Workshop Participants

Discipline	# of Participants
Social Services	40
Education	18
Health	16
Parents	5

Topics offered in the one day workshop included:

Addressing the Issues: University Hospital's response
Family Support Systems: Challenges and responses
Dealing with Death: Strategies for family and staff
Education Policies & Procedures: The Iowa model
Community Resources & Legislative Actions: It Can Be Done.

Evaluation of the conference indicated that participants rated the overall effectiveness of the conference at 3.20, based on a 4 point Likert scale with 0 being poor and 4 being excellent. Participants rated the conference as meeting the stated purpose at an overall rating of 3.4. Each of the individual presentations was also rated. Ratings of the presentations ranged from a 2.45 to 4.0, with the majority of the presentations rated over 3.0.

Regional & National Workshops

Over the course of the three year project, 18 presentations were delivered by project staff through regional and national presentations. Major topics addressed in these presentations included: developmental screening and intervention for chronically ill handicapped infants, case management, integration of educational intervention into a hospital setting and nursing care priorities in intervention. Workshops were presented at the following conferences:

Jackson, B. and Robinson, C. (October, 1989). Developmental Screening and Intervention for Chronically Ill Handicapped Infants. International Early Childhood Conference on Children with Special Needs, sponsored by The Council for Exceptional Children's, Division for Early Childhood. Minneapolis, Minnesota.

Jackson, B. (September, 1989). Participated in panel discussion, Case Management Models. Presented at the NEC * TAS IFSP Conference, Minneapolis, Minnesota.

Robinson, C. and Jackson, B. (September, 1989). Issues in Continuity of Care for Medically Fragile Infants. Presented at the "Coordination of Interdisciplinary Care for Persons with Developmental Handicaps and Chronic Illness," a national conference to commemorate the 10th anniversary of the University Affiliated Program for Developmental Disabilities, New York, New York.

Jackson, B. (August, 1989). Planning Early Intervention for Medically Fragile Infants and Toddlers. Presented at the "Supporting Medically Fragile Infants & Toddlers & Their Families in the Community" conference, sponsored by the South Carolina Department of Health & Environmental Control and the South Carolina March of Dimes, Columbia, South Carolina.

Jackson, B. (August, 1989). Case Study - Supporting Development in the Technology Dependent Child. Presented at the "Supporting Medically Fragile Infants & Toddlers & Their Families in the Community" conference, sponsored by the South Carolina Department of Health & Environmental Control and the South Carolina March of Dimes, Columbia, South Carolina.

Jackson, B., and Bell, J. (June, 1989). A Working Team for Medically Involved Kids. Presented at the "Family & Professionals, Unbeatable Teams for Children with Disabilities" conference, sponsored by the Nebraska Parent Information & Training Center, funded by the Nebraska Department of Education, Omaha, Nebraska.

Robinson, C. (June, 1989). (Moderator & presenter). Case Management and IFSP: A Family Approach. Panel presentation at Partnership for Progress III. Washington, DC.

Robinson, C. and Jackson, B. (May, 1989). Case Coordination: Implications for the handicapped infant with chronic illness. Presented at the annual meeting for the American Association of Mental Retardation. Chicago:Illinois.

Williams, L., Bell, J., Scoville, C., & Jackson, B. (May, 1989). Take a ride on the roller coaster: The family's experience with liver transplantation. Association for the Care of Children's Health, 24th Annual Conference. Anaheim, California.

Jackson, B. (May, 1989). Intervention techniques with handicapped and at-risk infants and toddlers, Early Intervention Faculty Institute, University Affiliated Program of South Carolina, Charleston, South Carolina.

Robinson, C., Finkler, D. & Jackson, B. (April, 1989). Case Coordination. Young Adult Institute's 10th Annual International Conference, New York, New York.

Jackson, B., Bataillon, K., & Gabriel, L. (April, 1989). Intervention Strategies with Chronically Ill and/or Handicapped Infants and Toddlers. Presented at the 10th Annual Conference on Early Childhood Special Education, Let's Coordinate for Kids, held in Kearney Nebraska.

Finkler, D., Robinson, C., & Jackson, B. (April, 1989). Case Coordination. 4th Annual, National Symposium on Information Technology. Charleston, South Carolina.

Jackson, B. & Bell, J. (March, 1989). Uniting with Families: Early Childhood Intervention in Kansas. 1989 Multidisciplinary Spring Conference, Lawrence, Kansas.

Finkler, D. (October, 1988). Family Focused Case Management for Medically Fragile Infants. Presented at the American Evaluation Association Conference, New Orleans, TN.

Robinson, C. & Jackson, B. (July, 1988). Panel presentation on *Medical - Developmental Interventions and Transitions from Hospital to Home and Community Service*. Presentation in Washington, D.C. Partnerships for Progress II, sponsored by NEC*TAS.

Jackson, B. and Seem, B. (June, 1988). *Case Coordination: Infants with a Chronic Illness and a Handicapping Condition*. Presentation at the Association for the Care of Children Health 23rd Annual Conference. Cleveland, Ohio.

Jackson, B. (June, 1988). *Developmental Screening and Intervention for Infants with Chronic Illnesses and Handicaps: Implications for Nursing Intervention*. Presentation at the Association for the Care of Children Health 23rd Annual Conference. Cleveland, Ohio.

Robinson, C. & Jackson, B., (April, 1988). *Identification, Referral, and Brief Intervention Strategies with Chronically Ill and/or Handicapped Infants and Toddlers*. Presented at the Midwest Association for the Education of Young Children 1988 Annual Conference, Omaha, Nebraska.

Bell, J. (March, 1988). *Case Coordination - Project Continuity*. Presented at Colorado Early Childhood Education Conference, Denver, Colorado.

Publications

Dissemination of project procedures and preliminary findings have also been made through publications. The following two articles were written based on the experiences of Project Continuity.

Robinson, C. and Jackson, B. (in press). Continuity of Care for Medically Fragile Infants. In R. Tompkins and M. Krajicek (Eds.), *The Medically Fragile Infant*.

Robinson, C., Jackson, B. & Raver-Lampman, S. (in press). Coordinating services for medically fragile infants. In S. Raver-Lampman, (Ed.) *Strategies for Teaching At-Risk and Handicapped Infants: A Transdisciplinary Approach*. Merrill Publishing Company.

Finkler, D., Robinson, C., & Jackson, B. (April, 1989). *Case Coordination: Implications for the Handicapped Infant with Chronic Illness*. Proceeding from the 4th Annual National Symposium on Information Technology. Charleston, South Carolina.

CONTINUATION

University of Nebraska Hospital and Meyer Rehabilitation Institute supported Project Continuity's staff efforts to seek continuation funding. Staff were successful in receiving State Maternal Child Health block funding for the continuation of continuity services from August 1, 1989 through June 30, 1990. Continuation funding through this same source is available beyond that date. The continuation funds support the implementation of the service model developed through Project Continuity, with new efforts to expand the project staff's role in supporting local communities in the transition of these infants and families into their home communities.

In June 1989 no new referrals were accepted on Project Continuity to allow staff to complete dissemination activities and plan for alternative services for families already enrolled in the Project. Once continuation funds were confirmed in August 1989, referrals were again accepted. A total of eight new referrals were obtained August 1 through September 30, 1990. This brought the total number of infants served on this project to 50.

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APPENDIX A

Classification System

CLASSIFICATION SYSTEM

I. Cardiovascular

- A. Congenital Heart Disease
- B. Congestive Heart Failure
- C. Bradycardia
- D. Infection
- E. Other

II. Pulmonary

- A. Bronchopulmonary Dysplasia
- B. Cystic Fibrosis
- C. Asthma
- D. Pneumonia
- E. Aspiration
- F. Tracheal Malacia
- G. Apnea
- H. Infection
- I. Other

III. Neuro-Muscular-Skeletal

- A. Trauma
- B. Cancer/Tumor
- C. Cerebral Palsy
- D. Myelomeningocele
- E. Hydrocephaly
- F. Microcephaly
- G. Intraventricular Hemorrhage
- H. Seizures
- I. Asphyxia
- J. Sensory Impairment
- K. Hyper/Hypo Tonicity
- L. Irritability
- M. Lethargy
- N. Infection
- O. Other

IV. GI

- A. Malnutrition
- B. Malabsorption
- C. Obstruction
- D. Reflux
- E. Short Bowel
- F. Failure to Thrive
- G. Biliary Atresia
- H. Hepato/Splenomegaly
- I. Cholangitis
- J. Transplant (liver)
- K. Rejection

L. Vomiting/Diarrhea
M. Chemical Ingestion
N. Infection
O. Other

V. Renal/Reproductive

A. Nephrotic Syndrome
B. Structural Malformation
C. Renal Failure
D. Infection
E. Other

VI. Endocrine

A. Diabetes
B. Hormone Deficiency
C. Other

VII. Congenital Conditions

A. Prematurity
B. Birth Trauma
C. Maternal/Fetal Infection
D. Fetal Alcohol Syndrome
E. Downs Syndrome
F. Genetic/Chromosomal Defect
G. Other

VIII. Skin

A. Burn
B. Rash/Lesion
C. Infections
D. Trauma
E. Breakdwon
F. Other

IX. Other

APPENDIX B

Health Measures Sample

Assessment of Parent's (primary caretaker) Knowledge and Understanding of Child's Diagnosis and Treatment Needs

Child's Name ______________________________

Parent or Caretaker Interviewed ______________ Interviewer ______________

Child's DOB ______________ Date ______________

1. Ask the parent to state child's diagnosis and/or present symptoms as he or she understands them. Record them.

   If there are areas of impact of which you are aware that the parent does not identify, probe from the areas of impact list. Make a note as to whether the mother spontaneously (S) identifies an area or whether you need to prompt (P) it.

   Diagnosis/System Involved:

   ____

   ____

   ____

   Management Needs:

   Nutritional/Metabolic ______________________________

   Elimination ______________________________

   Activity/Exercise ______________________________

   Sleep-Rest ______________________________

   Cognitive-Perceptual ______________________________

   Role Relationship ______________________________

2. For each area of functioning the parent identifies consider the three points listed below and select from the descriptions provided for each point which best describes this parent.

   a. understanding of the child's diagnosis (cause, prognosis) and symptoms __________

   b. understanding of the treatment implications, care demands __________

   c. level of confidence in meeting child's needs __________

Having interviewed the parent, circle the rating number under a, b, and c which best describes your evaluation of the parent's response to your questions. The numbers 2, 4, and 6 may be used to reflect a midpoint between descriptions.

(a) Understanding of the child's diagnosis (cause, prognosis) and symptoms according to the following criteria:

(1) Minimal: Minimal knowledge and understanding of diagnosis; parent only knows that child is ill and perhaps can identify major system involved.
(2)
(3) Fair: Knowledge and understanding is fair; parent may name disease or system involved, can name major symptoms but doesn't seem to understand how these symptoms affect health.
(4)
(5) Good: Knowledge and understanding is good; can identify all symptoms, can discuss etiology as an issue, and can describe impaired functioning.
(6)
(7) Extensive: Knowledge and understanding is excellent; in addition to qualifiers for rating of good, parent can talk about prognosis, expected changes and understands interrelated functioning.

(b) Understanding of the treatment implications and care demands according to the following criteria:

(1) Minimal understanding: Minimal understanding of the purpose or action of any interventions and implication for care.
(2)
(3) Fair understanding: Understanding is fair, can specify major interventions but has little understanding of the implications for home treatment.
(4)
(5) Good understanding: Understanding is good, can tell you most of what is being done, the reasons why, and the anticipated outcomes. Will be able to carry out home care procedures well in routine situations.
(6)
(7) Extensive understanding: Excellent understanding, can tell you all of what is being done, including alternative interventions, anticipated outcomes, and response-dependent alternatives. Will be able to accommodate to non-routine situations in delivery of home care.

(c) Level of confidence in meeting their child's needs according to the following criteria:

(1) Minimal: Level of confidence expressed is very low and presents a serious impediment to learning.
(2)
(3) Fair: Level of confidence is somewhat low and interferes to some extent with ability to learn.
(4)
(5) Good: Level of confidence is adequate.
(6)
(7) Extensive: Level of confidence is high and appropriate and facilitates this parent's provision of care.

Rating of Severity of Child's Illness

Child's Name ______________________ Child's DOB ______________________

Parent's Name ______________________ Person Rating ______________________

Date ______________________ Hospitalized at time of rating ________ Yes ________ No

	Degree of Involvement				Probable Duration			
I. System	None	Mild	Moderate	Severe	None	Temporary	Lifelong Risk	Lifelong Impact
Cardiac	1	2	3	4	1	2	3	4
Pulmonary	1	2	3	4	1	2	3	4
Neurological	1	2	3	4	1	2	3	4
Gastrointestinal	1	2	3	4	1	2	3	4
Musculoskeletal	1	2	3	4	1	2	3	4
Genital/Urinary	1	2	3	4	1	2	3	4
Metabolic/Endocrine	1	2	3	4	1	2	3	4
Disfigurement	1	2	3	4	1	2	3	4
II. Management Needs								
Nutritional-Metabolic	1	2	3	4	1	2	3	4
Elimination	1	2	3	4	1	2	3	4
Activity Exercise (cardiopulmonary)	1	2	3	4	1	2	3	4
Sleep-Rest Pattern	1	2	3	4	1	2	3	4
Cognitive-Perceptual Pattern	1	2	3	4	1	2	3	4
-Relationship Pattern	1	2	3	4	1	2	3	4

Guidelines for Use of Rating of Severity of Child's Illness

The purpose of this measure is to obtain a description of a child's level or degree of involvement of physiological systems and the degree of management needs in the context of a system of nursing diagnosis. In addition to degree of involvement, you are asked to rate the probable duration of that involvement of the system with respect to duration of management needs. Consider the current management needs and this probable duration, i.e., the child who is on hyperalimentation, the underlying condition may have lifelong implications but the management needs of altered mode of feeding may not be lifelong. In terms of probable duration of involvement or management needs, rate these dimensions with reference to the child's current status. With some conditions you might be able to anticipate future problems such as nutritional problems in the person with Down Syndrome, elimination problems in the person with cerebral palsy. Do not anticipate in making your rating; consider the present status of involvement in the individual as the basis for your rating.

Clarification Regarding Systems

Cardiac - Consider impairment in cardiac rate or rhythm, generation of conduction of electrical impulse and structural defects.

Pulmonary - Include signs of instability of pulmonary function that affect ventilation, perfusion, and gas exchange.

Neurological - Include sensory status as well as neurological status. Conditions such as hydrocephaly and spina bifida, IVH's, seizures, microcephaly under this system.

Gastrointestinal - In rating this system, consider underlying reasons of involvement, probable duration of altered means of intake if that is the issue and probable duration. For example, while hyperalimentation from the nonexpert's point of view may seem to be severe involvement, however, if its use is likely to be discontinued within a few months, a moderate rating might be appropriate.

Musculoskeletal - As a rating convention, consider cerebral palsy under this system.

Genital/Urinary - Incude genital abnormalities (edema, irritation, abnormal development). Unstable renal function as indicated by decreased output, abnormal lab values, presence of blood, mucous, or other sediment in the urine.

Metabolic/Endocrine - Consider abnormal growth and development patterns, food and/or formula intolerances.

Disfigurement - Consider disfigurement's impact independently. Do not weigh relative to other illness.

Clarification Regarding Ratings of Duration

Temporary - Use this rating level for a duration of symptoms or alteration of functioning (systems rating) or a management need (such as suctioning, gastrostomy feeding, etc.) that is likely to persist up to a year (include duration of two weeks to one year).

Lifelong Risk - Use this rating for conditions, systems where the presence of the underlying pathology (such as heart defects, milk protein intolerance, etc.) presents a significant risk to life span or quality of life throughout the life span.

Lifelong Impact - Use this rating for those conditions and management needs where it is certain that they will persist lifelong. An example might be implications of cerebral palsy for activity experience patterns or the implications of severe microcephaly for cognitive perceptual patterns.

Child's Health Status

Child's Name ______________________________ **DOB** ____________________

Person Completing Rating ____________________ **Date** ____________________

In responding to the following questions, consider ____________________
(child's name)
__________ (his or her age), and primary diagnosis of ____________________

____

and rate his/her health status on each of the following dimensions in view of that diagnosis. For example:

(1) If a child was two months premature and is now less than 18 months of age, correct for prematurity in judging level of functioning.
(2) If a child has a condition that inevitably results in deformaties, assess range of motion and other pertinent questions within that context.

Your data base for completing this form includes the child's medical and nursing records, your direct observations and observations contributed by other staff members. Items 10 and 11 may be marked not applicable if that is the appropriate response.

	Very Impaired	Impaired	Satisfactory Given Condition	Normal Limits
1. Frequency of illness/accidents	4	3	2	1
Nutritional intake:				
2. Mode	4	3	2	1
3. Amount	4	3	2	1
4. Nutrient balance	4	3	2	1
5. Texture	4	3	2	1

If available, record child's percentile for:

Height ______________ Weight ______________

6. Maintenance of respiration		4	3	2	1
7. Range of motion		4	3	2	1
8. Appropriateness of exercise routine		4	3	2	1
9. Appropriateness of sleep routine		4	3	2	1
10. Seizure Control	N/A	4	3	2	1
11. Return to routine after illness or surgery.	N/A	4	3	2	1

Child's Health Status

Guidelines Regarding Rating of Child's Health Status

The frame of reference for this rating is the child's underlying condition (prematurity, genetic syndrome, heart defect, cerebral palsy, etc.) and his or her current status (at the time of the report on which the rating is based). When reports reflect an extended period such as a hospitalization of several months over which time there has been a changing status, base your rating on a time period not to exceed the four weeks preceeding the point of the rating.

Definitions of Rating Categories

Very Impaired - Given child's underlying condition, his or her current status in regards to this health status indicator is very impaired. Thus, a child who is on hyperalimentation and this mode of nutritional intake is not working well, infections, etc. might be rated here.

Impaired - Again, consider underlying condition and whether the child is doing less well than one might expect given that condition. For example, a child with a heart lesion who is not gaining weight as well as one might expect might receive this rating for some indicators.

Satisfactory Given Condition - Use this rating when, given the child's underlying problems, you are satisfied with his or her status in this area.

Normal Limits - This rating may apply to status indicators which a child's condition may not impact upon and therefore status is normal, or where a child's status is such that, even given the child's condition, there is no apparent impact of the condition upon the child's health status.

APPENDIX C

Individualized Family Service Plan

University of Nebraska Medical Center
University Hospital

INDIVIDUALIZED EDUCATIONAL PLAN
INDIVIDUALIZED FAMILY SERVICE PLAN

Date:

Name: UNH #:

Address: Phone:

Birth Date: Age: Sex:

Parent/Guardian:

Address:

Phone:

Resident School District:

Home School:

Qualifying Condition for Educational Services:

Previous Services:

Medical History/Condition:

Date Admitted to Hospital: Physician:

Case Manager: Social Worker:

Date of Conference:

Assessment/Evaluation Results

Family Strengths	Child's Strengths

Individualized Family Service Plan (IFSP)

Child:______________________________ __________

Evaluation Codes

A - Achieved
A/% = Achieved/Move to Higher %
A/D - Achieved/Delete
PN - Progress Notes
NP = No Progress
D = Delete

Present Developmental Abilities	Outcomes	Intervention/Strategies/ Materials	Person Responsible	Evaluation	Date Completed

Individualized Family Service Plan (IFSP)

Family: ______________________________

Date: ______________

Evaluation Codes

A = Achieved
A/% = Achieved/Move to Higher %
A/D - Achieved/Delete
PN = Progress Notes
NP = No Progress
D = Delete

Identified Outcomes	Plan	Person Responsible	Evaluation	Date Completed

Patient________________________

IFSP
Implementation Record

I. Special Education and Related Services

Below Age Five — Duration — Does service follow school calendar?

1. ____/ ____/ ____/ to ____/ ____/ ____/ Yes____ No____

Hrs./Day _____
Days/Wk. _____
Months _____

Related Services — Duration — Does service follow school calendar?

1. ____/ ____/ ____/ to ____/ ____/ ____/ Yes____ No____

Hrs./Day _____
Days/Wk. _____
Months _____

2. ____/ ____/ ____/ to ____/ ____/ ____/ Yes____ No____

Hrs./Day _____
Days/Wk. _____
Months _____

3. ____/ ____/ ____/ to ____/ ____/ ____/ Yes____ No____

Hrs./Day _____
Days/Wk. _____
Months _____

Patient___________________

II. Child qualifies for transportation services Yes____ No____

Child requires special conditions necessary for safe transportation? Yes____ No____

III. Explanation of duration of service

I understand the content and purpose of the IFSP conference and the IFSP Yes____ No____

I have received a copy of the IFSP Yes____ No____

______________________________	______________
Parent Signature	Date

IFSP Conference Participants	Role	Date M/D/Yr

APPENDIX D

Developmental Intervention for Care Planning & Family Education Tool

DEVELOPMENTAL INTERVENTION
FOR CARE PLANNING
AND FAMILY EDUCATION

Name

Birthdate

Age

Date

AGE 0-4 MONTHS

Developmental Characteristics	Suggested Care Plan Interventions
Motor:	
☐ Lifts head when placed at shoulder or when placed on his/her stomach	Provide the child opportunities to improve head control by laying the infant on your shoulder or supported sitting
☐ Holds head steady	
☐ Moves arms and legs in play	
☐ Swats, reaches or grasps objects	
Social/Emotional/Communication:	
☐ Vocalizes, smiles and reaches toward familiar people	Provide opportunities for face-to-face interactions that encourage smiles and vocalizations Utilize safety mirrors in crib and during play time
☐ Communicates needs using differentiated cries	
Cognitive:	
☐ Visually tracks moving objects	
☐ Alternates visual attention between objects	
☐ Turns to source of sound	
☐ Utilizes banging, shaking, mouthing, looking in play with toys	Give the infant safe hand-held toys that are easily manipulated Position toys within the child's reach

Appropriate Play Materials & Equipment: Music box, tapes with soothing music or parents' voices, black/white mobiles, bright-colored objects, small rattles, cradle gym, slinky, mirrors, bells, infant seat, infant hammock.

AGE 5-8 MONTHS

Developmental Characteristics	Suggested Care Plan Interventions
Motor:	
☐ Sits with little support progressing to independent sitting	Provide the infant opportunities for supportive sitting and rolling
☐ Rolls in both directions	
☐ Stands firmly when held	
☐ Transfers objects from one hand to another	Give the infant safe, hand-held toys that are easily manipulated
☐ Grasps with whole hand	
Social/Emotional:	
☐ Pats and smiles at images in mirror	Utilize safety mirror in crib and during play-time
☐ Recognizes familiar people and discriminates strangers	Provide a balance of quiet and stimulating interactions
Cognitive:	
☐ Examines and explores toys	Utilize a variety of toys that promote examination
Imitates familiar action	
Communication:	
☐ Vocalizes using syllables, e.g. ba, ma with repetition	Imitate child's vocalizations/gestures, pause and wait for the child to respond
Communicates wants, e.g., touches toy for more or vocalizes/smiles for more in a game situation	Establish routine games with the infant, pausing and allowing time for the infant to respond
Self-Help:	
Eats food from a spoon with assistance	
☐ Holds, sucks or bites cookie	

Appropriate Play Materials & Equipment: Slinky, squeak toys, toys that can be poked and examined, e.g., helicopter rattle, toys with moving parts, radios, musical toys, mirrors, happy apples, hard-paged books, mat, crib gym, infant chair

AGE 9-12 MONTHS

Developmental Characteristics	**Suggested Care Plan Interventions**
Motor:	
☐ Moves in and out of sitting position ☐ Crawls ☐ Pulls to standing	Provide opportunities to practice crawling and standing skills
☐ Uses pincer grasp to pick up small objects ☐ Hits two objects together at midline	Provide opportunities to grasp small food items, e.g., Cheerios or raisins, if within prescribed diet
Social/Emotional	
Shows interest in other adults' or children's activities	
Exhibits difficulty separating from familiar people and displays stranger anxiety	Provide continuity of care givers to minimize separation anxiety
Displays full range of emotion, e.g., laughter, fear, anxiety and anger	
Cognitive:	
☐ Places objects in and out of containers	
☐ Searches for object that is covered	
☐ Uses a variety of actions with toys, e.g., stretch, slide, drop, squeeze	Provide a variety of toys with which the infant can discover new actions
Communication:	
☐ Communicates wants, e.g., repeats action of a game to signal for more or reaches to make wants known	Collaborate with family in interpreting and responding to child's indication of wants Introduce games such as Peek-a-Boo, Row-row-row your boat, allowing the child to communicate his desire to continue or discontinue the game
☐ Recognizes words that are familiar to them	Refer to toys and actions consistently using simple language
☐ Uses expressive jabbering (vocalizes with intonation using most vowel and consonant sounds)	Respond to infant jabbering by mimicking the child or by verbally interpreting the message
☐ Imitates unfamiliar vocalizations	
Self-Help:	
☐ Drinks from a cup with assistance	Introduce cup and spoon to promote eating skills

Appropriate Play Materials & Equipment: Books, busy boxes, See 'N' Say, balls, squeak toys, blocks, music, containers, pull toys.

AGE 13-18 MONTHS

Developmental Characteristics	**Suggested Care Plan Interventions**
Motor	
☐ Walks independently	Provide assistance in walking
☐ Crawls up and down steps	
☐ Walks up and down steps with assistance	
☐ Stacks 2-3 blocks	
☐ Dumps objects from containers	
Cognitive:	
☐ Demonstrates functional use of objects in play, e.g., gives doll a bite, combs hair	Provide child with familiar household or medical items, e.g., comb, stethoscope
☐ Identifies pictures in books	Schedule reading time with simple, realistic picture books
☐ Sequences objects into containers	Provide materials for sequencing, e.g., pegboards, shape boxes, stacking poles
Communication	
☐ Uses up to 20 words	Expand toddler's single words by using them in short sentences. *Toddler: "Ball" — Adult: "You want the ball?"*
☐ Follows simple directions	Maintain conversation with toddler during daily care
☐ Begins to point to body parts when named	Refers to body parts during typical care routines
Self-Help:	
☐ Removes some articles of clothing	
☐ Drinks and eats with assistance	

Appropriate Play Materials & Equipment: Books, peg boards, shape boxes, household items, balls, ride toy, bristol blocks, Fisher Price little people play sets, big mouth singers, wind-up toys, wagon

AGE 19-24 MONTHS

Developmental Characteristics	**Suggested Care Plan Interventions**
Motor:	
☐ Climbs on & off furniture and play equipment	Assist child in opportunities to engage in climbing activities
☐ Kicks a ball	
☐ Runs	
☐ Marks with drawing materials	Provide art experiences including coloring, painting, etc
Social/Emotional	
☐ Begins negativism	Provide toddler with a sense of control by offering choices
☐ Increases interactions with other children through parallel play	When appropriate, allow play in proximity of other children
Cognitive:	
☐ Completes simple puzzles	Provide puzzles with large, non-interlocking pieces
☐ Begins to engage in pretend play	Identify familiar routines and engage child in pretend play
☐ Activates mechanical toys	Offer a variety of mechanical toys (See 'N' Say, tape recorder, jack-in-box, Pop-n-Pals)
☐ Imitates actions in simple finger plays	Introduce simple, short finger plays (e g , itsy bitsy spider, wheels on the bus)
Communication:	
☐ Understands more words than can express	Communicate in a clear & simple manner when interacting with child
☐ Begins expressing two-word phrases	Avoid pressuring child by requesting certain words to be said
☐ Listens to short stories	Utilize books with short, simple story lines
Self Help:	
☐ Eats & drinks independently	Promote independence with meal time skills
☐ Indicates wet or soiled diapers	

Appropriate Play Materials & Equipment Pretend play materials, e.g., kitchen set, blocks, dolls, books, Pop-n-Pals, See 'N' Say, large Legos, vehicle sets, colors, paints, bubbles, balls, tape recorder, puzzles, shape boxes, non-pedal riding toys

Comments:

Recommended Referrals: _____Child Life _____Psychology _____Physical Therapy _____Occupational Therapy

_____ Speech Therapy _____ Social Work Other ________________________________

Primary Nurse: ______________________________ Date ___/___/___

Signature

CRI 76 9/89

Materials may be ordered from:

Media Resource Center
Meyer Rehabilitation Institute
University of Nebraska Medical Center
444 South 44th St
Omaha, NE 68131-3795
(402) 559-7467
FAX (402) 559-5737

Developed by.
Project Continuity Funded by U S Department of Education Office of Special Education — Rehabilitation Services Meyer Rehabilitation Institute and University of Nebraska Hospital University of Nebraska Medical Center

References:

Caplan F (197) The First 12 Months of Life Gross & Dunlap New York
Saint Michael Hospital (1985) Age Appropriate Play Kardex product of Professional Nursery Development and Clinical Research Center Milwaukee Wisconsin
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CRI 76 (9 89)

APPENDIX E

Developmental Progress Note

UNIVERSITY OF NEBRASKA MEDICAL CENTER
UNIVERSITY HOSPITAL & OUTPATIENT SERVICES

DEVELOPMENTAL PROGRESS

Date	Child's Current Age	Developmental Observations	Intervention Plan	Signature

8/88)

APPENDIX F

Case Coordination Process: Roles & Sequence of Activities

3/14/89

PROJECT CONTINUITY
CASE COORDINATOR ROLE

Responsiblity	Referral	Forms
Core Team (CT)	Referrals come to Project Continuity (PC) contact person (Core Team) via 3 sources: 1. Primary physicians 2. Primary or specialty nurses. 3. Project Staff	
CT	Determine eligibility	
	Intake	
	After receipt of initial referral:	
CT	1. Notify physician of referral.	Complete PC census form Get Project consent form signed
CT	2. If approved, contact family to describe PC. If family accepts services, arrange a time for initial staffing.	Register in OSS at MCRI Send letter to Dr.
CT	3. Document in chart whether parents accept or refuse PC services; inform primary nurse.	
CT	4. Conduct an initial staffing with family, primary nurse and core team to review child's current status, project roles, services available and family needs. Assign a case coordinator.	Provide family with project information. Get outside agency consent form signed. Provide service menu. Complete client data form.
CT	5. Based on initial staffing, contact appropriate staff to see child and/or contact attending physician for approval for support services evaluations. Upon approval contact support services. Coordinate with family, evaluation process.	Complete initial staffing note.
Case Coordinator (CC)	6. Collaborate with parents about current and projected family needs.	Complete family needs assessment.
	Development of Individualed Family Service Plan (IFSP)	**Forms**
CT	1. Coordinate development of IFSP plan with family through formal staffing or individual collaboration with parents.	IFSP form
CC	2. Have parents sign appropriate releases, e.g., other physicians, schools, SCC, VNA, etc. based on IFSP recommendations.	Release of information Send letter to appropriate agencies.

Referrals to Outside Agencies

Parent-Infant Educator	1. Referral to school, contact appropriate school personnel and offer consultation services of Project Continuity staff. Follow-up call to schools and/or parents to determine if services have been initiated, approximately 1 month.	See Nebraska Educational Directory. Send reports, release of information and referral letter to school and copy of letter to parents. Note anticipated starting date.
CC	2. Referral to home nursing. Follow-up/document services.	
CC	3. Referral to other agencies. Follow-up/document services.	

Intervention

CL/PIE	1. Provide developmental suggestions to parents. Coordinate with PCN.	Bedside suggestions
CL/PIE	2. Help PCN incorporate suggestions into daily routines.	Chart notes
CT	3. Implement IFSP.	
CT	4. Communicate with agencies providing services in local community.	
CT	5. Provide family support.	

Follow-up/Continuity Services

CT	1. Follow-up calls for documentation and needs assessment every 3 months or as needed and referrals/actions based on information.	Progress note forms to: OSS Primary Care physician, R.N. and speciality nurses. Outside Agencies
CT	2. Follow-up home visit by case coordinator as needed.	

Readmissions

CL/PCN/CC	1. Notification of readmission.	
	2. Implement Evaluation/Intervention Process.	

APPENDIX G

Recommendation from Case Coordination Critique

Project Continuity
Case Coordination - Seminar
June 6, 1988
Minutes

Chair: Cordelia Robinson
Barbara Jackson

Facilitator, Karen Faison

Persons Present:

Pat Gross
Brenda Sutton
Judy Quest
Judy Quinn
Deb Hanna
Doug Eicher
Mary Fraser-Meints
Judy Anderson
Chris Wright
Kaye Bataillon
Jo Larson
Barb Jackson
Karen Stevens
Jodi Albrecht
Mary Jo Iwan
Gail Krenzer
Joanie Dinsmore
Becky DeMuth
Mary Gordon
Deana Finkler
Gladys Lantz
Barb Elliott
Marcia Thiele
Linda Esterling
Jacque Bell
Jessie Rasmussen
John McClain
Corry Robinson
Bonnie Seem

The seminar was very helpful. A great deal of information was obtained from all participants. The Project Continuity Staff will meet regarding the information gathered and ways of disseminating such information to better serve children and families served by Project Continuity and participating agencies in conjunction with Project Continuity.

Barbara Jackson provided an overview of Project Continuity.

Participants broke down into small groups to review the six areas on the Family Needs Assessment (Bailey, D. & Simeonsson, R., 1987). The following is a report from the individual groups stating the needs and resources pertaining to the particular need.

1. Needs for information.

Needs	Resources
1. Medical Condition of Child/Diagnosis	- Primary Nurse/Project Nurse Physician Pamphlets Genetics
2. Local Services Educational Financial Housing	- I & R (United) Childfind

3. Information on Traveling Housing Travel	-	Social Work Department
4. Child Development	-	Child Life Dept., written material
5. How to Interact with Child	-	Educational Team
6. How are needs met when parents not there?	-	Foster Grandparent Program Family Friends Referral to Support Groups
7. Future needs of child (Honest)	-	Genetics Physician (Attending)
8. Network (Parent/Parent)	-	Parent Support Groups Child Life Informal Networking

2. Needs for support.

Needs		Resources
1. Counseling		
a. Professional	a.	Mental health clinics Private Counselors Social Workers Clergy
b. Peers/other families	b.	Pilot parents Informal networks Disease related associations
2. Respite Care		
a. Care of handicapped infant	a.	ENCOR or United Way Identified day care centers
b. Care of siblings	b.	PAL line Sitter companion (GOARC)
3. Medical Information - on going	-	Pediatric Society Home Health/Nursing Disease Related Assoc. March of Dimes Family Doctor
4. Advocacy	-	Pilot Parents/ARC/CMR Disease Related Assoc. Nebr. Advocacy Developmental Disability Council

5. Financial	- Insurance/Social Services Information on resources . hospital counselor . social service worker
6. Community Information/Support - Out of community - Family	- Pilot Parents/ARC Hospital Staff
7. Training	- Nurses/Home Health/Hospital PT-OT Spec. Education Early Intervention Staff Parent retreats

3. Explaining To Others.

Base - parent needs:
- To trust health care professional enought to feel free to ask questions.
- To feel they have some control of emotions/situtation/terminology in order to explain situation to others.

Needs	Resources
1. Understanding the medical terminology of the disability and being able to put into words. - guilt - reason - no one's fault	- Medical terminology/perhaps not MD Primary nurse. VNA nurse. Specialty nurse.
2. Who to share information with. - What level of explaination - Preparation for reactions others. - use of energy - permission to share or not to share - other extended family members - siblings	- Pilot Parents - Other parents followed on same "service". - Social Work. - Child Life.
3. Prepared for reactions	- Support from Primary nurse Mental health worker Social worker Child life Psych. Minister/Priest

4. How and what to explain	- Direct teaching/reading materials Health care professional needs to redirect/reinforce Be a sounding board Set example model Have parents demonstrate back Use video tapes Keep question list
5. Sibling/other children explanation To child himself others reaction Placement decisions	- Knowing resources - available persons Speciality nurse Parent support groups Advocacy agencies Other parents School district contact rights goals - Sibling interventions/support In hospital support reading material play therapy professional interview follow-up - Respite/babysitter
6. Let someone else explain Advocate	- Community resource Family preservation team Social services MHCP

4. Community Services.

Needs:	Resources:
Respite Care	- Regional MR Program - Community Program - Lenore Spencer - Dept of Social Services, Disabled Person & Family Support - Relatives and Friends

PT/OT and Speech and Language (S/L)	- MHCP - Schools - Private - Insurance - MCRI and Hospitals
Educational Care	- School - ESU
Psychological Services	- Assessment - Consultation - Emotional Support - Counseling - Private
Psychological Services cont.	- School - MCRI
Family Support Services Transportation Legal Equipment	- Social Services - ARC - Pilot Parent - Counseling - Religious Support - Citizen Advocacy

5. Financial Needs.

Needs:

Medical Care
Home Health Care
Special Equipment
Medications
Transportation Costs
Special Formulas
Therapy
Day Care
Prosthetic Equipment
Modifications to Home
Toys
All Diagnostic Evaluations
Counseling
Parent Training/Education
Belonging to Support Groups/Organizations
Telephone Costs/Other Utilities
Extended Diaper Services
Educational Costs
Case Management Costs
Dental Care
Respite Care
Insurance Costs
Support for Siblings
Loss of Pay
Loss of Time for Leisure

Resources:

Cash
Private Insurance
MedicAid
Medicare
MHCP
CHAMPUS
State Rental Program
Voluntary Agencies
SSI
AABD
Mayor's Office
WIC
Private Companies
Toy Libraries
Medicaid Waiver
Title XX
Child Welfare Funds
Disabled Persons Family Support
Special Grants
DD Councils
Energy Assistance (Heating & Cooling)

6. Family Functioning.

Needs:	Resources:
Separation of family members for medical services - both a marital & sibling issue (Role change and loss as well as stress)	- Housing - Long Distance Phone Credits - Sitter (Respite) for family care so parents can be together - Reimbursement for Travel Expenses, i.e. SSI - "Weekend" Switches - Respite - MSU, ENCORE
Little time for normal family relations because of care demands of child	- Respite for ill child so family is free for other activities - Home training for scheduling and routines; more efficient functioning e.g. FIT, ENCORE
Parent and sibling fears of hospital, child death and guilt	- Prepare sibs for child's experience; sib program must be developmentally appropriate - Church - Counsling for Sibs
Isolation	- Parent Support Groups - Respite - Use Extended Family
Marital Strain	- Transitioning child back to home change in roles of parents - Pilot parents, informal counseling - Marital Counseling, formal
Physical Exhaustion	- Respite
Family <u>In Control</u>	- Coordinating with all the service disciplines, establish "consultants to the family" - Professional sensitivity and training

The next phase of seminar involved reviewing four specific case studies asking the individual groups to list areas that they particularly felt were gaps and then listing areas they felts were constraints. Below we have compiled information from all the groups to make a listing.

GAPS

- Communication

  Medical/hospital to Home Community
  to Family
  to Physician
  to Others

- Case management responsiblities has system boundaries
- Boundaries/exclusion between and among service systems
- Some people don't qualify for needed services:
  financial
  disability
  at risk not eligible
- Little in the way of problem prevention programs
- Lack of easily accessible information
- Lack of networks
- Lack of training
  especially how to work systems
- Paternalism on part of many professionals, not just the doctors.
- Guides to services that parents can have and use.
- Attitudinal barriers to parents contacting on their own behalf.
- Respite care
  - Trained providers
  - Funding
  - Gaps in who is eligible for various programs
  - Some children - only fundable provider
  - Some require skilled nursing care
- Parent to Parent
  - Needs support
  - Hospitals & schools take more responsiblity for referral
- In-home support system
- Nursing Care Inadequate (8 hours)
- Important Early in Development
- Lack of opportunity to visit with other parents

- Is transportation available?

- Assessing early enough - and overlooking later needs

* Was attempt made to get father involved

- How long will mom's job last?

- Were grandmother's needs met - her role as mother

* Were nutritionists in home?

- Balance of needs

- Does mother know primary physician?

- Work with family on child development

- Who's responsible for feeding program?

- More respite care

* What about father's role
    family assessment could be filled out by him

- Redo family assessment after home

* Involvement of father earlier on
    Parent to parent?
    Perhaps a male case manager

- Initial information about what to expect early on

* Readmittance took place - would home health nurse have helped?

* Father - accepting role of educational services
    Ways to acclimate father
    Provide services less often - less people

* Coordination of services in hospital -
    Could educational team have came in sooner

* Failure to thrive - involvement of nutritionist

- Other children - involvement of others
    being in family
    friends

- Recreational program

** If family does not see the need, is it a need? **

CONSTRAINTS

Home Health

- Policies - what is allowed by agency?
- Funding mechanisms.
- How is something (letter, etc.) worded?
- Need proof that in-home care is cheaper than hospitalization.
- Finding RN's - availability of staff - problem covering holidays, nights weekends.
- Limitations in home physical environment.
- Do parents want someone there?
- Is there a physician willing to care for child?
- Community support for equipment itself.
- Liability issue.
- Why not support for other household functions (some exacerbated by extra in-home help).
- In-home help cannot provide care for others. How impact on father, mother? How on other siblings?
- Communication is not seen as priority - that Home Health person been seen as part of team.
- Payment cannot be made to other people who could provide service.
- Home Health persons may not have <u>time</u> to communicate.
- Little monitoring of provision of home health care.

Respite

- Funding.
- Finding trained respite providers.
- Liability.
- Only provide respite for handicapped child.
- In-home or out-of-home - no choice or no options.
- May have to move all equipment.
- May have to find own provider.
- Respite care is too much work.
- Child may be at risk of contracting other problems.
- Parents may be split on use of respite - guilt.
- Fears that if child in respite, will be removed altogether.
- Location.
- Providers may not know why they are there.
- Families may not know what to do with free time.

Mental Health

- No universal responsibilities to develop it.
- Private insurance often doesn't cover.
- Stigma.
- Public and private perceptions.
- Time to go for service.
- Education might help.
- Not enough skilled professional people in field.
- May be lack of knowledge on how to network with spiritual assistance, for example.
- May not have special parenting skills.

- Lack of parent training.
- Lot of insecurity.
- No bridges built to other parts of the helping agencies to facilitate good mental health.
- Lack of coordination often apparent.
- Families may not be dysfunctional - system may be.
- Timelines may have things occur so slowly, there is no good help.
- Funding - case manager.

Educational System

- Every school district has different dates.
- No state policy for length or start of program.
- If child is out of home, more is available.
- Eligibility - what to do with "at risk" child.
- Personnel.
- Not family centered.
- No well established linkages across agencies.
- Hard to get information.
- Attitudinal barriers - "Look at all that's being done."

Social Service

- Complexity

The last activity involved development of recommendations in response to identified constraints plus many of the points identified with other systems.

RECOMMENDATIONS

1. State level arbitration committee (60 % parents) to settle funding decisions across agencies.

2. All relevant state agencies put part of budget in general pool for hard-to-fund cases.

3. Project Continuity share with Interagency Council.

4. Sub-committee already working in Interagency Council.

5. Meshing of tax dollars so that client is more efficiently served - no protecting of turf.

6. Develop state dollars to fund programs so more discretion can be exercised apart from federal regulations.

7. Develop training on use of respite for care providers and parents.

8. Change needed in scope of practice laws. Liability issues sometimes arise.

Recommendations cont.

9. Need funding sources for people who do not need skilled nursing.

10. Some funding for daycare costs or regular costs.

11. Subsidize insurance (for companies or private organizations).

12. Develop incentives for people to provide respite.

13. Coordination with adult services - transition.

14. Training <u>across</u> agencies on case management.

15. Families trained to work with professionals.

16. Fathers, more attempts to involve them in provision of services and decision making.

With all the information compiled above, the group suggested the following agencies would benefit from receipt of such information:

- -State officials.
- -Legislative Health & Human Services; Daycare Committee; Family Committee.
- -State senators and representatives.
- -Insurance people.
- -Lawyers, County Attorneys, Judges.
- -Candidates - those writing platforms.
- -Advocacy persons.
- -Public at large.
- -Existing taskforces.
- -Health care providers.
- -Other service providers.

CASE: Mellisa

STRENGTHS: Medicaid

Resources, Ed, VNA

ADDITIONAL NEEDS:

NEEDS	**RESOURCES**
Family Functioning -father receptive to services/ role in the family.	-father provided needs assessment in addition to mom. -family intervention. -male case manager. -include father & other family members early on during hospitalization. -pilot parent idea while in hospital. -explanation to siblings about child's disability.
Home Health Nurses instead of Readmission. -family needs change over time.	-do update of family assessed after discharge.
Father accepting of educational services.	-individualized services, i.e., out of home, less frequently in a group setting.
Coordination of service -educational & medically	-team is involved in discharge planning (to include dad & VNA).
Training for family to avoid readmission.	-before discharge, how intense is training for both parents.
Weight gain	-nutritionist on team early on.
Assistance for caregiving to other children.	-Office of Aging, family friends, Girl Scouts to work with normal children. -Brenda Winn's program.

CASE: Randy

STRENGTHS: Mom's commitment; ability to initiate contact with Project Staff; mom's connection with ENCOR; eligible for almost all financial assistance; father remains involved; live in Omaha easy access; access to ENCOR respite; support m so many agencies; transportation; mom is high-function; able to care for children; able to work with others; support people; very cooperative.

ADDITIONAL NEEDS & RESOURCES:

NEEDS	**RESOURCES**
Follow younger sibling to assure sister is getting input that she needs.	Pediatric clinic; Well Baby Care; covered under Medicaid.
Did he have discharge plan?	VNA.
Services and follow-up should have started at time of discharge; neo-natal follow-up.	Primary nurse initiates extended follow-up; VNA follow-up.
Better intervention to work out family conflict - including extended family.	Encor or Social work from the hospital. Early periodic screening. Diagnostic test, DSS. Referred by family doctor.
Genetic counseling to Mom for family planning and the future - including dad.	Genetics clinic at MCRI. Case manager from ENCOR. VNA could reinforce this plan.
Support to Mom.	Help to get friends, neighbors, church connection.
Speech therapy for Mom.	Training by ENCOR to be more self sufficient.
Home based support. Assistance to resolve issues with initial family.	Good case management from ENCOR.
Transportation costs.	Could be paid through Disabled Persons Family relief program.

CASE: Sam

STRENGTHS: Weaned Sam from trachea.

Involvement of family and other agencies for support.

ADDITIONAL NEEDS & RESOURCES:

NEEDS	RESOURCES
Provide medical information to school.	Project Staff.
Information to family on medical and Development needs. (Developmental assessment should have been done earlier.)	Project Staff.
Advocacy	
Rights of family/child - educ. sys.	School, Nebr. advocacy, Legal aid.
Set up telephone access to VNA, Dr., Home Health if child has respiratory distress.	Project Staff.
CPR training and medical information for parents and respite providers.	Hospital, Community College.
Set up communication system between primary medical care and UNMC staff.	Project Staff.
Availability of educational materials.	Child Life, Public Library.
Knowledge of resources.	Child Life, Public Library.

CASE: Andy

STRENGTHS: Mother continues to work.

ADDITIONAL NEEDS & RESOURCES:

NEEDS

8 hours nursing care not enough, especially regarding twin.

Questioning if support system outside the home was sufficient.

Questioning parent support.

First 6 month support? Earlier assessment of Andy.

Attempt to get father involved.

Are grandmothers needs being met, (willing to be care taker or is this out of need.)

Balance needs for other twin. Can the brother receive early intervention along with Andy.

Start looking at differences, especially twin issues, strengths, child development.

Respite care for Mom, either alone or with well child.

Input from nutritionalist.

Does Mom know the primary physician.

Is there a feeding program? Who is responsible for those needs.

Has Mom been given time off work to attend various appointments?

Has transportation been a problem? Clinics can take several hours - parent having to take time off work.

RESOURCES

Due to time limitations, the listing of needs was comprised, however resources where not developed.

APPENDIX H

Description of the Case Coordination Knowledge, Skills and Abilities

Description of the Case Coordination Knowledge (K), Skills (S), and Abilities (A)

Found in: Furst, D. & Suh, Y., University of Nebraska at Omaha, Department of Psychology (1988). Job analyses performed on the position of case coordination for Project Continuity, pages 15 - 21.

NECESSARY KSAS

Knowledges

1. knowledge of Project Continuity acceptance criteria
2. knowledge of normal growth and developmental delays of infants 0-2 years
3. knowledge of pediatric caregiving staff (primary care nurse, attending physician, specialty nurse etc.)
4. knowledge of pediatric medical conditions
5. knowledge of basic medical terminology
6. knowledge of how the pediatric unit functions
7. knowledge of services Project Continuity can provide for eligible families and their infants
8. knowledge of how the services of Project Continuity interface with other hospital services
9. knowledge of contents of Project Continuity brochure
10. knowledge of family's health care program
11. knowledge of currently used services outside of Project Continuity
12. knowledge of currently needed services for child and family
13. knowledge of IRB procedure about release of information
14. knowledge of medical charting procedure sufficient to indicate parents' acceptance
15. knowledge of personnel involved in a certain case
16. knowledge of common needs of an infant with severe medical difficulties
17. knowledge of typical needs of families having a child with severe medical difficulties
18. knowledge of child's current medical/developmental condition
19. knowledge of general procedure to obtain necessary evaluations

20. knowledge of how long evaluations take to be performed
21. knowledge of when to refer parents to appropriate staff for evaluation feedback
22. knowledge of the components of the family intervention plan
23. knowledge of what services are being provided for child
24. knowledge of child's ongoing needs including health, education and social services
25. knowledge of whether child's current needs and status are met
26. knowledge of progress in child's status
27. knowledge of who the child's involved staff is
28. knowledge of when care conference staffing is appropriate
29. knowledge of care conference format
30. knowledge of reporting format about care conference staffing
31. knowledge of report filing procedure
32. knowledge of quarterly report format sufficient to gather required case information
33. knowledge of emotional processes that families in crisis situations typically experience
34. knowledge of the role of an advocate
35. knowledge of outside agencies that can potentially provide services to families
36. knowledge of what parents want to gain from Project Continuity
37. knowledge of sibling reaction to hospitalized family member
38. knowledge of services available to siblings through Project Continuity
39. knowledge of school personnel involved with a particular case
40. knowledge of outside agencies service options available for child's particular needs

41. knowledge of referral and funding procedure to outside agencies
42. knowledge of information that requires follow-up
43. knowledge of patient's home health care needs
44. knowledge of appropriate child care developmental intervention
45. knowledge of materials and resources available for bereaved parents and siblings
46. knowledge of grieving process typical for families in which a child has died
47. knowledge of significant dates to bereaved parents requiring follow-up contact
48. knowledge of Project Continuity related meeting time and place
49. knowledge of the role of case coordination in Project Continuity
50. knowledge of hospital's infectious disease policy
51. knowledge of format of discharge report

Abilities

1. ability to read medical charts
2. ability to identify delayed growth and development in infants 0-2 years
3. ability to communicate with pediatric caregiving staff in order to gather information for Project Continuity
4. ability to identify pediatric medical conditions in infants 0-2 years
5. ability to explain the benefits of participating in Project Continuity to eligible parents
6. ability to explain contents of Project Continuity brochure to parents
7. ability to analyze information from various sources to determine Project Continuity eligibility

8. ability to explain the services provided by Project Continuity to child care staff (attending physician, primary care nurse, and specialty nurse etc.)
9. ability to analyze information to make decision on child's acceptance into Project Continuity
10. ability to summarize child's current status in order to inform attending physician why child is appropriate for Project Continuity
11. ability to interpret the results of needs assessment
12. ability to explain the meaning of consent from
13. ability to organize meeting time so that necessary participants can attend
14. ability to interview families under stress in a nonthreatening, caring manner
15. ability to identify appropriate evaluations to be performed on infants
16. ability to present the background information on a child to appropriate personnel
17. ability to schedule specific evaluations to be performed by appropriate personnel
18. ability to write a report summarizing large quantities of information
19. ability to ensure evaluations are performed in a timely manner
20. ability to provide nonthreatening feedback about completed evaluations to parents
21. ability to provide nonthreatening feedback about completed evaluations to other child care personnel
22. ability to develop a family intervention plan
23. ability to be flexible with own schedule sufficient to meet with parents or child's staff as needed

24. ability to identify the child's ongoing needs are met
25. ability to evaluate additional needed services for child
26. ability to encourage involved staff to be in the meeting
27. ability to delegate report sending to secretary
28. ability to make appropriate recommendations
29. ability to summarize information during follow-up discussion with family and other health care staff
30. ability to keep track of quarterly report periods for children on own case-load
31. ability to identify appropriate schedule of contact specific to the needs of a particular case
32. ability to determine when contact with the family is not necessary
33. ability to provide appropriate emotional support (talking, listening, written information) based on family's current situation
34. ability to identify family's verbal/nonverbal cues as a guide to depth of intervention when providing emotional support
35. ability to offer parents opportunities for participation in Project Continuity in nonthreatening way
36. ability to assess the current depth of involvement that parents need in Project Continuity
37. ability to identify and respond to sibling reaction to hospitalized family member
38. ability to get individual education program information from and/or to involved school
39. ability to present details and needs of a case to outside agencies in order to procure services
40. ability to document in writing all contact with outside agencies

41. ability to write reports without breaching confidentiality

42. ability to delegate to secretary where correspondence should be sent

43. ability to communicate accurate information to parents

44. ability to conduct information gathering interview according to follow-up protocol

45. ability to determine when a home visit would be appropriate

46. ability to conduct oneself in a professional, caring manner while in a family's home

47. ability to determine the frequency and content of telephone follow-up activities

48. ability to determine when specific reevaluations or new evaluations are needed

49. ability to determine the most appropriate support resource for a family whose child has died

50. ability to identify family's coping style and available support systems

51. ability to determine appropriate frequency of follow-up contact needed by bereaved families

52. ability to prepare relevant case related information to present at Project Continuity related meetings

53. ability to objectively evaluate the effectiveness of case coordination

54. ability to recognize when consultation with project director about a specific case is appropriate

55. ability to accept and implement suggestions based on consultation with project director

56. ability to recognize and communicate information pertinent to other personnel

57. ability to recognize when child no longer meets Project Continuity criteria

58. ability to identify family's readiness to have child discharged from Project Continuity care

59. ability to summarize parents' and child's current status and reason for discharge

Skills

1. skill in verbal communication with parents of varying understanding levels
2. skill in writing letter in order for parents to understand the benefits of participation in Project Continuity
3. skill in verbal communication with child care staff
4. skill in interviewing parents sufficient to identify their medical, financial, social needs
5. skill in communication with primary care nurse
6. skill in active listening
7. skill in communicating persuasively with outside agencies on behalf of families
8. skill in communicating with core-team members in order to make case related decisions

APPENDIX I

Modified Nursing Quality Assurance

Learning Through Play: A Three-Part Video Series

Useful suggestions are presented for interacting with medically fragile and at-risk children, birth-12 months. Strategies, based on the Piagetian theory of cognitive development, illustrate ways to create and respond to opportunities that facilitate learning across a variety of settings in the home or hospital. Illustrations are based on work of Project Continuity, a family-centered intervention project for medically fragile infants and their families which provides services during hospitalization and facilitates the transition between hospital and home. The 3-part series is available as a set for $81 or individually for $30 each.

Case Coordination: The Project Continuity Model

This guide to case coordination for infants with chronic illness and their families describes the case coordination process through vignettes and the discussion of related issues based upon the Project Continuity model. An annotated bibliography and a resource checklist are provided. $5 each.

Developmental Intervention for Care Planning & Family Education

This form is designed for professionals responsible for implementing care plan inventions appropriate for young children. The checklist, prepared by an interdisciplinary team from the University of Nebraska Medical Center, identifies appropriate interactions with children at ages 0-4, 5-8, 9-12, 13-18 and 19-24 months. Inquire about volume discounts.

Order Form

Products available December 1989. Prices subject to change.

____ LEARNING THROUGH PLAY, $81 (entire 3-part set, includes 10% discount)
  ____ *Part I only (Birth - 5 months)* $30 each
  ____ *Part II only (5 - 8 months)* $30 each
  ____ *Part III only (8 - 12 months)* $30 each

____ CASE COORDINATION: THE PROJECT CONTINUITY MODEL, $5 each

____ DEVELOPMENTAL INTERVENTION FOR CARE PLANNING & FAMILY EDUCATION
(inquire about volume discounts)

Name ____________________
Title ____________________
Organization ____________________
Address ____________________
City ____________ *State* ______ *ZIP* ____________
Phone (______) ____________

Make checks payable to:

Media Resource Center
Meyer Rehabilitation Institute
University of Nebraska Medical Center
444 South 44th Street
Omaha, NE 68131-3795
(402) 559-7467

APPENDIX J

Workshop Flyer

The Planning Committee . . .

KAY GORDON, MS, CCC-SLP
Director of Special Education
Educational Service Unit #3

MARK HORTON, MD
Staff Pediatrician
Boys Town National Research Hospital

BARBARA JACKSON, MS
Department of Special Education
Meyer Rehabilitation Institute
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GENE SCHWARTING, PhD
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JESSIE RASMUSSEN, MS
Department of Special Education
Meyer Rehabilitation Institute
University of Nebraska Medical Center

DIANNE TRAVERS-GUSTAFSON, RN
Visiting Nurse Association

This conference is supported by the Meyer Rehabilitation Institute through First Start, a grant from the Governor's Planning Council on Developmental Disabilities Nebraska Department of Health and Project Continuity provided by the U S Department of Education, Office of Special Education and Rehabilitation Services, and with support from the Nebraska Department of Education, Special Education Office, and Educational Service Unit #3

The Purpose . . .

The purpose of this conference is to identify issues, barriers and strategies for responding to the needs of families with children who are medically complex. Questions to be addressed include

- Who should or can perform special care procedures such as trachea suctioning, catheterization and tube feeding?
- How do we provide educational services?
- What should we be doing to prepare families and caretakers for the possible death of the child?
- How do we pay for services?
- Who can provide care outside of the home? How do parents get a break?

The Audience . . .

This conference is designed for parents and professionals in health, education and social services who are in policy-making or leadership positions for the development and implementation of programs for families with children who are medically complex. Participants will include.

- Special Education Directors
- Planning Team Members
- Advocates
- Home Health Care Professionals
- Family Practitioners
- Pediatricians
- Child Life Specialists
- School Nurses
- Intensive Care Unit Team Members

The Medically Complex Child

June 15, 1989 o Lincoln, NE

The Medically Complex Child:

What
Do
We
Do?

Thursday, June 15, 1989

Cornhusker Hotel
333 South 13th
Lincoln, Nebraska

The Program . . .

9:00 - 9:30 a.m.
Welcome
JESSIE RASMUSSEN *Meyer Rehabilitation Institute, University of Nebraska Medical Center, Omaha*
Introduction
TOM TONNIGES, MD, *President Nebraska Chapter of American Academy of Pediatrics, Hastings*

9:30 - 10:15
Addressing the Issues: University Hospital's Response
RON TOMPKINS, *Associate Director of Nursing, University Hospital, Denver*

10:15 - 10:30 - **Break**

10:30 - 11:30
Family Support Systems: Challenges and Responses (panel discussion)

MARY JO IWAN, *Administrator, Special Services for Children and Adults, Nebraska Department of Social Services, Lincoln*

ANN RILEY, *Executive Director, Handicare: Early Childhood Development Program/Daycare, Iowa City*

NANCY CAHILL, *Director Family and Medical Support, Eastern NE Community Office of Retardation, Omaha*

TOM TONNIGES, MD, *President, Nebraska Chapter of American Academy of Pediatrics, Hastings*

11:30 - 12:30 p.m.
Dealing with Death: Strategies for Family and Staff

JACQUELINE BELL, *Child Life Coordinator, University of Nebraska Medical Center, Omaha*

CINDY SELIG, *Maternal Nurse Specialist, University of Nebraska Medical Center, Omaha*

12:30 - 1:30 - **Lunch** *(provided)*

1:30 - 2:30
Education, Policies & Procedures: Iowa Model

CHARLOTTE BURT
Consultant of School Health Services, Iowa Department of Education

2:30 - 2:40 - **Break**

2:40 - 3:20
Community Resources & Legislative Action

RON TOMPKINS
Associate Director of Nursing University Hospital, Denver

3:20 - 4:00 p.m.
It Can Be Done!

JULIE BECKETT
Associate Director of Consumer Affairs, National Maternal and Child Health Resource Center, University of Iowa, Iowa City

About the Speakers . . .

RON TOMPKINS, MS, MA, RN
Associate Director of Nursing, University Hospital, Denver

In 1986, Mr. Tompkins was responsible for planning and opening a six-bed transitional care unit for medically fragile children. He is co-authoring a book with Dr. Marilyn Krajicek entitled The Medically Fragile Child in the Hospital, Home and Community.

Presenting: Overview of the issues. University Hospital's Transition Clinic, community resources, legislation.

JULIE BECKETT, MA
Associate Director of Consumer Affairs, National Maternal and Child Health Resource Center, University of Iowa, Iowa City

Ms Beckett, who was instrumental in obtaining the Katie Beckett waiver, serves on the Iowa Task Force on Medically Fragile Children.

Presenting: Personal and professional experiences in obtaining appropriate programs and support systems for families with medically complex children.

CHARLOTTE BURT, MA, RN
Consultant of School Health Services, Iowa Department of Education - Special Education, Des Moines

Presenting: Transportation issues, care procedures and liability for Iowa public schools

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Registration Form

Registration

Registration, which includes lunch, is $15. Please make checks payable to ESU #3 - E.S.R.C. and mail by Friday, June 9 to:

Kay Gordon
Educational Service Unit #3
4224 South 133 Street
Omaha, NE 68137

For more information, call Meyer Rehabilitation Institute, University of Nebraska Medical Center, at (402) 559-7368. Registration is limited.

Name ____________________
Title ____________________
Agency ____________________
Address ____________________
City ____________ State ______ ZIP ______
Phone ( ) ____________________