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ABSTRACT

The Early Referral and Follow-up Project of the University of Nebraska Medical Center was designed to facilitate developmental assessment and intervention with long-term or repeatedly hospitalized children from birth to 3 years of age. Developmentally delayed children, handicapped children, and children at risk for delays were eligible for services. A major project activity involved assisting in the referral and transition of children from the hospital into appropriate services in their local school districts, accomplished through consultation with hospital and school district staff and through follow-up services. Evaluation services available to clients included developmental, speech, physical therapy, and occupational therapy assessments. This final report analyzes the referral process, the number of children referred and monitored, developmental interventions, cost of services, and outcomes of cases. Evaluation of project services indicated that school districts and parents perceived the project as providing useful, timely referral information and assessments of high quality. Staff efforts during the distribution of the Case Coordination Resource File. Appendixes include an outline of the case coordination role and sequence of activities; the evaluation criteria; definitions of classes of school district; and a project training workshop brochure. (JDD)

FINAL REPORT

EARLY REFERRAL AND FOLLOW-UP PROJECT

October 1, 1983
to
September 30, 1986

A Handicapped Children's Early Education Project
Funded by Office of Special Education and Rehabilitation Services

Project #G008303693

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TABLE OF CONTENTS

List of Tables.....IV
List of Figures..... V
Overview of Early Referral and Follow-up Project..... 1
Early Referral Services..... 4
Referral to the Early Referral Project..... 7
Initial Assessment..... 8
Referral to Services..... 9
Number of Children Referred and Monitored.....10
Timespans to Referral to Schools & Inititation of Services.....11
Cost of Services.....14
Developmental Interventions.....17
Frequency of Developmental Suggestions in Nursing Care Plans.....19
Nursing Intervention.....22
Follow-up.....22
Outcomes of Monitored Cases.....23
Continuation Efforts.....25
Satisfaction with Services.....26
School Satisfaction with Services.....26
Parent Satisfaction with Services.....29
Dissemination.....30
Guide for Referral and Case Coordination for Young Children in Hospital Settings.....30
Distribution of Resource Files.....31
Workshop Series.....31
Other Dissemination Efforts.....32
Publications.....33
Resource Center.....33
References.....35
Appendix A: Case Coordination Role & Sequence of Activities....36
Appendix B: Evaluation Criteria.....37
Appendix C: Definition of Classes of School District.....38
Appendix D: Workshop Brochure.....39

LIST OF TABLES

Table		Page
1.	Frequencies of Initial Diagnoses of Children Referred to the Early Referral and Follow-up Project	2
2.	Diagnostic Groupings, Gender, Mean Age at Time of Referral for Referred Group	3
3.	Diagnostic Groupings, Gender, Mean Age at Time of Referral for Monitored Group	4
4.	Frequencies and Percentage of Total Number of Children Referred or Monitored at Each Hospital	5
5.	Number of Children Referred to Each Type of School District in Nebraska	11
6.	Time Spans Between Referral to School and the Initiation of Services: St. Joseph Hospital as Illustrated in Quarters	13
7.	Time Spans Between Referral to School and the Initiation of Services: University of Nebraska Hospital	15
8.	Time Spans Between Initial Referral to School and Initiation of Services: St. Joseph Hospital	15
9.	Mean Time Cost for Assessment and Case Coordination by Disciplines for Referred and Monitored Children at Each Hospital	16
10.	Average Per Child Cost for Assessment in Case Coordination Services	17
11.	Frequency of Developmental Suggestions in Care Plans	20
12.	Frequency and Percentage of Care Plans with Developmental Suggestions for Project and Non-Project Children	21
13.	Frequency and Percentage of Care Plans with Developmental Suggestions for Each Time Period	22
14.	Outcomes of Monitored Cases	24

15. Mean and Standard Deviations of Mean Ages and MDI at Time of Initial Bayley for Monitored Cases Classified by Status at Project End.....25

16. Means and Standard Deviations of CA and MDI's at Initial and Final Testing for Monitored Cases Classified by Pattern of MDI Scores.....25

17. Disciplines of Workshop Participants.....32

LIST OF FIGURES

Figure | Page

1. Schematic Representation of Sequence of Early Referral Services..... 6

2. State Distribution of School Referrals.....12

3. Sample Developmental Plan.....18

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Early Referral and Follow-up Project

Overview

The primary purpose of the Early Referral and Follow-up Project was to facilitate developmental assessment of and initiation of intervention provided by the public schools of long-term or repeatedly hospitalized children birth to three years of age. Children who were suspected to be delayed or handicapped or who would be considered to be at-risk for developmental delays as a function of chronic health problems or unfavorable environmental conditions were eligible for services from this project. A major project activity was to assist in the referral and transition of children into appropriate services in their local school districts. This assistance was accomplished through (1) consultation to and collaboration with hospital staff including primary care nurses and child life care staff; (2) consultation to staff of local school districts regarding developmental assessment findings; and (3) follow-up services by project staff.

Setting Services were provided through the Early Referral Project at two Omaha, Nebraska hospital settings, University of Nebraska Hospital (UNH) from February 1984 through September 1986 and St. Joseph Hospital from January 1985 through September 1986. At UNH referrals were received from three locations, the Neonatal Intensive Care Unit, the Pediatric Intensive Care Unit and the Infant/Toddler Pediatric Unit. At St. Joseph Hospital children receiving services were also referred from three units, the Neonatal Intensive Care Unit, the general Pediatric unit and the High Risk Clinic.

Population Characteristics The Early Referral Project served 198 infants and toddlers aged birth to 3 years from February, 1984 through May, 1986. Those served were children who experienced long term or frequent hospitalizations and who were identified as developmentally disabled or at significant risk for developmental problems. The total number was comprised of 152 children referred from University of Nebraska Hospital and 46 from St. Joseph Hospital. The medical diagnoses of these children at the time of referral are presented in Table 1. Once referred, children were then placed into an immediate referral group if they met criteria for school eligibility or into a monitored group if they did not meet criteria of school eligibility. The medical diagnoses, gender, and mean age at time of entry into Early Referral for referred and monitored children are presented in Tables 2 and 3.

TABLE 1

FREQUENCIES OF INITIAL DIAGNOSES OF CHILDREN REFERRED TO THE EARLY REFERRAL AND FOLLOW-UP PROJECT

PRIMARY DIAGNOSIS	FREQUENCY AT UNMC	FREQUENCY AT ST. JOSEPH'S	FREQUENCY TOTAL	PERCENT OF TOTAL
Accidents	10	1	11	6
Asphyxia	4		4	2
Cardiac Defects	7		7	4
Developmental Delay	1	3	4	2
Fetal Alcohol Syndrome	6	1	7	4
Failure to Thrive	17	5	22	11
Genetic Syndromes	25	3	28	13
Gastrointestinal Prob.	6		6	3
Liver Dysfunction	4		4	2
Meningitis	3		3	1
Metabolic Disorder	1		1	1
Myelomeningocele	8		8	8
Neurologic Problems	22	8	30	15
Orthopedic Problems	4	1	5	3
Prematurity	8	14	22	11
Respiratory	16	2	18	9
Torch Complex	2		2	1
Unspecified	8	8	16	8
TOTAL	152	46	198	100

TABLE 2

DIAGNOSTIC GROUPINGS, GENDER, MEAN AGE AT TIME OF REFERRAL FOR REFERRED GROUPS

PRIMARY DIAGNOSIS	FREQUENCY	GENDER M	GENDER F	MEAN AGE* AT REFERRAL	RANGE IN* AGE AT TIME OF REFERRAL
Accidents	10	4	6	16	.2 - 39
Asphyxia	3	1	2	.35	.2 - 1
Cardiology	3	3	0	23	1 - 37
Developmental Delay	4	2	2	14	6 - 23
Fetal Alcohol	5	5	0	9	.2 - 17
Failure to Thrive	13	10	3	12	.3 - 37
Genetics	27	14	13	4	1 - 14
Gastrointestinal	1	1	0	14	-
Liver	4	1	3	13	9 - 22
Meningitis	2	1	1	8	7 - 9
Myelomeningocele	8	4	4	1	.2 - 1
Neurology	19	13	6	8	1 - 24
Orthopedic	5	5	0	13	1 - 40
Prematurity	9	6	3	3	1 - 8
Respiratory	9	3	6	6	1 - 26
TORCH	2	2	0	5	1 - 8
Unspecified	13	11	2	11	1 - 40
Total	137	86	51	9	.2 - 40

*Reported in Months

TABLE 3

DIAGNOSTIC GROUPINGS, GENDER, MEAN AGE AT TIME OF REFERRAL FOR MONITORED GROUP

PRIMARY DIAGNOSIS	FREQUENCY	GENDER M	GENDER F	MEAN AGE AT REFERRAL*	RANGE IN AGE AT TIME OF REFERRAL
Accidents	1	0	1	29	-
Asphyxia	1	1	0	1	-
Cardiac Defects	4	3	1	9	3 - 11
Fetal Alcohol Syndrome	2	0	2	.35	.2 - .35
Failure to Thrive	9	3	6	8	.2 - 25
Genetic Syndromes	1	1		4	-
Gastrointenstinal Problems	5	2	3	10	3 - 24
Meningitis	1	0	1	1	-
Metabolic Disorder	1	1	0	4	-
Neurologic Problems	11	7	4	11	3 - 26
Prematurity	13	4	9	5	1 - 19
Respiratory	9	6	3	7	.3 - 17
Unspecified	3	2	1	20	8 - 41
Totals	61	31	30	8	.2 - 41

*Reported in Months

Early Referral Services

In the following section the services provided to children in the Early Referral Project are reviewed. The temporal sequence of services provided as part of the Early Referral Project is presented in Figure 1. Once a child was referred and initial assessment done a decision was made to either refer the child for services, or, if the child did not appear to be eligible for school services then the decision was made to monitor the child's development and refer to school services when he or she became eligible for such services. With either initial outcome decision, to refer immediately or to monitor, some children received interim intervention services. All children received follow-up services. The frequencies and percentages of children referred immediately or monitored from each hospital are presented in Table 4. Prior to providing a description of each component in the sequence of services the role of case coordinator is described.

Case Coordination

The primary roles of the case coordinators were to accept referrals and to coordinate the services provided to individual children and their families. Case coordinators were responsible for collecting the initial information on the child, coordinating assessments, conducting case conferences, ensuring that necessary documentation was in the file, and making arrangements for follow-up. The case coordinators were responsible for tracking

TABLE 4

FREQUENCIES AND PERCENTAGE OF TOTAL NUMBER OF CHILDREN REFERRED OR MONITORED AT EACH HOSPITAL

SITE	REFERRED AND ACCEPTED BY SCHOOLS		REFFERED AND REJECTED BY SCHOOLS		ALREADY IN SCHOOL PROGRAM		MONITORED		PARENTS DECLINED PROJECT SERVICES		MOVED FROM 4 STATE REGION SERVED	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
UNMC	79*	52	2	1	12	8	47	32	10	6	2	1
ST. JOSEPH	19**	41	4	10	3	7	15	33	1	2	3	7

* Includes 20 children at UNH which were referred to Headstart programs or school districts outside of Nebraska.

** Includes 2 children at St. Joseph Hospital which were referred to Headstart programs or school districts outside of Nebraska.

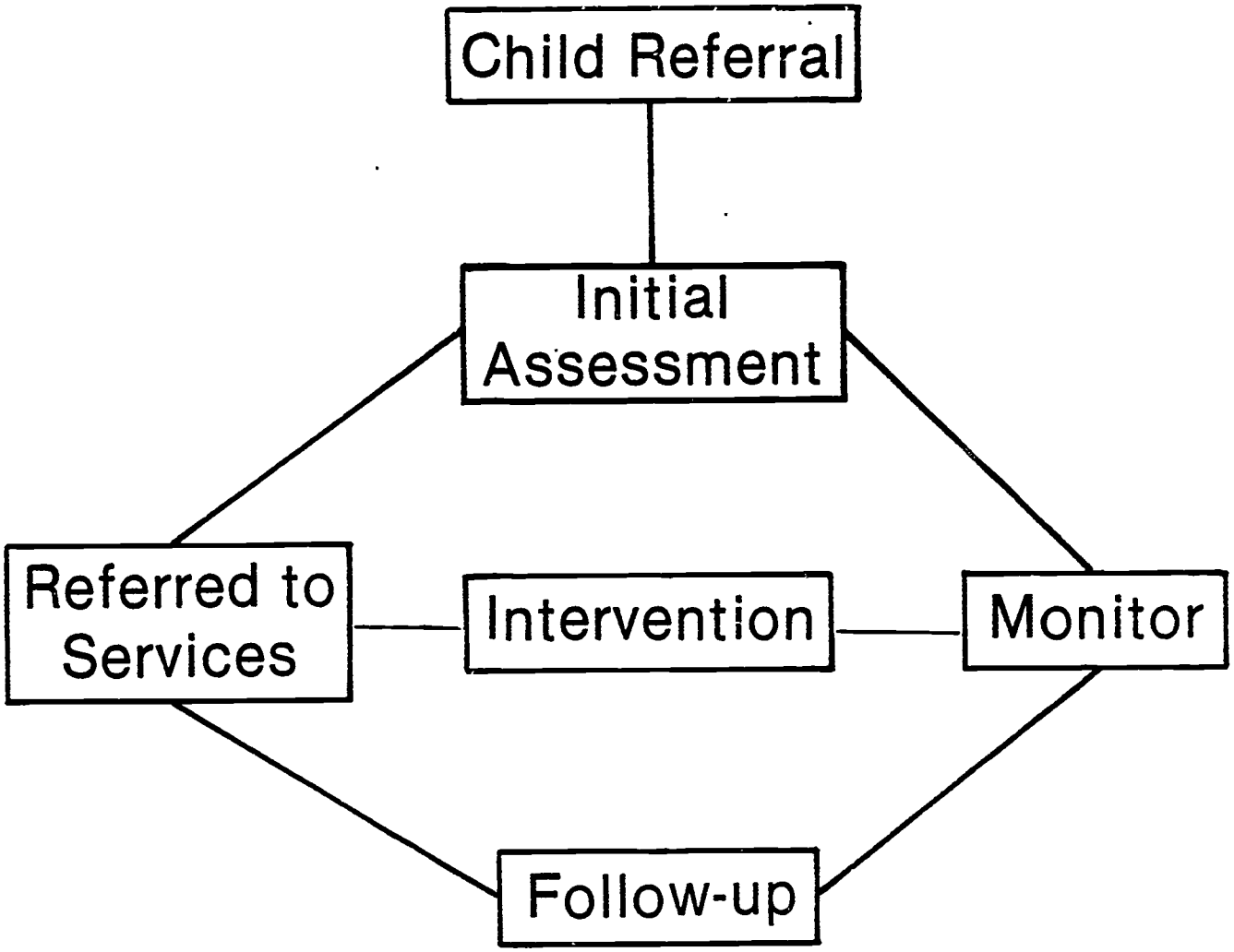


FIGURE 1. Schematic Representation of Sequence of Early Referral Services

each child through the Early Referral and other agency systems. The case coordinators monitored and advocated where necessary to see that the child's needs as identified by project team members were addressed and services were provided.

In both hospitals where the Early Referral Project was located, a nurse specialist and a parent/infant educator served as case coordinators. At University of Nebraska Hospital the nurse specialist was the case coordinator for the children in the Neonatal Intensive Care Unit. The parent/infant educator was the coordinator for the older children from the pediatric units. At St. Joseph Hospital the more medically fragile children were assigned to the nurse specialist and the parent/infant educator coordinated services for the children who were medically stable.

Initial guidelines were established regarding information to be obtained from parents and primary care staff for each child and criteria for referral to the Early Referral Project. A case coordinator packet was developed to describe the procedures for each phase in the service sequence. This packet included a flow chart of the process, as well as all the needed forms and letter shells for each case. A flow chart of this process is included in Appendix A.

Referral to the Early Referral Project

University Hospital. The Early Referral Project began accepting referrals at University Hospital in February of 1984. In the design of the project it had been anticipated that the attending physician would be the primary source of referral. However, it was found that those professionals with the most direct caretaking responsibility, primary care nurses, speciality service nurses and the child life coordinator, were more likely to set developmental needs as a priority and thus were more likely to initiate a referral to the project. A procedure of rounds in both UNH units was then initiated as the mechanism through which these primary care staff would meet with project staff to identify appropriate children for referral to this project. Initially these rounds were conducted on a twice monthly basis for the Pediatric and Neonatal Intensive Care Units. In the NICU the meeting kept the initial format for rounds, with the Medical Director of the NICU deciding upon whom to refer. Meetings were needed more frequently on the Pediatric Unit and consequently were scheduled weekly. This weekly referral meeting was accomplished by the case coordinator attending the Discharge Planning meeting that was already part of the unit procedure. Hospital staff included in the Discharge meeting were the child life coordinator, primary nursing staff, social worker, and the assistant unit director. Once children were identified through these procedures the attending physician for the individual child was contacted and his or her approval obtained prior to contacting the parents.

St. Joseph Hospital. At St. Joseph Hospital, the coordinator of the High Risk Pediatric Clinic, a nurse, served as the liaison between the hospital and the Early Referral Project staff. Children at St. Joseph Hospital were primarily identified through referral by the attending physician to the nurse liaison at St. Joseph Hospital who in turn notified the

appropriate case coordinator. Intake information was obtained by the St. Joseph staff when possible or by the Project case coordinator. Occasionally a referral was made by the social worker or the child life specialist, through a phone call to one of the case coordinators.

Initial Assessment

After receiving a physician approved referral the assigned case coordinator contacted one or both parents to explain the Project and to obtain written consent of participation. Usually at that time, the parent was also interviewed concerning family demographic information, health and developmental history of the child, the child's current status and problems, and the extent of existing community services provided to the family. A release of information was obtained by the coordinator to examine hospital medical records and other related medical reports pertinent to the child's status. Primary care nursing staff, attending physicians, and hospital therapists were also consulted for information in order to complete the data base on an individual child.

Assessment Procedures. Children who were transferred to, or directly admitted to general pediatric units were formally assessed to provide baseline developmental levels upon which to base intervention. An interdisciplinary team including a parent infant educator, maternal child health nurse specialist, physical and occupational therapists and speech pathologist provided inital and follow-up evaluations appropriate for individual child needs for the purpose of assessing development levels, determining eligiblity for school services, monitoring development and development of intervention suggestions.

Developmental assessments were completed using the Uzgiris-Hunt Sensorimotor Scales (Uzgiris and Hunt, 1975) and/or the Mental and Motor Scales of the Bayley Scales of Infant Development (Bayley, 1969). Physical, occupational and speech therapy evaluations were completed dependent upon the individual needs of the child. Criteria for evaluation by each discipline were developed and are included in Appendix B. Occasionally when infants and children at UNH were not referred until hospital discharge, it was not possible for assessments to be completed prior to the child going home. In these cases initial observations, probes and formal assessments were conducted at home or at the Meyer Children's Rehabilitation Institute on an outpatient basis. At St. Joseph Hospital the majority of evaluations occurred on an outpatient basis. The evaluation process concluded with staffings with primary care staff, and project staff and staff from other agencies involved with the child's care.

Assessment Procedures in NICU/PICU. The physical condition and the atypical experiential histories of children referred from the NICU necessitated a revision of the proposed assessment procedures. Project staff did not feel that the use of standardized assessment procedures such as the Bayley Scales of Infant Development or even the Brazelton Scales (Brazelton, 1984) were appropriate for use with these babies. Standardized testing was deferred until these children were at least four months of age.

Informal observations of these infants while still in the NICU settings were conducted with a philosophy of making as minimal an intrusion on unit routines as possible. Frequently, joint observations were made by the special education consultant and physical and occupational therapists with the primary care nurse. The infant's response patterns to daily care and treatments were noted. Short periods of probing by team members were sometimes used to assess auditory and visual processing behaviors, reflexive and motoric capacity, muscle tone, immediate concerns regarding potential deformities, and oral motor status. In older infants sensorimotor behaviors were assessed when feasible.

Infant responses were assessed with consideration of the infants state (Brazelton, 1984) and probing was terminated when there was evidence of loss of state regulation or physiologic disequilibrium such as changes in color, muscle tone, vital signs, oxygen saturation and/or behavioral signs that the infant was stressed. Infant capacity to regain state control was noted along with those environmental supports that seemed to facilitate more stable physiologic and behavioral functioning. The effects of social interactions and care-taking interventions on physiologic parameters and state organizations were among determinants in decisions regarding assessment procedures. If the infant showed evidence of physical stress in response to assessment procedures, especially physical handling, such procedures were deferred (Als and Gibes, 1984; Gorski et al, 1979; Gorski, 1984). With very sick infants, assessments were confined to observation and nursing staff input. When stability improved, more extensive probing was instituted to assist in the developmental intervention provided by staff at UNH and to provide baseline data for discharge planning. Among developmental priorities for assessment related to intervention were neuromotor concerns, management of deformity, and parent-infant interaction. Capacity for interaction was a concern especially for those infants with sensory problems, or those infants who responded to stimulus overload by withdrawal.

Referral to Services

After a child was evaluated and was determined to meet eligibility criteria for educational services, the case coordinator, with the parents permission, made a referral to the school district of residence. Contact was made with the Director of Special Education or the Superintendent of Schools. A release from the parents was obtained so that all reports could be sent directly to the schools to assist them in providing an appropriate educational program for the child. After a referral was made, the case coordinator was responsible for contacting the schools and the parents to find out when services were initiated and to provide assistance if they were not initiated.

In addition to referring children to their local schools for an educational program, referrals were made to other service agencies as appropriate. Some of these agencies were Head Start, Home Health Care Agencies, Nebraska Social Services, local Associations for Retarded Citizens, Community Offices of Retardation and financial assistance programs.

Project case coordinators remained in contact with families until all necessary school services were in place and in cases where it was feasible (family lived within 30 miles) to do so, interim intervention was offered by Project teachers and therapists until this occurred. When information was obtained through parents or other providers that services were not initiated as planned or were inadequate or inappropriate, the coordinators attempted to gather information concerning these problems and to explore options with parents and/or other professionals and agencies to facilitate problem correction. Problems were often in the areas of financial support, securing home nursing services or respite care services.

Number of Children Referred and Monitored

Of the 198 children referred, 52% of the University referrals and 41% of the St. Joseph Hospital referrals were immediately referred to their school district of residence following their referral to the Early Referral Project. Once referred a child could be accepted or not accepted by the school district. Of the 104 children who were initially referred only 6 were not accepted for services. A summary of the number of children who were referred and then accepted or not accepted or who were not initially referred was previously presented in Table 4 (see page 5). Of the 198 children referred to the Early Referral Project, 98 children received educational and/or support therapies, families of 6 children moved out of state prior to services being started, families of 11 children terminated services with the Early Referral Project, and 15 children had already been referred to services, 6 were not accepted for educational services and monitoring was continued and 62 were monitored by the Project. Fourteen children of the total referred group of 98 children died; seven died before referral occurred; four died after referral but before services were initiated and one died after services were initiated.

Referral to School Districts. School district referrals were made to a total of 46 different school districts in Nebraska, Iowa, Kansas, Minnesota and South Dakota. The largest number of children (76) were within Nebraska, 17 referred to school districts and agencies outside of Nebraska and 5 to Headstart Programs in Nebraska. The number of districts and frequencies of children according to class of Nebraska School Districts is presented in Table 5. Definitions of the classes can be found in Appendix C. The largest number of referrals to any one school district was 25 to the Omaha Public Schools which is also the largest district in the state. A total of six children were referred to schools and were subsequently determined by their school district to not meet eligibility criteria and as a result were not accepted for service. These children then continued to be monitored through the Project. The majority of these 6 cases which were found ineligible were due to a change in the interpretation of educationally relevant physical and occupational therapy.

TABLE 5

NUMBER OF CHILDREN REFERRED TO EACH TYPE OF SCHOOL DISTRICT IN NEBRASKA

Class of School District	Number of School Districts	Number of Children
1	9	8
2	2	2
3	27	39
5	1	25
Head Start Programs	1	5
TOTAL	40	79

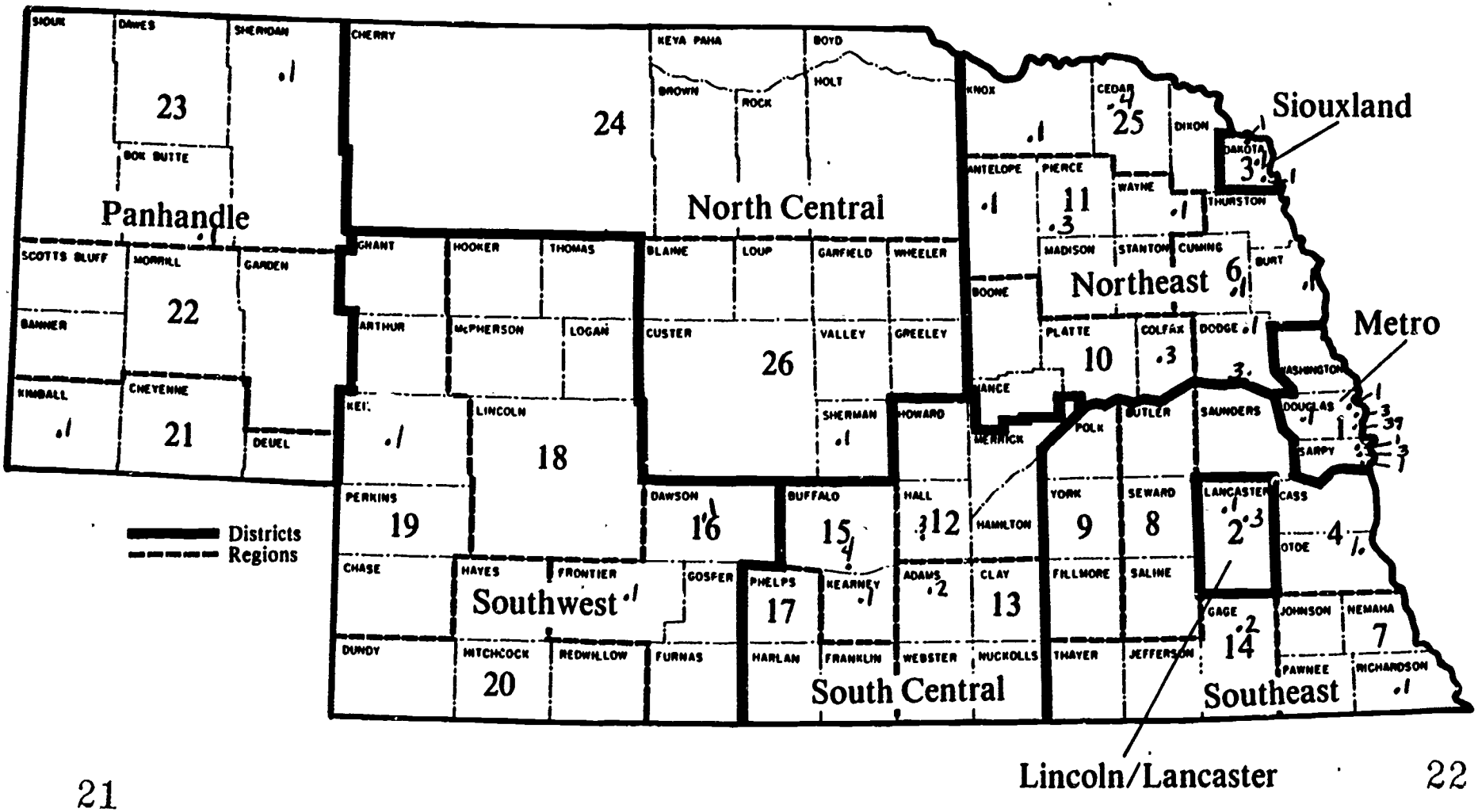
When the Early Referral Project was initiated in October 1983, physical and occupational therapy services were administered jointly through Services for Crippled Children (SCC) and the State Department of Education (NDE). As a result, eligibility for PT & OT services was decided at the state level rather than through each individual school district. In July 1985 SCC administration of PT & OT services was assigned to the local school districts. With this procedure, eligiblity was a decision of the local district and in some cases the interpretation of what constituted educationally relevant PT and OT was more restrictive than had been the case under the previous procedure. One district's interpretation of their requirement to provide PT and OT for disabled children was that it was the school districts responsibility only if the child also showed cognitive delay and therefore needed a teacher or that the child had a medical diagnosis of a severe degree of a condition which typically required therapy. Several children who were previously accepted for PT & OT services were then refused services because educational services were not recommended or their medical diagnosis of a condition such as cerebral palsy was mild in degree. Children served by the Early Referral Project came from locations rural, small town and city throughout the state. In Figure 2, a map of Nebraska, the locations and numbers of referred children from each location are indicated.

Timespans to Referral to Schools and Initiation of Services

Following referral to the project and determination of the child's eligibility for school services two time spans were documented for those children referred to school districts in Nebraska. These periods were the length of time from referral to the Early Referral Project to referral to a child's school district and then the length of time it took the schools to initiate services.

Variations in Length of Time According to Times of Year. Several impressions regarding potential variability in these time periods were considered. One impression of project staff was that the length of time from referral to the school district and the initiations of school services would vary depending upon the time of year and school district policy. In Table 6 data regarding

NEBRASKA DISTRICTS/REGIONS



21

22

Figure 2. State Distribution of School Referrals

. indicates location.
# indicates # of children at site.

the average time span from referral to the school district and initiation of school services is presented for three month periods for children referred from St. Joseph Hospital to Nebraska school districts. Staff impression was that children who were referred in from March through June would experience longer waits for initiation of services especially if the district policy was to not start new children after April first, which was the policy for the Class 5 School District. As can be seen in the information in Table 6 such a trend was not evident. There does appear to be a slightly longer time period for these children referred in the December through February quarter. No statistical analyses were done as it was felt that the small numbers of children precluded meaningful interpretation of findings.

TABLE 6

TIME SPANS BETWEEN REFERRAL TO SCHOOL AND THE INITIATION OF SERVICES: ST. JOSEPH HOSPITAL AS ILLUSTRATED IN QUARTERS

CALENDAR QUARTER	N	1 RANGE	2 RANGE
Mar-May Class 5	2	23 9-36	95 9-181
Jun-Aug Class 5	4	85 59-117	118 87-179
Sept-Nov Class 5	2	120 34-206	70 50-90
Dec-Feb Class 5	3	36 6-89	182 42-280
Jun-Aug** Class 3	1	180 -	31 -
Sept-Nov** Class 3	3	155 98-183	15 15*

**Denotes monitored cases.

*All three cases took 15 days.

1 - Mean Days from Referral to Project to Referral to Schools

2 - Mean Days from Referral to School to Initiation of Services

Timespan for Monitored and Referred Children at Each Hospital. Given the fact that time of year did not appear to be a significant factor in the

length of time from referral to the school district to initiation of services, a classification by time of each was felt to not be necessary. Subsequently both time intervals were looked at for each hospital site and for referred versus monitored children. Several trends were noted in this data regarding the mean time spans. This information regarding University Hospital is presented in Table 7 and the information regarding St. Joseph Hospital is presented in Table 8. In each of these tables the information is presented separately for referred and monitored children and within those subgroups separately according to class of school district.

Hospital Differences. One trend noted was that it took longer for Early Referral Project staff at St. Joseph Hospital to complete the initial referral to schools than was the case at University of Nebraska Hospital (UNH). Possible factors which may account for this difference include the fact that at St. Joseph Hospital, evaluations were done following discharge, rather than during hospitalization, which was the typical procedure at UNH. This procedure delayed the initial process of determining eligibility. A second factor is the point that a higher number of referrals at St. Joseph Hospital were children from families whose income level was poverty or near poverty level and in such cases it frequently took longer to contact and set up initial evaluations due to factors such as the inability to contact people by phone and the greater mobility in terms of place of residence.

Time Span for Monitored Children. It also appears that the inititation of services by the school district occurred more quickly for monitored children once they became eligible for services. The procedures for referral to schools did not differ from the initially referred group. An impression of staff that could account for the difference is that the families in the monitored group may have had more time to adjust to the fact that their child had problems and as a result once these children were eligible the parents more readily completed the referral process.

Class of School District. The data suggests that follow-up referral to the Class 5 District tends to take longer for the initiation of services. The Omaha Public Schools (OPS) referral process requires that the family meet at the school with the intake team and then complete the referral forms, including a medical information form, prior to services being initiated. A number of the Early Referral Project referrals to OPS were from poorer families and in a number of these cases the families previously mentioned mobility made it more difficult to follow through with these procedures.

Cost of Services

Project staff filled out and submitted weekly time reports of time spent in direct service and support activities. Staff reported time reports in 15 minute units from the Spring of 1984 through June of 1986. Travel time was included as a reportable category but staff tended to use it only for travel away from the Medical Center and did not include time walking from the MCRI or HBM buildings to the hospital unit, generally a 10 minute time expenditure each way. For staff who provided support to St. Joseph Hospital travel to that hospital was reported.

TABLE 7

TIME SPANS BETWEEN INITIAL REFERRAL TO SCHOOL AND THE INITIATION OF SERVICES: UNIVERSITY OF NEBRASKA HOSPITAL

SCHOOL DISTRICT CLASS	N	MEAN DAYS FROM REFERRAL TO PROJECT TO REFERRAL TO SCHOOLS	RANGE	MEAN DAYS FROM REFERRAL TO SCHOOL TO INITIATION OF SERVICES	RANGE
Initially Referred					
1	7	44	1 - 80	63	3 -205
2	1	39	-	7	-
3	26	38	1 -180	43	5 -202
5	9	34	5 - 76	155	32 -365
Initially Monitored					
1	1	23	-	38	-
2	1	205	-	171	-
3	9	201	87-480	21	4 - 90
5	5	157	43-378	100	30 - 212

TABLE 8

TIME SPANS BETWEEN INITIAL REFERRAL TO SCHOOL AND THE INITIATION OF SERVICES: ST. JOSEPH HOSPITAL

SCHOOL DISTRICT CLASS	N	MEAN DAYS FROM REFERRAL TO PROJECT TO REFERRAL TO SCHOOLS	RANGE	MEAN DAYS FROM REFERRAL TO SCHOOL TO INITIATION OF SERVICES	RANGE
Initially Referred					
5	11	69	9-206	124	9-28
Initially Monitored					
3	4	161	98-183	19	15-31

In order to get an approximate estimate of direct service time random samples of 10 cases each from monitored and referred groups for each hospital were drawn for a total of 40 cases. Working from those case names all staff time reports were reviewed to obtain any reports of time for each of the selected cases. Service time was reported in the categories of intake, evaluations, staffings and interpretations, continuing case coordination, reporting and direct intervention with child and a parent. For this analysis, intervention time was separated from all other activities in an effort to obtain an estimate of time costs of the assessment and referrall process. The average time costs in hours per child for each discipline in each of the four groups is presented in Table 9. The time costs for education and nursing are considerable higher as the persons in these roles also served as case managers. The number of cases in the group for which these persons served as case coordinator is indicated in this table, and the means for these roles were obtained by dividing the total hours reported for children in that group by the number of cases within the group for whom that person served as case manager. The means for the other disciplines and the group total mean were calculated by dividing the hours reported for that discipline by 10.

TABLE 9

MEAN TIME COSTS FOR ASSESSMENT AND CASE COORDINATION (CC)
BY DISCIPLINE FOR REFERRED AND MONITORED CHILDREN
AT EACH HOSPITAL

REFERRED	EDUCATION	NO CASES CC.*	NURSING	NO CASES CC.*	SPEECH	PT	OT	MEAN FOR TOTAL
UNH	12.4	(8)	9	(2)	1.3	2.1	1.7	16.8
SJH	11.8	(5)	5.8	(5)	0	1.3	0	10.1
MONITORED								
UNH	7.1	(7)	6.7	(3)	.6	.8	.4	8.8
SJH	7.1	(8)	10	(2)	0	.2	0	7.7

*Number of cases which the case coordinator of that discipline carried.

Several points regarding these results seem noteworthy. The overall time costs for referred children are greater than for monitored children and the time costs were greater at University Hospital than at St. Joseph Hospital. In 3 of 4 possible comparisons, the time costs for the educator were greater than those for the nurse specialist. Possible explanations for these differences are as follow. The project had greater access to children at UNH due to proximity and greater acceptance of on-site diagnostic work at

UNH. It is possible that more time was spent with immediately referred than monitored children as the immediately referred children were more likely to have presenting problems which warranted their being looked at by a physical, occupational or speech therapist. Finally the educators were more likely to do assessments on children for whom the nurse specialist was case coordinator than was the nurse likely to see the educators' children.

The assessment and case coordination costs of the Early Referral Project Services were analyzed as it was felt that those services were more likely to be of interest to possible replication sites. Cost in dollars was calculated by multiplying the hourly wage for each staff member by the number of service hours that staff member reported. The resulting figures probably err on the side of an underestimation as these figures do not include any overhead costs, leave time for staff, education time for staff to maintain their expertise and reported time probably also errs on the side of underreporting. The average cost per child in each of the four groups is presented in Table 10.

TABLE 10

AVERAGE PER CHILD COST FOR ASSESSMENT AND CASE COORDINATION SERVICES

GROUP	AVERAGE COST IN DOLLARS
UNH REFERRED	179.41
ST. JOSEPH REFERRED	100.45
UNH MONITORED	95.98
ST. JOSEPH MONITORED	77.17

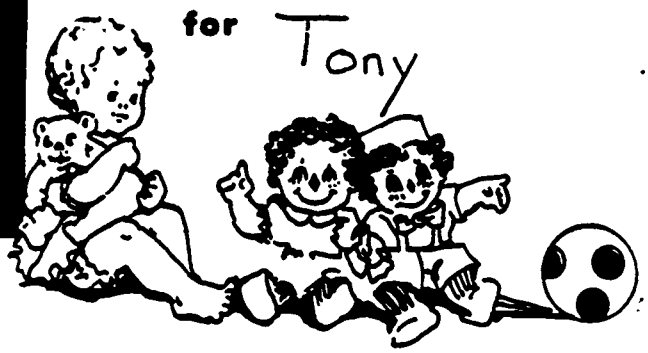
Developmental Interventions

On the Pediatric Unit at UNH, the Early Referral Project established and implemented a procedure for providing developmental intervention, educational recommendations and consultation to the child's primary care team, for incorporation into the child's care plan while hospitalized. To accomplish these objectives a format for a Developmental Plan was designed and left at the child's bedside. Instructions and explanations regarding this plan, which was written by the parent infant educator with input from other team members as appropriate, was provided to the parent and primary care staff. A sample Developmental Plan is presented in Figure 3. Upon repeated hospitalizations this consultation was again provided. The NICU's at UNH and St. Joseph Hospital had their own child development consultants whose functions were to provide developmental recommendations for primary care staff and for parents. Consequently, developmental intervention by Early Referral staff was not provided within the NICU at either hospital.

An unanticipated need for intervention efforts from Early Referral staff

Figure 3: Sample Developmental Plan

A Development Plan for Tony



- Provide Tony with a variety of different materials 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 Constructive 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 w/ Tony - "peek-a-boo, hide-seek, pat-a-cake". Watch how he tells you to play the game again. Tony will begin to recognize familiar games & 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 Children's Rehabilitation Institute
University of Nebraska Medical Center

Early Referral & Follow-up Project
Child Life Program

outside of the hospital setting occurred due to the admission policy of Omaha Public Schools (OPS) and several other Omaha area schools. OPS for example had a new admissions cutoff as of April first through August of each year. Consequently no children identified after mid March received educational intervention prior to the following August. During the first year of the project, however, such children were able to receive PT and/or OT during this period if those services were prescribed through the Medically Handicapped Children's Program or as it had been known in Nebraska, SCC. It was our understanding that the policy of the April 1 cut off was initiated because fewer teachers were available during the summer months. For children who were referred at those times, the parent infant educators, and therapists from the Early Referral Project provided periodic intervention to those families within close proximity to the Omaha area until school services were initiated.

Frequency of Developmental Suggestions in Nursing Care Plans

One of the projected impacts of the Early Referral Project was the expansion of developmental intervention in the hospital setting. In an effort to assess this, impact care plans of long term hospitalized children were examined to determine the frequency of identification of developmental issues as part of nursing diagnoses. Nursing care plans are required to be written on each child admitted to 7 North South, a Pediatric unit located in the University of Nebraska Hospital. These care plans are typically written by the primary care nurse working with the child and his/her family. The census record of 7 North South at University of Nebraska Hospital was examined and those client names extracted who had been hosptialized for 7 days or longer during one of four month long time periods: March 1984, September 1984, March 1985, September 1985. All children were considered who were patients with a 7 day or longer stay at any time during one of those four time periods.

The care plans of these children were then located through medical records or through a file on 7 North South containing care plans of discharged children. These care plans were then analyzed for use of developmental nursing diagnoses. The majority of these care plans were readily located. In Table 11 the number of care plans located with the number of developmental suggestions identified in the care plans are presented.

In reviewing the charts a nurse specialist made the determination as to whether the child was developmentally disabled or not after reviewing the care plan and identifying any developmental activities. After making the determination regarding these two points she then compared the census list to the Early Referral Project case list in order to identify project children. In Table 11 where frequencies of developmental suggestions and care plans are presented the project children are duplicated within the census count.

In an effort to determine whether children with developmental disabilities were more likely to have developmental issues addressed in their care plans the number of each type of case (project children; developmentally

TABLE 11
FREQUENCY OF DEVELOPMENTAL SUGGESTIONS IN CARE PLANS
TIME PERIODS

FREQUENCY OF SUGGESTIONS	MARCH 84			SEPT 84			MARCH 85			SEPT 85		
	PROJECT CHILDREN	CENSUS DD*	CENSUS NDD*	PROJECT CHILDREN	CENSUS DD*	CENSUS NDD*	PROJECT CHILDREN	CENSUS DD*	CENSUS NDD*	PROJECT CHILDREN	CENSUS DD*	CENSUS NDD*
NONE	4	9	11	5	6	9	1	5	2	2	10	16
1	2	4	6	3	0	5	0	5	7	0	2	2
2-4	0	2	2	0	1	1	0	1	0	2	2	0
No care plan	2	2	10	1	1	4	0	0	1	1	1	1
Total	8	17	29	9	8	19	1	11	10	5	15	19
Percent of Total with Developmental Issues Addressed	25%	35%	28%	33%	12%	32%	0%	55%	70%	40%	27%	10%

*DD-Developmentally Disabled
*NDD-Non-Developmentally Disabled

disabled and non-developmentally disabled) were summed across the four time periods. The resulting percentages are presented in Table 12. By examination it is apparent that the percentages are not different.

TABLE 12

FREQUENCY AND PERCENTAGE OF CARE PLANS (CP) WITH DEVELOPMENTAL ACTIVITIES (DEV.ACT.) FOR PROJECT AND NON-PROJECT CHILDREN

Group	Total Census	No. of CP Plans with Dev. Act.	Percent with Developmental Activities
1. Project Children*	23	7	30
2. Developmental Disabled	51	17	33
3. Not Developmentally Disabled	77	23	30

*Duplicated in groups 2 and 3

In a similar manner the time periods were examined to determine whether developmental suggestions were more likely to be written during different time periods. The resulting proportions are presented in Table 13. Also presented is the number of project children who were hospitalized during each of the identified months. One time period March 1985 appears to have had a substantially greater percentage of care plans with developmental suggestions written for the patients. While it is not possible to draw any conclusions regarding this variation it may be noteworthy that the time period was the one of the four with the lowest overall census of long term (over 7 days) patients and only one Early Referral Project child. An hypothesis that would be consistent with these findings is that more time may be available for refinement of care plans when the census of long term patients is lower.

Of greatest significance for project staff was the overall low percentage of care plans in which developmental suggestions were addressed. This finding suggested to us the need for addressing incorporation of developmental suggestions into daily care routines with a primary care nursing staff. One note of caution regarding interpretation of the lack of developmental suggestions in care plans is in order. That caution is that many of the techniques that we would want to see utilized may not be identified as specific activities on care plans but rather would be a style incorporated into other procedures. For example, using gestural communication along with a verbal description when carrying out a procedure with a child for whom a

TABLE 13

FREQUENCY AND PERCENTAGE OF CARE PLANS WITH DEVELOPMENTAL SUGGESTIONS FOR EACH TIME PERIOD

	Total Census	No. of Project Children	No. of Care Plans with developmental Activities	Percent with Developmental Activities
March 84	46	8	14	30
Sept. 84	27	9	7	26
March 85	21	1	13	62
Sept. 85	34	5	6	18

simultaneous communication system has been recommended. An examination of care plans was a fairly inexpensive means for establishing whether care plans had developmental activities documented within them. Within the context of Project Continuity (see page 25 regarding continuation efforts) other methods will be utilized to access the impact of the new project upon actual care routines.

Nursing Interventions

Another objective of the Early Referral Project was to establish and implement a procedure for communication of an infant's health care and developmental needs to the home district education team, who are responsible for implementation of a given infant's educational program. The Maternal Child Health Nurse Specialist provided consultation to parents, other project staff members and school personnel upon request regarding health care needs and related intervention issues. When a child's home care plan included services of multiple care providers, the project nurse assumed responsibility for communicating information among those people and for clarifying and interpreting theraputic goals and strategies of intervention to family members. Interpretations of medical considerations, such as the effects of medications on feeding and interactive behavior with parents and intervention staff were provided. The nurses in the role of case coordinators frequently assisted parents with psychological support while they worked through steps of adjustment to diagnosis of chronic illness or disability in their infants or toddlers.

Follow-Up

Once eligible children were referred, parent interviews, records of

staff communication, and current medical record information were used to update the data base on the child's status. Running notes describing a child's behavior during visits and informal sessions were written in triplicate and shared among team members. Staffing conferences among those team members were used to formulate comprehensive data bases and intervention objectives. In addition to the reports of formal assessments done by various Project members, summary status reports were written at 3 to 6 month intervals and sent to parents, doctors, schools and the referring hospital.

In some instances, the Project continued to provide selected assessments (e.g., speech and language evaluations or Bayley Scale assessments) upon request of the schools or parents after the child was receiving services through his local school system. In some cases the coordinators continued to facilitate communication among representatives of the multiple agencies serving those families even after school services were in place.

Outcomes of Monitored Cases

The parents of children, who at the time of initial assessment did not qualify for services from their local school district, were offered monitoring services. In some cases this service consisted of follow-up assessment only and in other cases children received intervention visits as well. The amount of service was offered based upon team recommendations, availability of staff time, and distance from Omaha.

A total of 62 cases were monitored in an effort to determine with what frequency children who initially were found to be at risk eventually became eligible for school district services. Approximately one-third of these cases became eligible for referral during this period. Another third could not be found upon follow-up or parents declined further monitoring. Of the remaining third, seven continued to be eligible for monitoring, in three cases parents declined referral, two children died and several children are followed by another agency or present another type of exception to this classification. The dispositions of monitored cases is presented in Table 14.

Initial standard score data was available for only some of the children. It generally was not available on the cases lost to further follow-up, the majority of whom came from St. Joseph Hospital. The means and standard deviations of the initial standard scores were calculated to determine whether initial scores would differentiate between those cases who changed in status from monitored to referred and those who remained in the monitored status. Three cases who were eligible for referral but whose parents declined referral were assigned to the monitored to referred group. Means and standard deviations for age at time of referral and initial standard scores or MDI's for monitored cases classified by status at project end are presented in Table 15.

It should be noted that 49 of the 62 monitored children were under 12 months of age at the time of initial referral. Of the 13 over 12 month old initially monitored cases, four were in the monitored to referred group, three were lost, parents of one child declined referral, parents of two

TABLE 14

OUTCOMES OF MONITORED CASES

DISPOSITION OF CASE	NO. CASES
Continue to Monitor	8
Monitor to Refer	20
Lost	13
Wanted to Refer, Parent Refusal	4
Parent Felt no Need for Monitoring	11
Followed by Other Agency	4
Died	2
TOTAL	62

children declined further follow-up and one child is followed by another agency.

Bayley Performance Patterns. While our initial plan had been to monitor all children's performance such repeated assessments were feasible only with about 25 percent of the monitored cases. These 15 cases were classified according to the pattern of Bayley scores, increasing or decreasing. Means and standard deviations for chronological age and MDI's at the time of initial and follow-up scores were calculated for each of these patterns. These means and standard scores are presented in Table 16. The chronological ages do not seem to be different at either point. For the Increasing Pattern Group the mean MDI changed from borderline to average and for the Decreasing Pattern Group the mean changed from within average range to borderline. As we continue to monitor children with funds from the Nebraska Department of Education we will look for relationships between diagnosis, and at risk condition for predictors of performance changes. We do not feel that the current data warrants anything more than this descriptive analysis.

TABLE 15

MEAN AND STANDARD DEVIATIONS OF MEAN AGES AND MDI AT TIME OF INITIAL BAYLEY FOR MONITORED CASES CLASSIFIED BY STATUS AT PROJECT END

	NO. CASES	CASES WITH MDI	CA MEAN	CA SD	MDI MEAN	MDI SD
Monitored to Referred	20	17	9.88	5.76	89.5	10.79
Continue to Monitor	8	8	7.75	2.07	94.63	9.75
Parents Refused Referral	4	3	10.00	2.94	80.30	20.40
Parent Declined Further Monitor	10	5	9.00	6.60	103.40	14.00
Could Not Locate	13	3	11.25	6.30	116.00	18.70
BTNI Monitor*	4	1	13.00	--	96.00	--
Died	2	--	--	--	--	--

*Boys Town National Institute (BTNI) is affiliated with St. Joseph Hospital and had a project to monitor children at high risk for hearing disorder.

TABLE 16

MEANS AND STANDARD DEVIATIONS OF CA AND MDI'S AT INITIAL AND FINAL TESTING FOR MONITORED CASES CLASSIFIED BY PATTERN OF MDI SCORES

MDI PATTERN	N	CA MEAN	CA SD	MDI MEAN	MDI SD	CA MEAN	CA SD	MDI MEAN	MDI SD	DIFF
Increase	6	5.17	2.03	81.66	23.78	15.17	8.40	102.33	10.21	20.67
Decrease	9	7.55	2.95	98.33	19.24	17.33	3.89	75.55	12.88	22.78

Continuation Efforts

University of Nebraska Hospital. During the third year of the project an emphasis was placed upon locating funds and mechanisms to continue services at the end of HCEEP funding. Three different funding sources have been identified to date. Hospital staff at UNH (child life coordinator and social worker) have been identified and provided materials that can assist families in referral of children clearly eligible for educational services. If diagnostic evaluations on these children are necessary during hospitaliza-

tion, consultation is available from MCRI staff. Payment for such evaluations could be assumed by the school district if contacted initially or such costs may be eligible for third party payment. The State Department of Education is interested in monitoring children who are at risk due to medical and environmental factors and have allocated money to MCRI to monitor this population. Early Referral staff identified a need for a more intensive program for the frequently or long term hospitalized infant that would provide continuity of services from the hospital to educational setting. HCEEP funding was awarded beginning October 1986 to develop a demonstration project to meet these children's needs. This project is called Project Continuity.

St. Joseph Hospital. At St. Joseph Hospital, all the children in the High Risk Clinic will be followed by one physician, who along with the nursing staff, are aware of the referral process and will make the appropriate school referrals. In the Neonatal Intensive Care Unit they will be going to primary nursing and the nurses will be made aware of the referral procedure. Most of the children on the Pediatrics floor will later be followed in the High Risk Clinic but it is yet to be determined who will be responsible from Pediatrics to ensure that children are referred for services.

Satisfaction with Services

School Satisfaction with Services

At this time a survey of school districts was initiated during the fall of 1985. Children in the Early Referral and Follow-up Project had been referred to 27 school districts in the state of Nebraska. The project services were assessed by school district personnel during an evaluation survey conducted during November, 1985 through January, 1986. The 27 school districts were invited by mail in early November to consider questions in six topic areas and to identify relevant personnel and appropriate times and phone numbers for an evaluation interview. School districts were given lists with the names of children referred to them by the Early Referral Project so that knowledgeable respondents could be identified. Telephone interviews on the topic questions were conducted during the following two months as responses were received. The paragraphs below summarize the results of interviews conducted with 26 of the 27 districts who responded to the written invitation. Interviews were conducted by project assistants trained by the evaluator. Because district/s had the evaluation questions well in advance of the interview and many of these were factual (i.e., from what sources do you usually obtain medical information for serving the medically involved or medically fragile child?, etc.) and responses were written out as heard, it was hoped that the use of internal staff would not bias the results.

Respondents included two superintendents, fourteen special education directors, three principals, three speech pathologists, and four teachers (N=26). Topic areas included questions concerned with (1) receipt and use of the project evaluation reports, (2) follow-up evaluation and consultation services, (3) sources and utility of medical information, (4) facilitation of

service referral and parental compliance, (5) quality of Early Referral Project services, and (6) budget impact.

Receipt and Use of Early Referral Project Reports. Almost all school districts filed and notified potential users by memo of the receipt of the project evaluation reports (N=24). About two-thirds of them sent the reports directly to the service deliverer in the appropriate discipline (N=17) and about one-third to the special education director (N=8). Reports were less frequently sent to other administrators such as principals (N=2) or teachers (N=4). Thus, while all potential users could know of and have access to reports, only those directly providing special services or responsible for supervising delivery of such services were actually sent the report, a finding consistent with the way reports were used by most school districts. Early Referral Project evaluation reports were used primarily as evidence of a child's meeting qualifying criteria for program admission (N=24), less frequently, for example, as a source of diagnosis (N=5) or alert to medical needs (N=4).

Follow-up Evaluation and Consultation Services. Somewhat less than half of the respondants were aware of the possiblity for free follow-up services by the Early Referral Project (N=12). Of these, six had used the project services for follow-up evaluations/consultations. Thus, follow-up services were used by less than a fourth of the school districts although about half (N=14) now said that they might use the Early Referral Project follow-up services in the future as needed.

Sources and Utility of Medical Information. The respondents identified physicians (N=20) as the most frequently used initial source of medical information for serving the medically involved or fragile child, parents (N=14), hospital (N=8) and Early Referral Project (N=6) as somewhat less but still frequently used sources. The large majority report the information received as useful (N=18) and adequate (N=19) and that they now understand the child's medical diagnosis and any therapeutic equipment and medical procedures needed (N=21) and the child's medications and their effects (N=19), needing no additional medical information on an Early Referral Project child at the time of the interview (N=18). However, two-thirds of the respondents would have liked medical information to have been included with the original Early Referral Project evaluation report (N=18) and would still find medication information useful (N=18). They report that contemporary medical information concerning changes in the child's condition most frequently comes from parents (N=23) and less frequently from physicians (N=11).

Facilitation of Service Referral and Parental Compliance. Almost all respondents felt that project contact with the child's family and explanation to them of public school responsibility in providing educational services to handicapped children facilitated enrollment in school programs and getting IEP and actual services provided (N=23). About two-thirds of school district personnel felt that the project facilitated school and/or Services for Crippled Children referral (N=18), that it was helpful to have SCC referral in place (N=17) and that Early Referral Project facilitated parental compliance with school requests for SCC (N=13), enrollment (N=16), IEP's (N=16) and

other services (N=16). Ten of the respondents felt that services were provided more quickly as a result of Early Referral Project referral (N=10).

Quality of Early Referral Project Services. The project evaluation reports were described as understandable and useful to administrators and/or teachers, and sensitive to medical issues (N=24), as well as timely (N=22). Most respondents said that the project helped schools establish the range of services needed and coordinate services among disciplines (N=16) although one respondent disagreed (N=1). Overall, the project services were described as good in quality by almost all respondents (N=23). None described services as poor. Those who used follow-up services reported that they met the needs projected and were provided in a timely manner (N=6).

Budget Impact. Almost all school districts reported that the project had no impact on their Early Childhood Program budget (N=21), although two respondents felt that the budget increased (N=2), perhaps because of Early Referral Project referrals increasing enrollment.

Summary. The evaluation of Early Referral and Follow-up Project services by school districts to whom the project referred children established that the project evaluation reports were instrumental in qualifying children for services, facilitated service delivery by identifying the range of services required and providing baseline information to practitioners, and facilitated parental compliance with school and SCC enrollment requirements, often resulting in more timely delivery of services than otherwise possible. The evaluation reports were described as understandable, useful, and timely.

Follow-up services were infrequently used by school districts although users evaluated such services positively. This is in part because half of the report recipients were unaware of the availability of such services. However, when so informed, only about half of the respondents thought they might have a future need for these free consultation or re-evaluation services. Thus, one can project that considerably fewer than half of those who are aware of such services will actually request them.

School districts reported that their most frequent source of medical information about medically involved/fragile handicapped children is initially the child's physician and later on, the child's parents. They report understanding the child's diagnosis, therapeutic equipment and medications at this time but would have appreciated receiving medical information with the initial reports. They also report that the project generally had no budget impact on their Early Childhood Program, although two districts reported an increase in budget, perhaps because of increased enrollment.

In conclusion, school districts perceive the Early Referral Project as providing useful, timely, referral evaluations of high quality, would appreciate medical information being included with the referral, but are less interested in using follow-up services. The Early Referral Project was seen as facilitating appropriate service delivery, often in a more timely manner, and in improving parental compliance.

Parent Satisfaction with Services. A survey of randomly chosen parents whose children were referred to the Early Referral and Follow-up Project was initiated during the fall of 1986. The surveys were conducted through telephone interviews. Of the 51 possible contacts, 21 were actually contacted, 11 were parents whose children were referred by the project for school services and 10 were parents whose children were monitored by Early Referral Project and not referred. The remaining parents were not contacted because of one of the following reasons: the child died or was now in foster care (N=7), the child was not hospitalized or was already receiving services at time of referral (N=7), the parents could not be located (N=9) or the parents were not home during repeated phone calls (N=7). The paragraphs below summarize the results of the interviews conducted with the parents. Respondents included 3 fathers, 18 mothers, and 1 grandmother. The grandmother does not remember any contact with Early Referral Project staff and therefore was not included in the interpretations that follow. Topic areas included questions concerned with (1) the referral process initiated while the child was hospitalized, (2) the quality of the evaluations performed, (3) developmental/educational services presented being received.

Referral Process. Nine of the eleven children referred for services are presently receiving services from their respective school districts. The remaining two are no longer being served: one family decided against it and the other child no longer qualifies for services. The majority of these parents (N=8) were informed that their children were eligible for free services from the public schools through the Early Referral staff. The others either knew about services prior to contact with Early Referral Project or through their pediatricians. Initial contact with both, referred and monitored children, occurred when the children were hospitalized. Parents of the referred group of children all felt that the information about school services was very useful and agreed that it was better to learn about all the services at the time of hospitalization. Two parents thought that the information was a bit overwhelming but were glad to know it because it gave them encouragement to face the future. All parents thought referral was appropriate for their children. The majority felt that it was necessary either because of documented developmental delays, known syndromes, or uncertainty about the future.

Quality of Evaluations. Overall, parents of both monitored and referred children felt that the results of the evaluations were explained to them in an understandable manner (N=17). However, two parents felt that the Early Referral staff used too many "big" words that confused them. Several parents indicated that more medical information concerning their child would have been useful (Monitored N=5; Referred N=4), but the majority felt that they had more than enough information. The majority of parents indicated that they had sufficient information concerning school services (N=12). However, 6 parents (Monitored N=3; Referred N=3) indicated that they could have used more information. In general, parents of both groups, were satisfied with Early Referral Project services. A couple of parents suggested that it would have been more useful if Early Referral Project staff had contacted them again about one month after initial contact. This would have given them time to "digest" some of the information more fully.

Developmental/Educational Services. Only two of the 21 families in the survey presently receive services from Early Referral Project staff. These two families are satisfied with the services. The services provided helped parents learn how to work with their children and what they should expect from their children.

Summary. The evaluation of Early Referral and Follow-up Project services by parents of referred and monitored children demonstrated that parents were informed by Early Referral staff of free services available to their children from the public schools. Parents reported that this information was sufficient and useful, necessary to them, and appropriately shared at the time of their child's hospitalization. The majority of parents felt that the results of Early Referral evaluations of their children were presented clearly. A small minority would have appreciated more medical and school service information and an opportunity for follow-up discussions with Early Referral staff. In general there was strong satisfaction with Early Referral evaluation and referral services were reported by parents.

Dissemination

Guide for Referral and Case Coordination for Young Children in Hospital Settings

During the third year of the Early Referral and Follow-up Project, staff efforts expanded to include dissemination efforts. A major dissemination activity was the development of a Case Coordination Resource File.

The Case Coordination Resource File was designed to be used by persons who serve in the role of case coordinator to assist such persons in understanding the school referral process for young children with handicaps. A second use for this Resource File is as a guide for identifying other service needs and in planning for those needs for individual children and their families. Contained in this Resource File is factual information regarding eligibility criteria for school services, the school referral process and comprehensive case coordination. It also includes resource information in the form of descriptions of agencies and services, selected articles for professionals and pamphlets for parents. As part of the Resource File, the following additional materials are provided.

. Speaking for Children: Directory of Resources for Nebraska Children - This directory, developed by the Junior League of Nebraska, is a guide to finding services for children in Nebraska. The listings that are provided in this guide were not intended as endorsements or recommendations of agencies, groups, or services.

. Nebraska Educational Directory - This directory published annually by the Nebraska Department of Education, provides a listing of all state education offices, educational service units, and school districts in Nebraska. Information regarding names, addresses and phone for school district personnel and facilities are listed.

. Parent's Handbook - This handbook is designed to provide families with an organizational method for filing and maintaining records and correspondence regarding their child. It provides parents a means of collecting and maintaining information on their child regarding family and birth history, medical history, developmental and educational history, a listing of professionals with whom they have contact, and a log regarding intervention efforts.

. Resource Guide for Nebraska Parent to Parent and Advocacy Organizations - This booklet is a directory of parent to parent support groups for Nebraska parents whose children are ill, injured, disabled or whose child has died. The listings are arranged by geographic location and by content focus. The directory includes groups which have particular disabilities or illnesses as their focus, Pilot Parent groups, and a listing of state agencies serving people who have disabilities.

. Directory of Nebraska Home Health Agencies -This booklet contains a summary of individual agency responses to a statewide survey of Home Health Care Agencies regarding the availablility of home health care services for chronically ill children and their families. Survey questions included the range of services offered by each agency, as well as information about the child that the agency wishes to be forwarded by the discharging hospital. The directory is intended to be shared with parents prior to the day of discharge to help facilitate pre-discharge planning with the agency that best meets their needs.

. Education Suggestions for Sensorimotor Substage II - VI - Educational suggestions were written for the purpose of providing examples of activities and strategies for parents or teachers who interact with children whose developmental level is between that of a newborn to 24 months. These suggestions were written only as examples that are characteristic of the sensorimotor stages of development and were developed so that a child's name could be substituted and the suggestions individualized.

Distribution of Resource Files

A total of 45 Case Coordination Resource Files were distributed by mail and in two workshops presented by project staff. The agencies represented among those given Files include statewide and local Social Service Agencies, Office of Mental Retardation, hospitals, school systems, Department of Health, and parent groups. In addition, the Resource Guide for Parent to Parent and Advocacy Organizations has been distributed statewide to all responding groups and to pediatricians and obstetricians. The Directory of Home Health Care Agencies has been distributed to all responding agencies.

Workshop Series

The Early Referral Project sponsored a two day training workshop for

professionals who were interested in learning more about school referral procedures, care needs of the child with developmental disabilities, and the needs of the families of such children. The workshop offering was announced through a mailing to major hospitals across the state in April, 1986, asking interested hospitals to co-sponsor the workshop with the Early Referral Project. Three hospital sites, Kearney, Omaha, and Scottsbluff demonstrated interest. This workshop was offered twice, the first time in Scottsbluff (July 1986) and the second time in Omaha (September 1986). The workshop in Kearney was cancelled due to a small enrollment number. A total of 48 persons participated in the workshops. A summary of information regarding the participants is presented in Table 17. The workshop was approved for 15 contact hours for nursing continuing education units through the Nebraska Nurses Association and Nebraska Physical Therapy Association. In addition, undergraduate or graduate credit could be earned from Kearney State College by attending the workshop.

TABLE 17

DISCIPLINES OF WORKSHOP PARTICIPANTS

Discipline	No. of Participants	No. of Agencies Represented
Nurse	27	10
Educator	10	6
Social Worker	3	3
Speech Pathologist	2	2
Physical Therapist	2	2
Child Life Specialist	2	2
Occupational Therapist	1	1
Psychologist	1	1

The courses that were offered in the two day workshop included the following topics: Case Coordination Process; Developmental Issues and Intervention Techniques with Handicapped and At-Risk Infants; Developmental Assessment and Treatment of Oral-Motor Feeding Skills; Social-Emotional Implications of Chronic Illness in Infants/Toddlers; Siblings: Reaction to Illness/Death and Dying; Medical and Educational Personnel Communication; and Family Reaction to the Diagnosis of Developmental Disability and Interpreting Findings to Parents. A copy of the brochure used to advertise the course is included in Appendix D. A syllabus was developed for the workshop that included objectives and readings for each course. A copy of the syllabus is submitted as an addendum to this report.

Other Dissemination Efforts

A conference presentation entitled "Identification, Referral, and Brief Intervention Strategies with Chronically Ill and/or Handicapped Infants and Toddlers" was developed for the purpose of disseminating information regard-

ing the Early Referral Project and the issues encountered in serving the chronically ill and/or handicapped infant in the hospital setting. Major topics addressed in this presentation were: Characteristics of the Hospital-Identified Population, Nursing Care Priorities and Intervention, Educational and Therapy Intervention Strategies with the Chronically Ill Child, Evaluation on the Impact of Intervention Upon Parent Skills, and Integration of Educational Intervention into a Hospital Setting. This workshop was presented at the following conferences:

Nebraska- Special Education Early Childhood Conference. Kearney, NE, April, 1985.

National Early Childhood Conference on Children with Special Needs, DEC/CEC, Denver, Colorado, October 6-8, 1985.

Nebraska Special Education Consortium, Grand Island, Nebraska, October 1985.

Annual Meeting American Association of University Affiliated Programs for Persons with Developemtnal Disabilities (AAUAP). Seattle, Washington, October 1985.

Professional Day sponsored by the Child Development Department at Iowa State University, Ames, Iowa, February 1986.

In addition to these presentations Early Referral staff are scheduled to present at the Iowa Council of Exceptional Children meeting in Des Moines, Iowa in November 1986. An abstract has also been submitted for presentation at the Association for the Care of Children's Health Conference in May 1987.

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 Early Referral and Follow-up Project.

Robinson, C. (1985, Summer) Early Intervention Services for Young Handicapped Children, Nebraska Psychological Association Forum: Special Issue: Child Psychology, 29-31.

Robinson, C., Rosenberg, S., Hartley, R., and Jackson, B. (1986) Early Referral and Follow-up Project: Individualizing family and child interventions for chronically ill disabled children. In J. Hurth, E. Lynch, and J. Olson (Eds.) Individualizing Family Services: Monograph Four of The Family Support Network Series. Moscow, Idaho: Warren Center on Human Development.

Resource Center

A collection of books, articles, and pamphlets on various topics in the area of developmental disabilities was collected during the course of the

project and is still available to staff and parents. The resources are presently being computerized so someone may request a printout on a particular topic by author, title or subject category. Some of the general topics included are parent and family issues, speech and language development, vision and hearing impairments and information on specific disabilities. The materials for parents are being reviewed by staff or parents so that a list of recommended resources is available. Presently we have identified approximately 106 books for parents. Staff continue to contribute resources on an ongoing basis and this Resource Center will continuie to be available as a resource to persons working with young handicapped children.

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Gorski, P., Davidson, M. & Brazelton, T.B. (1979). Stages of behavioral organization in the high-risk neonate: Theoretical-clinical consideraions. Seminars in Perinatalogy, 3 (1), 61-72.

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APPENDIX A

CASE COORDINATOR ROLE AND SEQUENCE OF ACTIVITIES

Early Referral Project
Case Coordinator Role

Referral

Forms

Referrals come to an ERP contact person (Director or a coordinator) via 3 sources:

Fill out nursing shift report (daily roster)

1. Rounds which are held weekly in conjunction with Discharge Planning meeting on 7 N/S
2. Primary physicians
3. Primary or specialty nurses

Intake

After receipt of initial referral:

1. ERP physician checks with attending physician for approval.
2. If approved, contact family & primary nurse to describe ERP & have consent forms signed if family wants services.

Complete ERP census form
Get consent form signed
Register in OSS at MCRI
Send thank you letter to dr. who referred child (include brochure)
Begin tracking form

3. Document in chart whether parents accept or refuse ERP services; inform primary nurse if possible.
4. If family accepts services, complete intake form and get input from primary nurse if possible.

Complete intake form if family wants services

5. Using ERP staff criteria, contact appropriate staff to see child. Attempt to help staff coordinate visits, e.g., let them know which staff are seeing child.

Evaluation, Staffing & Interpretation

1a. After evaluations are completed on inpatient, each staff member is to document in chart and give preliminary feedback to parents & primary nurse if feasible.

1b. If evaluations are to be done after child is dismissed, arrange evaluations in allotted time slots whenever possible.

Evaluation, Staffing, & Interpretation. (continued)	Forms
2. Arrange formal staffing after completion of evaluations if more than 2 disciplines are involved. For 2 or fewer, informal staffing may be done without formally scheduled meeting.	Send status report to hospital staff for children seen as outpatients.
3. Staffings should be scheduled within one week to review findings and formulate recommendations.	Complete staffing form. (to be developed)
4. Complete staffing form which summarizes results & recommendations.	
5. Contact parents (either in person or via phone) to review findings and recommendations	Releases of information
6. Have parents sign appropriate releases, e.g., other physicians, schools, SCC, VNA, etc.	Complete SCC packet* where appropriate. Send letter to school as appropriate.

Follow-Through
Referrals:

1) Referral to school contact appropriate school personnel and offer consultation services of Early Referral staff.	See Nebraska Educational Directory. Send reports, referral letter to school and copy of letter to parents. Note anticipated starting date.
Follow-up call to schools and/or parents to determine if services have been initiated, approximately 1 month.	
Document consultation efforts by Early Referral staff.	Tracking form (revised)
Follow-up calls to school and parents at 3 and 6 month (dated from referral date)	Progress note form (to be developed)
2) Referral to SCC (educational) Send referral letter to SCC including discharge summary, PT and OT reports, other reports if completed.	SCC letter, SCC referral form PT/OT reports.
Send copies of above information with letter to local school district.	School SCC letter
Follow-up within 1 month with schools/ parents to determine if services have been initiated.	Progress note

3) Miscellaneous referrals, e.g., SSI, SCC (medical), VNA. Make referrals as appropriate and document. Progress notes

4) Continued intervention services through ERP as outlined in staffing notes for child who is hospitalized long term.

Follow-up (monitoring and Re-admissions) include: Children who are not referred for services or are terminated.

Monitoring

Based on recommendations at staffing or parent and/or medical request.

1) Follow-up evaluations completed as recommended at staffing. Repeat procedures outlined under evaluation, staffing, and interpretation section (Steps 1-6).

2) If re-evaluation is requested either by parents, doctor, or other agency, arrange appropriate evaluations and repeat procedures (1-6) as outlined in evaluation, staffing, and interpretation section.

Readmissions to hospital

1) For child who is not receiving outside services: Upon notification of readmission, contact appropriate ERP staff to provide intervention services and determine if additional evaluations/services are needed and frequency of visits. At time of dismissal, arrange staffing to coordinate follow-up.

2) For children who are receiving outside services: If the child is to be hospitalized for more than 1 week, contact appropriate ERP staff to provide developmental suggestions to parents/staff during hospitalization (unless school services are continued during this period) and to determine frequency of visits.

APPENDIX B

EVALUATION CRITERIA

EVALUATION CRITERIA

Criteria for Psychological/Educational Evaluation

Assessment of infants with a broad based standardized developmental assessment such as the Bayley Scale is generally recommended with the following cautions.

Neonates to four months of age:

1. Formal standardized assessment is not generally recommended during this period; however, if assessment is needed for certification for services it is best to wait until the child is 3 months of age. In cases of significant prematurity, evaluation should be deferred until the child is at least 3 months corrected age.

2. Informal observations/developmental screening in collaboration with other disciplines is recommended for several categories of children who are at-risk for or who are demonstrating developmental delays.

Infants four months of age or older:

1. The Bayley Scales of Infant Development (Mental and Motor Scales) are recommended at this age, unless the child has significant motor or sensory impairments. In such cases it may be useful to administer the Bayley Scales but they should not be considered to be reliable for prediction of future status. This testing is done in order to evaluate the child's overall developmental age.

2. Educational assessment is also recommended at this age for the purposes of determining cognitive abilities, as well as serving as a basis for Developmental Suggestions.

3. These developmental assessments should be completed if possible when the child is medically stable. This will typically be close to the child's discharge from the hospital. Prior to this point systematic observations based upon developmental guidelines may be made.

Criteria for Speech/Language Evaluation

Neonates to infants six months of age should be seen by a communication specialist.

1. As early as possible if the child presents one of the following syndromes or physical disabilities putting him at risk for communication development:
    a. Cardiovascular accident
    b. Tracheostomy (longer than 3 weeks)
    c. Cleft palate/lip
    d. Hearing disorder
    e. Syndromes with oral motor involvement such as a physical sign, e.g., whistling face, cri-du-chat, Noonan's, etc.

2. Children six months or older should be seen by a communication specialist when social/affective/vocal/nonvocal behaviors seem out of synchrony. Such asynchrony has been observed in the following syndromes: Fragile X Syndrome, Down Syndrome, motor disorders, failure-to-thrive, Fetal Alcohol Syndrome, sensory deficits, prematurity (low birth weight), and long term NICU care (8 months or longer).

Criteria for Occupational Therapy Evaluation

Neonates to infants six months of age should be seen by OT if the following conditions are presented:

1. Cerebral vascular accident or babies demonstrating significant asymmetry in their position and movements.
2. Babies being given supplemental feedings because of weak and inefficient oral-motor skills.
3. Babies going home on tube feedings due to problems that may not be related to specific oral-motor problems such as aspiration, cardiac problems, short bowel problems, etc.
4. Children with identifiable neuromotor problems related to disorders such as myelodysplasia, hydrocephalus, or severe anoxia.
5. Babies with syndromes causing significant joint deformity of the upper extremities such as arthrogryposis, congenital amputation of multiple digits, or more extensive upper extremity involvement.

Children six to eight months or older should be seen by OT when the following conditions are presented:

1. Previously mentioned problems if no previous OT involvement.
2. A significant delay in fine motor skills associated with neuromotor problems; significant weakness; increased tone; obvious tremoring (Down Syndrome, cerebral palsy, myelodysplasia)
3. Failure to thrive babies.
4. Infants with significant oral-motor problems associated with feeding, gagging, choking, or refusal to advance in types of foods taken.

Criteria for Physical Therapy Evaluation

Neonates and infants up to four months should be seen by a physical therapist.

1. As early as possible if the child presents one of the following syndromes or disabilities making him at risk for motor development or postural deformities:
    a. Cerebral vascular accident or significant asymmetry in position and movements
    b. Myelomeningocele
    c. Arthrogryposis
    d. Osteogenesis imperfecta
    e. Amputation or limb anomalies
    f. Syndromes involving muscle tone, strength, or joint limitations

2. Children four months or older should be seen by a physical therapist when there is delayed motor development or poor quality of movement with a history such as:
    a. Prematurity (low birth weight)
    b. Intra-ventricular hemorrhage
    c. Hydrocephalus
    d. Bronchopulmonary dysplasia
    e. Failure to thrive
    f. Asphyxia (especially with low Apgar scores and seizures)

APPENDIX C

DEFINITIONS OF CLASS OF SCHOOL DISTRICTS

CLASSES OF SCHOOL DISTRICTS

Class 1. Districts maintaining only the elementary grades from kindergarten through the 8th grade.

Class 2. Districts under 1,000 population, maintaining both elementary and secondary grades.

Class 3. Districts of 1,000 to 100,000 population, maintaining both elementary and secondary grades.

Class 4. (Lincoln only) Districts of 100,000 to 200,000 population, maintaining both elementary and secondary education.

Class 5. (Omaha only) Districts of 200,000 or more population, maintaining both elementary and secondary education.

Class 6. Districts maintaining secondary grades only.

Class 8. State Operated Schools (this designation is assigned by the Department of Education and is not a legal classification).

APPENDIX D

WORKSHOP BROCHURE

Infants with Disabilities in Hospital Settings

A two-day workshop for professionals who work with infants and toddlers with disabilities

Meyer Children's Rehabilitation Institute
University of Nebraska Medical Center

THE PROJECT

The Early Referral and Follow-Up Project is a grant from the U.S. Office of Education, Handicapped Children's Early Education Program, to the Meyer Children's Rehabilitation Institute of the University of Nebraska Medical Center. The project was designed to establish procedures for identifying infants and toddlers with developmental disabilities while they are in the hospital setting. Project goals include assisting these children and their families with referrals to their local school districts.

THE TRAINING WORKSHOP

A two-day training workshop is available through the Early Referral and Follow-Up Project for professionals who are interested in learning more about school referral procedures, care needs of the child with developmental disabilities and the needs of the child's family.

The Early Referral workshop will be offered three times at three different locations: July 24-25 in Kearney; July 30-31 in Scottsbluff; and Sept. 3-4 in Omaha. Participants may choose to attend one or both days of the workshop. Registration fee is $6 per day and includes lunches and snacks. The fee is payable to Meyer Children's Rehabilitation Institute, University of Nebraska Medical Center, 444 S. 44th St., Omaha, NE 68131-3795.

SITES

1. July 24-25, 1986
   Kearney, NE
   Holiday Inn
   Mary Daake (contact person)
   (308) 234-7091
   Co-sponsored by Good Samaritan Hospital in Kearney

2. July 30-31, 1986
   Scottsbluff, NE
   West Nebraska General Hospital
   Kathy Scott (contact person)
   (308) 632-0334
   Co-sponsored by West Nebraska General Hospital

3. Sept. 3-4, 1986
   Omaha, NE
   Immanuel Medical Center
   Margaret Bross (contact person)
   (402) 572-2335
   Co-sponsored by Immanuel Medical Center

COURSES

The courses offered in the workshop include:

- **Case Coordination Process**
  Provides information about the coordination process used when referring children to local school districts if they meet infant preschool handicapped eligibility criteria. Issues addressed include identification, assessment, referral and family support.
- **Developmental Issues and Intervention Techniques with Handicapped and At-Risk Infants**
  Provides an overview of the developmental issues associated with infants identified as at-risk during hospitalization, and information about successful intervention strategies that can be used with infants who are handicapped or at-risk and their families.
- **Developmental Assessment and Treatment of Oral-Motor Feeding Skills**
  Provides an overview of the development of oral-motor skills, common oral-motor problems and suggestions for remediation.
- **Social-Emotional Implications of Chronic Illness in Infants/Toddlers**
  Increases caretaker awareness of developmental factors when assessing social-emotional behavior of infants/toddlers.
- **Siblings: Reactions to Illness/Death and Dying**
  Presents information about helping siblings adjust to a situation in which a brother or sister is disabled and is dying.
- **Medical and Educational Personnel Communication**
  Provides information regarding interdisciplinary team process and includes discussion on strategies for facilitating communication between medical and educational personnel.
- **Family Reactions to the Diagnosis of Developmental Disability and Interpreting Findings to Parents**
  Presents discussion about how a diagnostic interpretation can affect parental adjustment, and provides information on available literature regarding family reaction to a diagnosis.

SCHEDULE

Day 1

8:30- 9:00 a.m.	Introductory remarks
9:00-10:30 a.m.	**Case Coordination Process**
10:30-12:30 p.m.	**Developmental Issues and Intervention Techniques with Handicapped and At-Risk Infants (part 1)**
12:30- 1:30 p.m.	Lunch (provided)
1:30- 3 p.m.	**Developmental Issues and Intervention Techniques with Handicapped and At-Risk Infants (part 2)**
3- 5 p.m.	**Developmental Assessment and Treatment of Oral-Motor Feeding Skills**
5- 7 p.m.	Wine and cheese reception

Day

8-10 a.m.	**Social-Emotional Implications of Chronic Illness in Infants/Toddlers**
10-12 noon	**Siblings: Reactions to Illness/Death and Dying**
12 noon- 1 p.m.	Lunch (provided)
1- 3 p.m.	**Medical and Educational Personnel Communication**
3- 5 p.m.	**Family Reactions to the Diagnosis of Developmental Disability and Interpreting Findings to Parents**

COLLEGE CREDIT

Undergraduate and graduate credit may be earned by attending the workshop through Kearney State College. For more information, call Larry Betterman, chairman, department of special education, Kearney State College, (308) 234-8507.

The workshop has been approved for 15 contact hours for nursing CEUs (continuing education units) through the Nebraska Nurses' Association. Application has been made for physical therapy CEUs.

For further information, contact Dr. Cordelia Robinson at (402) 559-7451.

INSTRUCTORS

University of Nebraska Medical Center staff will present the courses offered throughout the workshop. Instructors include:

Kaye Bataillon, M.S., Parent Infant Educator, Meyer Children's Rehabilitation Institute

Jacque Bell, B.S., Coordinator, Child Life Program, University of Nebraska Hospital and Clinic

Rosemarie Hartley, R.N., M.S.N., Project Nurse, Early Referral and Follow-Up Project, Meyer Children's Rehabilitation Institute

Mary Lou Henderson, M.S., O.T.R./L., Director, Occupational Therapy, Meyer Children's Rehabilitation Institute

Barbara Jackson, M.S., Coordinator, Early Referral and Follow-Up Project, Meyer Children's Rehabilitation Institute

Cordelia Robinson, R.N., Ph.D., Director, Special Education, Meyer Children's Rehabilitation Institute

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