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ABSTRACT

This practicum was designed to improve communication and collaboration between health care providers and early childhood intervention educators who provide services to children (ages 7 months to 4 years) who are medically fragile or have other special needs and their families. The lack of communication or collaboration is documented, and a causative analysis is provided. In-service seminars were developed and presented by a licensed Clinical Nurse Specialist in pediatrics to both professional groups, separately, on topics concerning special needs children. Education laws were used as a frame of reference, with discussions emphasizing the significance of the laws to both professions in dealing with special needs children and their families. Informal interviews were conducted with families of special needs children to assess their perception of communication and collaboration between health care providers and educators involved with their children. Results indicated that the exposure to the in-service seminar resulted in communication and collaboration, as evidenced by documentation in the medical records of the special needs children. Appendices provide a copy of the medical records review instrument, family interview questions, an outline of the inservice seminar, and an inservice evaluation form. (Contains 23 references.) (JDD)

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Improving Communication and Collaboration
Between Health Care and Education Professionals
by Increasing Understanding of Common Issues
Concerning Medically Fragile and
Special Needs Children

by

Pia Habersang

Cluster 52 B

Practicum I Report
Presented to
the Ed.D. Program in Child and Youth Studies
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Education

NOVA UNIVERSITY 1994

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Lea Haberrang

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This practicum report was submitted by Pia Habersang under the direction of the advisor listed below. It was submitted to the Ed.D. program in Child and Youth Studies and approved in partial fulfillment of the requirements for the degree of Doctor of Education at Nova University.

Approved:

Date of Final Approval

Roberta Silfen, Ed..D.

Advisor



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The author wishes to thank Dr. Roberta Silfen for the guidance and the time to bring this practicum from its inception to its conclusion. Also, the author wishes to thank Dr. Ed Hammer for serving as verifier and being supportive of this practicum.

Finally, a big thank you to my family for their unending support and the encouragements throughout the practicum process.

This practicum is dedicated to the memory of my father who instilled in me inquisitiveness and courage to explore new horizons.



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ABSTRACT

Improving Communication and Collaboration Between Health Care and Education Professionals by Increasing Understanding of Common Issues Concerning Medically Fragile and Special Needs Children. Habersang, P., 1994: Practicum I Report, Nova University, Ed.D. Program in Child and Youth Studies. Descriptors: Health Care Provider/Educator/Collaboration/ Education Laws/ Special Needs Children.

This Practicum was designed to improve communication and collaboration between health care providers and educators who provide services to children with special needs and their families.

The writer developed and presented in-services seminars to both professional groups on topics concerning special needs children. These issues were discussed with the education laws as a frame of reference and the significance of the laws to both profession in the dealings with special needs children and their families. In addition, an informal parent interview provided insight about the parents' perception of how the two professionals were meeting their children's needs.

The results of the practicum indicated that the exposure to the information provided in the in-service seminar to the professionals resulted in communication and collaboration as evidenced by documentation of such in the medical records of the children with special needs, who were patients of the Pediatric Primary Care practice.

Permission Statement

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CHAPTER I

INTRODUCTION

Description of Community

The practicum was implemented in this Southwest town with a population of 160,000 (50% caucasian, 28% Hispanics, 19% African Americans, and 3% Southeast Asians). The local community-based pediatric primary care setting (PPC) provides health care and case management services to children from birth to age 18. The majority of the children served have chronic illnesses and/or disabling conditions ranging from mild to severe multi-system involvement. Children at risk for developing similar problems and "healthy children"--mostly siblings of involved children--are likewise among the patients of the practice.

Since its inception almost 2 years ago, PPC is the only practice of its kind in this region accepting Medicaid payments. Hence, the majority (approximately 64%) of the patients are indigent and come from the lower socioeconomic strata. Patients are referred to PPC



by: (a) parents, (b) other health care providers/agencies, (c) local and surrounding school districts--particularly Early Childhood Intervention (ECI) programs, and (d) the tertiary hospital's Neonatal Intensive Care Unit (NICU) and the Pediatric Intensive Care Unit (PICU).

The local school district provides the educational setting for 28,247 students. Out of the 2,765 students classified as special education students in the school year 1992/1993, 36 were in residential facilities, 10 in a psychiatric facility, and 17 were homebound for reasons such as total body cast, cancer treatments, or severe physical disabilities. However, at times, homebound education was based on the family's preference rather than medical necessity. In accordance with PL 94-142, the law requiring appropriate education for all children in the least restrictive environment, the school provides related services such as physical, occupational, and speech therapy through a local children's rehabilitation center--primarily in a consultative fashion.

The school district employs 21 school nurses to cover the health care needs of students in 34 Elementary, 8 Middle, and 4 High School buildings. Their responsibilities include: (a) to cooperate with parents, school personnel, physicians, health clinics, and other community agencies on school health matters; (b) to advise on the modification of the educational program when needed to meet the health care needs of individual students; (c) to advise



teachers on health matters pertaining to students; and (d) to attend to emergency situations of all students. Time constraints allowed each school nurse only limited involvement with the medically fragile students or students with special needs, such as intermittent catheterization, dispensing of medication, and coordination of special treatments.

Writer's Work Setting and Role

Professionals from different disciplines provide services to the PPC patients. PPC employs physicians and clinical nurse specialists; whereas educators, therapists, counselors, and audiologists partake in the assessment, evaluation, and treatment on a consultative basis. Administrative support staff assist patients with scheduling, check-in procedures, and billing issues. The majority of patients are initially cared for by the pediatricians in the NICU or PICU during an acute critical illness or trauma. The clinical nurse specialists/case managers are involved with PPC patients prior to hospital discharge to assure continuity of care as the patient moves from the hospital to the home and/or school setting. The case manager serves as liaison between health care providers and the school.

The writer, a licensed Clinical Nurse Specialist (CNS) in pediatrics, was the case manager for PPC patients and their families at the time of the practicum. She gathered pertinent



information from school and home prior to the patient's first clinic visit, clinically evaluated patients and families, and coordinated subsequent follow-up visits or activities in collaboration with physicians and other professionals as treatment and intervention modalities were formulated. Over the past fifteen years, the writer has practiced in a variety of settings and held different positions in the health care field which have created the foundation for compassion, understanding, and ultimately advocacy for children with special needs and their families. The many needs of children and families in the NICU challenged the writer, first as a staff nurse and later as head nurse, to pursue graduate studies in family-centered nursing. Subsequently, working with families provided an appreciation of the connectedness of systems--such as patient, family, school, community, and environment. This appreciation influenced the writer's approaches to interventions.

The writer collaborated with professional colleagues in nursing and with computer experts in the development and implementation of a computerized case software program. With the use of lap-top computers connected via phone modems to the mainframe station at the office, all providers of PPC were able to access patient information on a 24-hour basis. A necessary feature since patient's medical records need to be accessible on a moment's notice as professionals communicate with each other about particular patient concerns.



The writer's expertise in mediation, gained through active involvement with the local Dispute Resolution Center as a volunteer, added a valuable dimension to case management activities, particularly resolving conflicts between parents, school and/or health care providers.

In summary, in this Southwest town, medically fragile and special needs children receive services by a variety of professionals in various settings, such as the hospital, the office of PPC, the local school, and in their homes. The clinical nurse specialist coordinates the care through case management, provides direct patient care, and collaborates with the professionals in the education setting.



CHAPTER II

STUDY OF THE PROBLEM

Problem Description

Service providers in health care, human services, and/or education did not communicate or collaborate with each other concerning issues of mutual concern regarding medically fragile and special needs children. This created conflict and confusion for the children, their families, and the service providers leading to fragmented services and possibly services of a lesser quality.

For example, a teacher who observed a child to be less attentive in the afternoon classes, not knowing that the child is on seizure medication, possibly alarmed parents for no reason when requesting the parents have the student evaluated by the health care provider. Or, another example, the physician who was informed by the parent that a child with severe disability was frequently suctioned while at school, may have been concerned about a respiratory problem, when in fact this happened only during speech therapy while feedings were attempted—which should not even be



an issue, since the child had a gastrostomy button and did not require oral feedings during the school day.

Problem Documentation

Of over 150 patients seen between January 1, 1992 and November 30, 1992 in a Pediatric Behavioral Clinic, the writer's previous work setting, 82 (54%) represented "active cases" at the time of data collection. Referrals for school and behavior problems were from the following sources: (a) parents 23%; (b) physicians and other health care providers 58%; (c) school personnel 10%; and (d) other agencies-- such as the Department of Human Resources or Rape Crisis and Domestic Violence--9%. Of all active cases, only 29% had documentation in the medical records of communication between the health care and education disciplines—in the form of copies of correspondence, references to phone conversations, or statements regarding attendance at Admission, Review, and Dismissal (ARD) meetings. Only 4 (50%) of school referred cases had such documentation. This information was obtained from a retrospective review of medical records. In and of itself, the lack of documentation of any collaboration or communication does not verify the existence of the problem, since unfortunately many "non-medical" activities are not documented in the patient's medical record. However, informal discussions with teachers and parents further supported the



existence of the problem, as illustrated in the following case review.

J.D., a 16-year-old male with a diagnosis of encephalomyelitis--a demyelinating disease, was wheelchair bound for over a year and visited PPC on numerous occasions, always with the same concerns and symptoms of skin ulceration (a pressure sore) on his coccyx, probably the result of infrequent position changes during the day. The patient and his family were repeatedly encouraged by the health care providers to request modification of his daily schedule in school to accommodate position changes from the upright sitting position to the supine or prone. However, no changes were implemented. Ultimately, J.D.'s condition required bed rest and intravenous antibiotic treatments to relieve the pressure on his coccyx and to expedite the healing process. His education continued at home with a daily visit by the homebound teacher while his physical condition improved. However, the "regression" and separation from his peers depressed this teenager and created conflict and stress within this previously intact family.

Of note is that throughout the events leading to J.D.'s bed rest, neither the health care provider nor the educator attempted to communicate with one another directly to either inquire, clarify, or voice concerns.



Causative Analysis

Why did professionals not communicate and collaborate with each other? Of the multiple causes, the most apparent were:

(a) an increased number of children with special care needs and high acuity are educated in the school setting, (b) teachers' reluctance to include—that is mainstream—children with significant medical needs in the regular classroom, (c) educational laws dealing with the education of special needs children, and (d) different professional terminology for each discipline.

The acuity level, also described as the severity of a medical condition, of the "average" special education student enrolled in school has changed significantly over the past 10 to 15 years. With the advances of medical technology, neonates and children who previously were destined to die now have a chance at survival.

According to Gorski (1991), neonatal medicine advanced and shifted from a resuscitation and stabilization focus in the early 1970's to a developmental care approach in the mid 1980's, resulting in a decrease of infant mortality in the 24-to 29-week gestation neonate from 52% to 16%. However, the morbidity--cognitive and physical developmental delay and/or chronic lung disease--of these "survivors" now challenges educators and health care providers alike. Also, children who now have an increased chance of surviving trauma sustained in an automobile or drowning accident find themselves in need of special services, often beyond their school aged years.



As children with special needs are mainstreamed in regular classroom activities, teachers need additional support--administratively, in terms of manpower, or on a knowledge base level--in order to accommodate all students' needs. The lack of this support can have significant ramifications. For example, when teachers do not know how to suction a child with a tracheostomy or how to communicate with a nonverbal child of normal intelligence, parents may interpret this as reluctance to have their child included in the regular class room.

The third cause identified by this writer is the health care provider's unfamiliarity with--or ignorance of--PL 94-142, 99-457, and/or disabling and chronic conditions. Educational issues are not a part of the physician's training and the health care providers were not involved in the movement leading up to the passage of these laws.

Professional "jargon" interferes, or at best complicates, communication and collaboration between the two disciplines. For example, terminology used by the educators such as ARD, IFSP, KABC, WISC-R, WPPSI, PPVT, PPVT-R, LD, and ED, may elicit a negative response in the health care professional who at times does not initiate or encourage communication with the educator for fear of appearing uneducated and/or ignorant. The same holds true for the ed cator who receives information from the health care professional with a "slanted" terminology. This communication dilemma between the professions is further



aggravated when parents are expected to serve as the "gobetween", as illustrated in the previous case review.

Relationship of the Problem to the Literature

The writer's analysis of the first contributing factor to the gap in communication and collaboration between health care providers and educators--that of an increased number of special needs children in the school because of the advances in medical technology--is well supported in the literature (Gorski, 1991; Ramey et al., 1992; and Tucker and Roberts, 1990). However, the increase in the number of these special needs students is also attributed to the socioeconomic status of the families. For example, McCormick, Gortmaker, and Sobol (1990) found the low socioeconomic status of families emerging as the major factor influencing outcome and school performance of not only VLBW (very low birth weight) but also heavier birth weight infants, independent of the severity of their neonatal course. Starfield (1991) reports likewise that children of low socioeconomic status families are two to three times more likely to be born with low birth weight and are likely to have more health problems, and consequently more school problems.

A disturbing finding while conducting the literature review was that as early as fifteen years ago Levine, Palfrey, Lamb, Weisberg, and Byrk (1977) considered and identified the



socioeconomic factor as a major contributor to compromised neonatal outcomes. Indicators of early health and educational needs of 285 infants enrolled in a demonstration project revealed a preponderance of references citing poor environmental circumstances and a low socioeconomic milieux to be more of a predictor of children's outcome than medical factors. These findings were echoed recently by Goldberg, McLaughlin, Grossi, Tytun, and Blum (1992) who found an association of three factors emerging in predicting placement of newborns in special education once they are in third grade: (a) the gender of the child, (b) Medicaid coverage of the mother at the time of birth, and (c) medical complications. In contrast to Goldberg and his coworkers' findings, Kirby, Swanson, Kelleher, Bradley, and Casey (1993) stated that environmental risk factors occurred infrequently in their sample population and had a relatively low sensitivity or specificity and predictive value for developmental problems.

The second contributing factor to the problem--the attitude of educators towards providing inclusion for children with disabilities in the "regular" classroom--is supported by Rogers (1993) who validated parents' plight as they attempt to overcome the school employees' negative attitudes or teachers' reluctance when their child is to be considered for inclusion. Jenkins, Pious, and Jewell (1990) discussed a communication gap between special



education and regular education teachers interfering with collaborative efforts to educate special needs children in the mainstream setting.

In the pediatric literature, issues related to the educational laws are addressed manyfold and over many years (Downey, 1990a; 1990b; Morse, 1990; Wolraich, 1980). Professional jargon, educators unrealistic expectations of physicians, and lack of an understanding of medical terminology are cited as barriers and reasons for communication problems between the two disciplines (Morse). The period preceding the enactment of PL 94-142 (the Education for All Handicapped Children Act) in 1975 has been identified by Gottlieb, Williams, and Zinkus (1983) as the "golden age of concern" (p.1). The authors recognized that pediatricians became interested in more than the mere medical aspect of children in their practice when they embraced the concept of biopsychosocial issues facing these children and their families. However, comments by physicians such as: "I really don't understand all of the language in psychology, speech pathology, and education reports..." (Gottlieb et al., p.2) was evidence that physicians maintained the notion that educational issues are to be addressed by the educators and school psychologists, but not by pediatricians. This clearly signaled professionals not to communicate with each other.

The reluctance of physicians to become familiar with PL 94-142 or PL 99-457 (Education of the Handicapped Act Amendments



of 1986) was attributed to knowledge deficit (Wolraich, 1980) or an unclear definition of the physician's role in PL 94-142 (Palfrey, Mervis, and Butler, 1978). A perception echoed again by Downey in 1990. He argued, however, that since PL 99-457 deals with services for children 3 to 5 years of age--and with the states' discretionary coverage from birth to three--more physicians became involved because this age group of children has typically more medical than educational concerns.

Since the implementation of PL 94-142, numerous articles have been published addressing physicians' interaction with educators. Palfrey, Singer, Walker, and Butler (1986) reported that only 13.8% of school records of all special education students sampled, had evidence—in the form of a report from a physician—that communication between school and health care providers occurred. This finding was significant in light of parents' suggestion to their physician to contact the child's school for related services. Furthermore, only 1.8% of physicians attended their patients' IEP (Individualized Education Plan) conference.

In summary, the literature supports the cited causative factors for the gap in communication and collaboration between educators and health care providers, particularly the pediatric literature.



CHAPTER III

ANTICIPATED OUTCOMES AND EVALUATION INSTRUMENTS

Goals and Expectations

The goal of this practicum was for health care providers and educators to have an improved understanding of issues concerning the medically fragile and/or special needs child. The practicum was designed to increase professional collaboration and communication between the PPC and the school and to have evidence of such documented in the patient's medical record.

Expected Outcomes

The writer anticipated that upon completion of the three month implementation phase of the practicum 8 of 10 medical records of children diagnosed with developmental delay in the birth to five years age group would have documentation of communication between health care providers and educators in one of the following forms: (a) a copy of the IFSP signed by the health



care provider, (b) evidence of correspondence with parents and educators of the ECI program regarding the Individualized Family Service Plan (IFSP), (c) documentation of referral to related services, and (d) documentation of discussions regarding IFSP with the parents during a regular PPC office visit. For the children who have moved from the ECI program to the Early Childhood Education (ECE) program, the goal remained the same except the IFSP will be substituted with an ARD summary.

Measurements of Outcomes

Three methods were applied to evaluate the practicum outcome. First, a retroactive medical records review determined whether the anticipated communication and collaboration was documented (see Appendix A). The review was completed by this writer at the end of the implementation phase. Second, informal interviews of families whose children received services at PPC and who were enrolled in ECI and/or ECE were conducted (see Appendix B). The interviews took place during regular case management activities. The family's perception of the collaboration between school and health care was likewise ascertained. Third, at the end of each in-service an evaluation of the seminar indicated whether seminar objectives were obtained (see Appendices C and D).



CHAPTER IV

SOLUTION STRATEGY

Discussion and Evaluation of Solutions

The identified problem for this practicum was the virtual nonexistence of communication and collaboration between health care providers and educators who provide services to medically fragile and special needs children and their families. This statement was based on findings of documentation in the medical records and informal discussions with parents and providers.

A variety of possible solutions exist in the literature, each dealing with its unique approach based on the nature of the contributing factors. Among the solutions, one of the most logical was prevention. Providing every child with a healthy start, a head start, and a fair start was postulated by Edelman (1993) who believes that through education of professionals, lawmakers, and parents, children's causes can come to the forefront of families, communities, school, and both state and national platforms.



Hence, having people expand their own personal or professional world would lead to communication between professionals and improve services for the children. Fifteen years ago Palfrey et al., (1978) suggested a paradigm shift for health care providers from a "medical model" to an "educational model." The authors challenged physicians to become familiar with education issues, more specifically, the educational laws. Templin, Kuhn, and Palsha (1993) and Wolraich (1980) promoted the exposure of pediatric residents to developmental pediatrics during their training. Again, suggesting that an increase in subject knowledge of developmental disabilities improves attitudes towards the issue in general. The concept of educating the professional was recommended by Gottlieb et al., in 1983 as a means to counteract the "laissez-fair" approach of many pediatricians. More recently, Palfrey et al., (1986) saw the solution to interaction and improved collaboration between health care providers and school in the form of coordinated research.

Downey (1990a, 1990b) suggested a broad based involvement by the health care professional in educational issues and recommended that physicians function as the case managers for the zero to three-year-old child. He mandated that the medical component of each IFSP not only be discussed by a physician, but that a representative of the health care profession be present at each IFSP meeting. Downey speculated that with increased knowledge



attitudes change; hence, a paradigm shift may occur. Purvis and Whelan (1992) did not want to leave anything to chance and suggested that a multidisciplinary evaluation of children with special needs--including health care--should be mandated by law.

The concept of early intervention was yet another solution suggested by Goldberg et al., (1992). Though more in line with addressing other contributing factors, the authors proposed that early identification of problems of special needs children by health care professionals leads to a better understanding of the scope and type of services needed within the community and the schools.

George and Lewis (1991) and Hundert (1982) discussed the importance of preparing regular education teachers for the inclusion of special needs children by inviting the regular education teacher to observe the child in the special education setting and become familiar with the child's needs. A similar idea was previously espoused by Roth (1970) who recommended that a Child Development Teacher (CDT) serve as a resource teacher for the regular education teacher in order to help the special needs student remain in the regular class room.

Description of Selected Solutions

In reviewing the above mentioned solutions of prevention, joint research, case management, early intervention, and teacher modeling, educating professionals on issues related to special



needs children is a prerequisite for fostering communication and collaboration. This writer's rationale of why education provides the key to communication and collaboration between health care providers and educators was based on a common sense philosophy. Common sense dictates collaboration when there is an understanding that actions taken by various professionals do not have an isolated impact on the child and family. Therefore, the solution chosen by this writer focused heavily on "educating the mind", such as expanding the understanding of issues concerning special needs children to accomplish a paradigm shift.

Report of Action Taken

The practicum was implemented in three phases. During phase I, the planning phase, contacts with ECI agency and PPC staff were made to set up the in-services. During this phase the writer encountered one unexpected event. Administrative approval to conduct the in-service seminar for the Regional ECI staff was coupled with questions as to why a health care provider would address the ECI staff on issues related to educational laws? The hesitation of the administrative leadership of the Education Support Center was almost diagnostic of the problem identified for this practicum. However, the more positive events overshadowed this minor stumbling block. Several professional colleagues inquired about the purpose and need for such an intervention and verbally



concurred with the writer's approach.

Separate in-service seminars were provided for health care providers and educators during the implementation phase. The decision to hold the seminars separate was strictly a matter of convenience rather than a philosophical decision since continuing education times were already scheduled. Nurses and special education teachers from the local independent school district were invited to attend either one of the seminars due to scheduling conflicts during the pre-Christmas season.

The in-service for the health care group lasted two hours and 15 minutes and was held in the conference room of the community hospital. Contrary to initial plans, the seminar was not limited to the staff of PPC but was open to other health care providers as well. Five school nurses from the local independent school district opted to attend this session. Details of the in-service seminar will be addressed in the next chapter of this report. The second seminar provided for the ECI staff was 3 hours in length. Participants from both sessions completed an evaluation at the conclusion of the seminar (see Appendix D).

The third and final phase of the practicum consisted of informal interviews of the families of children with special needs to assess their perception of communication and collaboration between the health care providers and educators involved with their children. Again, detailed discussions of these findings will be



presented in the next chapter. Also, during this phase of the practicum a review of medical records was conducted by the writer. The practicum was implemented as originally proposed and within the suggested time-line.



CHAPTER V

RESULTS, DISCUSSION, AND RECOMMENDATIONS

Communication and collaboration between health care providers and educators who provide services to children with special needs was the focus of this practicum. In-service seminars for both professionals addressed common concerns of the educational laws and the education of children with disabilities or special needs.

The results and summary of the data focus on the proposed practicum outcome which was to find documentation of collaboration and communication between health care providers and educators in 8 of 10 medical records of children diagnosed with developmental delay and special needs.

Results

The findings of a retroactive review of 10 medical records of patients with a working diagnosis of developmental delay actively



enrolled in the PPC substantiates the positive results of the practicum. The background information of the medical records reviewed is summarized in Table 1.

Some of the associated diagnosis were complex partial seizure disorders, microcephaly, hydrocephaly with ventriculoperitoneal (VP) shunts, chromosome 9Q-syndrome, cleft palate, osteogenesis imperfecta, cortical blindness, hearing deficits, fetal alcohol expression, autism, and slick gut syndrome.

The children's ages ranged from 7 months to 4 years of age, with a median age of 25 months and a mean of 26.5 months. All children under the age of three years (8 of 10) were enrolled in the ECI program and the 2 older children participated in the ECE program. Each child was seen by a professional at PPC within the last two months, mostly for a sick call.



Table 1
Background Information of Medical Records Reviewed

Child	Diagnosis	Age	Referral to PPC by	ECI/ECE
A.G.	Hydrocephalus with V/P shunt, Complex partial seizures, Developmental delay, Hearing deficit.	2 yrs 10 mos	Private MD	Y
A.K.	Microcephaly, Complex partial seizures, Developmental delay.	10 mos	Parent	Y
A.A.	Chromosome 9Q-syndrome, Microcephaly Static encephalopathy, Cleft palate, Orthogryposis, Pulmonary Hypertension, Developmental delay.	1 yr 10 mos	ECI	Y
A.B.	Hydrocephalus with V/P shunt, Complex partial seizures, Developmental delay, Partial cortical blindness.	2 yrs 10 mos	Hospital ICU	Y
A.C.	Developmental delay, Spastic quadriplegia.	2 yrs 10 mos	ECI	Y
C.W.	Fetal Alcohol expression, Developmental delay, Mild spastic quadriplegia	1 yr 7 mos	ECI	Y
C.D.	Prematurity, Hydrocephalus with V/P shunt, Developmental delay	1 yr 7 mos	Hospital ICU	Y
R.S.	Developmental delay, Slick gut syndrome	1 yr	Parent	Y
M.F.	Prematurity, Hydrocephalus with V/P shunt, Cortical blindness, D delay.	3 yrs evelopmental	ECI 2 mos	Y
T.H.	Developmental delay, Autism	4 yrs	Parent	Y



The referral source to PPC of the children whose charts were reviewed was as follows: (a) 3 parents, (b) 1 by other health care professional, (c) 4 by ECI/ECE, and (d) 2 by hospital intensive care units (see Figure 1).

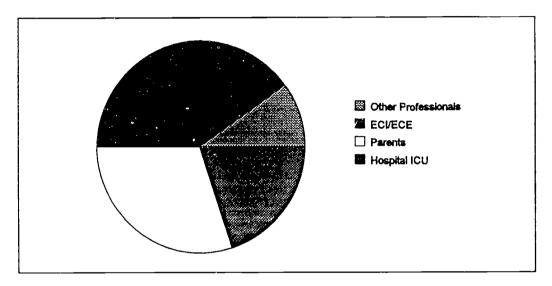


Figure 1. Source of Referral to PPC.

Table 2 and Figure 2 represent the findings of the documentation of communication between the health care providers and educators in the medical records. Five of 10 medical records reviewed had a copy of the IFSP or IEP. One medical record had a copy of the initial assessment and evaluation, but since no ARD meeting was scheduled prior to the date of the medical records review, the criteria of a copy of the IFSP or IEP is not applicable. Nine of the medical records contained correspondence from ECI or ECE other than the previously mentioned copy of the IFSP or IEP.



Nine of the 10 patients were referred for related services with appropriate documentation in the medical records. Documentation of discussions with the parents pertaining to educational issues was found in 6 of the 10 records reviewed. The discussions did not always occur during the most recent visit to PPC, but occurred after October 1, 1993.

Table 2

<u>Documentation in Medical Records of Communication</u>

<u>Between Health Care and Education Professionals</u>

Child	IFSP Copy	Correspondence w. ECI/ECE	Referral for Related Serv.	Discussion w. Parents
J.A.	No	Yes	Yes	Yes
A.K.	Yes	No	No	Yes
A.A.	Yes	Yes	Yes	No
A.B.	Yes	Yes	Yes	No
A.C.	No	Yes	Yes	Yes
C.W.	*No	Yes	Yes	Yes
C.D.	No	Yes	Yes	No
R.S.	Yes	Yes	Yes	No
M.F.	No	Yes	Yes	Yes
T.H.	Yes	Yes	Yes	Yes

Note. * Medical record contained evaluation of child.



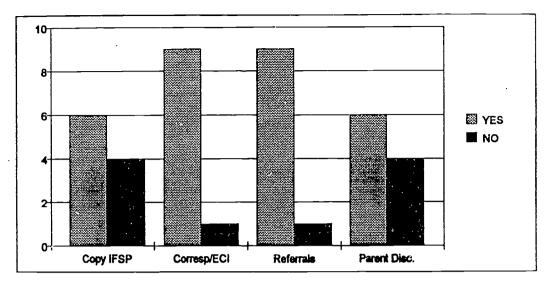


Figure 2. Summary of Documentation in Medical Records

Excerpts of interviews with parents conducted during regular visits to PPC are summarized in Table 3. The children whose parents were interviewed were not the same children whose medical records were reviewed. The criterion for parents to be interviewed was that they had a child with a diagnosis of developmental delay. At least half of the parents interviewed did not expect the health care provider to function in the role of an advocate for the educational needs of their children. One parent stated that requesting the PPC staff to attend an ARD meeting would be an imposition and would make the parents feel uncomfortable and would take up valuable PPC staff time.



Table 3
Selected Responses given by Parents during Informal Interview.

Parent	Excerpts of Interview
K.A.	I did not know there is so much we need to know about the law. I feel intimidated by the school.
R.S.	Since my child is still in the ECI program I guess I have nothing to worry about. Hopefully, my case worker will help me.
M.T.	We do not believe anyone at the school cares about our daughter as much as the physician and the nurses care.
D.I.	I am surprised that the professionals here have an interest in my child's education, despite the fact that she is in special education and probably does not have much potential.
P.K.	I have to live with the teachers in my community and would not want to alienate them by having my doctor come to the ARD.
G.C.	We want our daughter to get the best education, but we don't think it's possible at our school because her needs are so unique. We have heard about laws, but don't know what they means.
D.D.	Our son does not participate in extracurricular activities because he is in a wheelchair and it's always too much bother to arrange for other students to come over to our house.
T.R.	I don't understand why the school will not provide additional PT when we know it helps my child enormously?



Overall, the evaluation responses indicate the in-service seminars were successful. Table 4 and Figure 3 reflect these findings. A total of 21 professionals attended the combined inservice seminars. Due to an in-hospital emergency at the time of the in-service, only one of the two pediatricians of the PPC was able to attend, the remaining staff being nurses and clinical nurse specialists.



Table 4
In-Service Seminar Evaluation Responses Grouped by Profession

Professionals		MD	RN	PT	Psy	Cnsl	Diag	Sp/P	Oth
# 1	New information was presented.	1a	6a 2d	3a 1d	2a 1d	la	2a	1d	1a
# 2	Knowledge gained broaden under- standing of education laws.	1a	8a	4a	1a 2d	1a	2d	1d	la
# 3	Information received is applicable to prof. involvement with children.	1a	8a	4a	3a	1a	2a	1a	la
# 4	Inform. presented is preparation for communication between professionals.	1a	8a	4a	3a	1d	2a	1 d	1d
# 5	Information will be useful in prof. activities.	1a	7a 1d	4a	3a	1a	2a	1d	1a
#6	Have a clear under- standing and can make use of knowledge gained.	1a	7a 1d	4a	2a 1d	1a	2a	1d	1a
Key:	a = agree d = 0	disagre	æ	•		-	<u> </u>		
	MD = Physician RN = Nurse PT = Physical The Psych = Psychologis	-	t	Cnsl = School Counselor Diag = Diagnostician Sp/P = Speech Pathologist Oth = Bilingual Teacher					



According to answers on the questionnaire, 17 of the 21 professionals agreed that new information was provided (Question #1). Only 5 of 21 professionals disagreed with the statement that the knowledge gained would broaden their understanding of the education laws (Ouestion #2). All the respondents noted on the evaluation form that they already had a good knowledge base of those laws. A unanimous agreement was expressed by all professionals surveyed about the applicability of the information provided (Question #3). In addition, the health care professionals felt the information presented prepared them to deal with the other professionals; whereas only 2 of 5 educators felt likewise (Question #4). Through personal communication with several educators, it is apparent that a significant amount of skepticism remains. This mistrust of other professionals was expressed in comments such as: "My student's physician will never return my phone calls!" or " I don't have time to sit in a physician's waiting room!". Two professionals indicated they will not have any use in their professional activities for the information received (Question #5), while 3 professionals indicated that they do not understand how to make use of the knowledge gained (Question #6). Although each profession processed the information differently, overall respondents agreed the information was valuable and useful (see Figure 3).



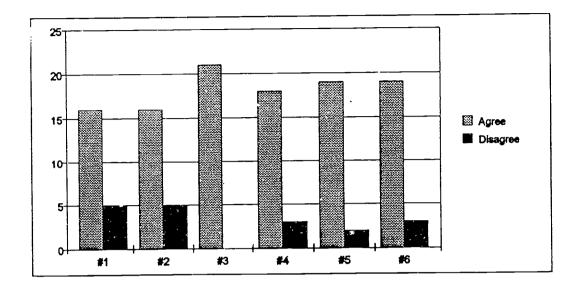


Figure 3. Summary of In-Service Seminar Evaluations

Discussion

Results of the practicum were positive and the objectives are considered met. Health care and education professionals gained an increased understanding of the issues concerning the care and education of children with chronic illnesses or special needs. This increased understanding resulted in documented communication between the two disciplines. Four parameters were used to evaluate the documentation in the medical records: (a) a copy of the IFSP/IEP, (b) evidence of correspondence with ECI/ECE, (c) reference to referral for related services, and (d) indications of discussion of education needs with parents. In the review, two of those parameters were positive 6 out of 10 times while the remaining two parameters were positive 9 out of 10 times.



Opening a dialogue between the two professions through inservice seminars was an important step in removing some of the barriers discussed in previous chapters. The two disciplines discussed common concerns during the question and answer period of the in-service seminar, which proved to be almost more beneficial than the information presented during the in-service seminars. The preparation and process leading to the in-service seminars were equally "therapeutic" in developing a climate for free flowing exchange of information and ideas about children with special needs. The in-service process helped in demystifying preconceived ideas of how the other professionals view certain issues.

The computerized case management record of the PPC patients allowed easy retrieval of pertinent patient information including references to verbal communications. The question remains of whether the communication between school and health care already existed but was simply not documented.

The parents' involvement in the "team" has become easier as a result of the practicum. Documentation in the medical records indicates that they feel more comfortable requesting that either their child's teacher or physician contact the other professional with questions or concerns.



Recommendations

The writer suggests several recommendations to further strengthen the communication and collaboration between school and health care professionals:

- 1. Include the family in the dialogue between the school and health care providers. As the informal parent interviews indicated, parents usually have a wealth of information about issues concerning their child.
- 2. Insist on periodic staffing of each patient/student to "brainstorm" and discuss concerns about the child's needs at school and at home. Staffing meetings should take place on a regular basis, but should be informal in nature to allow the exchange of ideas. Both the parent interviews and the observed interaction between the professionals during the discussion following the in-service seminars demonstrate the value of informality.
- 3. Expand in-service seminars programs within each profession to include information about collaborative practices.
- 4. Use the concept of "team" teaching--health care providers and educators— when presenting further in-service seminars, allowing both professions to present relevant issues and hear the other's opinion and point of view on specific topics.



Dissemination

At the time this report was written, the writer had been asked to present the findings at a research symposium held monthly by the nursing community in this town. Plans for future dissemination include submitting the results for publication and presenting future in-services on updated education laws.



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APPENDIX A MEDICAL RECORDS REVIEW INSTRUMENT



APPENDIX A

MEDICAL RECORDS REVIEW INSTRUMENT

Chart #	
Age of child: Referral source: Diagnosis:	
Where enrolled: Last PPC visit:	ECI ECE within last week: within last mo: within last 3 mo: n/a New Patient:
Copy of IFSP: Copy of ARD: Correspondence from ECI/ECE: Request/referral letter for related services:	yes: no: yes: yes: no: yes: yes: no: yes:
Documentation of discussion re: educational issues in progress notes since October 1, 1993:	yes: no:



APPENDIX B FAMILY INTERVIEW QUESTIONS



APPENDIX B

FAMILY INTERVIEW QUESTIONS

Do you have an understanding of PL 94-142 and Pl 99-457?
Is it your perception that your health care providers understand the issues involved regarding PL 94-142 and 99-457?
Do you consider your health care provider an advocate for your child in the education system?
What concerns do you have regarding the medical and educational needs of your child?
For office use:
Comments by parent/care-giver regarding above questions:



APPENDIX C IN-SERVICE SEMINAR OBJECTIVES AND OUTLINE



APPENDIX C IN-SERVICE SEMINAR

OBJECTIVES:

At the completion of this in-serve seminar, the participant will have an understanding of:

- PL 94-142 and PL 99-457
 Historical background
 Impact on the child, family, and service providers
- 2. How to function in the role of a child advocate in the spirit of PL 94-142 and PL 99-457

OUTLINE:

- I. History of Special Education LawsSpecial Education before the 1970's
- II. Statutory Provision
 Section 504
 - EAHCA / 94-142
- III. The People Impacted
 - Student
 - Parent
 - Professional
- IV. Identification & Evaluation
- V. Mainstreaming & Integration
- VI. Related Services
- VII. Other Issues Related to Special Education Law
 - Funding
 - Legal issues



APPENDIX D EVALUATION FORM FOR IN-SERVICE SEMINAR



APPENDIX D EVALUATION FORM

INSTRUCTION:

Please indicate by checking the appropriate box if the statements reflects your opinion.

1.	1. The information presented in today's in-service seminar is n information to me.		
	Agree		Disagree
2.	The knowledge understanding of	gained at today's i of PL 94-142 & PL	n-service seminar broadened my 99-457.
	Agree	- 	Disagree
3.	The information professional inv	n of today's in-serv volvement with chil	ice seminar is <u>applicable</u> to my dren.
	Agree		Disagree
4.	The information communicate we children with sp	ith professionals in	ice seminar <u>prepares</u> me to other disciplines regarding
	Agree		Disagree
5.	I have a clear u	e of the information of ho's in-service semina	n presented at today's in-service we to make use of the knowledge ar.
	Agree		Disagree



APPENDIX E CALENDAR FOR PRACTICUM IMPLEMENTATION



APPENDIX E <u>CALENDAR FOR PRACTICUM I IMPLEMENTATION</u>

WEEK	ACTIVITY	DISPOSITION/ COMMENTS
# 1	Contact agencies to set dates for in- service seminars: PPC, ECI, & SCHOOL,	
	Secure facility for seminars	
# 2	Prepare in-service seminar: agenda & material	
	Follow up on letters to agencies	
# 3	Confirm Dates with agencies	
	Prepare hand out material for seminar participants	
# 4-9	Conduct in-service seminars: for health care providers & educators	
	Hand out evaluation forms	
# 10	Conduct interviews with families to assess health care providers discussion of educational issues	
	Conduct medical records review	
# 11	Compile data: from evaluation forms & medical records review	
	Analyze data	
# 12	Follow-up letter to agencies with practicum findings	
	Finalize practicum report & mail	

