DOCUMENT RESUME

ED 215 485 EC 142 144

AUTHOR Waldstein, Arnold, Ed.; Pelz, Ruth, Ed.
TITLE A Framework for Statewide Planning.
INSTITUTION National Association of State Directors of Special Education, Washington, D.C.; North Carolina Univ., Chapel Hill. Technical Assistance Development System.; Western States Technical Assistance Resource, Monmouth, Oreg.
SPONS AGENCY Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE 82
CONTRACT 300-80-0753
NOTE 120p.

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Disabilities; Elementary Secondary Education; *Program Development; *Special Education; State Programs; *Statewide Planning

ABSTRACT

The booklet examines issues involved in state planning for special education. Three phases are identified, and steps are listed for each phase. The first, preplanning, includes steps to identify issues, analyze issues, identify constraints and resources for planning, secure administrative commitment, and identify participants. Plan development, the second phase, is described in terms of steps to develop purpose statement; conduct needs assessment; arrive at issues consensus; develop priorities; formulate goals and objectives; develop alternative strategies; analyze and select implementation strategies; specify tasks, responsibilities, and timeliness; develop plan for evaluation; and assure administrative and public support. Implementation, phase three, involves procedures to disseminate information, evaluate and report, analyze feedback and revise. Communication, collection of information, and group dynamics are explained to be influential factors at each stage. (CL)

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The Health Care/ Education Relationship

Services for Infants with Special Needs and their Families

Proceedings of the March 16–18, 1981 HCEEP Topical Workshop

Edited by David Gilderman, Denise Taylor-Hershel Sonya Prestridge Joan Anderson

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Produced by:
Western States Technical Assistance Resource (WESTAR)
Technical Assistance Development System (TADS)

CG 015 145

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Produced under contract number 300-80-0753 from Special Education Programs, United States Department of Education. The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Department of Education, and no official endorsement by the U.S. Department of Education should be inferred.

Printed in the United States of America

December 1981

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ACKNOWLEDGMENTS

Several people deserve special mention for their contributions to the HCEEP Health Care/Education Relationship workshop.

The members of the initial planning committee--Nancy Sweet, Linda Gilkerson, Linda Stone, David Grove and Jennie Swanson deserve special mention for their assistance in conceptualizing and planning the workshop.

Patsy Poche, Marcia Lobman and the entire staff of the Children's Center at Louisiana State Medical Center provided valuable assistance in identifying local resources, making local arrangements and serving as host project for the workshop. Also, Dr. Henry O. Smith, Director of Special Education, Louisiana State Department of Education, welcomed the participants to Louisiana and introduced the keynote speaker, Dr. Brazelton. Carl and Margaret Kemmerly graciously donated their home for the reception following Dr. Brazelton's speech.

Gary Lambour, Jane De Weerd and Sandra Hazen of Special Education Programs (formerly the Office of Special Education) provided support and encouragement for the workshop. Assisting the workshop coordinators--Sonya Prestridge and Joan Anderson (TADS), Denise Taylor-Hershel and David Gilderman (WESTAR), in the preparation of the workshop were Tal Black and Brenda Hardee of TADS and Zelalem Yilma, Sandra Manning and Gabrielle du Verglas of WESTAR. In addition, the time and energy expended by presenters and participants proved the essential component for making the workshop a success.

Arnold Waldstein and Ruth Pelz with the assistance of Valerie Woods of WESTAR prepared these proceedings for publication.

FOREWARD

The Special Education Programs (SEP) is pleased to have supported this conference, which was capably organized by WESTAR and TADS, the technical assistance providers for the Handicapped Children's Early Education Program (HCEEP). The conference represents one of a number of efforts by SEP to develop information and share successful practices in the new and growing field of infant intervention. In addition, it reflects recognition of the importance of bringing together professionals with knowledge and experience from medicine, social services and education to meet the needs of at-risk and handicapped infants and their families.

Projects demonstrating services for children in the birth-to-three age range have been a priority for the HCEEP for several years, and the percentage of these projects has steadily increased. For the 1980-81 year, more than half the children served in the projects were three years old or younger. Among the services now being developed and demonstrated are family-oriented interventions beginning in the intensive care unit and continuing as the infant moves into other hospital settings and eventually home. Such projects are developing new ways in which parents can interact with premature and at-risk or handicapped infants and new ways in which nurses can provide developmental stimulation. The HCEEP plans to continue its emphasis on programming for the birth-to-three group--a proportionately underserved group.

There are a number of other SEP activities which also reflect a commitment to bringing together practitioners in the medical and educational fields around common concerns. While not all of them emphasize infancy, the results of the better understanding and working relationships they are designed to foster should be felt in work with infants, as well as with older handicapped children. One of these efforts is jointly sponsored by Maternal and Child Health and SEP and carried out at Vanderbilt University. It addresses the problems of a neglected group--chronically-ill children and their families. Support and services for chronically-ill children, many of whom become handicapped, have been lacking; and their families have had to struggle largely without professional support. Diabetic children, for instance, require controlled diet and medication and often develop vision losses which could be avoided had proper educational services been available.

The HCEEP and the Handicapped Children's Model Program of SEP, which funds demonstration projects for school-aged children, are jointly supporting a project to demonstrate the provision of educational and related services for children with epilepsy at Good Samaritan Hospital in Portland, Oregon. A model with materials

designed for use in public school districts is being developed in the Beaverton School District (Oregon) and will be field-tested in other districts. The HCEEP is also funding a project at the Nisonger Center, Ohio State University, to develop a curriculum for pediatric residents and test it in eight sites across the country. This curriculum addresses child development; handicapping conditions; attitudes toward exceptional children; prevention; screening, diagnosis and assessment; interdisciplinary team management; working with parents; community resources; health and medical care; developmental, educational and psychological research; and legal and legislative aspects. A major goal of this project is to inform pediatric residents about parental concerns and techniques for better communication.

The Division of Personnel Preparation of SEP is supporting two projects which also focus on the medical/educational interface. A special project by the American Academy of Pediatrics in Evanston, Illinois, is developing an inservice curriculum for physicians to help them meet the needs of children with handicaps. The focus is on the requirements of P.L. 94-142, and the curriculum provides information placement, IEP development and instructional strategies, which are unfamiliar to most physicians.

And finally, the Division of Personnel Preparation is supporting a project at the Children's Hospital Medical Center of Boston to provide training for faculty fellows. Pediatricians receive a full year of training in the care of children who have handicaps that affect their education. In addition, other physicians and nurses will receive shorter training sessions. Community sites for training will be strengthened and expanded and curricular material revised and updated. New packages on education will also be added. A national symposium will bring together a representative national sample of former trainees to evaluate their training and address relevant questions regarding pediatric practice as it relates to caring for handicapped children.

Special Education Programs would like to compliment those who have contributed valuable new information to the field through this Infant Conference. We hope and believe that these proceedings will prove useful and will complement the work in health care and education carried out by projects serving older children and their families.

Jane DeWeerd
Chief, Early Childhood Section
Special Education Programs

INTRODUCTION

The Health Care/Education Relationship: Services for Infants with Special Needs and Their Families proceedings document is the product of a TADS/WESTAR workshop held in New Orleans, Louisiana on March 16-18, 1981. The workshop was developed to assist federally funded projects in the Handicapped Children's Early Education Program (HCEEP) to focus on the unique issues and experiences that projects must deal with when working with very young children in health care settings, e.g., hospitals, intensive care units, newborn nurseries and clinics. TADS and WESTAR planned the workshop with the assistance of a planning committee* composed of HCEEP project directors.

This committee, in collaboration with TADS and WESTAR, identified specific workshop purposes. The purposes were:

A. To identify issues of common concern.
B. To facilitate communication and cooperation among professionals from health care and education disciplines.
C. To exchange information and ideas on successful practices.

An initial survey (see Section IV), based on content suggestions from planning committee members, was developed and mailed to all HCEEP projects involved in health care settings. The purpose of the survey was to determine if sufficient interest existed in the field for such a workshop and, if so, what specific topics needed to be addressed.

Results from the initial survey revealed that indeed, sufficient interest did exist. Respondents to the survey indicated that a need for cooperative effort between educators and various health care and supportive disciplines was of critical interest. Thus, "Building Relationships" became the theme of the workshop, and workshop sessions were developed along the notion of creating support in medical environments for educationally oriented programs. The people attending this conference represented the following disciplines: medicine, nursing, occupational and physical therapy, social work, clinical and developmental psychology, law, speech pathology and special education.

*Members of the planning committee included Nancy Sweet, Children's Hospital, Oakland, California; David Grove, Child Neurology Clinic, Portland, Oregon; Linda Gilkerson, Project WELCOME, Boston, Massachusetts; Linda Stone, ECHO Infant Project, Orlando, Florida; and Jennie Swanson, Project Pre-Start, Maywood, Illinois.

This proceedings document is designed to provide readers with a synopsis of the workshop proceedings.

Section I consists of a synopsis of the keynote speech presented by Dr. T. Berry Brazelton. Dr. Brazelton is Chief of the Division of Child Development at Children's Hospital Medical Center in Boston. He is also an Associate Professor of Pediatrics at Harvard Medical School. Based on his extensive clinical pediatric practice, Dr. Brazelton published his Neonatal Behavioral Assessment Scale in 1973. His keynote speech can best be summarized in his own words: "An assessment of an infant is a multi-dimensional opportunity--for diagnosis, for prediction and for entering the parent-infant interaction."

Section II includes the texts of three speeches delivered on the workshop's theme, "Building Relationships." These sessions were interspersed throughout the workshop to provide a sense of continuity and continuous development of the theme.

Dr. Linda Gilkerson, Director of Project WELCOME in Boston, was the first of the theme speakers. Project WELCOME was funded to demonstrate a coordinated hospital/community model program for the delivery of continuous service to infants admitted to intensive care units in the Boston area. Dr. Gilkerson and her staff had been in operation 10 months when she presented their month-by-month growth process in building relationships within the medical setting to the workshop audience.

The second theme speaker was Dr. Jennie Swanson, Director of Pre-Start Project in Maywood, IL. Her project, which was in its third year of serving families of infants from an intensive care unit, had just selected three hospitals from 10 applicants to adopt Pre-Start components. Dr. Swanson recounts her project's building of relationships between medical and educational personnel.

The last of the theme speakers was Dr. Earladeen Badger. She has been Director of the Infant Stimulation/Mother Training Program since it began in 1973 within the Newborn Division of the Department of Pediatrics at the University of Cincinnati's College of Medicine. Dr. Badger described the United Services for Effective Parenting (USEP), an organization of over 200 parenting programs in the State of Ohio, which she and many colleagues were instrumental in developing. This successful coalition, which helps parents provide optimal developmental experiences for their children during the first three years of life, has been incorporated for three years.

Sections III, IV, V and VI present synopses of individual content sessions. Each synopsis contains highlights and essential comments from individual presentations. Section III includes abstracts of presentations on preterm and postterm assessment of very young children. Section IV presents abstracts of papers delivered on topics related to programs for newborns and infants with emphasis on intervention strategies and program evaluation. Section V includes a wide variety of abstracts revolving around parent and family involvement, and bonding and attachment. Section VI includes

abstracts of presentations which dealt with issues surrounding financial support for programs, and legal and ethical dilemmas in neonatal care.

An interesting highlight of the workshop was a synthesis session, in which presenters summarized their presentation to the entire group and then related the presentation to the workshop's theme. This session proved an excellent vehicle for concluding the workshop.

In her summary statement during the synthesis session, Janet Greenwood explained, "The need to strengthen relationships between the health care and education service providers was the result of a need to identify very early and intervene with handicapped children and their families." The questions of who provides the services--the medical or educational community--was not an issue in this workshop. The question of where those services are provided--the medical facility or the school--was not an issue. What was widely acknowledged at this meeting was that regardless of how the services are delivered, and by whom, the foundation for effective intervention with at-risk and handicapped infants is cooperation and collaboration between the medical and educational service providers. Handicapped children and those at risk for developmental problems are frequently identified at birth or shortly thereafter. In recognition of this fact, the service provider must build relationships with the medical community where these children are first seen and identified, if the goal of earliest intervention is to be realized.

Several of the presenters during the synthesis session emphasized the gradual respect-building phase of establishing relationships between educators and health care personnel. Susan Derco's comment, "Building relationships between health care and educational service providers is a process which typifies the same reciprocity evident in mother-infant interactions," exemplified those ideas. Jennie Swanson challenged the group to consider whether once the initial relationship is established through mutual respect, would they "be able to expand the repertoire of relations and establish new interaction opportunities."

The final section of this document includes a report on evaluation results of the workshop as well as copies of the workshop evaluation form, the initial survey, the workshop agenda and an address list of presenters.

The document should acquaint the reader with the variety of topics addressed at the workshop and foster further interest in the need for developing strong, positive relationships between educational and health care disciplines.

Section I

Synopsis of Keynote Speech

Section I is a synopsis of the conference's keynote speech, delivered by Dr. T. Berry Brazelton of the Child Development Unit of Children's Hospital Medical Center in Boston, Massachusetts.

Assessment in Early Infancy as an Intervention

T. Berry Brazelton

The increasing ability of medicine to conquer physical disease has made it possible for educators and medical personnel to concentrate on the prevention of physical and psychological disorders and the mitigation of the effects of disorders on the quality of life for affected individuals. One direction which has proven effective in increasing developmental potential for affected children and their parents is behavioral assessment of the neonate through the Neonatal Behavioral Assessment Scale (NBAS) (Brazelton, 1973). Behavioral assessment of the neonate functions as both an assessment and as a form of intervention, and has provided a deeper understanding of the effects of assessment on an infant's potential development. In addition, use of the NBAS has provided valuable clues and tangible strategies to assist parents in having appropriate and successful interactions with their infant.

Research indicates the importance of at least two ingredients which influence the success of behavioral assessment of the neonate as an intervention:

1. Timing and quality of intervention which fosters the sense of competence in the developing child.
2. A responsive environment which assists the child's effort at compensatory learning.

Unless professionals understand these processes as contributors to the risk for developmental failure, as well as enhancers of plasticity or recovery from a deficit, we cannot begin to play an appropriate role in aiding the recovery of the at-risk infant. In addition, unless we understand and assess the interactive processes between parents and their infants, we are not likely to enhance the environment's role in fueling an infant's recovery. Oversimplified, non-individuated intervention programs may do more harm than good. The individuation of intervention programs and attempts to make the targeted infant feel in control of his/her destiny are critical to insure a responsive environment and create optimal results.

Why Early Intervention?

When the environment fails to appropriately adjust to a high-risk infant, early intervention may prevent a compounding of problems. Research indicates that premature and minimally brain-damaged infants seem less capable of compensating in deprived, disorganized environments than do neurologically sound babies (Greenberg, 1971). Damaged infants do not always elicit necessary mothering, which further compounds their ability to recover from a disorder. Assessment of a handicapped infant's effect on the nurturing responsiveness of the environment can play a significant role in mobilizing preventive energies to eliminate a compounding of early developmental problems. There is, however, a need for extended use of sophisticated assessment methods for neonates which enable an accurate prediction of the infant's contribution to the likelihood of failure in the interaction between the environment and the infant. There is also a need for better assessment of at-risk environments. More complete assessment would allow for a greater understanding of the dynamics of developmental failures and provide guidelines for appropriate interventions. It is important to remember that minimally brain-damaged infants do make remarkable compensatory recoveries in a fostering environment. The more clearly infants and the problems they present are examined and understood, the more supportive professionals can become in creating optimal conditions for infant development.

Forces For Normal Development

To understand what might contribute to an infant's failure to develop, we must understand the critical forces for normal development which are constantly at work, in and around the infant. There are at least three such forces:

1. Maturation of the central and the autonomic nervous systems which regulate the baby's capacity to control reactions to incoming stimuli.
2. Forces of competence within the child which are elicited by a feedback system which relies upon the completion of a task and the sense of competence that an infant derives from the accomplishment of a task.
3. Reinforcement from the environment around the infant which feeds his/her affective and cognitive needs.

Correspondent to the forces which define the infant's environment are the physical and emotional capabilities of the parents. The base for parents' capacity to nurture a new baby stems from their genetic potential and the influence of past experience. Healthy parents who have been nurtured themselves can be expected to adapt to the individual baby. Stressed parents might have less capacity for

nurturing because that capacity is dominated by their own needs and negative past experiences.

Developmental Model

From research that began in the 1950's, it became apparent that very powerful and distinct mechanisms seemed to dominate the neonate's behavior. Based on behaviorally identifiable mechanisms (Als, Lester & Brazelton, 1979) which explain a child's bimodal fueling system for interacting with the environment, we have conceived a developmental model for the neonate. The model incorporates the child's ability to achieve homeostatic control. Fueled by a sense of achievement from within, as well as the energy or drive to reach out and incorporate cues and reinforcing signals from the surrounding world, the infant initiates an ongoing, self-perpetuating process of development. The primitive reflexive patterns present at birth become better organized and more efficient with each new homeostatic accomplishment, and they form the base for building more complex patterns of development and stimulus correlation. This developmental model of behavioral responses incorporates other researchers' efforts to define the neonate's development (Bower, 1966; Condon & Sander, 1974; Meltzoff & Moore, 1977; Sander, 1977).

Forces for Failure in the Interaction

The pressures on parents to create a positive environment for their at-risk infant can engender a failure to provide nurturing intervention. Parents and infants alike need predictable positive signs as incentives to further a healthy relationship. When the feedback systems are not being completed in an expected way, the power of violated expectations for both the parent and infant can be extreme (Tronick, Als, Adamson & Brazelton, 1978). The potential for withdrawal from each other, and for ensuing failure of future interactions as a result of negative experiences, is also predictable. If the system is violated by a partner's nonreciprocity, the infant, as well as the parent will respond in negative ways. This indicates that the infant, even at an extremely young age, is strongly affected by the disturbance of failed interactions.

Likewise, parents are vulnerable to even mildly distorted cues from the infant. Grieving takes place when even a minor violation of parental expectancy about the birth has occurred. Defenses take the form of denial, projection of guilt onto others and detachment from the loved one. Successful intervention efforts must allow for the negative forces of grieving, yet work to elicit positive forces by utilizing the baby's best behavior to demonstrate ways to establish hope and reciprocity in the parents.

Neonatal Assessment

Behavioral assessment of the newborn presents a two-fold opportunity. It allows the examiner both to bring the infant to "best performance" on various items on the NBAS and, as the examiner works to achieve organization and social interaction in the infant, to identify with the parents and help them design appropriate and successful interactions. Thus, the assessment process provides for identification with the infant and the parent. This is particularly advantageous when working with high-risk or damaged infants, as creating positive responses in the infant allows parents to see the positive behavior of their infant, providing parental motivation for the nurturing process.

Assessing high-risk babies in the presence of parents can also result in the parents' gaining an insight into the examiner's efforts to contain the infant, to adapt stimuli to the infant and to elicit responses which do not exhaust him/her. Parents are able to lock onto two aspects of the high-risk baby with which they can work:

1. The infant's need for physiological control in order to maintain homeostasis while producing behavioral responses.
2. The attentive responses, which are often difficult to elicit.

The potential energy for recovery and plasticity in both the infant and in the parent is impressive. Repeated observations, shared with parents over the infant's first year of life, provide a tremendous vehicle to demonstrate parents' effect on their baby's progress.

Importance of Assessment of the Infant

Infant assessment provides a multi-dimensional opportunity--for diagnosis, for prediction and for entering the parent-infant interaction. The Neonatal Behavioral Assessment Scale (1973) provides a context for systematically tapping into the power of infant assessment. Administering the assessment gives infants a chance to demonstrate their processes of organization, of mastering their immature physiologies and reflex nervous systems, and of achieving an optimal state of attention for interaction with their environments. As infants demonstrate these processes, the educator can understand the relationship of responses to environmental cues. By understanding, the educator can hope to predict how infants will act toward other caring adults and add motivation to the process of creating nurturing environments by arranging for successful parent-infant interactions.

References

Als, H., Lester, B.M., & Brazelton, T.B. Dynamics of the behavioral organization of the premature infant. In T.M. Field, A.M. Sostek, S. Goldberg & H.H. Shuman (Eds.), Infants born at risk. New York: Spectrum Publications, 1979.

Bower, T.G.R. Visual world of infants. Scientific American, 1966, 215, 80-92.

Brazelton, T.B. Neonatal behavioral assessment scale. Spastics International Medical Publications, Monograph #50. London: William Heinemann; Philadelphia: J.B. Lippincott, 1973.

Condon, W.S., & Sander, L.W. Neonate movement is synchronized with adult speech. Science, 1974, 183, 99-101.

Greenberg, N.H. A comparison of infant-mother interactional behavior in infants with atypical behavior and normal infants. In J. Hellmuth (Ed.), Exceptional infant: Studies in abnormalities (Vol. II). New York: Bruner-Mazel, 1971.

Meltzoff, A.N. & Moore, M.K. Imitation of facial and manual gestures by human neonates. Science, 1977, 198, 75-78.

Sander, L.W. The regulation of exchange in the infant-caregiver system and some aspects of the context-content relationship. In M. Lewis & L.A. Rosenblum (Eds.), Interaction, conversation and the development of language. New York: John Wiley, 1977.

Tronick, E., Als, H., Adamson, L., & Brazelton, T.B. The infant's response to entrapment between contradictory messages in face-to-face interaction. Journal of American Academy of Child Psychiatry, 1978, 17, 1-13.

Section II

Theme Speeches

Section II includes the texts of three speeches delivered on the workshop's theme, "Building Relationships."

Building Relationships: Year 1 - The Dignity of Risk

Linda Gilkerson

I'd like to share with you in an informal way, some highlights, reflections and hypotheses from Project WELCOME. Although the project has been in operation for only 10 months, we have grown and matured through numerous stages of development. We have experienced fully the exhilarating, exhausting, satisfying and certainly nervewracking process of defining ourselves as educators within a medical setting.

Project WELCOME is definitely moving in an upward trend, consolidating our services, building relationships with medical personnel and redefining our goals in a now familiar environment. In order to best express our process of growth, I'd like to first give you the details of our project, its origins, and how we collaborate with both an educational college and a medical facility. Second, I want to informally take you through our first 10 months, sharing the developmental milestones as we experienced them. And lastly, I will extract from this period of growth and point out some important concepts that have been learned from our experiences.

Influencing Characteristics

Project WELCOME is a collaboration between Wheelock College which specializes in early childhood education and one of the largest children's hospitals in the country, Children's Hospital Medical Center (CHMC), in Boston. Initially, the idea for Project WELCOME came from outside of the medical setting--from the educators. Since the Infant Follow-Up Program and Neonatal Intensive Care Unit (NICU) staff at CHMC had already identified the need for further follow-up and more community linkages, the original response to the overture from the college for a collaborative project was positive. This positive response to the project from its conception was a mandatory building block for future problem-solving activities.

CHMC has specific characteristics which both clarify the rationale for Project WELCOME and indicate the reasons behind some of our trials in establishing ourselves in the NICU. CHMC is a high-powered, research-oriented children's hospital affiliated with Harvard Medical School. No babies are born at CHMC; all infants seen in the NICU are transported to the unit from a large number of

community hospitals located all over eastern Massachusetts and in neighboring states. The NICU has 16 beds and provides highly specialized medical care for newborn infants during the most critical phase of their hospitalization. As soon as the babies are off the respirator and gaining weight, they go back to the referring community hospital. Consequently, the staff in the critical care unit at CHMC do not have the opportunity to care for their patients and families during the intermediate or recovery phase. After treatment at CHMC, parents must make the transition to a different set of caregivers and to a hospital which is much less intense (which can be very helpful) and to a staff which is much less experienced with critical care procedures (which can be very scary for parents). The staffs of the community hospital newborn nurseries are generally well equipped for the routine types of newborn care, but are not prepared for the types of psychosocial and developmental supports which these children and their families need, and to some extent, have come to expect from their NICU experience. In addition, within this hospital system, community referrals to non-medical services can be easily overlooked. In CHMC there is a very strong program of primary care including a well-developed system of primary nursing. The nursing care for each infant is planned and monitored by one nurse (the primary nurse) and is carried out by a consistent team comprised of a primary nurse and two associate nurses. In CHMC, nurses are expected to assume major roles in family support, developmental teaching and resource identification, as well as in providing medical care.

The state of Massachusetts is most fortunate to have over 50 early intervention programs sponsored by the Departments of Mental Health or Public Health. These programs serve infants who are at-risk or display developmental delays or disabilities due to biological or environmental causes. Unfortunately, the average age of referral to the programs ranges from 18 to 22 months. Clearly many families could benefit from these services sooner, and many of these early referrals could come from the initial service providers in tertiary and community hospitals. Thus Project WELCOME was conceived to increase family supports, strengthen the developmental focus of the hospital nurseries and provide information, consultation and assistance in making appropriate community referrals for infants needing specialized educational and developmental programs and their families.

Developmental Stages

In reflecting on the first 10 months of Project WELCOME, it appears as if we experienced a developmental progression in building relationships within the medical setting. My hunch is, based on experience in two HCEEP demonstration projects located in educational settings, that most projects go through a similar growth process. Here is what our experience was like from my perspective as Project Director.

Honeymoon: August & September. The project began in a spirit of good will and anticipation. Not yet fully staffed, there was little contact between the project and hospital personnel. What little contact there was generally placed few demands on either group. During this period, we moved into our offices, began an informal staff orientation, interviewed for the remaining positions and planned activities and timelines. It was a fun time; key hospital contacts were cautious but curious to see the project develop.

Tentative Steps: October & November. As we hired staff and orientation to their direct service roles was initiated, the project began to have a physical presence on the unit. The NICU staff started to ask, who are these people? Why are they here and what is Project WELCOME? It is important to point out that during this period the project staff were still being oriented and did not, as yet, have a direct service caseload. During these months, the discussion of job roles began in earnest and the realization grew, for both the project and nursing staff, that these initial, tentative steps were determining each person's realm of responsibility. Consequently, feelings began to come up (on both sides) for the nurses, "I'm not sure I'm going to like this" and for the project staff, "I wonder if this is going to work?" Inevitably when feelings mount in relationships, they either are expressed or go underground. Either way, they eventually have to be faced. This is called the crash.

Crash: December - Mid-January. How do you know when you have reached the crash? Your staff gets the flu, the continuation proposal is due, and it feels like the project has just begun. Your colleagues at the college are talking about their Christmas vacation holiday trip and planning their January break. You know that you will be lucky to have even a few days off (not that you will relax or forget about the project). Holidays are rough times in hospitals too, and your project catches some of the overflow. Signs of withdrawal are everywhere. The nurses think the project staff are in the unit too much. You agree and say you won't be back for awhile. You eat everywhere but the hospital cafeteria because the stress is too great. You begin to feel like Project UnWELCOME. And hardest of all, you begin to doubt yourself. What does one do?!

Coming Back Together: Mid-January - February. The continuation proposal is finished and you finally relax for a day or two. A friend reminds you that this project was conceived and built with a lot of rational thought and support from both the college and the hospital. You begin to open up to a few people and let them see what it has been like and what your worries are. Their reassurance and encouragement are wonderful, necessary sources of support. You begin to believe that yes, it's OK to go slowly; patience does pay off, and you believe that the project will work out.

At this time, all the staff positions are filled. At the unit, the staff are functioning in their roles as social worker, parent/infant

educator and nurse consultant with their first few cases. In addition, some individual-to-individual relationships begin to develop. Issues which a few weeks earlier were too hot to handle, now can be addressed. Communication is not yet relaxed or easy, but each coming together takes things a step further. Through these contacts, the project's intentions are clarified; misunderstandings are mended; and, best of all, the opportunity for working together seems possible. While it may appear as if this phase is like starting over, the project actually has reached a new and more advanced level. And so have the developing relationships. Confidence and excitement are growing again--you realize that it may be possible to succeed after all!

Humming: February - March. The project is fully operational and things seem to be rolling along, making each step no longer brand new. You have experience to rely on and relationships have begun to grow. Routines have been worked out--how families are identified, when developmental consultations occur, how families will be followed into the community hospital and what kind of contact will be maintained with the early intervention teams who receive referrals. Improvements, refinements and re-evaluations are needed and occur; but the basic model has been established and is functioning efficiently.

Rounding Out: April - June. Realizing how well the project has developed in many areas, we have the time to identify the areas that were not addressed previously and to set priorities for the second year. The project is blossoming; extensions of the year's work are naturally evolving. Based on the work that has been done, we can foresee the possibility of some long-term, relaxed and consistent relationships with key hospital personnel. The case-by-case contact and collaborations with hospital personnel have paid off. Our clinical coordinator said all along that when people worked together on an individual basis, things would go more smoothly. And they seem to be. Knowing the importance of the project work and feeling the time flying by, we are looking to the future. Continuation is already a part of our vocabulary and we've begun to think about activities and decisions in terms of their future ramifications as well as their present realities. While the Reagan budget seemed like another crash, we are committed to our goal of continuation.

New Perspectives

During the last 10 months, we have learned a great deal about being educators in medical settings. This pertains to recognitions about the values and shortcomings of educational programs, as well as the inherent difficulties of existing within a medical environment. While our situation is somewhat unique, we hope that our experiences are applicable and useful to a wide range of other programs with similar settings and problems. The following topics constitute the

major issues that we faced and the most important ongoing challenges for our project.

Identity Crisis: It is my view that most educators entering the medical world experience some type of an identity crisis, which is both professional and personal. Professionally, the need arises very quickly on entering hospital life to clearly define for oneself and for others: What is early childhood education? What do special educators know and contribute to the well-being of infants and parents? Why should education be part of the services provided here? Since there is no Department of Special Education in a hospital, generally there is little established groundwork for incorporating this new professional group. It's up to the project staff to create its own place in this environment.

I found it important to re-articulate my own training, work experience and areas of expertise. One wants to be ready for the question: What do you have to offer? and to answer this question with confidence and ease. Personally, I found it essential to recognize and address my own experiences with doctors, nurses and hospitals. What experiences have shaped my views? Am I ready to relate to these persons, not as a patient, but as a peer? Many of us have mixed attitudes about doctors, fluctuating between feelings of being saved or terrified by them. Overcoming the "aura" of the environment is one of the vital steps which must be taken. Using the approach that the physician (or anyone in that environment who is perceived as intimidating) is just one member of the team, no more or no less, is essential.

The outcome of these personal and professional challenges has been a unique and powerful opportunity to learn about myself and my profession in a new way.

Staff Support: As a Project Director you are growing and changing, but so is your staff. We have concluded that a project like Project WELCOME is not the place to begin one's career. Experience, maturity, grace under pressure and a strong self-concept are essential requirements in a medical/education collaboration. A staff that gets along easily and respects and values professionals from other disciplines is not a luxury, but a necessity. The project staff has to direct their energies externally to the many tasks and relationships which need to be built. There is no time for the staff to drain themselves on internal issues. Equally as essential to the project success is the inclusion (as paid staff members or consultants) of persons who are known and trusted by medical personnel--ideally a physician and a nurse. Their understanding of the setting, their advocacy for the project and their ties to the unit can make things happen that would be impossible without their involvement.

Datebooks, Beepers & Alarms: Schools and hospitals are different in many ways, some practical and some philosophical. One of our first realizations was the different way that time is managed and

schedules are set in a hospital. Schools and educators function out of datebooks; NICU nurses and physicians operate off of beepers and alarms. Therein lies a key to understanding many of the practical and underlying differences in these settings. To a great degree, education is process-oriented; we generally know in advance when major events are happening. Educators can prioritize, plan and stick with our plans. We implement and then we debrief and evaluate. We usually follow a consistent schedule; predictable routine and smooth transitions are valued. Think about what a fire alarm is like in a school: even though warned in avance, the children are keyed up and the adults on alert. The contrast to the daily routine is dramatic. An NICU is a fire alarm all day long. I must admit that as a preschool special education teacher there were times when my classroom seemed like a fire alarm all day long; however, these times were not typical; and when they occurred, it was felt that something had gone awry and needed to be changed. Not so in a NICU. These urgent moments are the focus of the staff's training as emergency medical specialists. This is part of what has drawn this group of persons to this particular environment. NICU staff are trained to shift priorities in a moment's notice. Process is important, but minute-to-minute demands have highest priority. For example, you can be welcomed on one day and ignored the next when two sets of twins have just been admitted and need attention. You can schedule an important activity and no one will appear because there's a crisis on the unit.

So you learn to adapt--a wonderful quality of educators. Instead of pulling out your datebook to arrange a meeting, you catch people on the run, call the night nurses after 11:00 PM to schedule an early morning time to see them before they go home. You remain unruffled in a group discussion when your handouts pass by one of the residents who has fallen asleep. You are aware and pull back when an infant is in crisis. You learn who can sit through a three-hour Advisory Board meeting and who does best in a ten-minute phone call. You use the paging system effectively and check the schedule sheet to see when the primary nurse is on duty. Our staff, particularly the parent/infant educator and social worker, have been masterful in this new model of stop-and-go communication which is a survival skill on an NICU project.

Emotional Climate: As educators, we have been trained to break tasks into very small steps, be patient and supportive, reinforcing and facilitating. We have not been trained to be confrontive. In a critical care unit, confrontation is part of the scene. Time for considering feelings is not always possible; direct challenges are used to get to issues quickly. There's a feeling that one always has to know what one is doing and be ready to defend it at any time.

In addition to being more direct, it is also my impression that hospitals can be more intimate than schools, both physically and emotionally. Staff and patients change clothes, take naps, eat, stay overnight--activities ordinarily reserved for home. Staff spend time

together which is usually spent with family and friends, time when you generally let down your guard--evenings, late nights, early morning, weekends, and holidays (Christmas Eve or Thanksgiving Day). Those of us 9-to-5er's who work in hospitals but who don't share in these times or who are not on call 24 hours a day, may miss out on part of the camaraderie shared by others. Some of life's most poignant and emotional experiences occur in hospitals--birth, death, recovery from serious illness or learning that a child has special needs. Feelings which are rare in schools are a part of each day in the hospital.

View of Development: Knowledge of child development is esential to being a successful early childhood educator. In fact, the more we know about and understand development, the better we are in our jobs. Development, as yet, does not hold the same place in the medical profession. It is quite possible to be a very good neonatologist without knowing a great deal about development. It is also possible, although less so, to be a successful neonatal nurse without extensive training in child-development. Developmental services in medical settings usually have low priority and a low status. Even physicians labeled "developmental types" find it difficult to function in the hospital environment.

Respect for Early Intervention: We believe that the earlier developmental and learning problems are identified and addressed, the more optimal the functioning of the child will be. We also view our services as supportive of parents. These beliefs are not shared by all health care professionals. In fact, the opposite can be true. Health care professionals may feel that early detection will alarm parents needlessly and that additional support may increase parents' feelings of inadequacy. Some physicians refuse to recognize the importance of behavioral programs until they see hard data in the form that they are most comfortable with--double-blind control group studies: "What I want to see is data like we have on the polio vaccine and then I'll believe in these programs." Some nurses have the attitude, "Developmental intervention? I do it already. What can <u>you</u> tell me?" Social workers may feel that early educational support is not what a family needs at all but that casework and social services are the real needs.

Educators may also have some overriding preconceptions. Let me mention a few of these. The first is "Oh, how wonderful! You're working with physicians." Yes, it is wonderful to work with physicians and nurses but no more wonderful than providing consultation to family day care workers or teaching in a preschool classroom. The second attitude is "Let's get this child into a program," which is a fine idea as long as the program has specific and helpful services appropriate for that individual child and family. The last attitude I'll mention is our proclivity to take on the world without giving ourselves adequate time or training or support. We are such effective, on-the-spot, practical thinkers that we can neglect

developing a strong and careful theoretical base for our work. The medical world's dependence on research and on protocol provides an important challenge to our ability to demonstrate our effectiveness on paper, as well as in person.

Stereotype of Infant Stimulation: In Project WELCOME we have taken care to explain the difference between infant stimulation and developmental intervention. Most people have heard of infant stimulation programs and many hold a narrow view of what these services are. They believe that infant stimulation programs "jazz up" babies and exhaust parents. Over and over, we say that early intervention programs usually have a family focus as well as a child focus. In addition, we emphasize that intervention program staff typically are knowledgeable about a wide range of community services, that they serve as strong family advocates and as effective case managers.

Regarding developmental intervention, our parent/infant educator has continually pointed out that not all infants need to be stimulated. Calming and soothing techniques coupled with reading the infant's cues for time out from interactions are some of the most important messages one can convey to parents. Research shows that a low-key approach to young infants tends to elicit "approach" behavior, while a high-key approach elicits "away" behavior. Our philosophy views developmental intervention or, better yet, developmental teaching as attitudes more than activities, observations as well as manipulations and interpretations as much as elicitations.

Because the early intervention programs in Massachusetts are relatively new and because they differ in their staff composition, hospital personnel who do not have direct contact with the programs may hesitate to make a referral of a high-risk, post-critically-ill infant to programs with "just teachers." More likely however, hospital personnel will not have enough information about the services to consider a referral. Thus one of the major thrusts of our early intervention liaison person has been the gathering and dissemination of information about early intervention resources for the NICU and other in-patient and out-patient clinics in the state.

Focus on Disciplines: Differentiation among disciplines tends to be more strictly and overtly observed in hospitals than in schools. Outward signs are evident in nameplates with educational degrees and the use of titles in speaking and writing. Differences in dress (uniforms versus street clothes) and income and status are very present. Not only are disciplines more clearly delineated (how many transdisciplinary teams are located in hospitals?), but traditionally one discipline--medicine--has had substantial power and authority over the others in a hospital. These hierarchies are beginning to be jiggled by liberation movements in the nursing profession and by consumers; however, in most settings the traditional model remains.

In this discipline-oriented atmosphere, the established relationships of doctor-to-doctor, nurse-to-nurse, and social worker-to-social

worker are often the most effective lines of communication. A useful rule of thumb is that when there is doubt about whom to ask about something, no one profession can speak for another. A project approved by the physicians may not have the support of the nurses and vice versa. Educators may want to change nursing practices, but nurses have to want these changes for themselves. It takes time to understand the existent lines of communication in a hospital. In fact, understanding the communication system in this system is one of the major activities of a first-year project.

Basis for Collaboration

Hospitals face all of society's oppressions: sexism, classism, racism, ageism (oppression of older persons), adultism (oppression of younger persons), anti-Semitism, ablebodiedism and others. We are defining oppression here as the systematic invalidation or putting down of one group by another. Not only do medical settings deal with the oppressions from outside (in the larger society) but also with the internalization of these oppressions. Internalized oppression occurs when a group begins to believe the invalidation of itself and treats members of its own group in oppressive ways. Nurses with Master's Degrees may have difficulty establishing working relationships with nurses with two-year degrees and vice versa. Pediatricians who treat the low-status group of children may be less respected or less well-paid than physicians who treat adults. Physicians who do developmental research may be looked down upon by the "hard scientists." In education, internalized oppression occurs as well, when kindergarten or special education teachers are not accepted as full participants in the informal network among teachers in a school building.

Where does education fit into the hospital? Educators enter the hospital as another low status group. Therefore the chances for conflict are greatest with other groups who have been similarly viewed in society and who have related responsibilities (groups such as nurses or social workers). Oppression is perpetuated in our society by keeping people separate and making them believe that if one group gains, then the other must lose. A way to combat the internalization of oppression is, in every situation, to treat each member of one's own group with nothing less than complete respect. Oppression in the larger society can also be interrupted in the same manner, by treating each member of every group with complete respect--every nurse, social worker, physician, therapist, teacher, unit clerk, housekeeper, administrator or food services worker. This is the kind of profound change that must occur to make any institution a safe place to work where every individual can function optimally.

As part of an educational/medical collaboration, the staff of our project has had the opportunity to view each other and hospital personnel as trusted allies. That is the secret to building relationships. While not without risk, it is a goal which is within our reach and certainly worth obtaining.

Building Relationships Between the Medical and Educational Communities: What Is, What Was and What Might Be

Jennie E. Swanson

In the last six years the relationship between educational and medical personnel has improved considerably, but the need for developing firm and workable relationships between these two disciplines is an extremely pressing matter. No longer is the major issue that of creating a place for educational personnel within medical settings; we must now consolidate the already existent health care/educational relationship and extend the present service system to rectify the most obvious weak points in our services to infants and families.

I would like to approach this topic of building relationships in a number of ways. Initially, I will talk about the published Report from the Select Panel for the Promotion of Child Health, Better Health for Our Children: A National Strategy (1981), which summarizes the state of child health care in this country. I consider this report as **What Is,** a formal, comprehensive statement of the child health field. Next, I will present my personal experiences upon entering this field and briefly outline the development of the Pre-Start program in Maywood, Illinois. These experiences, from my perspective, represent **What Was.** And finally, I would like to look toward the future and suggest some prospective joint goals for medical/educational professionals. These projections of **What Might Be** are gleaned from my personal experiences and represent some tangible suggestions for extended medical/educational linkages.

What Is

The report, Better Health for Our Children: A National Strategy (1981), elucidates a number of especially germane concerns relating to the need for educational, health care and medical personnel to build strong service relationships. Specifically appropriate to this presentation, the report indicates that although enormous strides have been made by health care agencies, the inequitable distribution of services, the lack of emphasis on preventive care and the lack of interagency cooperation are substantial detriments to the creation of more efficient and wide-spread delivery systems. Better Health for Our Children: A National Strategy (1981) lists five overriding concerns:

1. Many forms of disease prevention and health promotion are demonstrably effective, especially for children and pregnant women, but still are neither widely available nor adequately used even when available.

2. The health status of American children has improved dramatically over the past two decades, but not all groups have shared equally in the progress. Sharp disparities persist in both health status and the use of health services according to family income, ethnic background, parental education, and geographic location.

3. The profile of child health needs has changed significantly over the course of this century, partly because new problems have emerged. But the organizational, administrative, financial, and professional training aspects of our health care system today have not been adapted to cope with current health problems which have intertwined psychological, environmental, social, and behavioral components.

4. While the family is and will remain the primary source of health care for children, the current health care system seldom recognizes or supports this role. Nor has the system acknowledged or adequately responded to the health implications of the changing composition and circumstances of the American family.

5. The nation's increased investment in maternal and child health over the past two decades has spawned many new programs, but they are not working effectively in relation to one another. Public programs have made a significant contribution to improving the health of the nation's mothers and children, but there remain gaps in and between services, fragmentation and duplication in both programs and services, and conflicts among various levels of government and among a variety of programs (p. 2).

The report further states that "Many of the strongest influences on child health lie beyond the reach of personal health services. These include the social environment, the physical environment, nutrition, and health-related behavior" (p.3).

The report recommends that extended service systems be established to perform three major functions: 1) to organize and structure services for families with handicapped, chronically ill or severely ill children, and for high-risk pregnant women and low-income families; 2) to integrate the efforts of maternal and child health authorities with school-based efforts under P.L. 94-142; 3) to change the profile of primary care to emphasize health promotion and disease prevention. In essence, this report substantiates the

field's advancements but calls for extended relationships between educational and health care professions as a means to offer more efficient, comprehensive services to a larger population.

What Was

I first began to explore the opportunities which were available to an infant/family facilitator(educator) in 1975. At that time, I had been the director of an early childhood/special education program for three years and became increasingly aware of the need for earlier intervention. Research findings which were reported in the literature indicated that a high percentage of handicapped children began life in perinatal high-risk centers. But when I contacted the six high-risk centers in the Chicago area to inquire about openings for an infant/family educator or a child development specialist, I was told that there was no such position in any of the centers and that there were no plans to hire one in the near future.

During this period of exploring opportunities in infant education (and having little success) I was on tenure in a large public school district. My salary was ample and reflected my status as the only woman in central administration. But a gnawing sensation within me would not let me rest. My belief in early facilitation made me restless to try a new, earlier approach to intervention. I wanted to pursue this career, and finally one Sunday morning, I found a small, three-line ad for a Perinatal Education Coordinator in the newspaper want adds. I bounded to Webster's dictionary to look up perinatal. Much to my delight, it meant "around birth." One drawback was present, however; the position required a Master's degree in nursing. I rationalized that a doctorate in human growth and development would more than compensate for my lack of nursing experience. I made an appointment for an interview and finally accepted the position at Loyola University's McGay Hospital which paid one-third of my present salary and was only part-time (three days a week). Although my family supported my career change, they were amused at my excitement over a job with less pay, no contract, no tenure and no pension. I convinced them that the fringe benefit was the exposure to the newborn high-risk nurseries and the follow-up clinic in the hospital. I quickly decided to spend my two free days a week volunteering in these areas and extending my knowledge base in this field.

Dr. William Coyer, the Director of Newborn Care at that time was beginning to realize the value of early facilitation, parent support and education. We designed a high-risk follow-up team composed of a neonatologist, a neurologist, a social worker, an orthopedic specialist and myself (a child development specialist). This transdisciplinary team initially met once a month and saw four infants in an afternoon. While effective, it soon became clear that this model of follow-up was too costly, too time-consuming and not systematic (i.e., access was not available to all of those in need of services). The team next set about trying to develop a follow-up

model which was responsive to parent needs and pocketbooks, and which incorporated the best information we could garner from medicine and education. We applied for funding from the Handicapped Children's Early Education Program for a Model Demonstration Project based on this model, but we were not funded. We went back to the drawing board and applied for funding a year later. That time we were successful, and thus began (in 1978) the Pre-Start Program.

Since January 1981, the Pre-Start model has gained wide-spread acknowledgment and replication. All infants and their families from the Loyola Neonatal Intensive Care Unit (approximately 535) will receive services based on the Pre-Start Model. In addition, the present evaluation/data management system of Pre-Start will be incorporated as a regular part of Loyola Hospital's follow-up procedures. Beginning in July 1981, three hospitals (selected from 10 applicants) will adopt Pre-Start components for their follow-up programs. The hospitals are Christ Hospital and Cook County Hospital in Illinois and Methodist Hospital in Indiana. Three Illinois school districts also have been selected to participate in a medical/educational internship with our project. Public Health nurses in Western Cook County have requested follow-up training for their home visiting program which serves rural, urban and suburban areas. The largest high-risk population is from Cook County Hospital, an inner city high-risk center with a high percentage of public aid patients; this center has requested Pre-Start Outreach services as well.

This sounds like a rags to riches story. But, let's look closely at the agony, pain and joy of building relationships between medicine and education in a bit of verse called "Rebirth of a Teacher."

Rebirth of a Teacher

I was a fetus--safe, secure, nurtured,
and protected;
Then a combination of signals were slowly
detected.
It was time to venture forth to a new
life outside;
There were no hand holders and no healers
to help my pain subside.
The early days and weeks of life were
blurry bits of hell;
I was in a land I didn't understand; and
I had no one to tell.
The language was a litany of alien multi-
syllabic words;
The context was often difficult--a conglomerate
of absurds.
I was in the sensorimotor phase when it came
to the medical school scene;

I needed concrete experiences and a meaningful
behavioral scheme.
Sure, I had the capacity to reach a high
potential;
But somehow I couldn't break the code--that
was the differential.
Then one doctor who was a teacher in
disguise;
Said, "Here's a pocket medical dictionary and
I'll teach you besides."
Just jot down your questions and then we'll
talk about them;
And as he taught me, I found I also taught him.
He said that doctors know very little about
how children think and feel;
I said, "I don't know anything about the whole
physiological deal."
Then the Chairman of OB said, "Jennie, I think
that you're the key."
I said, "Key to what?" He said, "To evaluate
maternity."
The long-term outcome of the infant was what
he meant;
Then I realized the meaning behind the medical/
educational complement.
This doesn't mean it's easy; a non-med and a
woman even at that;
There's not a place that's carved out; there
is no welcome mat.

Each of us, as teachers, must make our way alone.
We have to first be learners and suffer the
agonizing plight;
Of cognitive disequilibrium on which Piaget
shed the light.
It is, he said, the basis of intellectual thought;
So if it's cognitive conflict that is sought,
Just go to your local medical school--
Volunteer--listen--learn and share--that's
the rule
And, if one day you reach the logical operational
phase,
You will soon surmise;
For a teacher in a medical school, you'll first
be a learner, if you're wise.

Although neonatal programs are each somewhat unique, and hospital administrations do differ, certain conceptions and misconceptions of educators and medical personnel may be present in any circumstance where educators and health care personnel work

together. From my experience, the following have been important realizations gathered over the past five years.

1. Physicians generally do not have experience or knowledge of infant development areas other than physical or motor development.

2. Physicians are often hesitant to refer an infant for early intervention services due to a lack of knowledge and/or availability of information about the effectiveness of such services.

3. Educators are generally not aware of the high concentration of at-risk infants in the perinatal centers.

4. Educators typically do not use a scientific approach to problem-solving and methodology and, therefore, may appear unscientific.

5. The relationship of health and education has not been emphasized in research until recently, i.e., the physiology of learning, stress effects on health and learning, orienting responses and heart rate effects and education for self-help for health.

6. The professional jargon is quite different for medicine and education.

7. Two separate systems exist in medical center operations, medicine and nursing, each with a different administration. Doctors give orders; nurses carry them out. Educators may not easily adapt to this situation and consequently may have difficulty developing a collegial attitude with doctors.

8. Approaches to problem-solving may be different in each discipline. Educators often socialize and "process" ideas to solve problems. Medical personnel tend to use authority figures or journal articles as sources for problem-solving and may resent the time required to "process" ideas.

9. The ultimate evaluation of perinatal expertise and technology is the long-term outcome of the infant. This outcome is affected by environmental influences, particularly the parent/child relationships. Early referrals and facilitation of infants with special needs seem to result in a better infant outcome. The medical/educational team will probably slowly become the standard in all of our Chicago area centers. (Three centers in Chicago now have parent/infant educators.)

10. The hospital is the entry point for most of the infant population and is the logical access point for early screening. Parent/infant educators usually have the skills and ability to do the screening and to coordinate programs with the public schools under P.L. 94-142.

11. Both physicians and educators have substantial contributions to make to infants and their families. We need to get together professionally rather than expecting the parent to coordinate the two disciplines (neither of which is a precise science at this time).

What Might Be

In projecting future trends and possibilities of medical/educational collaborations, I would like to restrict my comments to the area of how we as professionals perceive the parents of handicapped infants and children and how a new perception of the parents' role could, in turn, affect the way we administer our services and how effective these services will be.

I believe that we have focused on the problems, rather than the competencies of parents. Parents of children with special needs face a unique situation and need special support services. It doesn't take a lot to love a baby:

who grasps your finger on contact,
who looks into your eyes,
who excites upon your appearance,
who quietens to your voice,
who is cuddly and easily soothed,
who has regular sleep periods,
who feeds with gusto and is satisfied after feeding, and
whose looks are so appealing that you are drawn to interactions.

But when you are a parent of an infant with special needs, perhaps you have a baby:

who doesn't grasp, suck, or cry,
who is either asleep or feeding,
who gives few, if any, visual cues of your presence,
who has labored breathing with deep retractions and nasal flaring,
whose skin is transparent, and
whose size and condition scream "Fragile--Handle with care."

Then you are a parent who will be challenged to be more. You are not to be pitied; you are to be admired when you meet the challenge.

While this positive perception of a parent is simply an attitudinal change, it could have large-scale and important ramifications

in the orientation of our service systems. From this change, the conceptual basis of our services may result in a plan which emphasizes the positive adaptation to the crisis of the parent of an at-risk infant. Consequently, the goal of medical/educational linkage stressing a jointly coordinated, positive education plan might result in:

1. A new perspective on parenting which focuses on competencies.

2. A new way for professionals to relate to parents--not as therapists, teachers, healers, experts--but as partners and friends. As a partner who isn't afraid to be involved: one who bases respect on one's competencies and personhood--not on one's credentials; one who is emotionally available and listens caringly; one who doesn't over-react or overprotect and usurp the rights of parents; one who is a resource and helps increase the parent's options for actions; one who is competent enough to allow others to be competent.

3. An active opportunity for educational collaboration in research, joint courses, joint professional appointments and team clinics.

4. A new role for parents which identifies the parents as the primary facilitators of the infant and active members of the team, not merely as recipients of the team's decisions and recommendations.

5. A new appreciation by the medical and the educational communities of the importance and impact of the early years on the quality of life in the later years.

In summary, medical/educational cooperation is both possible and necessary for an increase of effective health care and educational systems in this country. The report of the Select Panel for Child Health elucidates the gains that cooperative efforts have caused in the past and also points out that extended joint efforts are the way of the future. My personal experience confirms the report's conclusions.

The future possibilities and opportunities for collaboration are just beginning to be explored. The guidelines and processes for Health Care/Educational linkages are already existent in numerous centers scattered throughout the country. At this point in time, I feel strongly that it is not a question of whether the health care/educational relationship will expand, but when, and how the disciplines will take the initiative to implement the beginning stages of extended interprofessional functioning in a preventive program for infants and their families.

Reference

*The Report of the Select Panel for the Promotion of Child Health (Executive Summary). Better health for our children: A national strategy. U.S. Department of Health and Human Services, Public Health Service, DHHS(PHS), Publication # 7955071, 1981.

*This document is available at no cost from the Office for Maternal and Child Health, Health Services Administration, Room 739, Parklawn Building, Rockville, Maryland, 20857.

A Grassroots Approach To Institutional Change

Earladeen Badger

> There is no machinery for change. It comes about unexpectedly. It comes about through an individual, through a small group, through prophets. And you can't program prophets, or recruit them. These people just run up and invent their own way. That is the way that change happens. (Wills, 1972, p. 36)

I intend to develop this concept for change by describing how the actions of numerous individuals served to strengthen and amalgamate over 200 parenting programs in the State of Ohio. The statewide organization which resulted, United Services for Effective Parenting (USEP), helps parents to provide optimal developmental experiences for their children during the first three years of life. Although USEP's ideology is based on many well-known assumptions and values (Family Impact Seminar, 1978; General Accounting Office, 1979; Keniston, 1977; National Research Council, 1976), its uniqueness is that USEP came into being without benefit of federal mandate or initiative. USEP was initiated and has succeeded because imagination and adaptability in problem solving are still possible in grassroots efforts. As a result of its grassroots origins USEP can serve as a case study of institutional change. By examining the early beginnings of USEP and following its growth into a statewide organization, one basic idea becomes clear: Change is possible and can be implemented through the hard work and creative planning of dedicated people.

Early Roots of USEP

It is with a great deal of pleasure that I share my subjective impressions about the roots of USEP. My experiences over the last 15 years as an early childhood educator have shown that how we evolve as adults is a result of our early experiences (most early childhood educators should subscribe to this belief). Our evolution as professionals and as a profession can, as well, be examined from the vantage of its beginnings. My experience with various educational programs and with USEP from its conception has shown that certain aspects of program development are common to most educational models. By tracing my involvement with various programs I hope to

show how USEP evolved and to itemize the components of this organization that appear essential to its success and growth.

In the field of early childhood education, it is a documented fact that no activity, regardless of its worth, can have a large impact if conceived and executed in a vacuum. For example, the program designers of university-based research models funded during the 1960's spent little time sharing the results of their developing technology outside of their academic peers. These research programs were experimental in nature and consequently, a rationale can be made for their lack of dissemination activities. But, during this era, additional federal funds were deployed to ameliorate the learning deficits of poor children through the Head Start Program. The ramifications of the Head Start Program were considerably different than the university-based research programs. These two program prototypes, university-based research and Head Start service, developed along parallel lines and served the same population of disenfranchised preschoolers. But when funding ran out for the university-based research models towards the end of the 1960's, there was no widespread replication of the educational models. The research never impacted the field of education to any great extent. Head Start program deliverers, on the other hand, continued their service efforts with little technical assistance in either program design or evaluation; those areas in which the research programs were supposed to provide technical assistance and innovation.

My involvement with the Parent and Child Centers (PCCs) as the Project Advisor gives further evidence of the relationship between the efficacy of educational innovation and the evaluation and dissemination efforts of a new program. Beginning in 1967, 35 centers were funded by the office of Child Development to serve children aged birth to three and their parents. Originally, I naively believed that the Mother Training Program (Karnes, Teska, Hodgins, & Badger, 1970) I had developed in a university setting could and should be transplanted to the field settings provided by the PCCs. At this time, I had just completed an OEO Leadership Training Fellowship (1969) at the University of Illinois and was confident about what I might provide in the areas of program development and evaluation. J. McVicker Hunt, a staunch believer in the efficacy of early educational intervention for children of poverty and Chairman of the Special Task Force appointed by President Johnson (which created the PCC concept) was likewise enthusiastic about my plans to transport the Mother Training Program to these federally funded demonstration centers.

My experience from 1969-1972 as a special program consultant with the PCCs was extremely sobering. With the exception of two rural programs, Southern Illinois and Northwest Georgia, where I was able to work cooperatively and effectively with parents, staff and the delegate agencies in building program cooperation, I functioned primarily as a trouble shooter between the PCC, the delegate agency and the Office of Child Development. Urban PCCs in particular were plagued with administrative and organizational

problems which negatively influenced program development. These organization problems filtered down to staff and parents, resulting in high turnover of staff and poor family participation. Not surprisingly, the PCCs resisted evaluation of their program impact on children and families. Consequently, 14 years later with the exception of three of the PCCs which have since been designated as research sites, the PCC models have operated in a vacuum. And unfortunately, the survival of birth-to-three programs in this country cannot be argued from the PCC experience. In addition, another pertinent point is manifest from the PCC experience. The federally funded PCCs spent $175,000 a year to create an effective learning environment (Work, 1972). Obviously, money alone was not the guarantee of a successful program as many PCCs were indeed well funded, but lost track of their major goal--that of bringing children and parents together to support their mutual growth and development.

In 1973, I drew from my successful experience in working with low-income parents in the original Mother Training Program, the positive involvement with parents in the Southern Illinois and Northwest Georgia PCCs, and the experimental edition of the Infant and Toddler Learning Program (Badger, 1971); and I began to develop the Infant Stimulation/Mother Training (IS/MT) Program within the Newborn Division of the Department of Pediatrics, U.C. College of Medicine in Cincinnati, Ohio. From its inception, the IS/MT Program had strong grassroots qualities. The lack of any substantial funding precluded the involvement of individuals whose services could be bought and attracted instead a cadre of professional volunteers. The quality of our efforts to intervene with a socially high-risk group of parents (mothers 16 years and younger) sprang from a commitment to start at the beginning and to provide comprehensive health, educational and social services in a humanistic manner.

The interest in the IS/MT Program both within and outside the medical center assured me that this early educational intervention model was not going to occur in a vacuum and incur the fate of the PCCs. Based on the success of a coordinated research and service-oriented pilot program (Badger, Elsass & Sutherland, 1974), we began to expand our services through an adapted service program, recruiting a new group of mother-infant pairs each month. Program replication by other community agencies also began to occur as we trained a new instructor with each series of 20 weekly classes. To date, approximately 1000 mothers and their infants have been involved.

In 1974, when the IS/MT Program became involved in spawning new programs, I saw the need for extended coordination, accountability and coalition-building. Since most new programs had only incidental funding from their sponsoring agency, program deliverers required a good deal of outside support and consultation. The lack of funding created a need for cooperation which in turn, resulted in an overall camaraderie from the beginning of USEP in Cincinnati. With token funding and low-service priority for birth-to-three programs in their respective agencies, providers felt the need to get together on a

monthly basis for emotional support. This movement toward cooperation demonstrated that health care, education and social service agencies could unite at the delivery level to share information, resources, referrals and staff development programs for the benefit of all. This sharing occurred informally at first, but it soon became apparent that funding needs, program accountability and a central referral system could be accomplished through the institution of a corporate identity for USEP. USEP's constitution and by-laws could provide an organizational structure which would legitimatize programs for high-risk infants and their families in several ways. By forming a coalition, we were able to accomplish five goals:

1. To increase the visibility and acceptance of these programs.
2. To marshal community and state support for the inclusion of Family Life Programs in Ohio's Title XX service plan.
3. To expand promising pilot programs with Title XX monies.
4. To involve the University of Cincinnati's College of Medicine, the Health Department's Maternity and Infant Care Project and the State Department of Maternal and Child Health by providing funds and office space for a central referral clearinghouse within the Newborn Division of the Department of Pediatrics.
5. To identify, refer and track parents with children younger than 3 years of age who were interested in joining programs within the USEP network.

An Intermediary Stage of Development

In 1977, USEP as a collective movement of agencies in Cincinnati was an important model of interagency coordination and cooperation. This loose coalition of individuals--comprised of teachers, nurses, social workers, psychologists, pediatricians, and experienced, informed parents--was able to identify problems and solutions related to program development and to implement a coordinated plan of action. According to Marris and Rein (1967), such a cooperative effort is not possible through a strategy of bureaucratic coordination and national planning. Instead, advocacy succeeds when "it demands no prior commitment, and threatens no jurisdiction. It does not predetermine the targets of reform, or theorize its plans, but exploits its chances. The flexibility makes it less vulnerable, more resilient under attack, and surest of its goals" (Joint Commission on the Mental Health of Children, 1969, p. 162).

Statewide interest in USEP seemed to warrant that the USEP concept, if not the organizational model, be spread to other cities. But how to proceed? Since the funding of birth-to-three programs was, at best, tenuous, our tactic was to involve decision-makers at the state level. A selected audience of 40 state leaders--heads of state departments, therapists, educators, social workers and doctors-attended a one-day symposium (May 19, 1977). The upshot of this

symposium was that a 12 member steering committee was formed to bring together birth-to-three programs in the State of Ohio. Although most of the symposium participants were interested in a statewide organization, only 12 members of the audience responded enthusiastically to the organizational model embodied in USEP. The steering committee's first order of business was to find out where the programs were and whom they served. A program questionnaire was prepared and circulated by Home Extension Agents in each of the 88 Ohio counties. The questionnaire resulted in a state directory of birth-to-three programs. In addition, respondents indicated an interest in attending a state conference for infant/family educators. The resulting conference, the Ohio Statewide Parenting: Birth-to-Three Conference held in May 1978, became a consolidating event for educators in Ohio and the direct impetus for the formation of USEP-Ohio.

The Conference was planned around the basic grassroots philosophy that enlisting personal support was as important to early childhood practitioners as exchanging program information and strategies. The conference, it was hoped, would offer an innovative approach to learning, i.e., person-centered education (Fairfield, 1977) by providing an environment for interaction among participants who already manifested professional educational expertise. In addition, the conference was designed to add to the baseline data gleaned from the program questionnaire and to specify the expertise of the participants by covering four in-depth areas of major concern: Intervention Strategies, Program Logistics, Child Development (Theory into Practice) and Program Evaluation.

The 120 persons who attended the conferences were a diverse group, drawn from institutional delivery systems, small privately funded programs and State Department heads who had been involved in the "Decision-Makers" Symposium of 1978. In spite of the differences in the audience's background, all the participants were united by their commitment to the fullest development of parents and their children. As a result, the conference provided a wealth of information and established a unified group of child advocates throughout the state of Ohio.

Formation of USEP-OHIO

By May 1978, the groundwork for a statewide organization was well established in Ohio. At the wrap-up session of the Birth-to-Three Conference, the leadership of the USEP steering committee was formally recognized, increased from 12 to 30 members to provide equal geographical representation and delegated three major responsibilities:

1. To prepare and circulate a state-of-the-art report and directory of programs from the data collected from the program questionnaires and the summaries of the four conference workshops.

2. To share relevant program information through a periodic newsletter.
3. To continue coalition-building among birth-to-three program providers by planning a second statewide conference.

The 30 members of the new steering committee demonstrated incredible energy and enthusiasm. During the first meeting, the State of Ohio was divided into 12 geographic regions; and everyone agreed to work within assigned areas to begin coalition-building efforts. The Cincinnati experience was shared so that other regions could replicate the USEP model. Furthermore, the Committee members agreed to document their coalition-building efforts by sending progress reports to the Cincinnati office for inclusion in bi-monthly newsletters. And not surprisingly, they also eagerly agreed to plan and lead workshops for the second annual statewide conference. The personal investment that every member promised was a dramatic testimonial to the potency of grassroots efforts as instruments of social action.

With the commitment of the steering committee members, USEP-OHIO became a non-profit corporation with a constitution, bylaws and IRS tax exemption status. Two of the major corporate officers were located in the Cincinnati office which was housed at U.C. College of Medicine. Members of the expanded steering committee, later called the Ohio Council, were appointed as the organization's Board of Trustees.

Progress of USEP-OHIO

It has been three years since USEP-OHIO became incorporated and the 30 members of the Ohio Council began to provide leadership and direction in coalition-building efforts within 12 designated state regions. The Committee had four major goals:

1. To build bridges between programs at the local, regional and state levels.
2. To offer consultation to the membership and community at-large.
3. To coordinate program services and resources.
4. To establish local, centralized referral sites.

These goals have been actualized through the use of meetings, a newsletter, the USEP-OHIO Directory of Services and the annual statewide conference. These communication devices serve not only to strengthen and coalesce the efforts of program providers, but also to address program continuation and survival.

The leadership provided by the Ohio Council is the strength of USEP-OHIO. Council members have worked diligently and creatively to replicate the Cincinnati experience in their regions. While coordinating programs and services at the local level is the

most difficult and time-consuming part of their job, they have nonetheless persevered. The reinforcement they receive from other Council members as they share their respective successes and failures has served to intensify their efforts in regional coalition-building. We have learned that 1) each city has to develop its own methodology, 2) the Cincinnati model can offer only a guideline, 3) a core group within a limited geographic area needs to be strengthened before reaching out to distant counties, 4) a change in the monthly meeting site and an interesting program or speaker are keys to success, and 5) the strengths of all the members of the regional group must be recognized and utilized. To date, one of the 12 regions has secured State Developmental Disabilities Funding to replicate Cincinnati's central referral site, and three other cities with the highest density of programs appear ready to follow suit.

Interestingly, over the past three years, USEP has not grown in numbers. Many programs have lost their funding but new ones have taken their places. Community colleges, hospitals, health care agencies and prenatal programs (Red Cross, Birthline, Birthright) have begun to expand their service commitment to include training in parenting. Thus, USEP-OHIO has functioned to provide sustenance and support to both traditional and non-traditional program providers. It has encouraged a diversity of program models, recognizing that parents should have choices, based on their needs and the expectations for their children.

Conclusions

USEPs grassroots efforts hinge on the leadership provided by a small group of program practitioners. Our success can be explained by Edelman's (1973) description of the necessary leadership component of grassroots efforts: "Someone or a small group has to stay with the effort throughout, or those whose interest, however genuine, is only a secondary priority will not stay involved long. There is a word for it: Leadership" (p. 641). As federal cuts continue to be felt, the dedication of our members will undoubtedly be our prime resource. And hopefully, our experience in coalescing birth-to-three programs in the State of Ohio will encourage others to similarly exercise their leadership capabilities on behalf of young children and their parents.

I believe that USEP has translated the training and dissemination foci of our HCEEP Demonstration and Outreach grants in novel ways. The Infant Stimulation/Mother Training (IS/MT) Project training grant, which focuses on hospital-based maternity and infant-care nursing staff, broadens our USEP constituency to include prenatal and perinatal program deliverers. Revising the State Directory of USEP Programs should result in the identification of an additional 200 programs and likewise enlarge and strengthen our membership. In addition, next year we will sponsor a national workshop to train leaders from other states how to replicate the USEP concept. And finally, the Yale Bush Foundation's outside evaluation of USEP

(available December 1981) may serve to reinforce child and family advocacy efforts at the local and state levels by documenting our record of accomplishments.

The success of USEP-OHIO has been a grassroots victory where individuals (both professionals and interested laypeople) have provided through organizational mechanics what federal funds or mandates have failed to provide in the past. This success has resulted in the following outcomes which are both the tangible products of our efforts, as well as the organizational developments to insure future growth. The outcomes of USEP-OHIO are:

1. Grassroots efforts to coordinate programs at the service delivery level which address the survival of early intervention efforts at a time of tenuous funding.
2. Personal development of program practitioners through a support system which provides a forum for sharing, resolving and directing individual and group concerns.
3. Professional development of program practitioners through their collaborative efforts in developing a sound educational psychology for the infant and preschool years.
4. Coordination of programs that can be demonstrated at the service delivery level even if this is difficult or impossible at the administrative level.
5. Cooperation rather than competition among program deliverers through the sharing of resources, referrals, staff development and program information.
6. Improved service to families when communication transcends professional disciplines as well as the boundaries of agencies and institutions.
7. Program accountability as a natural outcome of a process which promotes self-evaluation and peer approval.
8. Child and family advocacy as well as program survival through unified, informed action on social policy issues.

References.

Badger, E. Infant and toddler learning program. Paoli, PA: Instructo/McGraw-Hill, 1971.

Badger, E., Elsass, S., & Sutherland, J. Mother training as a means of accelerating childhood development in a high-risk population. Paper presented at Society for Pediatric Research, Washington, DC, May 2, 1974.

Edelman, P. The Massachusetts task force reports: Advocacy for children. Harvard Educational Review, 1973, 43, 641.

Fairfield, R. Person-centered graduate education. Buffalo, NY: Prometheus Books, 1977.

Family Impact Seminar. Interim report. Washington, DC; Institute for Educational Leadership, April, 1978.

General Accounting Office. Report to the Congress of the United States, February 6, 1979.

Joint Commission on the Mental Health of Children. Crisis in child mental health: Challenge for the 1970's. New York: Harper and Row, 1969.

Karnes, M., Teska, J., Hodgins, A., & Badger, E. Educational intervention at home by mothers of disadvantaged infants. Child Development, 1970, 41, 925-935.

Keniston, K. & the Carnegie Council on Children. All our children. New York: Harcourt, Brace, Jovanovich, 1977.

Marris, P. & Rein, M. Dilemmas of social reform. New York: Atherton Press, 1967.

National Research Council. Toward a national policy for children and families. Washington, DC: National Academy of Sciences, 1976.

Wills, G. Working within the system won't change anything. The Center Magazine, July/August, 1972.

Work, H.J. Parent-child centers: A working reappraisal. American Journal of Orthopsychiatry, 42(4), 1972.

Section III

Preterm and Postterm Assessment

Section III includes synopses of three presentations concerning preterm and postterm assessment.

The Behavior of the Fetal Newborn: Theoretical Considerations and Practical Suggestions for the Use of the Assessment of Preterm Infants' Behavior (APIB)

Heidelise Als

The concept of the continuity of individual development is often seen as a basis for the uniqueness of the individual, yet it has been difficult to support through recent research evidence, most of which indicates the unpredictability of later behaviors and functioning from early behavior and functioning.

The synactive model of development proposed by Als and Brazelton subsumes the transactional (Sameroff & Chandler, 1975; Sigman & Parmelee, 1979) and transformational models (Kagan, Kearsley & Zelazo, 1978; Lewis, 1973; McCall, Hogarty & Hurlburt, 1972; Piaget, 1963). It postulates that the organism, from the unicellular stage on, develops through interaction and transaction with its environment--actually eliciting through genetic programming the feedback it needs for its own development--and undergoing change in the process. Throughout this process a continuity is present which is both species and organism specific. This continuity can be discovered through tests which will identify and measure the behavioral parameters (degree of differentiation and modulation of organization) of development at each stage.

Evidence for a synactive theory of development comes from neurobiology and anthropology. Recent studies in neurobiology indicate that one of the nervous system's most striking features is the high degree of precision and orderliness with which nerve cells are connected not only to each other, but to peripheral tissue such as skin and skeletal muscles. What needs to be more fully understood is how the ground plan contained in the genes is translated into organism specific normal wiring. This is especially important as recent studies have shown that a maladaptive circuitry may develop as a result of environmental stresses or disturbances within the organism.

Anthropological studies (Als, 1975, 1977; Katz, Rivinus-Als & Barker, 1973; Rivinus-Als & Katz, 1971) have resulted in a second line of evidence. They have focused on fixed or predictable behaviors of newborn infants and their primiparous mothers, particularly on newborn alert behaviors. These alert behaviors elicited maternal responses (attentiveness, etc.), which in turn increased the infant's attention and brightness until the infant broke the cycle through eye aversion, yawning, sneezing, fussing--thus resetting the attentional cycle.

The infant's continuous biphasic balancing process of reaching out and defending is seen in the interplay of various behavioral subsystems (the autonomic, motor, state, attentional interactive system and self-regulatory ability). In an immature or dysmature infant, the infants initial response to the interacting caregiver's may be too intense or its dampening mechanisms not well established, causing an undifferentiated response involving the entire body. A return to baseline behavior may then involve an active avoidance behavior on the motor and autonomic systems levels of functioning such as irregular respiration or a bowel movement. Once modulation is reached, the infant can then move on to new levels of differentiated integration with each subsystem simultaneously negotiating with one another and enhancing the integrated system. The emerging band of modulation in its flexibility and width becomes the index of individuality. The task for us is to determine with what supports and in what situations the infant is able to bring about smooth and balanced functioning which is critical for his/her realization of new pathways.

Assessment of a fetal newborn needs to encompass the infant's degree of flexibility and differentiation and the degree of modulation of functioning. The Assessment of Preterm Infants' Behavior (APIB) (Als, in press; Als, Lester, Tronick, & Brazelton, in press-a, in press-b) was developed with these considerations in mind. The APIB sees the maneuvers of the Brazelton Neonatal Behavioral Assessment Scale (BNBAS) (Brazelton, 1973) as packages of increasingly demanding environmental inputs. During the administration of each package, the infant's reactions and behaviors are monitored along five systems of functioning: autonomic-physiological, motor organizational, state organizational, attentional/interactive and self-regulation. The kind of examiner facilitation necessary to bring an infant to optimal performance and help him/her return to an integrated balanced state is also monitored.

The scoring system of the APIB is organized so that fullterm BNBAS scores are also recorded and can be used for comparative studies; certain scores can also be examined individually or grouped into dimensions or clusters. In addition, specific regulation behaviors are grouped into defensive behaviors and groping behaviors to alert us to the infant's level of overload versus investment in achieving a particular goal.

The administration of the APIB takes between 30 and 45 minutes while the scoring takes 1½ - 2 hours. Training in the scoring and adminstration of the examination is required--as well as extensive experience in the care and handling of preterm infants in the intensive care nursery. The examination itself is appropriate when the infant no longer needs oxygen or other life support lines for maintenance.

Exploratory group comparisons of a subsample of 10 preterm and 10 fullterm infants of a larger longitudinal study (Als, in press) indicate that the preterm infants are more poorly organized, more highly sensitive and overactive to environmental inputs, more easily

stressed and overstimulated, and require more finely tuned, sensitive environmental structuring and support to free up differentiated performance.

Using the TICAS method (Bartels & Wied, 1973, 1977) of analysis to identify systematic patterns of behavioral configurations allowing for classification of individual infants, four clusters of infants were identified: cluster one includes infants with good motor capacity, attentional capacity and overall subsystem organization scores; cluster 2 includes infants with motor capacity, attentional capacity and overall subsystem scores in the midrange; cluster 3 includes infants with motor capacity and overall subsystem organzation scores above average, but attentional capacity scores very poor; cluster 4 includes infants with low scores in each of the three areas. The cluster membership cuts across the medical classification of preterm and fullterm status and appears to yield conceptually meaningful, behaviorally distinct subgroups of infants.

Assessment of 20 preterms and 19 fullterm infants observed at 9 months post-expected due date in the K-Box paradigm (Als, in press; Als & Duffy, in preparation) and on the Bayley Scales of Infant Development resulted in four clusters of infants--with cluster membership cutting across the medical classification of preterm and fullterm status. Cluster classification stability from the newborn period to the 9 month point for the 20 initial infants (a subsample of the 39 subjects studied at 9 months) was high--with a highly significant rank order relationship of behavioral competence cluster membership.

The results of this work indicate a continuity of behavioral patterns of competence which can be identified--allowing the structuring of appropriate early support and intervention and the measurement of its effect.

References

Als, H. The human newborn and his mother: An ethological study of their interaction. Unpublished doctoral dissertation, University of Pennsylvania, 1975.

Als, H. The newborn communicates. Journal of Communication, 1977, 27, 66-73.

Als, H. Infant individuality: Assessing patterns on very early development. In J. Call & E. Galenson (Eds.), Proceedings of the First World Congress on Infant Psychiatry, Cascais, Portugal, 1980. In press.

Als, H., & Duffy, F.H. The assessment of preterm infants behavior and development - Vol. I, Basis for infant grouping; Vol. II, Predictor of later behavior. In preparation.

Als, H., Lester, B.M., Tronick, E.C., & Brazelton, T.B. Towards a systematic assessment of the preterm infant's behavioral development. In H.E. Fitzgerald, B.M. Lester & M.W. Yogman (Eds.), Theory and research in behavioral pediatrics (Vol. 1). New York: Plenum Press, in press-a.

Als, H., Lester, B.M., Tronick, E.C., & Brazelton, T.B. Manual of the assessment of preterm infants' behavior (APIB). In H.E. Fitzgerald, B.M. Lester & M.W. Yogman (Eds.), Theory and research in behavioral pediatrics (Vol 1). New York: Plenum Press, in press-b.

Bartels, P.H., & Wied, G.L. Extraction and evaluation of information from cell images. In Proceeding of the First Annual Life Science Symposium: Mammalian Cells, Probes and Problems, LASL, Los Alamos, NM, October 1973.

Bartels, P.H., & Wied, G.L. Computer analysis and interpretation of microscopic images: Current problems and future directions. Proceedings of the Institute of Electrical, Electronic Engineers (Pro. I.E.E.E.), 1977, 65, 252-261.

Brazelton, T.B. The neonatal behavioral assessment scale. Clinics in Developmental Medicine, No. 50. London: William Heineman, 1973.

Kagan, J., Kearsley, R.B., & Zelazo, P.R. Infancy, its place in human development. Cambridge, Massachusetts: Harvard University Press, 1978.

Katz, S.H., Rivinus-Als, H., & Barker, W. Physical anthropology and the biobehavioral approach to child growth and development. American Journal of Physical Anthropology, 1973, 38, 105-118.

Lewis, M. Infant intelligence tests: Their use and misuse. Human Development, 1973, 16, 108-118.

McCall, B., Hogarty, P.S., & Hurlburt, N. Transitions in infant sensorimotor development and the prediction of childhood IQ. American Psychologist, 1972, 27, 728-748.

Piaget, J. The origins of intelligence in children. New York: W.W. Norton Co., 1963.

Rivinus-Als, H., & Katz, S.H. Evolution, newborn behavior and maternal attachment. Comments in Contemporary Psychiatry, 1971, 1, 95-104.

Sameroff, A.J., & Chandler, M.J. Reproductive risk and the continuum of caretaking casualty. In F.D. Horowitz (Ed.), Review of Child Development Research (Vol 4). Chicago: The University of Chicago Press, 1975.

Sigman, M., & Parmelee, A.H. Longitudinal evaluation of the preterm infant. In T.M. Field, A.M. Sostek, S. Goldberg & H.H. Shuman (Eds.), Infants born at risk. New York: Spectrum Public, 1979.

The Role of Communication in Infant Assessment

Nancy Johnson

Open communication on the part of early interventionists helps to facilitate positive relationships with parents and with members of the health care community. This is particularly true when sharing assessment information. Assessment serves a variety of purposes: to provide information which allows diagnostic or predictive statements to be made; to accurately describe current skills and characteristics for planning intervention strategies; to document developmental progress. It is very important that an assessor understand the purposes of assessment from the perspective of the parent and from that of the referring professional before planning an assessment. It is also important to explain his/her view of the assessment and the information that may or may not be gained prior to actually conducting the assessment. A paternalistic attitude toward parents should not be assumed. However, since parents are ultimately responsible for planning for their children, they also have the right to know, based on our professional judgment, what assessment information might mean for the future. Parents should also receive an honest appraisal of the limitations of this information.

Psychologists and educators appear to be most comfortable using assessments to describe current skill or behavioral functioning levels and to plan for intervention. Criterion-referenced tests are generally the most appropriate instruments for this type of planning.

Assessment for documenting developmental progress is a more complex issue, especially if there is an interest in demonstrating that a child is progressing or changing as a result of intervention. The use of treatment and control groups is often precluded by ethical considerations and subject variability. Nevertheless, information on effectiveness is vital to accountability and the survival of early intervention programs. Strategies employed include pre and post-assessment on norm-referenced developmental tests, assessment of rate changes by assigning age levels to items on criterion-referenced tests, and assessment of developmental progress by computing the percentage of items passed in any given domain at each assessment. However, many challenges still remain for those who are involved in assessing gains made by high-risk and handicapped infants. The general focus of assessment must be at least twofold:

1. Critically evaluating procedures and creatively developing new procedures.
2. Communicating about and sharing the information gained from assessment with parents and other professionals with an open mind toward competing or alternative viewpoints.

Assessment of Preterm Infants

Jennie E. Swanson

The assessment of preterm infants at the Pre-Start Project at Loyola University Medical Center in Maywood, Illinois involves parents in much of the process. As parents are alerted to the specific competencies of their infant, they begin to develop a more positive attitude toward their baby, which, it is hoped, leads to more successful transactions.

The initial focus of assessment identifies the strengths and competencies of the critically-ill preterm infant in the neonatal intensive care unit (NICU). As the infant reaches the term date (expected due date), the Assessment of Term Characteristics (Swanson, Bagnuolo, Coyer & Riccardi, 1979) is administered. This tool includes a description of the infant's physical characteristics, an analysis of behavioral organization related to brain-level maturation and function, and a description of the transactional direction of the parent/child interactions.

The assessment process is more important than the content, since the parents are involved as partners in the assessment. This process allows parents to be actively involved in seeing what their infant can do and in learning caregiving behaviors suited to their infant's unique characteristics.

Partners in Child-Development (Kise & Swanson, 1978), a paperback booklet, is given to parents to assist in their observation of their baby's development and to record competencies as they emerge. As they begin to share their observations with the staff, parents become better observers of their child's functioning.

In addition to the parents' recording of progress, the staff uses the Swanson Infant Follow-up (Swanson, 1980) at regular intervals by conducting a systematic parent interview at 1, 3, 7, 12, 18, 24, and 30 months of age (corrected for prematurity). This has resulted in early identification of developmental delays and/or abnormalities. The involvement of parents in the process of assessment has resulted in increased self-confidence and competency as they better understand their child.

References

Kise, L., & Swanson, J.E. Partners in child development. Box 350, Dekalb, IL, 1978.

Swanson, J., Bagnuolo, L., Coyer, W., & Riccardi, M. Assessment of term characteristics. Pre-Start Project, Loyola University Stritch School of Medicine, Maywood, IL, 1979.

Swanson, J.E. Swanson infant follow-up. Pre-Start Project, Loyola University Stritch School of Medicine, Maywood, IL, 1980.

Section IV

Programs for Newborns and Infants
Intervention Strategies and Evaluation

Section IV includes synopses of 12 presentations concerning programs for newborns and infants with an emphasis on intervention strategies and program evaluation.

The Role of Educational Specialists in NICUs

Jean G. Cole

At Project WELCOME in Boston, the educational specialist's role is to work closely with the primary nurse (P/RN). The specialist's roles and responsibilities in the neonatal intensive care unit (NICU) include: gathering data--from the primary nurse and through observation--of the infant's weight, age, medical condition and behavior; assessing intervention needs; preparing, based on this data, an Individual Development Plan (IDP); updating the plan weekly after consulting with the P/RN; and administering the Neonatal Behavioral Assessment Scale (NBAS) when the infant is medically stable.

When an infant is ready to be transferred to a community hospital, the educational specialist meets with the P/RN and parent to write up a new IDP, meets weekly with parents and the community hospital nurse to provide consultation and input on the IDP, attends all discharge meetings, facilitates referrals to community intervention programs (if needed), provides consultation and follow-up, and assesses the infant again at 40 weeks of age on the NBAS and determines progress--before terminating involvement with the infant.

In an orientation procedure developed at Project WELCOME, staff are first familiarized with the NICU environment including staff, intervention techniques, care plans, medical problems and terminology, transport teams, the referral process, family involvement and parent support, and the administrative structure. They are also introduced to the community hospital referral process, follow-up of high-risk infant's clinic and hospital policies.

The next stage of orientation is to develop a relationship with NICU nurses through ongoing discussion and consultation. This begins with readings selected by the nurse consultant and a review of pertinent research findings. It also includes teaching sessions by the nurse consultant to explain medical issues in the readings, to answer questions and to share information on nursing care plans and the primary nursing role. After the initial orientation, there is a one-month observation period in which the educational specialist discusses nursing care plans for each infant, becomes familiar with equipment (respirators, radiant warmers, bilerubin lights, isolettes, etc.), holds informal meetings with nurses, observes at the follow-up clinic, and attends medical and multidisciplinary rounds.

A Nursing Care Plan for Infant Stimulation and Parent Education/Support in a Newborn Special Care Unit

Susan Diamond Derco

In the past, nursing care in the Newborn Special Care Unit (NBSCU) at Cincinnati General Hospital was focused primarily on biological survival. A redefinition of nursing care at the hospital resulted in the Care Plan for Infant Stimulation and Parent Education/Support.

An examination of research literature on the positive changes elicited as a result of tactile, visual, auditory, kinesthetic and vestibular stimulation of the newborn lent strong support for the Care Plan for Infant Stimulation. In addition, research focusing on the parent-infant relationship (the bonding process, attachment difficulties and grieving related to the birth of a premature infant, and the special needs of these parents) provided the rationale for the development of the Care Plan for Parent Education/Support.

The intent of the plan was to redefine nursing care to include an awareness of and intervention in the areas of social, emotional and cognitive development.

Methods of Implementation

The Care Plan for Infant Stimulation became part of an interlocking patient care system. This plan includes a nursing diagnosis, expected outcome and nursing orders--which are, in effect, guidelines and activities to promote stimulation. These stimulation activities are subdivided on sensorimotor and social levels. Separate guidelines are established for three categories of infant wellness (critical, intermediate and crib). Through implementation of the plan, awareness of the nursing staff increased and the techniques became an ongoing part of the daily care and interaction with each infant.

The Care Plan for Parent Education/Support involved three means of intervention: primary nursing, role modeling and a parent support group. Primary nursing insures a continuity of patient care and interaction and provides the parents with a single resource/support person to deal with. The primary nurse also serves in an educational role, providing the parents with information about their infant and aspects of infant care. Role modeling by nursery

personnel is used to demonstrate and encourage care techniques and parent-infant interaction.

In addition to providing individual support, the NBSCU formed a parent support group with a number of goals, among which are: 1) the provision of a setting for parents of premature infants to share common feelings and concerns and to offer mutual support, 2) the sharing of accurate information related to the care of a premature infant, 3) assisting parents through the various stages of the grieving process, 4) encouraging the process of bonding, 5) strengthing parents' ability to deal with the procedures and policies of the nursery.

Training and Dissemination

As a result of training and dissemination efforts, through an outreach training grant, 131 participants from 27 hospitals attended one of three short-courses offered between October 1980 and April 1981. Nurses from nine hospitals in the greater Cincinnati Area have received further consultation and on-site inservice. A nursing coalition has also been formed between Cincinnati General Hospital and the nine area hospitals to discuss program development and share information.

From the Beginning: The EMI High Risk Nursery Intervention Program

Wanda B. Elder

The EMI High Risk Nursery Intervention Program at the University of Virginia Hospital developed out of a concern for earlier referrals to the follow-up program for handicapped infants at the hospital's Children Rehabilitation Center. The average age of referral to that program was 11 months, meaning that many of the infants and their families had already lost considerable ground in developing functional adaptations to their special needs. In the process of informing the physicians and nurses in the Neonatal Intensive Care Unit (NICU) of the effectiveness and appropriateness of follow-up intervention, the staff of the Rehabilitation Center was asked to consult about developmental intervention in the NICU itself. This led to the development of the nursery intervention program--strongly supported by evidence in the literature for the need and beneficial effects of such intervention.

Basing the intervention on research findings, the staff of the Rehabilitation Center and the nurses in the NICU developed three major goals for the nursery intervention:

1. To provide techniques for nurses and parents which would help them appropriately meet the perceptual, cognitive and affective needs of their infant without interfering with the standard nursery routine of medical care.
2. To assist the parents in the development of attachment behaviors which are often disrupted by atypical neonatal behavior, separation and the parents' reaction to the crisis of prematurity by maximizing parental involvement in infant care and intervention, and providing parent education and counseling.
3. To plan holistic discharge and referral procedures to community follow-up infant/parent intervention programs.

The program's philosophy is to serve all infants in the NICU once their medical condition has stabilized in order to ameliorate the negative effects of extended hospitalization and separation on all families--not just those with special needs.

Intervention activities include general and developmental activities. General intervention principles which apply to all infants include: simple environmental adaptations such as subdued lighting, facilitation of state changes through soothing or alerting techniques, avoidance of overstimulation through the observation of an infant's individual temperament and tolerance levels, and an attitude of warmth and responsiveness in staff implementation of activities. Developmental intervention activities include kinesthetic, visual, auditory and tactile stimulation, as well as attachment mediation.

Premature infants under one month adjusted-age receive daily brief exposure to developmental intervention activities which are incorporated in a standardized care plan for cognitive/affective development.

Older infants are assessed on the EMI developmental checklist (Wallens, Hastings & Elder, 1979), and have individualized intervention activities.

The Parent Component of the program includes attachment mediation activities; parent orientation to the NICU (equipment and its function, infant activities); education in caregiving through explanation, demonstration, practice and implementation; involvement in support systems (parent support groups); and family rounds (which are held to coordinate planning and consistent communication among disciplines, to evaluate family-functioning and needs, and to discuss discharge and follow-up referrals when necessary).

The EMI High Risk Nursery Intervention Program has developed a model for other hospitals to adopt. It has provided training workshops and developed materials for dissemination. These include From The Beginning (Wallens, Elder & Hastings, 1979) a manual discussing the rationale for and implementation of neonatal intervention; Focus On Interaction, a slide-tape presentation for parents on developmental activities performed in the Unit, the creation of developmentally appropriate mobiles and stabiles for the nursery, and an infant carrier design of appropriate proportions for premature infants with pockets for necessary support equipment.

The service model is constantly being updated as new information on the needs and capabilities of premature infants emerges, and it is hoped that hospitals which choose to adopt the model will also adapt it to their unique requirements.

Reference

Wallens, P.L., Elder, W., & Hastings, S. From the beginning: The EMI high risk nursery intervention program manual. Charlottesville, VA: University of Virginia, 1979.

Some Considerations about Theory and Assessment of Behavior Change in Infant Intervention Efforts

S. Gray Garwood

It is paramount that an understanding of the theoretical dynamics of behavioral change be included in all aspects of an early intervention program, e.g., program philosophy, structure, daily operation and assessment and evaluation procedures. Theory provides both a guide for the selection of questions and a useful context from which to interpret data. Often, however, this theoretical basis is not present.

Developmental and/or behavioral change can be viewed from two rather global standpoints: the mechanistic and the organismic. The mechanistic view contends that the forces initiating behavioral change are external to the individual, and thus, development is not a consequence of internally mediated restructuring. The same principles govern behavior change in all organisms with complex behaviors resulting from linkages occuring among less complex behaviors (chaining). This view provides the fundamental basis for traditional behaviorism and reinforcement theory. The underlying assumption is that development is essentially quantitative and continuous, and complex behavior is the cumulative result of gaining more and varied behavioral responses.

The organismic viewpoint holds that development initiates from within the individual. Development consists of continuous change as lower levels of behavior become restructured/integrated into higher levels of behavior. The individual acts on the environment, thereby generating new experiences which, in turn, call for a restructuring of earlier behaviors to fit into higher-order stages of functioning. Change is viewed as primarily qualitative in nature.

Both views of development provide a theoretical rationale for program philosophy, structure, operation, assessment and evaluation. The mechanistic view would see programmatic intervention efforts focusing on:

1. Defining the nature of a child's problems and establishing priorities about the order in which these problems would be dealt with.
2. Conducting task analysis.
3. Defining target behaviors.

4. Maintaining an accurate record of frequency of occurrence of target behaviors.
5. Selecting appropriate times/places for intervention/instruction.
6. Determining reinforcers, negative consequences and instructional aids/procedures.
7. Testing for generalization or transfer.
8. Insuring that behavioral gains are maintained. (Birnbrauer, 1978)

Ample evidence exists which attests to the effectiveness of this approach.

The organismic viewpoint has generated the cognitive-developmental model which focuses on:

1. Identifying sequences of cognitive growth implied by cognitive-developmental theory.
2. Translating these sequences into curriculum.
3. Assessing a child's current status with respect to these sequences.
4. Determining where in a particular sequence to intervene.
5. Providing experiences deemed relevant to facilitate the desired behaviors.
6. Reassessing a child's status after exposure to these experiences.

Assessment of change in infants must be ongoing and must include a number of diverse but related disciplines. These assessments are typically standardized, but non-standardized as well as clinical data are collected. Unfortunately, such a diversity of data bases makes overall program evaluation difficult. Program evaluators should therefore be aware of the vulnerability of infant program evaluation efforts and should proceed with care, deliberation and caution.

Reference

Birnbrauer, J.S. Some guides to designing behavioral programs. In D. Marholin (Ed.), Child behavior therapy. New York: Gardner Press, 1978.

Evaluating Early Intervention Programs

David Grove

In the last decade there has been an increase in the number of intervention programs serving handicapped infants and their families. This trend is partly due to the mounting evidence from the neurosciences and other disciplines about the effectiveness of early environmental stimulation. Although the rationale for early intervention is widely accepted and supported by many professionals who work with handicapped infants, a systematic way of evaluating programs is lacking.

The difficulty in evaluating the efficacy of programs becomes obvious once the complexity of the problem is examined. First, control groups or experimental control of environmental variables is difficult to obtain and ethically unjustifiable. This situation confounds the problem of separating the effects of treatment from changes related to maturational factors. Second, most programs for young handicapped children have a heterogenous population, and this poses difficulties in the generalization of results from one population to another. In addition, other technical problems surround the area of measurement techniques and the use of precision instruments to document child progress.

Changes resulting from intervention programs can be assessed at four levels. At the primary level, specific behavioral or cognitive changes brought about in the infant can be documented. Two types of assessment instruments can be employed for this purpose. The first are standardized tests, yielding a MA (mental age) or DQ (developmental quotient). These instruments compare the child's development to the established developmental norms. Other types of assessment instruments, called criterion-referenced tests, are more useful for educational programming. Criterion-referenced tests do not yield comparisons to a standardized norm but assess a child's competency in specific developmental areas.

At the secondary level, changes which were not specifically planned for or programmed for can be assessed. Intervention programs can effect change in other areas which were not specifically targeted for intervention. For instance, intervention in gross-motor development (e.g., locomotion) might have beneficial effects on the child's language development as well. As an infant learns to

explore physical environments and encounters new objects and situations, linguistic repertoires are generally expanded.

At the third level, the overall impact of a program on the general community can be assessed. Employment opportunities resulting from community-based intervention programs, increased awareness about handicapping conditions in public schools, or creation of parent support groups are a few examples. The cost-effectiveness of early intervention programs can be assessed in such general areas, in addition to more specific child-change data.

At the fourth level, possible neurological effects of environmental stimulation are of interest to health professionals. However, this area of research is relatively new, with little information currently available on the topic.

Another question pertinent to the discussion of evaluation of early childhood programs is related to the treatment component. What constitutes treatment data? Early intervention programs for handicapped children appear to be similar, but in reality they differ. Each program has its unique treatment components. Therefore, it is difficult to determine what specifically constitutes treatment. We need to ask what constitutes a treatment trial, or how long do we deliver the treatment before a change in behavior can be observed.

Several other methods of potential application to early childhood program evaluation are worth mentioning: a panel of experts may be polled for their opinion; treatment outcomes can be rated on a graduated scale, ranking for most positive outcome, best outcome, (goal attainment scaling); a variable can be measured before and after the treatment (pre and posttesting).

A Review of Infant Intervention Studies

Joan Karp

Over the past 16 years, a number of experimental studies have been conducted to determine the effectiveness of various intervention strategies with infants while they are in the hospital and following discharge. A wide variety of experimental methods have been used with hospitalized infants, the most frequent being control-group experimental designs demonstrating effects of different types of sensory stimulation. In general, home- and center-based studies have employed quasi-experimental designs using comparison groups with statistical controls for maturation, or single-subject designs demonstrating the effects of a total program. It appears that intervention is being applied in more generalized ways and that measures of infant behavior are becoming increasingly sophisticated.

A review of intervention programs suggests that most studies examine programs for infants hospitalized for long periods after birth, due to birth complications or high-risk health hazards such as prematurity or low birth-weight. Of prime importance for hospital staff are stabilization of an infant's physical systems and facilitation of physical growth so that the infant is of the appropriate size and integrity to leave the hospital as soon as possible. In an effort to identify the lacking cognitive and emotional growth systems, researchers have instituted procedures to alter the sensory, vestibular and proprioceptive input for infants, and to measure behavior and growth resulting from these inputs.

Intervention strategies which seem to positively affect the growth and well-being of hospitalized infants include:

1. Having mothers see and touch their infant as soon as possible after birth.
2. Having mothers touch, rock and stroke their infants during hospitalization.
3. Placing interesting visual stimuli in the infant's field of vision.
4. Talking to the infants with the speaker's face in view.

Research studies demonstrate that many commonalities exist among post-discharge interventions which have been effective with infants hospitalized for long periods of time and with infants who

have serious sensory, physical or cognitive difficulties. Successful post-discharge techniques include:

1. Regularly scheduled visits with parents at home or at a center.
2. Individually prescribed intervention goals and objectives for parents and children.
3. Teaching parents to effectively interact with children.

LSUMC Infant Education Program

Judy Martindale
Patsy Poche

Medical professionals involved in working with young handicapped children are increasingly referring children to educationally-oriented intervention programs. This is due, in part, to public campaigns for deinstitutionalization and in part to educators' efforts at designing and implementing effective intervention programs.

The Childrens' Center at Louisiana State University Medical Center utilizes a team approach, involving a wide variety of disciplines, in carrying out its intervention efforts. This approach has been developed over the past eight years and has contributed greatly to the center's success. The carefully constructed relationship between the various disciplines involves realization of limits in professional training and an ability to share with and gain from other team members. Training students from many disciplines in evaluation and classroom programming is an important aspect of the program.

Initially children are seen by three primary team members including a physician, an educational consultant and a social worker. Recommendations for further developmental assessment come from this group. Once children are placed in the program they receive services from faculty and students in physical, occupational and language therapy, in special education and social work. Each child has a staff case manager referred to as a Preceptor. In addition, a student is assigned to an infant and works closely with that child's Preceptor. Students are trained to carry out all phases of programming--from planning through evaluation--in all developmental areas with their assigned infant. Student training involves didactic classroom sessions and actual work with the infants. Subjects covered include cognitive skills, non-verbal and verbal communication, gross-motor and fine-motor development, self-care, and social-emotional development. The students' work culminates in a transdisciplinary report on their assigned infant. They thus gain an understanding of the transdisciplinary process as defined by the LSUMC training program.

Competency Skill Level of the Professional Working with Infants: Where and How are Skills Acquired?

Selerya O. Moore

The development of strong training programs for professionals working with infants and families has been a major concern for a number of years. The recent move of infant educators into health care settings has further heightened the need for individuals with special competencies. This issue has been addressed by a number of professionals and groups.

In 1981, the opportunities for receiving training for working with infants and families in health care settings is limited to the following:

1. Study in university programs geared toward infant development and parent education through didactic and practicum experiences.
2. On-the-job training in a health care facility where skills are acquired through interaction with personnel.
3. Interactions with other professionals during special workshops and conferences where specialized approaches and intervention techniques are shared.

University opportunities have increased over the last 10 years; they provide students with information on current research and theories. On-the-job training gives professionals flexibility and depth; it allows them to learn from medical personnel. Professional exchange helps update knowledge and skills.

In addition to the skills and knowledge gained in formal and informal training, an educational specialist must possess a positive self-concept and a high level of confidence in order to effectively move into medical settings.

New Faces and Approaches in the ICN: The Role of the Educational Specialist

Nancy M. Sweet

The new professional role of developmental/educational specialist has emerged as a result of the growing number of infant educators with specialized competencies, research efforts concerned with the benefits of supplemental stimulation and the impact of the intensive care nursery (ICN) on the development of high-risk infants and their parents.

The basic competencies of the educational specialist (infant educator) include:

- Knowledge of infant capacities, responses and development (normal and atypical).
- Understanding of parent-infant and general adult-infant interactional variables.
- Awareness of adult educational and supportive techniques used with populations under stress.

Additional competencies, unique to the ICN include:

- An understanding of neonate medical conditions and their consequences.
- A basic understanding of medical treatment procedures.
- The ability to function as part of a medically-oriented multidisciplinary team.
- Knowledge of the capacities of organization of the premature or seriously-ill newborn.

There are a number of factors in the ICN which help shape the role of the educational specialist. These include the components of ICN intervention as well as the philosophy of intervention. Components of intervention include the structure of the project, the target population (infants, parents, nurses, etc.) and staffing. The intervention philosophy must be clearly described. It involves some combination of the components listed above, as well as specific intervention strategies with each target group, and a theoretical framework which ties everything together. The significant issues in the intervention philosophy are:

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1. The conceptualization of the high-risk infant as a learning organism. Knowledge of the most recent research concerning infant maturation and physiological integration. Knowledge of behavioral cues and responses, and the negative consequences of overstimulation.

2. Work with ICN parents. Issues to be dealt with include the bonding process, grief related to the birth of a premature infant, parental expectations of normality and whether a preventative or therapeutic approach is being taken with the infant.

3. Work with nurses and other professionals in the ICN. The primary issue to be resolved is the relationship of the educational specialist to the other professionals in the ICN. Is the educational specialist the primary provider of developmental intervention or the facilitator of developmental intervention skills in the parents and nurses?

Elements which have been identified as critical to the educational specialist gaining access to the ICN include: developmental expertise as well as knowledge of medical terminology and ICN procedures; a physician support/liaison (in addition to general physician support for the developmental intervention) to act as a consultant and educator for the educational specialist; a nursery support/liaison to promote communication between the nursing staff and the intervention program.

Activities which have also been helpful include providing feedback to nurses and other staff on infant post-hospitalization progress, preparing parents for transition of the infant from tertiary to secondary-care hospitals, providing training programs for ICN nurses, and concrete assistance to the ICN nurses in infant care and interaction with parents.

The ICN Interact Project located at Children's Hospital in Oakland, California has been successful in gaining access to the ICN environment and can serve as a model for others attempting to establish such a program. The role of infant educator (educational specialist) has evolved over a period of time and includes a number of specific activities to be carried out with infants, parents, nurses and other ICN disciplines. With infants, these activities include behavioral observation and developmental assessment, preparation and daily implementation of maturationally appropriate developmental activities, and environmental modification. The infant educator works with parents in preparation for and assistance with feeding and gives recommendations for altering care practices which influence development. Activities with nurses include involving them in behavioral asessments and in planning, implementing and evaluating developmental activities; providing formal training sessions and information about infant development and other areas of interest. Work with other ICN disciplines includes participation in weekly

multidisciplinary ICN rounds and coordination of primary intervention roles with other disciplines working with infant or parents.

Currently, the Educational Specialist role is filled by professionals from a diversity of backgrounds including early childhood education, occupational and physical therapy, nursing, and other areas. Most educational specialists have gained their competencies through a combination of coursework, experience and special training in procedures such as the use of the Neonatal Behavioral Assessment Scale. Until a university-level training program is developed, educational specialists will continue to be identified by role and competencies.

Humanizing the Intensive Care Nursery Environment

Kathleen A. VandenBerg

Normal human development and growth demands a nourishing and stimulating environment. Infants have strong needs for touch, movement, sensory stimuli and sustained contact with a caregiver that provides reciprocal gratification. But many of these needs may not be met if an infant is hospitalized for long periods of time in an intensive care nursery (ICN). There are many factors which may inhibit or distort development in hospitalized infants, including: extreme immaturity; serious illness; an abnormal physical environment; treatment procedures which restrict movement, alter consciousness, invade body boundaries, or cause considerable stress to the infant; and abnormal care patterns due to the great number of caretakers in an ICN. The infant's relationship with its parents may also be jeopardized by: parental reaction to the birth and illness of a premature newborn; concerns over the baby's survival; parents' loss of control; the separation of infant and parent; and the effects on parenting of the ICN environment. Project ICN Interact, an Handicapped Children's Early Education Program demonstration project at Children's Hospital Medical Center in Oakland, California attempts to minimize these factors through its work with infants, parents and nurses.

Infants: The Project ICN Interact staff assesses each infant and arrives at an Individual Development Plan. Interventions under the plan are designed to meet the following criteria: they must be relative and appropriate to the changing needs of each infant and sensitive to the infant's cues; they must be geared to the infant's cycles and not given at set times; they must be consistent with the infant's gestational age; they must be consistent with the ICN environment and must not interfere with medical treatments. In work with babies under 40 weeks (preterm infants), ICN Interact makes the following recommendations: offer one sensory modality at a time; space out the handling; observe cues from the baby; use restraints cautiously; handle gently and sensitively; reduce light by covering the isolette with a blanket or by shielding the baby's eyes when held; position infant in a prone or flexed position with hands to mouth. In addition, ICN Interact staff suggest consistency in caregiving as a means of understanding how to soothe and handle the

baby and accurate assessment of needs as an aid in avoiding undue stress on the infant. All visual and auditory stimulation should be geared to what the baby can handle.

Parents: ICN Interact staff provide several kinds of support to parents, including: listening and offering support; explaining and modeling developmental activities and encouraging parents to carry out programs; encouraging parents to see the baby as a human being and not as a medical problem; assisting parents to carry out caregiving tasks; asking what parents want nurses to do for their baby; extending visiting hours and allowing siblings to visit during weekends; providing support at the time of discharge; and helping parents to plan follow-up and continual care.

Nurses: Because nurses play such a vital role in the ICN, the project focuses on building relationships with the intensive care nursing staff through the following: involving nurses in the assessment; educating the nurse in the developmental plan; offering training courses; encouraging consistency in caregiving through the primary caregiver nurse; working with nurses using a clinical nurse specialist as a liaison; maintaining open communication between ICN and secondary nursery nurse; eliciting input from the nurses concerning their needs and the needs of the baby.

Increased involvement of the nurses helps the educator gain acceptance in the ICN. This goal is also furthered by attending interdisciplinary rounds and by helping to orient new residents who rotate through the ICN.

The Brain and Early Infant Intervention

John Willis

Crucial questions remain unanswered in the study of early intervention as it relates to notions about neurological functions: Can available treatment permanently improve the eventual neurological function of a given infant? What sort of treatment is useful? How should it be given?

It is known that certain types of sensory deprivation in early life will produce neurological abnormalities (Helveston & Ellis, 1980; Timney & Mitchel, 1979; Von Noorden, 1973; Webster & Webster, 1979). Evidence suggests that enhanced sensory input might effect some positive neurologic change, but this has not been proven; nor is it known at what age the input must occur or how to apply it.

The answers to these questions have remained elusive for a number of reasons. Since infant programs serve a very heterogeneous group of children, it has been impossible to obtain a distinctive control group. It has therefore been difficult to thoroughly assess the efficacy of particular methods of treatment. These difficulties are compounded by our inability to predict the course of infant development. It is often impossible to distinguish the positive effects of treatment from the natural results of growth and development.

Current studies of evoked potential are promising, but we are still awaiting the identification of a solid tool for predicting a given infant's future. In the meantime, infant interventionists would do well to ally themselves with investigators in the field of neonatal neurophysiology. Future studies seem likely to suggest that intervention techniques must capitalize on the young infant's sensory processing capabilities and must begin, perhaps, at birth.

References

Helveston, E., & Ellis, F. Pediatric ophthalmology practice. St. Louis: C.V. Mosby, 1980.

Timney, B., & Mitchell, D. Behavioral recovery from visual deprivation: Comments on the critical period. In R.D. Freeman (Ed.), Developmental neurobiology of vision (Vol. 27, NATO Advanced Study Institutes, Series A, Life Sciences). New York: Plenum Press, 1979.

Von Noorden, Gunter. Experimental amblyopia in monkeys. Investigative Ophthalmology, 1973, 12, 721.

Webster, D., & Webster, M. Effects of neonatal conductive hearing loss on brain stem auditory nuclei. Annals of Otology, Rhinology and Laryngology, 1979, 88, 684.

Methods of Educational Intervention

Shirley Zeitlin

The Developmental Infant Program in Home and Hospital (DIPHH) is housed in Kingsbrook Jewish Medical Center (KJMC), Brooklyn, New York and is funded through the Handicapped Children's Early Education Program. DIPHH focuses its efforts on children aged birth-to-five years whose chronic medical conditions require long-term hospitalization, recurrent hospitalization or frequent visits to the hospital's out-patient clinic. The primary goals of the project are to assist children in achieving optimal development and attaining adaptive coping behaviors. (DIPHH defines coping as strategies a child uses to meet personal needs and to adapt to environmental demands.) The project works toward achieving its goals by implementing activities in five components: education of the child, the Parent to Parent Program, training of teacher interns and hospital staff, outreach, and child progress evaluation.

Each child involved in the program has a Personalized Learning Plan (Zeitlin, 1976) which provides DIPHH staff with a structure for collecting information on the child in his/her environment, allows for educational planning and the setting of priorities, and provides a structure for implementing learning priorities and evaluating educational experiences. The Personalized Learning Model, an outgrowth of Lewin's Field Theory (Lewin, 1951), consists of four interactive components: data collection and analysis, development of long and short-range plans, implementation, and evaluation.

DIPHH employs the Assessment of Basic Capabilities (ABC) (Spivack 1980) in assessing developmental capabilities. The ABC, a norm-referenced, developmental assessment for children aged birth-to-three years, investigates development in four areas: sense perception/cognition, movement/coordination, social, emotional/self-help and communication/verbalization. DIPHH relies heavily on the use of videotaping for the purposes of repeated observation of important behaviors. The Coping Inventory (Zeitlin 1978), a criterion-referenced observation instrument, is used by DIPHH to assess coping behaviors and skills in children who are at least two years of age. The Coping Inventory checklist is used with children who are developmentally and/or chronologically too young to be assessed by the observation form. This form consists of 48 items divided into two general categories: coping with self and coping with the environment. In

addition, three bipolar dimensions are used in describing coping style: productive/non-productive, active/passive and flexible/rigid. Videotaping is used at regular intervals for data collection. The information from the above-mentioned assessments is analyzed, and education plans are then devised, implemented and evaluated.

Another strong feature of the DIPPH project is its Parent to Parent Program. The project's social worker assists parents in assessing emotions and examining coping strategies within their life milieu. Parents are strongly encouraged to direct and redirect their own growth, relying on the social worker primarily as a resource person or consultant.

References

Lewin, K. Field theory in social sciences. New York: Harper, 1951.

Spivak, F. Assessment of basic capabilities (ABC) infant level. Great Neck, New York: H.C.H.C. Inc, 1980.

Zeitlin, S. Kindergarten screening: Early identification of potential high risk learners. Springfield, IL: Charles Thomas, 1976.

Zeitlin, S. The coping inventory. Upper Montclair, NJ: Innovative Educational Materials, 1978.

Section V

Parent and Family Involvement

Section V includes synopses of nine presentations concerning parent and family involvement, and bonding and attachment.

Communication with Multi-Cultural Families in a Newborn Intensive Care Unit

Valerie Casuso

Jackson Memorial Hospital in Miami, Florida houses a 65-bed newborn intensive and special care unit. A jointly funded Handicapped Children's Early Education Program and hospital project gives assistance to families served by the hospital, as well as providing intervention to selected newborns. The project, entitled Comprehensive Care to the High Risk/Handicapped Newborn and Family, screens over 500 newborns and mothers annually and provides hospital-based intervention for 55 infants, with home-based follow-up for the 20 highest risk infants.

Project staff visit all mothers of infants admitted to the newborn Intensive Care Nurseries (ICN), for reasons other than observation, to provide the earliest possible crisis counseling. During this time, staff assess the need for continuing social services and/or counseling, and then coordinate the initial visit of the mother to the nursery. The project provides weekly evening information and counseling groups and predischarge teaching.

The majority of admissions come from three different minority groups--Cubans, Blacks and Haitians--all with differing attitudes concerning pregnancy, illness, hospitalization, child-rearing, interfamily relationships and religion. Differences in the three cultures result in differences in parental visitation, behavior in the unit and interactions with hospital staff.

The Cubans, for example, tend to be comfortable with medical staff, emotionally demonstrative and assertive. They have strong, extended families (one problem in the ICN has been a hospital policy which prevents visitation by family members other than parents). Although they are Catholic, the Cubans often have superstitions about childbirth which affect communication about their infants. They may believe, for example, that a birth defect is the "will of God", a divine punishment, the fault of the mother or they may deny that a defect exists.

Blacks, on the other hand, do not communicate easily with medical staff. They tend to appear aloof and detached and they don't interact with their infants as much as mothers of other cultures. They do not visit hospitalized infants as often. While Cuban mothers often foster dependence on the part of their children, black mothers encourage independence. The typical black family

seen at the hospital nursery consists of a young, unemployed single mother, often living with her own mother, who is also single.

The Haitians have a strong sense of responsibility to their extended family and community. All babies are accepted by the community, and they are generally raised by a number of adults. Fathers show great pride in their babies; both parents visit hospitalized infants often unless prevented by financial or other problems. However, doctors, hospitals and medical explanations are extremely unfamiliar to them. Voodoo spiritual beliefs pervade all aspects of Haitian culture. Language problems further complicate communication.

In each case, the family's behavior is viewed as normal within the culture. Health professionals must be sensitive to this and avoid making judgments from the viewpoint of their own culture. They must be attentive to the communication problems that cultural differences may cause and must focus on making communication a two-way process--asking questions to see that the messages are being understood--and refrain from use of medical jargon.

Other proven methods of ensuring successful communication include:

1. Providing printed information about the unit in English, Spanish and Creole.
2. Making sure that parents understand the reasons for the infant's placement.
3. Providing photographs and information about the baby to the mother and other family members during necessary separations.
4. Preparing parents for the first visit--what they will see.
5. Using an interpreter when needed.
6. Finding ways for the mother and father to participate in the infant's care.
7. Providing parent group activities.
8. Encouraging staff sensitivity to cultural and religious differences.

In addition, staff should become familiar with specific cultural patterns of the ethnic communities they serve. Knowledge of and sensitivity to minority culture is essential if effective communication is to take place between health care providers and families they serve.

Range of Family Supports: The Effects of Hospitalization on Siblings

Mary C. Cerreto
Vicki A. Switzer

The effects of hospitalization on siblings of handicapped children have long been ignored, although recent research has indicated that such children are at risk for emotional and behavioral problems.

Separation and loss are handled differently by children depending on their stage of development and the cognitive and emotional resources available to them at each stage. When a handicapped child is hospitalized for any length of time, the siblings may experience separation and loss in several ways. These include not only the loss of the sibling's companionship, but a loss of parents' physical presence, and with that an accompanying loss of security and daily routine. How this will effect the sibling is related to:

1. The basic tasks of development and needs at each stage.
2. The particular age and stage-related meaning of loss and separation to the child.
3. The specific behaviors of adults in the sibling's environment.

Moving through each stage of development, one can perceive the effects of hospitalization on siblings of different ages. An infant is in a critical period of developing personal/social relationships and is extremely dependent on adults. Separation and loss during this stage are overwhelming, as the infant has no time differentiation or resources to organize his or her emotions and experiences. The effects can be lessened through consistency of caretakers and the establishment of routine for the child.

The toddler stage is characterized by exploration, assertion and the ambivalent situation of wanting independence but being dependent. The toddler also experiences high levels of separation anxiety and may blame the handicapped child for the "loss" of parental time and presence. The toddler needs an adult model and needs opportunities for acting out and verbalizing concerns and feelings. The child at this stage can be prepared for separation to help lessen his or her anxiety.

Three- and four-year-old preschoolers continue to explore and ask "why?" They are becoming more reality-oriented and are

developing greater self-control. Separation and loss are extremely difficult at this age, and the child may feel responsibility or guilt for the illness. Adults can help by encouraging the child to verbalize feelings, to act out impressions and fears, and by providing reality-based explanations.

The five-year-old child is developing conscience and has a strong sense of "it's not fair". The separation and loss are seen in this light, and the parent may be viewed as uncaring or angry as the five-year-old continues to feel guilty and responsible for the separation. Adults can assist the five-year-old child by being honest and by admitting they don't understand "why".

The school-age child has become more outer-directed and peer-oriented and possesses increasing learning and skill orientation. This child views loss and separation more realistically but needs help from the adult for comfort and talking.

The adolescent is in a stage of ambivalence and transition. Loss and separation are felt deeply and can be dealt with if a supportive adult is available to provide honest reasons and explanations and to help sort out emotions.

In addition to facing the issue of loss and separation, siblings of handicapped children are faced with a variety of concerns related to the developmental disability. These concerns include dealing with feelings toward parents, friends and the special sibling in the family. The need of siblings is for age-appropriate information related to these concerns. Issues here include questions about the etiology of the condition; answering the questions of peers about the condition; dealing with ambivalent feelings such as anger, embarrassment, sadness and feelings of neglect by the parent; the assuming of a heavy workload of household and child-care duties; feelings of loss and grief for an ideal sibling; an understanding of the fate of the handicapped child; and the need for periodic genetic counseling.

Intervention to assist the siblings in facing these issues will range from the simple provision of information or support, to the formulation of a behavioral plan of action.

As programs begin to meet the needs of siblings of handicapped children, our range of support will truly become a "family" approach.

Assessing Family Needs

Carole A. Cooper

The Children's Center of the Louisiana State University Medical Center, School of Allied Health Professions in New Orleans provides evaluation services for handicapped infants and severely handicapped preschoolers in the state of Louisiana. The evaluation process is a multidisciplinary team approach including the assessment of family needs.

The process of assessment begins when a child is referred to the Children's Center by her/his local education agency. The team social worker receives the referral and makes initial contact with the family, scheduling the necessary appointments and discussing problems or concerns the parents may have.

The evaluation itself includes several steps. The first is a half-hour meeting with the educational consultant, social worker, parents and child in a comfortable, unstructured, non-threatening environment. During this time the relationship with the parents evolves, and questions and concerns can be answered. Next, the Center's pediatric neurologist completes a medical assessment, attended by the educational consultant and the social worker. The latter work closely with the physician and gather data to be incorporated into their own reports. These three core-team members then plan further assessments and make arrangements for the second appointment.

The second appointment may include assessment by the physical therapist, occupational therapist, speech therapist and eduational consultant. During this time, one team member has the primary interaction with the child while the others assess the child simultaneously. This is followed by a staffing of the entire team in which all members share their assessments, including observations of parent behaviors and needs.

Throughout this entire process, the social worker also assesses the family situation through both observation and quiet moments alone with the family. She or he evaluates three primary kinds of family needs: emotional, informational and concrete (such as the need for therapy or financial assistance). Emotional needs are particularly difficult to gauge with a standardized list of questions or a single instrument. Information may be gathered through direct questions and through non-verbal cues (obtained spontaneously throughout the day and also in the course of discussing topics such as

"social history"), parental concerns and expectations and the family support system.

Another productive approach is mentioning and discussing specific problem areas encountered by other families with handicapped children. Discussions at the parent conference following the formal assessment (when the child's condition and its implications are dealt with) also may reveal much information about the parents' emotional needs.

Assessing parents' needs for information also requires a staff person who is sensitive to the clues parents give when discussing the child's condition. Parents are at different levels of awareness and understanding of the handicapping condition and its implications.

The assessment of concrete needs may be less difficult, as parents often find the questions easier to answer. Information is obtained throughout the assessment process in discussions between the various team members and the parents, and through the use of a form developed by the State of Louisiana to assist in determining eligibility for various services available to handicapped individuals.

Barriers to Parent Involvement

Susan Hastings

The birth of an atypical infant requiring specialized medical attention in a high-risk nursery requires great adjustment by the parents. Many factors in this situation will affect the parents' involvement with their infant and participation in his or her early development, especially when parents are unable to visit their infant in the hospital.

The barriers to parent visitation and involvement are medical, emotional, financial and geographic (particularly in rural areas served by a large referral hospital).

Medical barriers are present when the mother herself is hospitalized because of her medical condition following delivery, or if the infant must be transported to another hospital with specialized facilities. One technique found to be important in the latter situation is taking the infant to the mother for a brief visit prior to the infant's transfer to the other hospital. This does much to relieve a mother of many of her fears and fantasies about the baby's condition. Another important step is to try to have the mother transferred from the maternity ward where she will feel very isolated and alone.

There are many emotional barriers which may prevent parents from visiting and becoming involved with their infant. The baby and its condition may be feared by the family because of lack of understanding or knowledge; the parents may experience intense guilt and grief over the child and may cope with the stress by removing themselves from it; or they may fear the hospital itself. Whatever the emotional barriers are, the staff must attempt to discover them and assist in their removal. This may entail telephoning the family when possible, providing updated medical information and keeping the family informed about the infant's progress.

Financial and geographic barriers to visitation are often found in large referral hospitals in rural areas. Families may live up to 500 miles away from the hospital, have no transportation to the hospital or money for child care for siblings at home. Frequent telephoning is critical in these situations to keep the parents informed and to provide personal details and stories about the infant. If problems are mainly financial, the exploration of support services for the family is essential. Lack of a telephone, car, or child care can be overcome through coordination of telephone calls with public health workers,

neighbors, or relatives and by the provision of transportation and child care by religious and charitable organizations.

Another approach which has been tried is the use of volunteer surrogate parents at the hospital who visit and receive information about the infant and who transmit this to the natural parents. "Graduate" parents who have had their own infants on the neonatal intensive care unit (NICU) often make excellent surrogate parents because of their empathy and understanding of the experience. Activities which mean a lot to the natural parents are those which enable them to bond with their infant before he or she comes home--through receiving pictures of the infant or letters written "by" him/her, through their sending toys and clothing to the infant as well as family pictures.

Staff issues which arise when parents do not or cannot visit the infant include feelings of anger and resentment by staff members who have themselves become attached to the infant. In order to prevent the possibility of their communicating these feelings to the family, it is important that staff be given opportunities to vent their feelings and to receive information on the family's status.

Of great importance is the promotion and reinforcement of attachment mediation behaviors in the infant, so that the infant will respond when the parent is available. These behaviors fall into three categories and fill the function of promoting attachment. Signaling behaviors--such as crying, smiling and vocalizing--are reinforced by responding to the infant consistently in an affectionate manner. Orienting behaviors--including the alerting response, visual tracking, auditory tracking and rooting--are reinforced through eye contact; and contacting behaviors--such as sucking, grasping, cuddling and reaching--are reinforced through holding, cuddling and caressing the infant. These efforts are designed to result in the development of attachment readiness in the infant so that he or she will adequately respond to the parents when reunited with them. All activities, however, must be carried out in such a way as to prevent over-stimulation of the infant.

Full acceptance and support of the parents and the family system during this time of stress is essential so that the infant and family will have optimal opportunity for full and healthy development.

Clinical Realities Associated with Facilitation of the Attachment Process

Richard Iacino

Jackson Memorial Hospital is located in downtown Miami, Florida and serves large numbers of low-income (and thus high-risk) families from many cultures, including: Blacks from Haiti, North and South America; Anglos; and Latins from North, Central and South America, Cuba and Puerto Rico. Languages include English, Spanish and Creole French.

Four key issues have been raised in Jackson's intervention program (based in the Neonatal Intensive Care Unit): the appropriateness and usefulness of the current concept of bonding; the possible effects of differing cultural/ethnic backgrounds on the attachment process; the usefulness of delayed bonding as a parental coping mechanism; the potential for competitive attachment between the medical care staff and the parents.

The concept of bonding has, in the past, been overused, overextended and unsatisfactorily defined. An alternative concept which appears to have more utility is that of a constellation of attachment behaviors. This would be more credible and more readily subject to the rigors of research. It would allow for the description of widely varying behaviors and thus help pinpoint the focus of family intervention efforts.

The second issue is raised by the varying degrees of success in changing attachment behaviors among infants of differing cultural/ethnic groups. A longitudinal study of a subsample of infants and their families has suggested the possibility of differing constellations of attachment behaviors depending on the cultural/ethnic background of the family. This points to a need for planning culturally appropriate intervention strategies.

The third issue is concerned with the possible usefulness of the delay in attachment as a parental coping mechanism. One aspect of this delayed attachment is associated with low-income status; the families may be inundated with a succession of survival problems requiring constant crisis intervention. With only the energy and time to deal with several priority issues, the crisis of a hospitalized infant is not placed at the top of the list until it is necessary to do so—near discharge time. Until that time, the parent is relieved that the infant has good care and may even postpone or block discharge from

the hospital. With such mothers, it may be appropriate to develop individualized programs related to real life situations.

The fourth issue is related to how the attachment behavior of the medical care staff in a unit affect the attachment process of the parent. Observation and studies have shown that the nursing staff become attached to infants in their care in varying degrees. The occasional situation in which there develops a competitive attachment between the staff and parents has potential for damage and must be identified by the family intervention staff in order to be resolved by both staff and parents.

The issues which have been raised are clinical impressions of phenomena which might be investigated more thoroughly. In the meantime, awareness of these issues suggests considerations to be made in intervention programs.

Issues in the Use of the Bromwich Parent Behavior Progression Scale

Ellen Khokha

The Parent Behavior Progression Scale (PBP) is a clinical tool which provides for systematic assessment of parenting behaviors in parent/infant interactions. It was conceptualized by Rose Bromwich and developed for use in the UCLA Infant Studies Project (a home intervention project for parents of high-risk infants). The focus of the Project was an interaction model which strove to enhance the self-confidence and competence of parents, thus influencing infant development. The reciprocal nature of the parent/infant interaction can be discouraging to a parent of a handicapped infant if the infant is unresponsive or difficult. Intervention aimed at assisting the parents to discover the infant's strengths and skills, and to find enjoyable activities they can share will affect parental attitudes and caregiving behaviors. The PBP serves as an effective tool for identifying parents' attitudes, feelings and behaviors as a basis for determining intervention.

The PBP consists of six levels (see chart below) arranged in a quasi-hierarchical format. Thus behaviors in Levels V and VI are more complex than those in Levels I-III and may contain behaviors from those levels as components.

The PBP comes in two forms: Form I for parents with infants 0-9 months developmental age (including older severely handicapped or delayed children) and Form II for parents of infants 9-36 months developmental age. Specific instructions for the use and scoring of the PBP are included in the Parent Behavior Progression Manual. There are several considerations and cautions which should be heeded when using the PBP, and these are also discussed in the manual. Staff using the PBP must thoroughly understand the instrument and must have developed a strong rapport and relationship with the parent. Great sensitivity and understanding are required in assessing parent/infant interaction and in determining the focus of intervention. For example, behaviors in Levels I - III should not necessarily be intervention goals even if the assessment indicates an absence in these areas. Activities aimed at Level IV may be more appropriate first. Then as the parent experiences positive and satisfying interaction, the affective behaviors of Level I - II will be more naturally elicited. An important note is that the scoring should not be done in the presence of the parent. (See "Parent Behavior Progression:

Issues Concerning its Use", Westar Series Paper #2, by Rose Bromwich, 1979.)

Use for the PBP

The PBP is currently being used by a number of programs as both a clinical and evaluation tool. Clinically, it is an effective means of:

1. Increasing staff awareness and sensitivity to parent's feelings, attitudes and behaviors.
2. Helping staff identify behaviors in parents' repertoire which are positive and should be supported, which are being blocked by a particular infant, or which could be added to enhance interaction.
3. Providing a base for setting goals and formulating intervention plans.
4. Training staff in the area of parent/infant interaction.

As an evaluative tool, the PBP can provide useful formative data of a program's intervention plans.

Six Levels of the Parent Behavior Progression.

LEVEL I The parent enjoys her infant.

LEVEL II The parent is a sensitive observer of her infant, accurately reads behavioral cues and is responsive to them.

LEVEL III The parent engages in a quality and quantity of interaction with her infant that is mutually satisfying and which provides opportunities for development of attachment.

LEVEL IV Parent demonstrates an awareness of materials, activities, and experiences suitable for her infant's current stage of development.

LEVEL V Parent initiates new play activities and experiences based on principles that she has internalized from her own experience, or on the same principles as activities suggested to or modeled for her.

LEVEL VI Parent independently generates a wide range of developmentally appropriate activities and experiences (which are interesting to the infant) in familiar and new situations and at new levels of the infant's development.

For a copy of the manual or for more assistance and information, contact:

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ERIC

Providing Support for Parents of Handicapped Infants

Ura Jean Oyemade
E. Elaine Vowels

With the increased emphasis on intervention in early infancy, a large number of programs focusing on various disorders have been developed. However, these programs have met with varying degrees of success. Several broad issues relate to the ineffectiveness of these programs, including the failure to incorporate cultural values and goals in the training programs and the failure to assess the exact etiology for the lack of performance of certain child-rearing techniques before designing a treatment program.

The Handicapped Infant Intervention Project in Washington, D.C. is designed to avoid these pitfalls through the incorporation of several unique features. These include:

1. Emphasis on discussions with parents regarding problems and solutions, thus incorporating various cultural views.
2. Use of an individualized approach to training where each parent is assessed, and goals are developed based on needs articulated by the parents.
3. Emphasis placed on the identification and development of other support services which may be more critical for meeting the parent's and child's needs.
4. Individualized modules developed to provide an opportunity for the students to master the material at their own pace.
5. Parent-to-parent teaching incorporated to increase the number of beneficiaries of the training program.
6. Certificates from the University awarded to give parents a sense of professional accomplishment.

As a result of these features, as well as other aspects of the program, there has been a marked increase in participation and motivation by the parents. In addition, the attainment of the goal of improved performance of parenting behaviors was enhanced.

Communication Strategies with Parents

Ronald J. Schmerber.

When working with parents, it is important for physicians to keep in mind that they and the parents are people first and only secondarily the players of their respective roles. It is not worthwhile for physicians to view issues only from within a strictly medical standpoint. Rather, the key element in successful communication is the viewpoint of people responding to each other as people. In working with parents of preterm or high-risk infants, there are several things that professionals must take into account.

They must examine their own emotional availability, must understand their own feelings honestly and be able to relate to what parents feel, as well as what they say. They must be aware of family needs, acknowledge their importance and allow parents to express them. Although it may be tempting to try to take control of a crisis situation, professionals must learn to share control with the family, to be a resource rather than a protector and to suggest choices rather than make them. They should recognize that time is very important, and they should attempt to be available without forcing themselves on parents. They should try to listen without analyzing or projecting and be sensitive to "little things" such as taking photographs of the baby or providing contact with other parents who have had a child in an intensive care nursery.

Parents of preterm or high-risk infants are under great physical and emotional stress. They may experience anger, guilt, sadness, irritability, loss of appetite and difficulty sleeping. Professionals should help parents view these feelings as normal, not negative. The most important thing to remember when communicating in difficult situations is that parents are people who need both the respect and support of the professional.

Four General Theories of Maternal-Infant Bonding and Attachment from Birth Through the First Year

Linda L. Stone

The area of maternal-infant bonding and attachment is of great interest to professionals working with high-risk infants, particularly since these infants are at a greater risk for abnormal attachment and bonding patterns than others. Counseling of families, intervention strategies and the documentation of change are all enhanced when the concepts of bonding and attachment are incorporated into program components.

Four general theories of the formation of the mother-infant bond are: the psychoanalytic-object relations theory (Freud); the ethological theory (Ainsworth, Blehar, Waters & Wall, 1978); learning theory as it relates to infants (Gewirtz, 1972); and "the maternal sensitive period" as it relates to early bonding (Klaus & Kennel, 1977).

The psychoanalytic theory was initiated by Freud toward the end of his life, though never completed. Freud maintained that the maternal-infant bond was the result of the importance the mother places on gratifying psychological needs of the infant and stimulating the infant's erotic zones. This bond is strengthened as the infant moves from a state of primary narcissism (where the mother does not exist apart from the infant and its subjective experiences) to an awareness of the separateness, and attempts to hold onto and maintain contact with the mother. This model generally claims that the relationship between infant and parent is unidirectional rather than reciprocal, that the parents shape the infant's behavior but are little affected or shaped by his/her.

Object relations theorists, also psychoanalytic, feel that the infant is born with social motivations and is "object seeking" in an interpersonal mode. The mother-infant bond, in psychoanalytic theory, is thus seen as developing out of the gratification of the infant's needs by the mother. Its strength in infancy allows the mother to influence the baby's emerging personality.

The ethological theory views behavior as evolutionary and subject to the pressures of natural selection. An innate motivational system and a series of innate behaviors in the infant (crying, smiling, sucking, clinging) serve to elicit a response from the parent. This interaction leads to attachment which has survival value for the species. Ainsworth et al. (1978) have identified four phases in the

development of this mother-infant attachment, three occurring in the first year. As the infant passes through these phases he/she moves from the initial pre-attachment phase, where discrimination between persons is lacking, to a phase of attachment in the making (3-6 months of age) where the infant can discriminate familiar from unfamiliar figures and between one familiar person and another, to a phase of clear-cut attachment (6-12 months of age) where the baby actively seeks and achieves proximity and contact with the preferred figure.

Learning theory as advocated by Gewirtz (1972) rejects the usefulness of the concept of an attachment "bond" and suggests that attachment is learned. Thus "behaviors that indicate attachment" are influenced by environmental circumstances and will vary from child to child. The behavioral interactions between mother and infant (baby's signals, mother's reponses) affect the strength of the attachment.

Maternal sensitive periods, as suggested by Klaus and Kennel (1977), refer to the predictable pattern of maternal involvement with her infant from birth to approximately three months of age. This involvement begins with tactile manipulation of the newborn followed by eye contact. As the infant grows older (around 4-6 weeks), true eye contact and social smiling emerge, increasing the mother's sense of pleasure and affection. By three months of age the attachment bond is strong, as the two become involved in increasingly reciprocal social interchange.

This mother-infant interaction and resulting attachment greatly influence the baby's developing skills. The secure relationship between them provides a comfortable base from which the baby can explore the world, developing cognitively, perceptually and emotionally. Without this attachment, mothers experience great difficulty in parenting; child abuse and neglect may result. Thus, the fostering of this process needs to be included in program curriculum for high-risk neonates in an intensive care nursery setting.

References

Ainsworth, M.D., Blehar, M.C., Waters, E., & Wall, S. Patterns of attachment: A psychological study of a strange situation. Hillsdale, NJ: Lawrence Erlbaum, 1978.

Gewirtz, J.L. Attachment and dependency. Washington, DC: Winston, 1972.

Klaus, M.H., & Kennel, J. In Schwartz and Schwartz (Eds.), Vulnerable infants: A psycho-social dilemma. New York: McGraw Hill, 1977.

Section VI

Fiscal, Legal and Ethical Issues of Neonatal Care

Section VI includes synopses of two presentations concerning the fiscal, legal and ethical issues of neonatal care.

Strategies for Insuring the Survival of Infant Programs: A Discussion of the Issues

Janet Greenwood

Programs for young handicapped infants can survive without federal assistance; many have. Early studies show that most of the first Handicapped Children's Early Education Program (HCEEP) demonstration projects have been able to secure two or more sources of funding, usually including the local education agency. These successes depend in part on the early emphasis on planning for continued funding and also, on effective, well-organized lobbying on the part of parents, project staff and community leaders.

However, financial survival will become increasingly difficult as federal funds are cut and more human services compete for state and local funds. In order to be successful, early intervention programs will need to prove their value as preventive programs, programs that can save money in the long run by reducing the cost of support services. They will need to become more visible, to educate physicians, government leaders and the public as to their effectiveness. They should become familiar with programs and services provided by various local and state agencies and should establish personal contacts with representatives of any governmental units that might help fund the program.

If a program is to continue its existence, strong support must come from the fiscal agent. This is particularly true of programs in hospital settings. It is virtually impossible at this time for hospitals to be reimbursed by third parties for out-patient follow-up services. Medical assistance has no specific category to cover such costs. Therefore, new ways must be found to secure funding for follow-up care of newborns discharged from intensive care units.

Pennsylvania, for example, is developing a model whereby services might be paid for by Blue Cross if a program has a written prescription from a physician for services and if the services are provided by registered nurses, physical or occupational therapists, or speech and language pathologists. The services provided by early childhood specialists, however, are not reimbursable under the present system. (For more information on funding sources see WESTAR's "Public and Private Funding," by Brian McNulty & Arthur Moreau, 1980, ERIC Document Reproduction Series No. ED 191 220.)

Dilemmas in Neonatal Intervention

Carmelo Tardo
Kenneth Sills
Susan Piggott

Advances in medical technology often bring with them ethical dilemmas, and neonatal technology is no exception. Modern neonatal intensive care saves many lives, both normal and defective, and thus raises many questions. Major issues include decisions about non-resuscitation at birth, withdrawal of established life support and lethal intervention for medically hopeless infants. The choices we make to resolve such ethical questions involve our perceptions of human nature, morality and our obligation to each other as human beings. How and why decisions are made is a very important matter.

Decisions regarding the care of newborns are by law the right and responsibility of parents, but in practice they are frequently made by physicians. Parents have often been excluded from ethical discussions of neonatal intensive care unit (NICU) technology. For the physician, key decision-making guides include medical data, the physician's personal values and the medical-moral principle: "Do no harm, unless the patient benefits." To better involve the parents in ethical decisions, an educational process should be initiated by the physician before or immediately upon the birth of a high-risk infant. An analysis of the parents' life situation (economics, other children, parental relationship, religious and moral beliefs, ability and willingness to care for a handicapped child) should be made. The potential impact of a decision on the parent should be evaluated and emotional support provided. It might also help parents in their decision-making process if an educator or some other specialist would provide them with a realistic picture of the child's prognosis and its implications.

The legal system has not yet solved any of the dilemmas resulting from the problems faced in the NICU. To date, no "wrongful life" suits have been successful, although parents have won compensation for a doctor's failure to inform them of tests that could have detected Down's syndrome. No parent or physician has been prosecuted for withholding exceptional care from a defective newborn. The legal basis for past decisions by the courts may be challenged in some areas, such as when a fetus is viable and consequently by law a "person". (Some legal writers propose a special definition in the case of severe handicaps.) The courts have at times made medical decisions about when and whether it is proper to

withdraw a life support system but they have often refused to decide. In general, the judicial system is inadequately equipped for such matters and tends to defer the problem, as well as the answer, to the medical community.

Section VII

Supplementary Information

Section VII includes supplementary information--the workshop evaluation report and questionnaire, the preliminary survey form, the workshop agenda and the presenters list.

EVALUATION REPORT FOR THE HCEEP WORKSHOP ON THE HEALTH CARE/EDUCATION RELATIONSHIP: SERVICES FOR INFANTS WITH SPECIAL NEEDS AND THEIR FAMILIES

New Orleans, Louisiana
March 16-18, 1981

This report summarizes the responses gained from The Workshop Evaluation Questionnaire received from 60 of 102 participants at the conclusion of the HCEEP workshop on The Health Care/Education Relationship: Services for Infants with Special Needs and Their Families. Respondents described their overall satisfaction with the meeting and noted the extent to which each workshop purpose was met. Individual sessions were evaluated in terms of quality and usefulness, and open-ended questions assessed strengths and weaknesses of the meeting. The forms elicited additional comments concerning the value of the meeting, location, organization, theme presentation and accomodations. The geographical and/or project affiliation of individuals who completed the evaluation form are reflected in Table 1. Table 2 illustrates that participants were more than adequately satisfied that workshop purposes were achieved.

Table 1

Geographical/Project Affiliation

HCEEP Demonstration Project (East)	17
HCEEP Demonstration Project (West)	26
HCEEP Outreach Project (East)	4
HCEEP Outreach Project (West)	5
State Implementation Grant	1
Former HCEEP Project	2
Other	5
TOTAL	60

Table 2

Extent to Which Workshop Purposes were Achieved

	PURPOSE	N	MEAN
A.	To identify issues of common concern.	60	5.98
B.	To facilitate communication and cooperation among professionals from health care and education disciplines.	60	5.59
C.	To exchange information and ideas on best practices.	60	5.75

NOTE: Ratings on a 7-point scale, with 7 being the most positive.

Quality and Usefulness of Sessions: Sessions addressing 19 topics of interest were rated for their quality and usefulness. As reflected in Table 3, participants gave most sessions positive ratings. The means for quality and usefulness of 14 of the sessions were above 5.0 on a 7-point scale. The sessions entitled "The Development and Implementation of the Assessment of Premature Infant Behavior," the keynote address by Dr. Brazelton and the session entitled "Accessing Funds: A Discussion of the Issues" received particularly high ratings for the quality of presentation. "Assessment of Preterm and Postterm Infants," "Accessing Funds," "Humanizing the ICN" and "The Development and Implementation of the Assessment of Premature Infant Behavior" all received high ratings for the usefulness of the presentation. In general, the ratings imply that the sessions were well presented and that their content was appropriate in terms of its usefulness and applicability for participants.

Table 3
Quality and Usefulness of Workshop Sessions

	QUALITY		USEFULNESS	
	N	Mean	N	Mean
The Development and Implementation of the Assessment of Premature Infant Behavior	47	6.68	44	6.22
Keynote Address - Dr. T. Berry Brazelton	59	6.38	53	5.88
Accessing Funds: A Discussion of the Issues	6	6.33	5	6.80
Communication with Multi-Cultural Families	7	6.28	7	5.85
Humanizing the ICN	9	6.27	8	6.25
Dilemmas in Neonatal Intervention	10	6.20	7	5.57
Methods of Intervention in Newborn Nurseries	26	6.05	21	5.61
Synthesis Session	24	5.83	20	5.60
Assessing Family Needs: An Introduction to the Parent Behavior Progression Scale	10	5.60	21	5.28
The Role of Educational Specialists in ICNs	23	5.60	21	5.28
Communication with Parents	12	5.33	12	5.16
Range of Family Support	8	5.31	7	5.14
Bonding and Attachment: The Research and Realities	26	5.26	24	5.20
Assessment of Preterm and Postterm Infants	27	5.25	25	6.25

SESSION	QUALITY		USEFULNESS	
	N	Mean	N	Mean
Assessing Family Needs	2	5.00	2	5.00
Appropriate Evaluation in Infant Intervention Programs	14	4.53	14	3.92
Methods of Educational Intervention	7	4.42	7	4.57
Assessing Family Needs: The LSU Medical Center Model	6	4.16	6	3.33
Appropriate Evaluation of Infant Intervention Programs	9	3.72	8	3.62

NOTE: Ratings on a 7-point scale, with 7 being the most positive.

Synthesis of Written Comments

Participants were requested to provide narrative responses to general questions, each discussed separately below.

1. What was the most positive part of the workshop for you? Nearly one-half of the participants who responded to this question stated that the most positive part of the workshop was meeting and sharing ideas with other people involved in health care/educational settings. Several respondents indicated that the information presented was the most positive aspect of the workshop. In addition, many respondents mentioned individual speakers and/or sessions as being the most positive component of the workshop. A few participants stated that information on parents was most helpful.

2. Was the theme "Building Relationships" adequately discussed? Of the 45 participants who responded to this question, 35 (77%) agreed that the workshop theme had been adequately discussed. Six participants (13%) stated that the theme had not been discussed in enough detail, and four respondents (8%) felt that the theme was only partially addressed. Those who believed that the theme was not sufficiently addressed suggested that a more integrated approach, i.e., involvement of nurses, doctors, etc., would have been advantageous.

3. Do you feel the workshop was worth the time and effort you invested?

Twenty-two participants responded to this question. Nineteen (86%) agreed that the workshop was worth their time and effort, whereas three respondents felt that the workshop was not.

4. Overall Satisfaction.

Participants noted their overall satisfaction with the workshop on a 7-point scale, with 7 as the highest rating. The mean, based on 57 responses, was 5.63. This positive rating indicates that the workshop provided a very satisfactory learning experience for participants.

5. In your opinion, what was the weakest component or aspect of this workshop?

Narrative responses to this question were varied but revolved mainly around timing and agenda concerns. Several participants stated that the time allotted to sessions was insufficient. Others mentioned that too much information was presented in too short a time frame. Some participants expessed concern over hotel accommodations. Several participants listed poor scheduling as the weakest aspect.

6 & 7. General statements about the organization of the workshop, the accomodations, time of meetings, etc. were elicited.

Responses to these questions varied, especially in regard to the poor quality of hotel accomodations. In general, however, most respondents rated the organization of the workshop favorably.

Summary

Workshop evaluation results indicate that workshop purposes were more than adequately met and that most participants found individual sessions of use and of high quality. It is evident from quantitative data and written comments that the WESTAR/TADS-sponsored HCEEP workshop on building relationships in health care/educational settings was a successful endeavor.

Produced by David Gilderman (WESTAR).

WORKSHOP EVALUATION QUESTIONNAIRE

This questionnaire is designed to gather your opinions concerning the quality and usefulness of this workshop. We will use the information you provide to determine the effectiveness of this meeting and to improve future meetings of this kind. We appreciate your most honest and objective opinions. Thank you.

Please indicate your professional affiliation:

HCEEP Demonstration Project (East)	___	SIG	___
HCEEP Demonstration Project (West)	___	TA/OSE Staff	___
HCEEP Outreach Project (East)	___	Former HCEEP Project	___
HCEEP Outreach Project (West)	___	Other (please specify)	___

I. To what extent did you perceive the workshop to have achieved its purposes? (Please circle the appropriate response for each item.)

		Very Well			Adequately			Not at All
A.	To identify issues of common concern.	7	6	5	4	3	2	1
B.	To facilitate communication and cooperation among professionals from health care and education disciplines.	7	6	5	4	3	2	1
C.	To exchange information and ideas on best practices.	7	6	5	4	3	2	1

II. The workshop agenda was structured so that participants could choose among several topics. Please rate sessions that you attended in terms of both quality and usefulness.

Session Title	QUALITY Excellent	Average	Poor	USEFULNESS Very Useful	Of Some Use	Not Useful
Monday, March 16						
Keynote Address	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Tuesday, March 17						
Methods of Intervention in Newborn Nurseries	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Appropriate Evaluation in Infant Intervention Programs	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Assessing Family Needs: An Introduction to the Parent Behavior Progression Scale	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Range of Family Support	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Dilemmas in Neonatal Intervention	7 6 5	4 3	2 1	7 6 5	4 3	2 1
The Role of Educational Specialists in NICUs	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Assessing Family Needs: The LSU Medical Center Model	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Communication with Parents	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Appropriate Evaluation of Infant Intervention Programs	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Bonding and Attachment: The Research and Realities	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Assessing Family Needs	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Humanizing the ICN	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Assessment of Preterm and Postterm Infants	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Accessing Funds: A Discussion of the Issues	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Communication with Multi-Cultural Families	7 6 5	4 3	2 1	7 6 5	4 3	2 1
Methods of Education Intervention	7 6 5	4 3	2 1	7 6 5	4 3	2 1

Session Title	QUALITY Excellent	Average	USEFULNESS Very Useful	Of Some Use	Not Useful
Wednesday, March 18					
The Development and Implementation of the Assessment of Premature Infant Behavior	7 6 5 4 3 2 1		7 6 5 4 3 2 1		
Synthesis Session	7 6 5 4 3 2 1		7 6 5 4 3 2 1		

We are very interested in your feedback. Please list any comments you wish to make on an individual session.

III. Please respond to each of the following questions. Your answers will be carefully reviewed and considered.

1. What was the most positive part of the workshop for you? Please explain.

2. Was the workshop theme "Building Relationships" adequately discussed?

3. Do you feel this workshop was worth the time and effort you invested?
   Yes __ No __

   COMMENTS:

4. Please indicate your overall satisfaction with this workshop. (Please circle appropriate response.)

Extremely Satisfied		Satisfied				Not at All Satisfied
7	6	5	4	3	2	1

5. In your opinion, what was the weakest component (or aspect) of this workshop?

6. List any comments you would like to make concerning the workshop location, organization, time of meetings, accomodations, etc.

7. List any other comments.

HEALTH CARE/EDUCATIONAL ISSUES INTEREST SURVEY

Part I

1. How do health care and educational services interrelate in your setting?

_____

_____

_____

2. Do you and/or members of your staff plan to attend the health care/educational issues workshop?

___ Yes ___ No ___ Maybe.

If yes, how many? ___

If you do not plan to attend the workshop, you need not complete Parts II and III. Please return in the envelope provided. Thank you.

Part II (Complete only if interested in attending the workshop):

Following is a list of potential topics for workshops, small group discussion, or presentations identified by the Workshop Planning Committee. Please indicate your level of interest in each topic by circling the appropriate number.

Suggested Topics		Level of Interest High Mod. Low
1.	Defining the roles of health care and educational services in programs for very young children.	5 4 3 2 1
2.	Creating support in medical communities for educationally oriented programs.	5 4 3 2 1
3.	Strategies for developing hospital based programs.	5 4 3 2 1
4.	Dealing with management and power structures in health care settings.	5 4 3 2 1

Suggested Topics		Level of Interest				
		High		Mod.		Low
5.	Organizing and coordinating a multi-disciplinary team in ICU settings.	5	4	3	2	1
6.	Determining leadership roles when involving health care personnel.	5	4	3	2	1
7.	Facilitating positive communication across staff disciplines.	5	4	3	2	1
8.	Coping with staff stress.	5	4	3	2	1
9.	Methods of intervention in health care/educational settings.	5	4	3	2	1
10.	Effects of educational intervention in ICUs and newborn nurseries.	5	4	3	2	1
11.	The role of educational specialists in ICUs.	5	4	3	2	1
12.	Humanizing the ICU for infant, family and staff.	5	4	3	2	1
13.	Assessment of preterm and postterm infants.	5	4	3	2	1
14.	Factors contributing to high risk.	5	4	3	2	1
15.	Ethical issues in identifying high-risk children.	5	4	3	2	1
16.	Relationship of PL 94-142 to hospital settings serving infants (IEPs, etc.).	5	4	3	2	1
17.	Appropriate evaluation: Clinical vs. educational.	5	4	3	2	1
18.	Group evaluation vs. individual case evaluation.	5	4	3	2	1
19.	Strategies for accessing funds for educators in health care settings.	5	4	3	2	1
20.	Health insurance trends affecting program costs and payments.	5	4	3	2	1

Suggested Topics		Level of Interest				
		High		Mod.		Low
21.	Coordinating follow-up in the community (health care, social service, educational).	5	4	3	2	1
22.	Role of parents vs. medical staff in intervention.	5	4	3	2	1
23.	Assessing family needs in ICU programs.	5	4	3	2	1
24.	Facilitating bonding/attachment.	5	4	3	2	1
25.	Range of family support, including counseling, sibling involvement, visitation and attitudes.	5	4	3	2	1
26.	Communicating with parents - do's and don'ts.	5	4	3	2	1

Part III (Complete only if interested in attending the workshop).

A. List other topics in addition to those identified above.

B. What do you think are the three most critical issues faced by service providers in health care/educational settings?

1.
2.
3.

C. What do you think are the three most critical issues faced by families of at-risk or handicapped children in health care/educational settings?

1.
2.
3.

D. What are some unique strengths of health care/educational settings in serving very young children and their families?

_____

_____

_____

E. Which topic areas in Part II do you consider to be strengths in your project?

Please list by topic number:

_____

_____

_____

Other strengths:

_____

_____

_____

F. Would you be willing to contribute to the workshop program in one of your strength areas?

___ Yes ___ No If yes, which area(s):

G. Can you recommend any other resources (persons, publications, programs) that might be useful in planning and conducting the workshop?

_____ _____

_____ _____

_____ _____

H. Please list any other health care/educational programs in your area that may be interested in participating in this workshop.

ERIC

THE HEALTH CARE/EDUCATION RELATIONSHIP: SERVICES FOR INFANTS WITH SPECIAL NEEDS AND THEIR FAMILIES

WORKSHOP AGENDA

Monday, March 16

5:00 - 7:30 p.m.	Registration
7:30 - 8:00	Welcome and Introduction Sonya Prestridge, TADS
	Welcome to Louisiana Henry Smith, State Director of Special Education in Louisiana Patsy Poche, Director of Children's Center of LSU Medical Center Edith Kong-Lam, Director of New Orleans Public Schools - Model for Preschool Handicapped
8:00 - 9:00	"The Future Uses of Assessment in Intervention" T. Berry Brazelton, Chief of the Division of Child Development at The Children's Hospital Medical Center in Boston, MA, and Associate Professor of Pediatrics at Harvard Medical School
9:00 - 9:30	Questions & Answers
9:30 - till	Reception

Tuesday, March 17

8:00 - 8:30 a.m.	Coffee and Late Registration
8:30 - 8:45	Workshop Overview and Announcements David Gilderman, WESTAR
8:45 - 9:15	THEME, "Building Relationships" Linda Gilkerson, Boston, MA.

Tuesday (Continued)

9:15 - 10:30	TOPICAL SESSIONS
	- Methods of Intervention in Newborn Nurseries
	- Infant Intervention Evaluation Issues
	- Assessing Family Needs Using the Parent Behavior Progression Scale: An Introduction
	- Range of Family Support Services
10:30 - 10:45	Break
10:45 - 12:00	TOPICAL SESSIONS
	- The Role of Educational Specialists in the Intensive Care Nursery
	- Dilemmas in Neonatal Intervention
	- Communication Strategies with Parents
	- Assessing Family Needs
12:00 - 1:30 p.m.	GROUP LUNCHEON THEME, "Building Relationships" Jennie Swanson, Maywood, IL.
1:30 - 2:45	TOPICAL SESSIONS
	- Bonding and Attachment: The Research and Realities
	- Infant Intervention Evaluation Issues
	- Humanizing the Intensive Care Nursery
	- Issues in the Use of the Bromwich Parent Behavior Progression Scale
2:45 - 3:15	Break
3:15 - 3:45	THEME, "Building Relationships" Earladeen Badger, Cincinnati, OH.

Tuesday (Continued)

3:45 -	5:00	TOPICAL SESSIONS
		- Assessment of Preterm and Postterm Infants
		- Strategies for Insuring the Survival of Infant Programs: A Discussion of the Issues
		- Communication with Multi-Cultural Families on a Newborn Intensive Care Unit
		- Methods of Educational Intervention

Wednesday, March 18

8:30 -	9:00 a.m.	Coffee
9:00 -	9:15	Announcements Joan Anderson, TADS
9:15 -	10:15	"The Development and Implementation of the Assessment of Premature Infant Behavior" Heidelise Als, Boston, MA.
10:15 -	10:30	Questions and Answers
10:30 -	10:45	Break
10:45 -	11:45	Synthesis Session
11:45 -	12:00	Closing - Thank you's and workshop evaluation Denise Taylor-Hershel, WESTAR

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