

Six Simple Steps to Building a Medical and Early Intervention Transitional Coalition

By Denise Merrill

STEP ONE: EDUCATE YOURSELF

Realize that the Neonatal Intensive Care (NICU) staff is unfamiliar and uncomfortable with early intervention tools like the IFSP. Your first step will be to educate the medical community about early intervention services, programs, and options. One roadblock that may arise is the fear from medical professionals in "labeling" NICU graduates as "handicapped." Many others may say that it is virtually impossible to make a diagnosis of developmental delay in the neonatal stage. This is where you would begin the educational process of Part C within IDEA. If you are not completely familiar with the federal standards and regulations, obtain a copy and study it. This will help you to clearly state the guidelines to medical professionals when they question the validity of your transitional coalition. The eligibility list for screening and tracking of infants at risk developmentally also includes children with:

- Birth weight under 1500 grams
- Received care in the neonatal intensive care unit (NICU)
- Born to a chemically-dependent mother

If you have never seen a Level III neonatal intensive care unit, plan to visit one before you begin your coalition building. Set up a meeting with the neonatal department head and tell them about your coalition plans and solicit their support. Tour the NICU and meet with the NICU staff and the families who are currently there. If possible conduct your own needs assessment to discover possible "gaps" in the system that you and the medical community may not be familiar with. Each community and its programs are different; therefore, each community needs its own individualized transitional plan.

STEP TWO: IDENTIFY THE PLAYERS

The next step in building a coalition is to identify those individuals who are a connection to the family within the scope of medicine as well as early intervention. Many hospitals will also maintain a neonatal follow-up clinic for infants at risk medically and developmentally. Therefore, they must also be a critical key in not only identifying infants at risk but also referring infants into appropriate early intervention programs and services. The goal is to make this coalition a multidisciplinary, community-based, interagency project.

- Identify hospitals in your area with a Level II and Level III Neonatal Intensive Care Unit (NICU).

- Contact the head NICU nurse, primary care nurses, case managers, patient care coordinators, developmental specialist, department heads, and social workers.
- Identify NICU/Pediatric follow-up clinics.
- Identify pediatricians in your area.
- Identify pediatric specialists in your area.
- Does your state have a birth defects surveillance system in place? Find out how the system operates by contacting your states' health officer at the Department of Health and invite them to participate in your coalition.
- Identify the Local Education Agency (LEA) within your school districts. They are also responsible for identifying children at risk for delays within their districts.
- Invite Head Start directors and staff.
- Invite preschool administrators and teachers.
- Invite a representative from the Local Interagency Coordinating Council (LICC).
- Invite your county officers from MH/MR for infant/toddler programs.
- Invite organizations such as ARC, The March of Dimes, Easter Seals, local PTA Council Presidents, and the Lions Clubs to be on your coalition. The more groups involved is better for increasing outreach and referrals.
- **DON'T FORGET** to invite NICU graduate families, families who act as peer counselors, or parent/child advocates. They will play an important role in advising this coalition since they have been through the process.

STEP THREE: MAKING THE CONNECTION

Now that you hopefully have a key individual from each discipline, your first program would be to bring all sides together for a one-day forum. TIPS School in Nashville, Tennessee, is currently conducting such a program. You will need to setup the program to allow each side to learn about the other. Early childhood educators and interventionists will gather to hear a panel of experts from the NICU discuss the medical environment, developmental supportive care, and the discharge plan. Simultaneously, medical personnel are guided through the channels of early intervention services from referrals to program options. After this breakout session both sides then come together to discuss concerns, questions and to network. This is also a good time to discuss possible new tools or models to bring together the discharge plan and the IFSP. At the conclusion of this program, secure commitments from individual attendees to be a part of the Medical and Early Intervention Transitional Coalition Team. If your program was effective, this should not be too difficult. It may just be a matter of time commitments or the characteristic WIIFM (What's In It for Me). Again, if your program was effective in demonstrating the need for collaboration, the attendees will see the immediate need and the WIIFM.

STEP FOUR: BUILD AN EFFECTIVE TEAM

Don't get caught in the "I must do everything" syndrome. I, too, sometimes suffer from this debilitating affliction. The point of a coalition is to equally share in the transitional process. One side cannot be the driving force. Responsibilities must be shared equally among all

disciplines. Understand that each person involved is also a volunteer. People volunteer for several reasons such as:

- * Because someone they love benefits
- * To set an example for children
- * Because they were asked
- * To meet people
- * They enjoy working with people and causes
- * To gain skills and/or experience
- * To use otherwise unused gifts or talents
- * Out of concern
- * To test leadership skills
- * To feel a sense of power and success

STEP FIVE: DEVELOP A WRITTEN PROCEDURE

Although fostering relationships and networks between all disciplines is vital to your coalition's success, it is equally important to develop a written protocol to keep this connection together. Personnel changes will emanate. By developing a written model that brings the discharge plan and the IFSP together, these personnel changes will have little effect on the success of this project. The state of Colorado developed such a coalition, which consisted of nurses, therapists, social workers and various state agencies, community centers, and parents of special needs children. They met for two years to develop the basic principles and a guidebook that implements the plan to ensure that children at risk for developmental delay are identified and referred to community-based services before they leave the NICU. This group was also successful in writing and implementing an interim IFSP for use in the NICU.

Maryland's PRIDE is another example of such a coalition. This group is a unique community-base collaboration among a NICU, an early intervention program, and a NICU follow-up clinic. These coalitions are rare. To date, I only know of five throughout the country who actively pursue such a project. Many are community-based like Maryland's PRIDE whereas Denver's is a statewide initiative.

STEP SIX: ASSESSMENT

In order to be effective, you must continually assess your methods and efficiency. Take the time to listen and evaluate. It's hard to be unbiased about projects that you have a great passion for; however, if helping children is at the forefront of your mission statement, it becomes easier to accept and hear critiques, even those that are unsolicited. In the beginning, you may need to meet every month or every other month until your written protocol is developed. After that it's wise to meet on a quarterly or bi-yearly basis to "iron" out concerns that will most likely creep up.

Also, remember that an effective coalition is one that supports each other's views and respects each other's differences. This coalition will be forging new ground. It may not be easy; however, your reward will be seen in the faces of families and children alike.

RESOURCES

THE CENTER FOR FAMILY AND INFANT INTERACTION

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The purpose of the Center for Family and Infant Interaction is to promote the best outcomes and relationships between families and their infants, particularly those infants who have developmental challenges and/or special health care needs at birth. The Center addresses this goal through education, consultation, research, and support of professional/parent collaboration. Infants and their families throughout Colorado who begin their lives in intensive care nurseries benefit from this program.

The Colorado Consortium of Intensive Care Nurseries. The Consortium is a network of 28 neonatal intensive care units (NICU's) in Colorado who are committed to support developmental and family-centered care. Each NICU has formed teams which include a manager, a staff person, a parent who has had an infant in the intensive care unit, an Early Childhood Connections representative (Part C) from the community, and a public health nurse. This group meets regularly to plan and troubleshoot difficulties in implementing developmental care in a family-centered framework and to identify infants eligible for Part C community based support. Through this teamwork, the program's mission is to enable infants and their families, with the implementation of developmentally supportive care, to have more optimal medical and developmental outcomes; with family-centered care, to have more opportunities for making a contribution to their own infant's as well as others' outcomes; with early identification, to have more resources available early in their lives; and with families having enhanced leadership skills, to have more opportunities for making a difference in their communities for their own infant as well as others.

Major Goals

1. Implement developmentally supportive and family-centered care
2. Refer infants and their families appropriately to community support services
3. Integrate community professionals into the work of the NICU collaborative teams.

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