

MAKING THE CONNECTION BETWEEN MEDICINE AND EARLY INTERVENTION: A FAMILY'S STORY

By Denise Merrill

The current national trend focuses on the importance of early childhood education. Professionals in the field are promoting the significance of development in the first three years of life. For a child born prematurely or with birth defects, early intervention is imperative. As a parent of a former 24 weeker - neonatal lingo for a baby born at 24 weeks gestation - who is also blind from Retinopathy of Prematurity (ROP), I know how important early is in intervention.

My son, Paul, was born at 24 weeks gestation and weighed 748 grams, or one pound, ten ounces. The prognosis wasn't good. Just one month prior to my son's birth, June of 1991, the drug, Surfactant, had been approved by the FDA for neonatal use. According to our son's neonatologists this is one reason why Paul is still with us today. It was explained to me that this drug, Surfactant, helped to make my son's lungs expandable and that all babies manufacture this substance naturally in the later weeks of pregnancy. Obviously, babies born before 33 weeks lack this vital substance; and many of them die or suffer a lifetime with bronchopulmonary dysplasia (BPD), a life threatening and debilitating disorder.

The first two weeks of my son's life were heart wrenching. The Neonatal Intensive Care Unit (NICU) scared the "explicit" out of me. My baby looked liked a fetus, not the Gerber baby that I had expected. We were told that Paul had less than a 20 percent chance of surviving. And, if he did survive, Paul would most likely sustain some or several forms of disabilities. At that time the physician proceeded to give us a rundown of a long list of "handicaps." Overwhelmed by our newly acquired knowledge of disabilities, my husband, Eric, and I struggled to understand the medical jargon that rolled off the tongues of doctors and nurses alike.

During the second week of intensive care our son's primary neonatologist calmly told us, "Your son has a level IV intraventricular hemorrhage in the right ventricle. We have consulted a pediatric neurosurgeon who is considering an emergency shunt procedure. However, your son's lungs collapsed last night, and he is on high levels of oxygen, and the pressure levels are to the limit. We are unable to conduct the surgery until your son's lungs are stable. Any questions?"

Yes, where can I find the nearest exit and will I ever wake up from this nightmare? By some miracle in which to this day I am still in awe, the level IV bleeding resolved on its own, and Paul's lungs regained their elasticity. He became stable in a relatively short amount of time; and after three months, he began to look more like the Gerber baby that I had dreamed about. However, three days before a long awaited discharge, the pediatric ophthalmologist told us that there was something wrong with Paul's eyes. Paul would need to stay an additional week in order for them to conduct Cryo-surgery. We left a week later knowing that Paul had Retinopathy

of Prematurity Stage V plus disease. We didn't know, nor were we told until a year later, that our son was blind.

Birth Defect Surveillance Systems

During this entire time we were living in Bayville, New Jersey. New Jersey has a Birth Defects Registry/Special Needs Registry which tracks and reports by law, all birth defects, including structural, genetic, and biochemical. Since Paul's eye condition was considered structural, we were referred to the Ocean County Health Department which provides early intervention services. Eric and I were confused. As a part of our son's discharge plan we were receiving services from the NICU Follow-up Clinic provided by the medical community. What we didn't know at the time was that this follow-up clinic was more about medicine than education or development. Although they evaluated Paul, no one told us that our son was blind nor did they explain to me that my son should also be involved in the early intervention programs and how that differed from the NICU Follow-up Clinic.

As the Public Affairs Chair for The West Penn Chapter of the March of Dimes Birth Defects Foundation, I learned about a bill in 1992 that would mandate all states to register and track birth defects. I was astonished to learn that in the United States only five states, through their own state law, required this type of surveillance. As a mother, who discovered from a caring and sorrowful eye surgeon that my son was blind, a day after Paul's first birthday, I know how much time we had lost in helping our son and family receive appropriate services.

President Clinton signed into law the Birth Defects Prevention Act (P.L. 105-168) which authorizes the Centers for Disease Control and Prevention (CDC) to provide surveillance, research, and services aimed at the prevention of birth defects. Not only will this surveillance system help to identify factors that may help to eliminate birth defects, it will also identify babies who need early intervention services. However, in order for this system to be effective, it is crucial for the medical community and the educational arena to work towards a multidisciplinary, collaborative effort to foster development in children at risk medically and developmentally.

Making the Connection

If Eric and I were in denial, it was only because we didn't know how severe our son's eye condition was. How were we to know that ROP Stage V plus disease meant that Paul was blind with some light perception and peripheral vision? Doctors told us that it was nearly impossible to discover what Paul could see until he was old enough to tell us. And, Paul appeared to have some vision. So when it was time to crawl, we not only allowed him to do so, we expected it. Within his first year of development we knew that Paul was behind; however, we were told it was due to his premature birth and that in time, Paul, like most premature babies, would eventually "catch-up" to his peers.

Unfortunately, one does not outgrow blindness. I am not suggesting that the doctors told us this; however, the lack of continuum of services between the NICU and early intervention is apparent in our case. Although the New Jersey Birth Defect Surveillance System tried their best to get us into their programs, Eric and I were receiving conflicting reports from the medical community. Had we been told that our son needed developmental services beyond the medical field we would have done so. Eric and I were under the impression that Paul was getting what he needed. The Follow-up Clinic provided evaluations, reports, and services. We drove him weekly to the clinic, which tracked his breathing and heart rate through an apnea monitor. They placed him on the floor and observed how he moved his arms and legs and how he drank from his bottle. Eric and I kept charts on his food consumption and medicine doses to control his severe reflux. It appeared as if we were receiving the services that Paul needed until I attended a Parent Care conference for families of premature babies and learned about early intervention services. Immediately I knew that Paul had additional needs that were not being met. Suddenly, the subtle developmental problems became acutely enormous.

Fortunately, by the time that Paul was a year old, he was enrolled in a weekly home-based early intervention program in which we were introduced to the IFSP and a whole new dictionary of terms. What we lost in that year can never be returned. But, somehow in spite of my lack of knowledge, Paul has progressed and flourished into a wonderful young boy who rides a bike, plays golf, and for the most part, is unafraid to move about freely. Had I known that Paul was blind, would I have kept him quietly seated on a bean bag chair? To this day I don't know what I would have done; however, if the medical community and the early intervention service providers had been in communication with each other, I may not be wondering about that question today.