

System of Risk Triage

A Conceptual Framework to Guide Referral and Developmental Intervention Decisions in the NICU

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The identification of the types and intensity of services and community supports needed to promote optimal development in at-risk infants has received little attention. This gap has resulted in children and families that are over-, under-, or mis-served. We describe an innovative process, beginning within the first week of neonatal intensive care unit admission, for determining the types and intensity of developmental and family support services that may be indicated. The approach, referred to as SORT, the System of Risk Triage, juxtaposes an infant's biological-biomedical risk conditions with psychosocial-physical environment circumstances to determine the infant's risk for subsequent developmental delays/disabilities. The determination of each infant's risk profile implies a list of service options that may be shaped according to each infant's needs and each family's interests. Although the SORT has been used in neonatal intensive care units nationwide, the process and framework have potential for broader application. **Key words:** *biological risk, environmental risk, family, intervention, newborn, neonatal intensive care unit, prevention*

SINCE the passage of Public Law 99-457 in 1986, the early identification of children who might later express developmental delays/disabilities has gained emphasis. Even though the law, now referred to as the Individuals With Disabilities Education Act (IDEA, 1991), has been in effect for 18 years,

states continue to struggle to identify and make programs available to all infants and toddlers who might benefit from early intervention services. The National Early Intervention Longitudinal Study for 1999-2000 reported that 1.8% of all children from birth to age 3 required and received services through early intervention programs nationwide, while the percentage of children aged 6-21 who required and received special education services was 11.4% (U.S. Department of Education, 2001). This 6-fold increase in the percentage of children who required and received special services at school age suggests that current systems used for the early identification of children who are at risk may not be effective.

Identifying children who may benefit from early intervention services by the presence of early risk factors generally is accepted (Meisels & Wasik, 1990; Olds et al., 2004). Prospective studies have examined the outcomes of children with known biological risk conditions that were present at birth (Hack et al., 2005; Marlow, Wolke, Bracewell, & Samara, 2005). Possibly, the most extensive

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longitudinal study of the relationship between early biological and environmental risk factors and developmental outcomes was conducted with a cohort of 53 000 children followed through the Collaborative Perinatal Project of the National Institute of Neurological Diseases and Blindness (Broman, Nichols, & Kennedy, 1975). Their findings were similar to those of Werner, Bierman, and French (1971) who studied the children of Kauai. Both studies found significant associations between early risk factors and later outcomes. The 2 strongest factors associated with later outcomes, however, were not biological factors, but environmental risk factors including maternal education and quality of the caregiving environment (Goleman, 2006; Kochanek & Buka, 1991; Sameroff & Chandler, 1975; Schore, 2000; Stern, 2002).

Outcomes are the result of a complex interplay of intrinsic (biological) and extrinsic (psychosocial-physical environment) factors. Sameroff, Seifer, Barocas, Zax, and Greenspan (1987) and Bee et al. (1982) found that as the number of risk factors increased, there was a corresponding increase in developmental delays and disorders. Horowitz's (1988) structural and behavioral model suggests that the concept of combining biological and environmental risk conditions can be seen as a dynamic process, whereby the factors continually influence each other to affect outcomes. This suggests that systems developed to identify and intervene with children who are at risk must also be dynamic in nature.

Infants who are born very sick or preterm and require neonatal intensive care are at increased risk for later neurodevelopmental disorders such as learning disabilities, attention deficit disorder, clumsiness, cerebral palsy, and mental retardation (Vohr et al., 2000). However, it is very difficult, at the time of birth, to identify which infants will do well later and which infants subsequently will demonstrate developmental disorders.

A number of studies have reported that, in fact, infants requiring hospitalization in a neonatal intensive care unit (NICU) have highly variable outcomes. Outcomes are as-

sociated with many factors including preterm birth, low birth weight, brain injury such as intraventricular hemorrhage and periventricular leukomalacia, pulmonary insufficiency, and, ultimately, the adequacy of each infant's psychosocial environment (Collin, Halsey, & Anderson, 1991; Hack et al., 1994; Kitchen et al., 1991; McCormick, Gortmaker, & Sobol, 1990; Mouradian, Als, & Coster, 2000; Picuch, Leonard, Cooper, & Sehring, 1997).

The American Academy of Pediatrics (2006) guidelines recommend that all infants and children should be screened for developmental delays, recognizing that children with risk factors for developmental delays warrant closer, more intensive surveillance. Unfortunately, many follow-up programs operate as though all infants cared for in an NICU are at equal risk for later neurodevelopmental disabilities, offering a "one size fits all" developmental clinic where families bring their children at predetermined intervals. This may work well for some infants and families, but not for others. For example, infants born preterm at 34 weeks' gestational age are much less likely to demonstrate developmental problems secondary to their preterm birth in comparison with infants born at 25 weeks' gestational age. Family problems with transportation, work, or lifestyle conflicts may make it difficult for some parents to participate in a follow-up developmental clinic even when an infant's risk is known to be high. Eventually, children with more obvious long-term developmental disabilities are identified through their primary healthcare provider or school setting. This haphazard approach, however, ends up being costly for the children, families, and the service systems. The early opportunity to prevent or minimize developmental problems has been lost. On the other hand, intensively following every child who has been cared for in an NICU may be a poor use of limited resources.

The primary emphasis of studies related to risk factors and their usefulness in identifying children who are at risk for developmental disabilities has been to test the efficacy of various single and combinations of risk factors to

predict developmental outcomes. There has been little or no emphasis placed upon using the risk indexes for the purpose of designing developmental support and follow-up plans to promote optimal developmental outcomes (Olds, 2002; Ramey, MacPhee, & Yeates, 1984). Wallace contends that the aim of using the concept of risk in healthcare services should be to “provide special attention to those with the greatest need and to make predictions about the level of care needed” (1982, p. 111).

CAPTURING OPPORTUNITIES FOR PREVENTION

The System of Risk Triage (SORT) described in this article provides a framework that combines infant biological-biomedical and psychosocial-physical environment risk criteria to identify infants who are at risk for poor developmental outcomes. The SORT not only identifies each infant’s risk for subsequent developmental problems but, more importantly, also sets in motion a dynamic process to monitor and support the developmental course of each infant cared for in the University of New Mexico Health Sciences Center NICU. Integrated into this system is the initiation of an Individual Family Services Plan process for infants and families who qualify for part “C” birth to 3 early intervention services. This early qualification and initial plan development encourages a seamless continuum of services from the NICU to home and community.

The System of Risk Triage

The SORT uses a matrix framework that has been refined over 20 years. Three infant biomedical risk categories are placed along the vertical (*Y*) axis and are juxtaposed with 3 psychosocial environment risk categories along a horizontal (*X*) axis. These 6 risk categories combine to form 9 distinct biomedical-psychosocial environment risk profiles (Table 1). Upon admission to the NICU, a neonatal developmental therapist with knowledge and experience related to biomedical and psychosocial conditions

makes the initial risk profile determination. Available information is gathered and summarized from multiple sources including medical specialists, social services, family therapists, medical records, and family interview. Developmental risk profile assignments are reviewed weekly and updated as additional information becomes available throughout the nursery course. This developmental risk profile assignment forms the basis for optimal referral and intervention decisions throughout the nursery course and through transitions to home.

Biomedical risk axis

Newborn biomedical conditions or events that generally are known to increase an infant’s potential risk for subsequent developmental delays/disabilities are clustered into 3 categories along the vertical *Y*-axis. These categories are in order of probability that a developmental disability will become apparent at some point over the child’s developmental course. The categories are assumed to be independent of each other and are descriptive in nature. Presence of one or more infant factors qualifies an infant for a category. Informal evaluation of category assignments consistently exceeds 90% interstaff agreement. When staff agreement cannot be reached at the weekly clinical review meeting, then category assignment is postponed until further information is obtained, typically by the second week following NICU admission. The system remains flexible throughout the nursery course. The categories and examples of factors that are assembled to make up the categories are presented in the following descriptions. A complete list of the factors that make up the categories is available upon request.

Category 1—increased biomedical risk: An infant’s biomedical condition is associated with increased risk for developmental delays/disabilities in comparison with the general population. The majority is expected to demonstrate development that is within expected ranges (Escobar, Littenberg, & Petitti, 1991).

Table 1. Intervention planning based on risk profiles^a

		Psychosocial environment axis		
		A Adequate psychosocial environment	B High-risk psychosocial environment	C Identified psychosocial environmental concerns
Infant biomedical axis	1 Increased biomedical risk	<p>Risk profile 1A <i>Inpatient:</i> Development followed through daily rounds and upon referral.</p> <p><i>Outpatient:</i> Ages and Stages Questionnaire and handouts mailed periodically to family. Therapist follow-up provided for failed ASQs.</p>	<p>Risk profile 1B <i>Inpatient:</i> Development followed through daily rounds and upon referral. Family therapist involved.</p> <p><i>Outpatient:</i> Ages and Stages Questionnaire and handouts mailed periodically to family. Therapist follow-up provided for failed ASQs. Nursing or social services home visits are encouraged.</p>	<p>Risk profile 1C <i>Inpatient:</i> Development followed through daily rounds and upon referral. Family therapist involved. Child protective services considered.</p> <p><i>Outpatient:</i> Ages and Stages Questionnaire and handouts mailed periodically to family. Therapist follow-up provided for failed ASQs. Extended family and community resources mobilized. Child protective services considered.</p>
	2 High biomedical risk	<p>Risk profile 2A <i>Inpatient:</i> Individualized therapies, developmental interventions, and family teaching incorporated into ongoing nursery routines.</p> <p><i>Outpatient:</i> Family selects home-based developmental program or follow-along clinic. Extended family and community resources may be mobilized.</p>	<p>Risk profile 2B <i>Inpatient:</i> Individualized therapies, developmental interventions, and family teaching incorporated into ongoing nursery routines. Family therapist involved.</p> <p><i>Outpatient:</i> Family selects home-based developmental program or follow-along clinic. Extended family and community resources including social services may be mobilized.</p>	<p>Risk profile 2C <i>Inpatient:</i> Individualized therapies, developmental interventions, and family teaching incorporated into ongoing nursery routines. Family therapist involved. Child protective services considered.</p> <p><i>Outpatient:</i> Family selects home-based developmental program or follow-along clinic. Extended family and community resources mobilized. Child protective services considered.</p>
	3 Established condition present	<p>Risk profile 3A <i>Inpatient:</i> Individualized therapies, developmental interventions, and family teaching incorporated into ongoing nursery routines. Direct therapy considered.</p> <p><i>Outpatient:</i> Infant and family referred for ongoing developmental interventions. Extended family and community resources may be mobilized.</p>	<p>Risk profile 3B <i>Inpatient:</i> Individualized therapies, developmental interventions, and family teaching incorporated into ongoing nursery routines. Direct therapy considered. Family therapist involved.</p> <p><i>Outpatient:</i> Infant and family referred for ongoing developmental interventions. Extended family and community resources including social services may be mobilized.</p>	<p>Risk profile 3C <i>Inpatient:</i> Individualized therapies, developmental interventions, and family teaching incorporated into ongoing nursery routines. Direct therapy considered. Family therapist involved. Child protective services considered.</p> <p><i>Outpatient:</i> Infant and family referred for ongoing developmental interventions. Extended family and community resources mobilized. Child protective services considered.</p>

^aBaseline individualized relationship-based developmentally supportive environments are maintained in the NICU. Interventions are planned in response to each infant’s combined biomedical-psychosocial risk profile.

Infants in this category usually have an uncomplicated hospital course. Examples include children with birth weight above 1250 g; gestational age more than 32 weeks; and ventilator assistance required for less than 10 days.

Category 2—high biomedical risk: An infant’s biomedical condition is associated with high risk for developmental delay/disability. It is anticipated that approximately half of these infants will experience some form of developmental disorder, delay, or disability. Examples include children with birth weight below 1250 g; identified central nervous system injury; gastrointestinal problems requiring surgery; and prenatal exposure to illicit substances.

Category 3—established biomedical risk: An infant’s physical or neurobiological diagnosis is associated with developmental delay/disability. All of these children eventually will need special developmental services. Examples include children with chromosomal anomalies; fetal alcohol syndrome or effects; congenital malformations such as cleft lip/palate or limb reduction; or severe sensory loss (blind, deaf).

Psychosocial environment axis

The psychosocial environment axis categorizes environmental risks and safety nets available for each infant. Each of the 3 categories includes factors that are based upon different types of risks. For example, some

factors highlight psychosocial circumstances that are known to interfere with building relationships, such as presence of maternal depression, while other factors indicate lack of physical resources, such as no permanent address or no phone. The 3 categories are independent, broad, descriptive, and nonjudgmental, and intentionally are not scored. No weighting has been assigned to the listed factors in each category, so that program and staffing decisions may remain flexible and be based upon clinical judgment regarding unique family differences in context. Typically, a mix of protective and worrisome conditions exists within each family situation. Protective circumstances, such as extensive available social supports and stable home, must be weighted against more worrisome risk conditions, such as a teenage mother. As in the child biomedical risk axis, the psychosocial environment axis assignments are used dynamically. The psychosocial environmental risk categories are listed as follows:

Category A—adequate psychosocial environment: It is anticipated that the family has at least adequate psychosocial, physical, and material resources to support their infant's growth, developmental progress, and general well-being. Examples include presence of an identified consistent, predictable primary caregiver; consistent maternal social supports; predictable physical resources; mother is a high school graduate or has a General Education Diploma; mother uses language and behaviors that demonstrate "claiming" of the baby; family takes initiative to be in phone and physical contact with the staff and infant in the NICU.

Category B—high-risk psychosocial environment: It is anticipated that the family will need help with identifying, developing, and securing adequate psychosocial and/or physical resources to support their infant's growth, developmental progress, and general well-being. Examples include mother has multiple

caregiving responsibilities; care of other children in the home is inconsistent; parents are difficult to find or contact; recent maternal loss of a significant person; the mother is isolated from family and friends.

Category C—identified psychosocial/physical environment concerns: Family psychosocial environmental circumstances are precarious and infant's future safety is in question. Examples include recent or current violence in the home; removal of infant's sibling(s) from the home; active involvement with child protective services; prior record of family involvement with the criminal justice system; home life is organized around substance or alcohol abuse.

THE SORT AND CLINICAL APPLICATIONS

The primary use of the SORT is to guide decision making regarding allocation of staff time and effort in the nurseries and after the hospital discharge. The purpose is not only to allocate and shape services in ways that match infant and family needs and preferences but also to ensure that these services are provided in an efficient, effective, and timely manner. The intent is to encourage and not to interfere with infant and family processes.

In New Mexico, an array of prevention and intervention services is available to infants and their families, from entrance into the University of New Mexico Children's Hospital NICU and special care nurseries through discharge to home. As a prevention-intervention baseline, NICU and special care nurseries medical, nursing, and specialty staff practice from the philosophy of relationship-based developmentally supportive care. Caregiving and family interactions are shaped according to infant and family individual differences to promote optimal infant neurobehavioral organization and family relationships. The longitudinal continuity service systems are superimposed upon this baseline and designed to correspond to the combined infant-family needs as reflected in the biomedical-environment risk profile. In this way, staff allocation and

programs are configured to match infant and family needs, in contrast to offering families predetermined programs that may or may not fit their unique circumstances.

Over time, gaps in New Mexico service systems have been identified and Developmental Care Program staff members have worked with state and community agencies to fill these gaps. The New Mexico Departments of Health and Children, Youth and Families have been instrumental in identifying and filling service gaps for at-risk newborns and their families. New Mexico is 1 of 8 states that includes biomedical risk and 1 of 7 states that includes environmental risk in their definition of eligibility for part "C" of the federal IDEA (Shackelford, 2006). By including infants who are at risk, states recognize the great potential for *preventing* or *reducing* disabling conditions. Many children who are at high risk at birth for later disabilities do well functionally at birth. As such, they often do not meet most state criteria for the presence of developmental delay, disorder, or disability that would qualify them for early intervention services. For example, a child born weighing less than 1000 g at birth may maintain milestones in all developmental domains for the first 8 months, until the child fails to sit independently. At this point, the child may be determined to qualify for early intervention services. This exclusionary deficit approach creates a major conflict for parents and professionals who understand the implications of waiting for failure instead of encouraging positive development during early weeks and months. Thus, parents who choose to make the most of their infant's neurodevelopmental potential must proceed without professional help until their infant and they "fail." By including infants who are at risk, states recognize the great potential for capitalizing upon important early opportunities to promote positive early brain development (Als et al., 2004; Gunnar & Barr, 1998; National Research Council and Institute of Medicine, 2000; Schore, 2000; Stern, 2002).

In Table 1, developmental service options are superimposed upon the SORT matrix to

reflect the array of options in relationship to infant and family characteristics. An array of short-term and long-term preventive, enrichment, and intervention services is available to match unfolding infant neurodevelopmental and family adjustment needs from birth.

Case example (risk profile 1B)

An infant born preterm at 34 weeks' gestational age and weighing 2010 g at birth was transported by air to the University of New Mexico NICU from a small northern New Mexico community. The infant required brief supplemental oxygen by nasal canula and moved easily from gavage to nipple feeding. On the basis of the SORT, the infant was determined to fit biomedical category 1. The infant's mother was 16 years old, unmarried, and had stopped attending school due to her unplanned pregnancy. These conditions met the criteria for psychosocial environment category B.

In the NICU, infant neurobehavioral organization and family-infant relationships were promoted through individualized developmentally supportive nursery care and family instruction with bedside nurses. Neurodevelopment was followed through interdisciplinary rounds. No additional specialized developmental contacts in the hospital were anticipated unless there were changes in the infant's neurodevelopmental course that prompted a developmental consultation.

On the basis of the 1B designation, the family therapist was assigned to help the family anticipate and prepare for transition to home. It was determined that the mother had received regular prenatal care, was living with her extended family, and the mother's future plans included living at home where her mother and sister could provide child care while she finished high school. The father was interested in continuing his relationship with the mother and the baby. In the NICU, the mother looked at, talked to, and held her infant in mechanical ways. She had difficulty problem solving what to do in response to her infant's fussiness, but was eager to learn about her baby's behaviors

and care. Over the NICU course, the mother became more attuned to her infant, took over most of the care, and began asking for more information about how to encourage her child's development. Community-based services that could help the mother monitor and encourage her infant's development were discussed. A community program referral was made for periodic home visits, to provide developmental screening, anticipatory guidance regarding child development and health as well as services coordination. Regular healthcare visits with the infant's pediatrician continued, including periodic developmental screening. After 8 home visits over 2 years, the family and the home visitor agreed to discontinue the home visits since the child and family were doing well. The parents were encouraged to call back if they had any questions at any time, and given information about their local Child Find and 3- to 5-year old programs through their local public school. The mother finished high school, the parents continued to see each other, and they came back to the annual NICU family-staff reunion to show off their "miracle child."

DISCUSSION

The SORT process provides a framework for identifying the type, frequency, and intensity of services needed to support at-risk infants and their families and to determine staff allocation for optimal service delivery. The SORT guides the design of hospital- and community-based developmental and support service plans for at-risk infants and their families. The strengths of the SORT include:

1. The process encourages development and maintenance of an array of integrated services based on child and family needs, rather than separate isolated services.
2. Infant biomedical and psychosocial environmental factors are combined in order to yield a risk profile for each infant and family, leading to individualized developmental enrichment and family support plans.
3. The SORT is also useful in identifying where services are weak or absent, and thus has potential as a tool for program-wide or statewide planning. For example, in New Mexico in 1984, few services were available statewide for infants who were in risk category 1. A collaborative public health-University of New Mexico NICU follow-up program was developed to fill that gap and continues to be an important part of statewide services. In this program, a public health nurse or social worker visits the home and provides family support and information, screens the baby's developmental progress, and reassesses the environmental supports. The public health program has adapted as other community-based programs have broadened to fill the service gaps.
4. The process, while developed for an NICU population, could be applied to any identified newborn population such as a nursery, a hospital, a preferred provider organization, a health maintenance organization, or a total state population.

The use of SORT is in place and operational, but refinement is needed. The outcomes of the children and families allocated to each category need evaluation to determine the reliability and validity of the SORT. For the child axis, the major dilemma is the distinction between infants in risk category 1—children at "increased risk," versus infants in risk category 2—children at "high risk." The psychosocial environment risk categories are broad and have been kept in descriptive language without scoring or preweighting to allow for maximum flexibility in the face of ethnic diversity and alternative family lifestyles. For example, some scales that assess attachment give low scores for lack of mutual visual regard between the caregiver and the infant; however, in the Navajo tradition, looking away shows respect. As another example, in the psychosocial environment axis, being married is placed as a descriptor in category A on the basis of research stating that usually

being married brings more resources to the family and exerts a positive influence on childrearing. However, in some situations such as with a chronically abusing spouse, the marriage becomes a detriment. The absence of predetermined weightings or scores allows for interpretation based upon individual characteristics and circumstances, not upon statistical averages. In addition, longitudinal record review of infant and family profile categories and the extent to which services were delivered and proven effective would provide insight into the effectiveness of the referral decisions.

One potential for misuse is to apply the process as a strict protocol, which obviates the inherent flexibility and local relevance. Misuse might also occur by using the process and criteria in a rigid manner to sort families in or out of services (or healthcare eligibility), without taking into account the rapidly

changing nature of the developing infant or major family adjustments that typically occur following the NICU experience. In general, it takes about 18 months to 2 years for a family to recover from the NICU experience and to return to the previous level of adjustment or stability that was perceived to be present before the birth event and the NICU experience. During that same period, infants have had an opportunity to recover from and make the most of their early beginnings. Some families need help during this recovery process, after which time services may no longer be wanted or needed. With a broad focus on prevention, early help can contribute to later positive outcomes (Olds, 2002). Additional research is required to evaluate the SORT framework for decision making regarding services allocation. In addition, the ability to apply the SORT to other settings and other age stratifications needs examination.

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