

# Medically Fragile Infants

The population of medically fragile children in need of special care has tripled in the past 30 years as strides in technology and health care have enabled doctors to save young lives that would otherwise be lost. Some 10 to 15 percent of the nation's children now require special care for chronic illnesses, physical disabilities, and developmental disorders.

The complex needs of these children and the relatively recent surge in their numbers pose a serious challenge to parents, medical professionals, educators, and policymakers to find effective and efficient interventions at a time when reducing health-care costs has become a national concern.

## **THE MEDICALLY FRAGILE CHILD**

Perhaps the most visible among the medically fragile population are technology-dependent children, such as those who require mechanical ventilation, renal dialysis, and apnea monitors. Others include children with acquired immune deficiency syndrome (AIDS), cystic fibrosis, and those with physical and mental conditions that will likely impair development, such as Down syndrome and cerebral palsy. Children with delays in speech, cognitive, language, and self-help skills may also be included.

Congenital anomalies, followed by chronic medical conditions, and perinatal conditions were the leading causes of hospitalization among a group of infants who spent 30 consecutive days or more in Children's Hospital, Pittsburgh, according to a study done by the University of Pittsburgh School of Medicine. In Massachusetts, a statewide census of technology-dependent children produced similar findings: the largest group had congenital anomalies, followed by chronic medical diseases, and perinatal conditions.

Part H of P.L. 99-457, the federal law that addresses medically fragile children, allows policymakers and medical professionals to broadly define the class of young patients eligible for special care. As a result, individual states are given the discretion to go beyond the seriously-ill population and include children who are at risk due to socioeconomic factors such as abuse and neglect, troubled family histories, substandard living conditions, and inadequate medical care.

## **TRENDS IN INTERVENTION**

Intervention strategies involving medically fragile children have, in recent years, focused on programs that engage both the child and the family. The trend toward a “family-centered” philosophy is fueled by evidence that a nurturing environment improves the child’s chances for a positive outcome. Giving momentum to the family-centered movement is the amended Part H of P.L. 99-457, which charges individual states with developing comprehensive, coordinated, family-centered services for children from birth to age two. Policymakers and medical planners are also moving from the concept of a single treatment model for all families to one that tailors programs to the individual needs of the child and family.

While biologic risk may determine whether a dysfunction will occur, there is evidence that the severity of a child’s dysfunction may depend on his or her environment. Reviews of programs used to treat medically fragile children show that developmental progress often depends on the active involvement of both child and parent. The best results have been realized when the programs and staff consider the context in which children and families live.

A child’s environment is a complex set of factors, the most influential being the child’s family. The family determines whether therapies become part of a child’s daily routing. And the family is the

intermediary between medical professionals and the child. The smooth marriage of outside professionals and families, for example, has been shown to produce a greater likelihood that prescribed therapies will yield positive outcomes. Other factors influencing the child's environment include the parents' education, occupational status, financial means, attitudes, the family's housing, and parents' values.

Poor environmental factors have been linked to several developmental and medical problems in children. Adverse environmental factors, for example, are assumed to be the cause of low IQ scores in mildly retarded children. Factors associated with low birth weight infants readmitted to the hospital include a young and undereducated mother, a father absent from the home, a family on public assistance, and few medical visits. And the link between poverty and the lack of medical care is illustrated in the estimate that as many as 43% of poor, high-risk infants receive inadequate health care.

P.L. 99-457, which provides funding to states for planning intervention programs, includes language that clearly indicates the government's desire to emphasize treatment that embraces the family as well as the compromised child. Components of the law include comprehensive evaluation of child and family needs by multidisciplinary teams, and development of individualized family services plans to support a family's ability to sustain and nurture the child.

Another important trend in intervention is the emerging role of the parent. Parents, in recent years, have assumed a greater share of the authority and responsibility of caring for their medically fragile children. Supported by federal law, their influence is likely to increase. Parents, for example, are given a voice on local and state Interagency Coordinating Councils established to plan services for the medically fragile. And as their involvement heightens, parents may assume a broader range of roles, including service coordination, teaching, and advocacy.

The impact of these trends on the medical professional is far-reaching. The complex environment of the child must be evaluated and treatment strategies designed that involve both child and family and are suited to their individual needs. At the same time, medical professionals are more likely to have to defer to the wishes of the family, realizing that what they see to be in the best interests of the child might not concur with the family's views or circumstances.

## **IMPACT ON THE FAMILY**

The families of medically fragile children face emotional and psychological strains, changes in lifestyle, and sometimes economic hardship. Intervention strategies that address the family's welfare have helped parents cope with the stress of caring for a compromised child and shape a more nurturing environment.

The type of handicap, the child's birth order, the parents' personalities, and whether the cause of the disorder is known are all factors that color how parents come to accept a medically fragile child. How they are informed of the handicap by medical professionals may also be a factor. Mothers often find themselves thrust into the role of a quasi-medical professional, jeopardizing the natural parent-child relationship. Parents' career goals might be put on hold to meet the demands of the medically fragile child, causing both financial and emotional distress. Siblings, too, experience stress, which varies depending on birth order, ability to resume normal activities, and the overall level of anxiety in the home.

Caring for a medically fragile child has been found to affect fathers and mothers in different ways. An Early Intervention Collaborative Study done by the University of Massachusetts Medical School noted that stress reported by fathers tended to focus on their feelings of attachment to the

child and on aspects of their child's temperament. Mothers expressed distress over their function as a parent, their sense of isolation, and how caring for the medically fragile child affected their marriage and family. Parental stress that was high enough to warrant referral for mental health services tended not to stem from the type or severity of the child's disability. Instead, it was more focused on a lack of cohesion and adaptability within the family.

The study also reported that certain services help ease the strain on parents who care for a medically fragile child. More home visits, for example, helped curb stress among mothers. And more center-based services led mothers to perceive support networks as helpful.

## **THE HOSPITALIZED CHILD**

For acutely and chronically ill infants, a lengthy stay in a hospital means living in an environment that is often monotonous, unpredictable, chaotic, and non-supportive. Despite their developmental needs, these infants generally cannot access community-based intervention services provided under P.L. 99-457.

Infants who spend long periods of time in hospitals, especially those receiving life-sustaining care, face several developmental barriers. Normal sensory and social exploration may be inhibited. Feeding tubes, for example, prohibit the infant from experiencing sucking, swallowing, and tasting. Physical restraints or confinement to cribs and playpens may inhibit play. Varying shifts of caregivers may be confusing to the infant. And, despite improvements in hospital policies, prolonged infant-parent separation still occurs.

Documented behavior of infants and young children confined to hospitals for long periods of time show that they are often passive and distracted. They make few attempts to communicate

verbally. They show little interest in tasks that require eye-hand coordination. Their range of expression is often narrow. And they show an inhibited perception of their abilities to move.

Community-based intervention services provided by law for the medically fragile child do not reach the population of seriously-ill children who are confined to hospitals. For most, it is not a question of their eligibility. University of Pittsburgh School of Medicine researchers found that 90% of the 135 hospitalized infants they studied were eligible for some form of developmental service, such as early intervention programs, identification, screening, and tracking. All of the infants spent at least 30 consecutive days in the hospital. Among them, the developmental problems of those who stayed two months or longer tended to be the most severe. In noting that those infants had no access to community-based services, the researchers urged that early intervention be initiated in hospital settings for the population of infants most seriously at risk.

## **ASSESSMENT**

Heightened interest in early childhood intervention has sharpened the demand for evaluating the disabilities, needs, and development of medically fragile children. Many at-risk children are not assessed who should be, due to a shortage of professionals to conduct testing and the lack of understanding of state eligibility requirements. The trend toward family-centered treatment also demands that assessment methods be designed that can accurately evaluate the complex relationship between compromised infants and their environment.

The surge in the demand for evaluations and a shift in methods to accommodate the child's family has led to a shortage of trained assessment professionals. As a result, high numbers of children who should be assessed are not. The shortage has also led to employing persons who have no formal training to conduct assessments.

In the hospital setting, there is evidence that a significant number of infants are not being assessed for developmental needs during their hospital stay. For example, assessments were done on only 44% of hospitalized infants eligible for developmental intervention who were part of the study conducted by the University of Pittsburgh School of Medicine. Researchers suggested that the gap indicated that more pediatricians need to understand and apply state eligibility regulations to their patients who spend extended time in the hospital.

The standardized, norm-referenced assessment (SNRA), the most common method of evaluating medically fragile children, is considered well suited for comparing a child's performance to a reference group, an important factor in the placement and eligibility for at-risk infant services. Deviation in the SNRA, however, may result in placement decisions based on subjective and unreliable impressions. The flexibility of SNRAs has also been questioned, and there is evidence to suggest that no single SNRA can provide the complete, in-depth perspective of the child's development that is required to make a comprehensive development assessment.

The widely-used "single-source" or "single-factor" assessment approach has also drawn criticism as being too limited to accurately predict whether the child will experience a developmental delay.

With the single-source approach, infants and toddlers are considered as being at developmental risk if any one of several conditions are met. The conditions include: having a high-risk biological problem, such as pre-term birth or poor prenatal care; being raised in a high-risk environment, such as in a financially poor family or by a young, undereducated mother; and failing a screening test. But not all children who meet one of the conditions experience developmental delay. Isolated events or factors that occur early in a child's life may not have continuing impact on

development. Biological problems such as pre-term birth do not alone imply the child's developmental potential will be compromised, as does being born into poverty. The screening instruments that are used have also been found to be brief, highly inferential, and usually inadequate for making accurate predictions of risk or disability in early childhood.

Multiple-risk indexes are among the suggestions being made to improve the accuracy of assessment information. Such indexes include biological variables, such as congenital problems at birth; caregiving factors, such as a mother's education, family stability, and standard of living; other behavioral factors, such as maternal ratings of very low or very high infant activity level; and delayed development as measured by psychometric instruments.

## **APPROACHES OF OTHER NATIONS**

America's embrace of the sanctity of life has placed saving the life of the medically fragile infant above all other considerations. The U.S. tends to intervene more aggressively with at-risk infants, while other Western nations temper the use of heroic intervention with consideration of the child's prognosis and other factors.

In the U.S., for example, neo-natologists tend to view the lower limits of intervention at around the 500-gram, 24-week gestation period, while other Western nations do not initiate extraordinary measures with babies under 600 grams. Some, such as Britain and Sweden, generally practice stricter limits, setting the lower level of intervention at 750 grams.

In Britain, the infant's prognosis is a key factor in determining whether extraordinary care is continued. When initial treatment is given, the child's progress is monitored. A poor prognosis may lead to the rethinking of the child's care and could result in the termination of extraordinary care. In

Sweden, only those infants who are likely to have a good prognosis are given treatment under a policy that emphasizes the quality of life over the saving of a life.

While intervention policies in Britain and Sweden result in the survival of fewer medically fragile children, those who do survive are offered a broad range of government-provided care that is unmatched in the U.S. The most profound difference between American and other national approaches is found in long-term care, with the U.S. providing less and other nations providing more. In Sweden, for example, the state provides specialized housing, equipment, surgery, and therapeutic day care for the at-risk child, and offers parents 60 days paid leave from their jobs to stay with their child in the hospital.

## **THE CHALLENGES AHEAD**

In the U.S., the demand for effective assessment and treatment of a rising population of medically fragile children is growing amid pressure to contain national health care costs. At the same time, new approaches to intervention are emerging that address the needs of the family as well as the child.

Important questions are being raised as decisions are made on how the nation should care for its medically fragile children. Among them: Are limited public resources for early childhood intervention being used in the best possible way? Are there new approaches that might result in greater good for a larger population of disabled children and their families? And how can medicine better assess the competence of a child with developmental disabilities, evaluate the needs of the family, and support a nurturing environment that is critical to the outcome of therapy?

This report was written by Jeffery Fraser and is based upon the following articles:

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