

Talking to Parents: Enhancing Parent-Professional Relationships

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ABSTRACT: The care of children with special needs has increasingly become home and community based, due to changing medical, social, economic and legal norms. PL 99-457, with its emphasis on parents and professionals working together to develop an individualized family service plan, brings a legal dimension to collaborative parent-professional encounters. In this rapidly changing health care environment, the nurturing family must be recognized as the focal point and mainstay of the child's life. Family-centered care rests on open parent-professional communication. When professionals "listen" to parents and learn about their vulnerabilities as well as their capacities to cope, children with special needs can only benefit. This article, drawing heavily on parent's statements, discusses the crucial beginnings of the parent-professional dialogue—at the time of diagnosis. How parents are informed of their child's problem will have long-range consequences and set the tone for the child's future care. Pediatricians are in a unique position to give support to families when they convey information with sensitivity and understanding.

INTRODUCTION

The concept of family-centered care in the overall well-being of chronically ill and/or disabled children has evolved around several current medical, social, economic and legal phenomena. Children with severe congenital anomalies or life-threatening illnesses—children who in only the recent past would not have survived—are now living with their families within our communities. Due to parental advocacy and a reexamination of social values, deinstitutionalization and the care of the child in a nurturing home have become prevailing goals. Economic factors, including DRG (diagnosis related group) requirements, have added further impetus to early discharge of chronically ill children from acute care settings. These children are frequently readmitted with shorter lengths of stay. Implementation of PL 99-457 brings a legal dimension to the total care of the very young child "at medical and/or developmental risk" within the family unit.

The following article draws heavily from the statements of parents of children with special needs. In a time of rapid change in the delivery of health care,

Pediatricians and others should be aware of the importance to the family of sympathetic and compassionate parent-professional communication in helping families deal with the stress of learning about their child's illness.

parents seek to broaden the professional's view of the world of the chronically ill and/or disabled child and emphasize the critical role of the family. As professionals "listen" to parents and learn about both their needs and capacities to cope, children reap the rewards of enhanced parent-professional communication (1).

I. Significance and Implications of PL 99-457

Under PL 99-457, the 1986 **Amendments to the Education for All the Handicapped Act**, states are offered the option to serve handicapped or developmentally delayed children from birth to three years of age.

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This law provides financial support to individual states for developing programs for handicapped infants and toddlers. Within five years, states must begin to serve all eligible children in order to continue receiving federal money.

A major component of PL 99-457 is its focus on both the vulnerabilities and strengths of families caring for very young children "at risk". Based on the framework of the child-centered, individual educational plan, PL 99-457 requires professionals and parents working together to expand quality and depth of care by **developing an individualized family service plan**. Pediatric expertise and awareness of the needs of chronically-ill infants and/or those who are dependent on medical technology are key elements of effective planning and intervention.

The parent-professional partnership and spirit of collaboration necessary to fulfill the promise of PL 99-457 challenge existing pediatric health care institutions. Will young families with needy children be further burdened? Or, will a more responsive atmosphere, stressing shared decision-making power, lead to an "... environment in which parents and professionals can work together closely and easily for the benefit of the children in need" (2)? **Pediatricians** are being called upon to understand the implications of family-centered care and to participate as leaders in creating innovative programs that will ultimately answer these questions.

II. Central Role of Communication

A family-centered model of care rests upon the goal of open, honest parent-professional communication. Supportive listening skills and sensitive conveying of information are tools which forge essential elements of positive parent-professional encounters. Open parent-professional communication, as in all relationships, is not a static reality, but a shared responsibility, changing over time. Communication that works is not synonymous with avoidance of disagreements. On the contrary, differences of perspective may occur frequently and need to be worked through and valued.

III. Respect for the Family Unit

The foundation of open communication with parents is recognition of the family's role as the mainstay of the child's life (3). Indeed, however much caring professionals may hope to contribute to a child's growth and development or recovery, the ultimate responsibility lies with parents. Professional contacts are typically fragmentary, episodic and transitory. The parents' roles stretch into the future. They alone see the child in all settings. They are the most consistently involved of all the child's caregivers. They keep the appointments, implement programs and administer medications. In the final analysis, they care most deeply of all about "the whole child"—their child.

Professionals who accord parents respect for their critical, physical, emotional and financial commitment to their children with special needs leave a legacy of hope and support that may sustain and encourage families during times of devastation and despair. Without such basic respect and appreciation, a collaborative parent-professional process cannot develop.

IV. Diagnosis: Impact on Parents

At the time of the initial diagnosis parents and health professionals often begin their dialogue at a period of great stress for both (4). However, this sharing of the initial diagnosis sets the stage for building a therapeutic relationship. When the child is a neonate, parents are especially vulnerable. Great care must be taken to give truthful information in a compassionate way that strengthens parent-infant bonding.

The diagnosis of a serious illness and/or handicap in one's child presents parents with a crisis of overwhelming dimensions (5). Previous ways of viewing and integrating reality are challenged. Parents describe the magnitude of their pain in terms of an existential crisis, a gripping confrontation with the unfairness, injustice and fragility of life. It is a time of disequilibrium, grief and intense emotional reactions (6). A parent shares her feeling:

The time surrounding the birth of a baby who is very ill or who has disabilities is terribly sensitive. For a lifetime, parents have planned for and dreamed about the birth of their child. Suddenly, hopes are shattered. The loss is one of enormous proportions. Parents grieve. It appears that few people seem to understand.

Parents may cling to irrational guilt since it is often easier to accept blame with its fantasy of control, rather than the total loss of control with which they must grapple. "Why my child?" is a frequent, if unanswerable, question. Just as parents are beginning the complex, difficult journey through the normal grieving process, they are also being introduced to the pressing demands of caring for a baby with special needs. For many parents, sadness, anger, guilt and denial coexist with fear and doubt—fear of the future and doubt in their ability to meet the special needs of their infant. Despite pain and fear, most parents take the first steps toward bonding with their baby—their child whom they hope to love and cherish as a valued family member (7).

V. Critical Need for Environmental Support

Parents do not struggle within a vacuum. They are immersed within a hospital setting whose personnel may either aid their efforts to bond with their infant or, through ignorance or thoughtlessness, unwittingly erect additional barriers and burdens. Parents are immensely vulnerable at the time of diagnosis, the peak of the crisis. Parents are attuned to and dependent on the environ-

ment—both positive and negative. Perhaps at no other time are environmental supports as crucial to rebuilding hope and confidence as they are at this juncture in the family's life.

For people in turmoil, the importance and value of apparently simple helping acts are magnified many fold. Basic support, such as quietly listening to parents' worries and concerns, goes a long way in encouraging parents to regain strength and faith in themselves. A mother adds:

When the neonatologist told me about my second son's intraventricular bleeding, I flipped out—screamed and cried. The neonatologist sat with us and took the time to stay with us. I know that he must have been incredibly uncomfortable. I later wrote to him to thank him for his special kindness. I will always appreciate the support he gave at that crucial moment.

Many health care professionals, working in acute care settings with limited time exposure to parents and infants, experience difficulty in appreciating the far-reaching significance and consequences of how parents are treated during the diagnostic phase. Years and "lives" later, parents vividly recall, in exact detail, the setting and tone of how they were told of their child's diagnosis.

Kind, nurturing acts become powerful therapeutic tools. Health care provider's reinforce parents' self-esteem with caring responses, such as referring to parents and infants by name and gently wrapping or touching the infant. In the technological, life-saving, busy hospital environment, these simple gestures of respect may appear small and inconsequential. However, from the parents' perspective, physical and emotional support will be remembered long after the child's hospital stay. One parent recalls:

I'll never forget a very kind pediatrician who stood silently with me at my baby's bedside and gently put his arm around me. I was, and remain, most grateful to him for this simple gesture of support.

Parents derive comfort from knowing that health care providers have faith in their resilience even though they may be temporarily overwhelmed. Such faith and positive regard will have long-lasting effects on the parent-child relationship (8). A parent emphasizes:

The medical people who were the most supportive and helpful let their caring and feeling come through to us. They would warm the stethoscope, wrap the baby after a procedure, give me a hug when I needed it. They were always professional, but treated us with kindness, care and respect for our abilities to cope.

VI. Conveying Information to Parents

Bad news is bad news. Nothing can make the announcement of a serious problem light-hearted or pain-

less. It is neither easy to hear nor easy to give such news. The special way (time, setting, tone) in which diagnostic information is actually given to parents can either enhance parents' abilities to respond effectively as partners in their child's care or destroy their trust in medical personnel. Parents stress the following basic issues:

When the initial diagnosis is given, every effort must be made to inform both parents *together*. They need each other during this time of adversity.

Privacy is crucial. However, a supportive health care professional, such as a nurse or social worker, or a family member may provide additional comfort.

Good communication skills (sitting at eye level with parents, acknowledging parental shock and distress and choosing clear, direct, accurate statements) are essential. One parent reports:

Parents NEVER forget what is said at the time of diagnosis, and, often, it sets the tone for the child's medical experience. Choose your words carefully, and let the message be as hopeful as you dare. It's O.K. to say you don't know, but be sure to follow it up with reassurances about what is known and what can be done. Feeling helpless is bad enough without feeling hopeless as well.

Time is needed to evaluate parents' reactions and possible misconceptions. Careful, sensitive listening to parents' unique worries and concerns should guide practitioners. More than one session will be necessary for parents to absorb the information and to ask questions that arise after the initial shock (5).

Parents, under extreme stress, may deny or distort information and/or display hostility or anger. Health care professionals must expect and accept strong emotions as part of the grieving process. Parents need to be reassured that intense feelings are aspects of normal grieving. While acknowledging that it is painful for health care providers to witness their anger, hurt or fear, parents value those who do not flee or minimize their grief.

The pediatrician who gives the broad spectrum of the child's possible capabilities without making long-range predictions helps parents to take one step at a time. A parent poignantly urges:

Don't destroy my vision of my child as a human being. Give me the normal hope of love between a parent and child for however long, short, retarded, gifted, normal, physically impaired or chronically ill our relationship may be. I don't need extensive medical details as much as I need information about how to live my new life. If the health care professional can't provide this, it really is his or her responsibility to put me in touch with someone who can. This is my first contact with the vulnerability of life.

Parents need to be given information, however painful. One parent stresses:

Doctors who felt they had to protect us by keeping information from us caused much pain. The unknown was far more terrifying than being told the hard facts.

In reality, there is often a great deal of uncertainty concerning diagnosis and prognosis. In such situations, frequent communication with parents decreases anxiety. Another parent frankly states:

There is no easy way to tell parents. For us, it was a day to day trauma, and we had frequent discussions about the prognosis for our daughter. I wanted answers, and I didn't want to wait. The doctors couldn't give me those answers, and it was difficult for me to live with that uncertainty. I am grateful that they did not make any sweeping judgments and that they taught me to take it one day at a time.

Anxious professionals, at a loss for words, often grope for something "right" to say. Empty cliches or random, gratuitous comments may be blurted out and increase parental pain. Parents appreciate physicians who openly acknowledge and share their distress and discomfort. Simple, honest statements, such as "I wish I knew what to say" or "This just isn't right or fair", send a message of concern and caring. A moment of shared silence often comforts and heals.

Physicians leave parents with hope when they actively encourage parent-to-parent support and refer parents to appropriate community services. One is never more alone than after one's child has become or has been found to be ill or disabled. Professionals who "build bridges" between people understand that support for parents gives strength and courage in the long struggle to help a child with special needs.

CONCLUSION

A family-centered philosophy of care provides a focus and model for what many pediatricians in the

community do in their daily practice. Pediatricians who value open communication with parents and respect and support the crucial contributions parents make to the total care of their medically or developmentally fragile children serve as excellent role models. The interpersonal skills and knowledge such pediatricians bring to their work are invaluable assets in the training of young physicians and other health care professionals.

REFERENCES

1. Shelton T, Jeppson E, Johnson B. Family-centered care for children with special health care needs. Assoc. for the Care of Children's Health. Washington, DC, 1987.
2. De Graw C, Edell D, Ellers B, et al. Public Law 99-457; New opportunities to serve young children with special needs. *Journal of Pediatrics*, 1988; 113:972.
3. Dunst CJ, Trivette CM, Davis M, Cornwell J. Enabling and empowering families of children with health impairments. *CHC*, 1988; 17:71-81.
4. Turnbull, H., Turnbull, A. *Parents Speak Out*. Columbus, Ohio. Charles E. Merrill, 1987.
5. Olson J, Edwards M, Hunter JA. The physician's role in delivering sensitive information to families with handicapped infants. *Clinical Ped*, 1987; 26:231-4.
6. Poyadue FS. Parents as teachers of health care professionals. *CHC*, 1988, 17:82-4.
7. McCollum, A. *The Chronically-ill Child: A Guide for Parents and Professionals*. New Haven. Yale Univ Press, 1981.
8. Clyman, R.I., Sniderman, S.H., Ballard, R.A., et al. What pediatricians say to mothers of sick newborns: An indirect evaluation of the counseling process. *Pediatrics*, 1979; 63:719-23.