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ABSTRACT

This paper argues that there is a critical need to reframe the fundamental policy questions which fragment early childhood intervention services and health care, in order to construct an integrated system of comprehensive services that includes basic health care and developmental support for all children and their families and that provides appropriate educational/therapeutic services for those with special needs. The core principles and goals of Part H of the Individuals with Disabilities Education Act should be incorporated into a universal system of health supervision, developmental facilitation, and family support. This approach requires: a more sophisticated approach to systematic screening for early identification and management of disability; major changes in medical training; a commitment to a joint agenda by the health care and early intervention professional communities; and a collaborative process of parent and professional monitoring and managing over time. The paper defines the essential features of pediatric health supervision, the goals of developmental and behavioral surveillance, and the principles of early childhood intervention. (Contains 17 references.) (JDD)

HEALTH CARE POLICY AND PART H SERVICES: EARLY INTERVENTION AS A CONCEPT (NOT A SEPARATE PROGRAM)

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The health and development of young children are highly interrelated. Each reflects dynamic adaptive processes that depend on the influences of both biology and environment. Each is determined by a delicate balance between vulnerability and resilience. Each is characterized by considerable variation within a normal range. Each includes a vaguely defined domain of dysfunction (e.g., non-specific abdominal pains, chronic fatigue, clumsiness, slow learning) and a distinct realm of frank disease or disability (e.g., diabetes, rheumatoid arthritis, mental retardation, cerebral palsy). The separation of development from health in the early years of life is particularly artificial and counter-productive.

Within this context, the interface between early childhood intervention services and health care presents a complex set of policy challenges. These challenges are deeply rooted in a tradition of highly fragmented categorical service systems (e.g., health, education, social welfare) that have been separated functionally, staffed by various combinations of professional disciplines, supported by a multiplicity of independent funding streams, and burdened by an array of poorly coordinated administrative structures. Barriers to effective professional collaboration have been especially problematic in the care of infants with developmental vulnerabilities. Although an increasing number of individual working partnerships are succeeding at the community level, persistent tensions between the early intervention and health care systems result in continued frustration for service providers and a lack of coherence for service recipients.

When we address the relation between health care and Part H services (now Subchapter VII of the Individuals With Disabilities Education Act), we face a formidable dilemma–that of developing policies that promote greater collaboration between two professional communities that share a strong commitment to serve young children and their families, but also share a history characterized by variable cooperation and miscommunication (Harbin & McNulty, 1990). Each has a critical contribution to make. Each can be enriched by the other's expertise. Skeptical physicians who have questioned the impact of early intervention programs on infants with neurologically-based disabilities (e.g., Ferry, 1981) have much to learn from the determined optimism and parent-empowering sense of advocacy embodied in the Part H mandate. Early childhood educators and developmental therapists who resent those who doubt the effectiveness of their service efforts have much to learn from the hardnosed questioning of clinical scientists who demand rigorous efficacy data before recommending any treatments for their patients. A creative integration of the advocate's faith and the scientist's skepticism would represent a major step forward toward the development of a vital and self-renewing system of family-centered care.

The basic premise of this paper is that there is a critical need to reframe the fundamental policy questions in this area. Rather than ask how health care can be linked to a network of early intervention programs, we should be exploring how we can construct an integrated system of comprehensive services that includes basic health care and developmental support for all children and their families and that provides appropriate educational/therapeutic services for those with special needs. Rather than focusing primarily on the formulation of criteria for referral from health care settings to early intervention programs, we should be promoting the incorporation of the core principles and goals of Part H into a universal system of health supervision, developmental facilitation, and family support. Rather than channelling limited resources into the construction of better mechanisms for communication between separate service domains, we should be investing our creative energies in the formulation of new roles and redefined relationships among health care and early intervention service providers within a single, unified system of care.

Developmental Surveillance and Early Intervention in the Context of a Comprehensive System of Child Health Supervision: Reframing The Challenge

The vision of a universally-available system of family-centered, community-based, culturally-sensitive, comprehensive health and developmental services for all children is a natural focal point for beginning the policy debate. Within such a model, a more sophisticated approach to systematic screening and the early identification and management of dysfunction and disability would be viewed as an essential part of basic health supervision (American Academy of Pediatrics, 1988; Green, 1986; Meisels & Wasik, 1990).

Because the realities of current medical practice in the United States present significant impediments to the achievement of this goal (Blackman, Healy, & Ruppert, 1992), major changes will be needed in both training and service delivery. On a pragmatic level, the problem lies in the severe constraints on time and the associated inadequacies of reimbursement for talking and listening to parents. On a more fundamental level, much of the struggle is rooted in the significant deficiencies of pediatric education in the social sciences. In a broader context, the mandate for comprehensive preventive intervention for all children and their families extends beyond the boundaries and capabilities of both the health care and early intervention systems, and includes issues related to a wide range of domains, including child care and social welfare (National Commission on Children, 1991).

If "child-find" strategies and early intervention programs under the Part H mandate are developed independently, separate from the primary health care system, the administrative fragmentation of services for families with young children will increase. Therefore, it is essential that the health care and early intervention professional communities make a firm commitment to a joint agenda with respect to developmental and behavioral surveillance, intervention, and support. Rather than focusing primarily on the determination of eligibility criteria for entry into an early intervention program, we should be asking how health care and early intervention service providers can share responsibility for the well-being of all children and families. Indeed, a more rational model would consider routine health supervision and early intervention as complementary components of a single system designed to provide truly comprehensive care, rather than view early intervention programs as alternative service systems that "take over" the responsibility for ongoing management when a child or family demonstrates an arbitrary level of impairment or dysfunction.

In order to conceptualize the proposed model, it is important that we define the essential features of pediatric health supervision, the goals of developmental and behavioral surveillance, and the principles of early childhood intervention.

The Essential Features of Pediatric Health Supervision

The ultimate objective of the provision of comprehensive primary health care is to facilitate the healthy growth and development of children. In its most basic form, health supervision serves as a stable source of professional support for families in their responsibilities for child protection and well-being. Thus, state-of-the-art pediatric care is both proactive and reactive. It combines attention to both the promotion of health and the prevention or treatment of injury and disease. It relies on the technology of immunizations and medication, as well as the art of counselling and anticipatory guidance. It focuses on both physical health and emotional well-being. Perhaps most important, as the threats to children's health in our society have changed (e.g., from the ravages of polio to the impacts of family and community violence), child health supervision has been charged to broaden its focus (Green, 1991).

Consequently, although the prevention and treatment of acute and chronic illness remains an important medical responsibility, contemporary practitioners also struggle with an increasingly complex set of health challenges whose origins are rooted in risk taking behavior (e.g., substance abuse, sexually-transmitted disease), psychosocial stressors (e.g., family discord, social isolation), and the impacts of poverty (e.g., malnutrition, homelessness). Thus, our concept of pediatric health supervision evolves over time, and is grounded in a multidimensional model that views the well-being of children and their families in a sociocultural context (Green, 1991; Korsch, 1988; Select Panel for the Promotion of Child Health, 1981).

The Goals of Developmental and Behavioral Surveillance

The assessment of development and behavior during the early years of life must address three overarching goals. First is the need for early identification and the coordinated mobilization of necessary services for children with significant impairments and for their families. This includes children with diagnosable developmental disabilities such as cerebral palsy, hearing impairment, blindness, pervasive developmental disorder/autism, and mental retardation. The second goal is the need for open acknowledgment and supportive management of children with identified vulnerabilities or variations in abilities that may or may not evolve into a significant disorder. This larger, but less well-defined, group includes children with demonstrable developmental concerns (e.g., mild expressive language delays, fine and/or gross motor inefficiencies, and "hyperactivity" during the early preschool years), as well as youngsters without identifiable impairments who are at risk for later problems because they live in dysfunctional caregiving environments (e.g., families in which there is active parental substance abuse or significant social isolation).

The third goal of developmental and behavioral surveillance is the avoidance of premature labelling, which can contribute to the creation of self-fulfilling prophesies as well as the unnecessary utilization of scarce resources for children who truly will "outgrow their problems."

Generally speaking, the level of sophistication of developmental and behavioral surveillance in medical settings has been uneven. Although many shortcomings in the pediatric management of developmental problems have been documented in the past (Shonkoff, Dworkin, Leviton, & Levine, 1979), increasing numbers of pediatricians, nurse practitioners, and allied professionals are demonstrating that much can be accomplished in the health care setting (Dobos, Dworkin, & Bernstein, 1992).

The Principles of Early Childhood Intervention

The essential features of early intervention programs complement the goals of child health supervision (Shonkoff & Meisels, 1990). Guided by both federal legislation and current knowledge of human development, contemporary services are based on three core principles. First, they are conceptualized within a transactional/ecological framework. Thus, unlike traditional therapeutic and educational treatments that were administered directly to young children, current services are designed to promote the development of the child in the context of his or her family, and view the family in the context of its community and culture. Second, early childhood intervention is a highly individualized experience. Thus, services are determined not simply by the child's diagnosis or by the family's demographic characteristics, but by a carefully tailored plan that addresses individual needs and builds on the specific strengths of all family members. Third, the ultimate goal of an early intervention program is the promotion of mastery in both the child and the family. For the child, this objective extends beyond the facilitation of traditional psychomotor skills and into the multiple domains of social competence. For the family, services are designed to foster success in the parenting role, particularly for those whose children follow an atypical developmental trajectory.

In summary, early childhood intervention in the 1990s goes far beyond narrowly-defined therapeutic objectives such as the prevention of contractures and the stimulation of language. Similarly, child health supervision embodies far more than the administration of immunizations, the auscultation of the chest, and the recording of developmental milestones. The core agenda for each is reflected in its commitment to preventive intervention and the promotion of healthy growth and development. The essential contribution of each is manifested in its capacity to provide education and support for parents and children in the context of a trusting relationship. Their shared investment in family-centered care underscores the need for a unified service delivery system in which the child and family (and not the service providers) are the focus.

An Integrated Approach to Developmental Concerns in Young Children: A Collaborative Process of Monitoring and Managing Over Time

In a newly-designed universal system of health and developmental services, developmental surveillance of all children would be best implemented through a collaborative process conducted jointly by professionals and parents. The question is not whether or when to address concerns, but how to establish relationships in which developmental and behavioral issues can be examined in an open and supportive manner. Parents would be informed at the outset that child health and developmental supervision is based on a shared dialogue around issues related to health-promotion, disease and injury prevention, child rearing, the facilitation of child development and adaptive behavior, and family functioning. Questions related to language skills, motor coordination, sleep patterns, and discipline are as legitimate as queries about earaches, coughing, rashes, and weight gain.

When surveillance is truly collaborative, the parent assumes the responsibility to raise issues and concerns, and the professional accepts the responsibility to ask developmentally appropriate questions, observe the child's function, and provide guidance and support in a responsive manner (Dworkin, 1989). Developmental and behavioral surveillance is a shared experience conducted within the context of a trusting and stable parent-professional relationship. Health care and early intervention providers could and should work together to build a family-centered, primary care service system that provides a vehicle for the establishment of such relationships.

The surveillance of child development and behavior is best operationalized as a clinical process that typically achieves understanding over time. With the exception of well-defined disabilities that can be identified definitively on the basis of specific diagnostic criteria (e.g., Down syndrome, spina bifida), the significance of most developmental variation cannot be ascertained without the benefit of a longitudinal perspective. Thus, the ongoing relationship between a family and a primary provider within a comprehensive system of health and developmental services offers an ideal model for early screening that is free of the pressure for immediate (and often premature) resolution at an arbitrary point in time. In those circumstances where the deferral of a diagnosis is appropriate, the context of basic health and developmental supervision provides a useful arena for active watching (and not simply passive waiting).

This approach is not unlike the skillful management of many common pediatric clinical concerns. The problem of slow weight gain in infancy provides an illustrative example. Although a single recorded weight below the third percentile does not necessarily imply pathology, it alerts the health care provider to gather more data (e.g., additional history regarding potential risk factors for failure to thrive, detailed information on feeding practices and the caregiver-child relationship, and a careful examination for physical signs of potential contributors to poor growth). In the absence of a specific diagnosis, a reasonable management plan would include an overview of the problem for the parents, a follow-up appointment for a weight check, and specific interim instructions regarding feeding strategies and the recording of the child's daily food intake. Over time, the slope of the child's growth curve will either confirm a normal pattern of weight gain or signal the need for further investigation. In the latter case, the primary care provider takes responsibility for ongoing evaluation and management up to the limits of his or her expertise and seeks subspecialty consultation when indicated. Throughout the process, the conscientious clinician shares information with the family and defines an active role for the parents.

The approach to a developmental or behavioral concern within the context of basic health supervision could follow a parallel pattern. For example, if a child appears to be progressing slowly in the production of single words, a member of the primary care team can elicit additional information about other areas of development; explore the caregiver-child relationship; learn more about the language environment in the home; confirm (through appropriate assessment) that the child does not have a hearing impairment; and offer suggestions for the parents about strategies for facilitating communication during the interval until the next follow-up visit. As described for the management of possible failure to thrive, rather than simply offering the passive hope of a wait-and-see response, this approach demonstrates the value of active watching. When conducted appropriately, such active monitoring within the context of basic health supervision is a legitimate form of "early intervention," and should be viewed as no less.

Upping the Ante: Meeting the Need for Specialized Intervention

Sophisticated developmental and behavioral surveillance within the context of a universal system of child health supervision and family support can serve as a normative vehicle for monitoring the emergence of abilities in children over time. It requires tolerance of uncertainty, comfort with ambiguity, and a willingness on the part of the professional to view the parent as an active and informed partner. When faced with the occurrence of a significant disability, the challenge for the primary care provider is to make a timely diagnosis, to confront an unsettling reality in a sensitive and supportive manner, and to mobilize necessary services in a coordinated fashion. When encountering more subtle concerns, which comprise the largest percentage of developmental variation addressed in the context of regular health supervision, the clinical challenge can be exceedingly more complex. Consequently, it is often useful for professionals to abandon a "normal/abnormal" paradigm and focus on the assessment and management of developmental and behavioral "signs" and "symptoms." Under such circumstances, it is particularly important that the basic service system includes a range of professional resources (both health and developmental) whose availability is not hampered by cumbersome administrative barriers or restrictive eligibility standards (Shonkoff & Meisels, 1991).

Within the proposed framework, providers of primary health and developmental services would compile a comprehensive inventory of both symptoms and potential protective factors in the child and the caregiving environment and ask a simple question: What is needed here and how can these needs be met? When reassurance is all that is indicated, it must be provided in a credible fashion that is responsive to the parents' agenda. When careful monitoring is warranted, it should be conducted in an active manner, with well-defined professional and parental responsibilities and clearly-articulated expectations for follow-up evaluation. If identified intervention needs (e.g., the provision of educational materials and a modest level of support) can be met within the context of a system of primary health and developmental supervision, no further referral may be required.

However, when the child's or the family's needs exceed the capabilities of the primary care team, additional, specialized resources must be mobilized. In all circumstances at all levels, efficient use and coordination of services is essential. Early intervention for children with developmental and behavioral vulnerabilities should be viewed as a concept and not necessarily as a specific program that is separated functionally and administratively from a core system of primary health and developmental services. If the goal is a family-centered model, then family support and instruction in the basic techniques of developmental facilitation must be an integral part of general child health supervision. When child and/or family needs cannot be addressed entirely by the primary care system, the mobilization of specialized early intervention services should not represent a reduction in primary care responsibility. Rather it should mark the beginning of a collaborative process characterized by ongoing interdisciplinary communication, shared and well-defined management responsibilities, periodic review of the changing status and needs of the child and family, and continuing education for everyone involved.

Two separate service systems, even if they are linked closely, will have to contend with the burden of restrictive eligibility standards, inevitable bureaucratic inefficiencies, and the psychological barrier of the need for referral to a non- normalized program. A single integrated system in which early intervention and pediatric health care are blended within a comprehensive service model offers the best hope for well coordinated and non-stigmatizing care in a mainstream setting for young children with a broad range of developmental disabilities or concerns.

The Challenge For Policy Makers: System Change and a Major Commitment to Training

It is certainly not in the interest of young children with developmental vulnerabilities and their families to divide the locus of professional responsibility between two service systems that each seek to offer primary care and support. If we wish our policy toward children with special developmental needs to be family-centered (rather than professionally-centered) and guided by the concept of "least restrictive environment," it is essential that pediatric health care and early intervention services be unified in a comprehensive system that promotes and protects the healthy growth and development of all children. The design and implementation of such a system will require vision, persistence, professional generosity, and political courage. It will demand a considerable investment of energy, a hefty dose of flexibility, and abundant good will from service providers in both the early intervention and the health care communities.

In a retrospective analysis of the landmark report of the *Select Panel for the Promotion of Child Health*, Schorr (1983) reflected on the longer-range tasks facing the American health care system and noted: "First, we must take steps to increase the understanding by policy makers and the public that our nation can, and must, create a less narrowly medical system of health services" (p. 16). A current effort to develop national guidelines for child health supervision ("Bright Futures"), supported by the Maternal and Child Health Bureau and the Medicaid Bureau, is seeking to operationalize that vision. As the implementation challenges of Part H and the national debate about the need for universal child health care evolve simultaneously, an important "window of opportunity" is provided for a broad-based approach to health and developmental services. Specific policy strategies in this regard can be directed to multiple audiences. At the federal level, bold legislation is needed to promote the creative integration of the "family-centered, community-based, coordinated care" philosophies of both early intervention services (under the Individuals with Disabilities Education Act) and maternal and child health services (under Title V of the Social Security Act) (Hutchins & McPherson, 1991). At the state and local levels, regulatory reform and budgetary incentives can be developed to promote greater service integration under the much heralded banners of "one-stop shopping" and "seamless" service systems. At all levels of government, requirements for multidisciplinary authorship of joint funding applications and the use of discretionary grants to support innovative demonstrations of medical/educational collaboration are some of the policy mechanisms that can be used to stimulate the development of integrated models of service delivery. It is essential that we get our "acts" together (for the sake of children and families) and construct a new, unified service system that reflects the best of both pediatric health care and early childhood intervention. Such efforts should be viewed as a significant transformation of both systems.

The call for a fundamental restructuring of the delivery of health and developmental services obviously has far-reaching implications for the professional practices of pediatrics and early childhood intervention. Consequently, the training needs are monumental. Pediatricians require more extensive education about the principles of child development and the functioning of family systems, as well as in the multidisciplinary management of children with developmental disabilities. In a complementary fashion, early childhood educators and developmentalists require training that prepares them to work comfortably with children and families in collaboration with health care professionals. Because of the critical shortage of appropriately trained personnel in the early intervention field, issues related to professional status, salary levels, and career mobility must be addressed. Within the proposed model, opportunities to work in a universal system of health and developmental services might provide more secure and promising career incentives, thereby enhancing the recruitment and retention of new generations of talented professionals.

Summary and Conclusions

All young children require basic health and developmental services. Sensitive and sophisticated developmental surveillance within that service context depends on stable, trusting relationships in which all concerns can be addressed collaboratively among professionals and parents. When the identification and initial management of developmental problems are an integral part of a universally available system of child health and developmental supervision, they are conducted in the least restrictive environment. When the needs of a child or family exceed the capabilities of a primary care team (which may include both health and developmental professionals), the mobilization of specialized resources is essential.

When special needs demand special services, it is critical that such resources be anchored to the normalized context of a family-centered, community-based system of primary care that serves all children, including those with either special medical or developmental needs. Whether a primary care provider is the sole, central, or secondary source of intervention, he or she offers the relatively unique option of a continuous professional commitment that can extend from birth through adolescence. When primary care teams have the technical skills and the inter-personal sensitivity to play a positive role in the identification and ongoing care of a child with developmental disabilities, the bond that they form with the family in the early years of life can serve as an important protective factor to promote long-term adaptation.

A policy strategy that seeks to bypass the health care system (because of its current limitations regarding some aspects of early intervention) in favor of an independent network of family-centered therapeutic/educational service programs is likely to further undermine the skills and potential long-term contributions of health care providers. Stated simply, if the pediatric community is not expected to take greater responsibility for the family-centered care and management of children with developmental disabilities, then pediatricians will be increasingly vulnerable to "learned helplessness" in this area of expertise, and the overall quality of comprehensive health care for children with special developmental needs will not grow.

When we ask how health services can be integrated into an early intervention system, we are defining a child's basic health care needs in relation to his or her special developmental status. This approach violates the philosophy of normalization. When we ask how early intervention programs can supplement pediatric health care, we suggest that therapists and educators adopt the medical model to guide their practice. This may be viewed as professional imperialism. Thus, the fundamental policy question should not be, "How can we integrate health services into early intervention programs for children with special needs?" Nor should it be, "How can we absorb early intervention programs into the health care system?" Rather, we should ask, "How can we develop a comprehensive primary care system to monitor and promote the healthy growth and development of all children, and how can we guarantee that community-based early intervention services are an integral part of that system in order to assure that state-of-the-art therapeutic, educational, and supportive services are provided for children with developmental disabilities and for their families in the least restrictive environment?"

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