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ABSTRACT

This paper reports on a symposium of experts in child and family development and health care which met to discuss integrated systems of services. The symposium was part of the Carolina Policy Studies Program which is addressing policy implementation of Part H of the Individuals with Disabilities Education Act (IDEA). The paper notes IDEA's limitation to health services that are directly related to education. Recommendations of the policy analysts suggest a future focus on the following areas: (1) rigorous evaluation of the costs and benefits of existing programs; (2) creation of model programs of services for children and families that are based on empirical evidence; (3) full integration of family-centered care into all services; and (4) basing all efforts on the full interrelatedness of child health and child development. The law's inclusion of a variety of change and reform mechanisms is noted, among them family empowerment, multidisciplinary cooperation, and the development of Individual Family Service Plans. (DB)

THE COORDINATION OF HEALTH AND OTHER SERVICES FOR INFANTS AND TODDLERS WITH DISABILITIES: THE CONUNDRUM OF PARALLEL SERVICE SYSTEMS

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INTRODUCTION

The contents of this volume have been produced by consultants to, and staff of, the Carolina Policy Studies Program (CPSP) as part of a study on the policy implementation of Part H of the Individuals with Disabilities Education Act (IDEA). Part H is designed to provide resources for children with disabilities (birth to three years of age) and their families. CPSP sought to discover how health services can be coordinated with other services as a part of their overall study on the implementation of this law. Since IDEA limits the payment of health services under this law to those services directly related to education, there has been some concern about how the health services–which will most often be the first contact the family has with the professional disciplines–would work together with other services, including psychology, social work. and education.

Our panel was composed of the following invited experts:

Vince L. Hutchins, M.D., M.P.H., formerly the Director of Maternal and Child Health, U.S. Health and Human Services Bureau, is the Executive Director of the National Ready to Learn Council, Carnegie Foundation for the Advancement of Teaching. Dr. Hutchins has been actively involved in the development of family and health policy at the national level for over 20 years.

Jack P. Shonkoff, M.D., is Professor of Pediatrics and Chief of the Division of Developmental and Behavioral Pediatrics at the University of Massachusetts Medical School. He has served as a consultant and panel member for the Committee on Child Development Research and Public Policy of the National Academy of Sciences, and for the Panel on Child Care Policy; he is a member of the Board of Directors of the National Center for Clinical Infant Programs and is on the Executive Committee of the Section on Child Development of the American Academy of Pediatrics.

Thomas T. Kochanek, Ph.D., is a faculty member at Rhode Island College and Brown University. Dr. Kochanek has focused on the conceptualization and implementation of models related to the system of health, education, and social services for families and children with special needs.

Phyllis R. Magrab, Ph.D., is a recipient of the U.S. Surgeon General's Award for Distinguished Service for her commitment to the development of public policy directed toward children with chronic illnesses and disabilities and their families. She serves as Professor of Pediatrics, Director of the Child Development Center, and Chief of Pediatric Psychology, at Georgetown University.

Deborah Klein Walker, Ed.D., is the Assistant Commissioner for the Bureau of Family and Community Health in the Massachusetts Department of Public Health. She is chair of the Association of Maternal and Child Health Program's Committee for Children with Special Health

Care Needs and the immediate past chair of the Maternal and Child Health Bureau's Research Panel. Dr. Walker was on the faculty at Harvard's School of Public Health and Graduate School of Education. Her research focus is on early intervention and maternal and child health.

James J. Gallagher, Ph.D., is Kenan Professor of Education and Director of the Carolina Institute for Child and Family Policy at the Frank Porter Graham Child Development Center of the University of North Carolina at Chapel Hill. Dr. Gallagher has been active in the field of exceptional children and public policy for over 3 decades. He served as Associate Commissioner of Education and Chief of the Bureau of Education for the Handicapped in the U.S. Office of Education, 1967-1970.

Background

In 1986, the United States Congress passed Public Law 99-457, which expanded the Education of the Handicapped Act (P.L. 94-142) by mandating community-based, family-focused, comprehensive, interdisciplinary services for infants and toddlers with developmental disabilities, birth through age 2. Through this legislation, the U.S. Congress sought to ensure early intervention services for young children with disabilities, which were characterized as inadequate and fragmented with little coordination among and between programs and sources of funding (Harbin, Modigliani, & Olsen, 1988; Hauser-Cram, Upshur, Krauss, & Shonkoff, 1987).

In 1991, Public Law 99-457 was re-authorized and combined with P.L. 94-142. The legislation is now referred to as the Individuals with Disabilities Education Act (IDEA). Like the previous legislation, IDEA calls for services that are comprehensive, coordinated, family-focused, and community-based. Research conducted at the Carolina Policy Studies Program (Fullagar, Crotser, Gallagher, & Loda, 1992), suggests, however, that such a system remains a goal rather than an achievement. As Vince Hutchins elaborates in his chapter in this volume, entitled "Federal Policy for Early Childhood: Evaluation of Services for Children with Disabilities," there are multiple agencies, services, and organizations–health, allied health, mental health, education, social, welfare–but no system. Jack Shonkoff, in "Health Care Policy and Part H Services: Early Intervention as a Concept (Not a Separate Program)," portrays current "early childhood intervention services and health care" as "rooted in a tradition of highly fragmented, categorical service systems (e.g., health, education, social welfare) that have been separated functionally, staffed by a multiplicity of independent funding streams, and burdened by an array of poorly coordinated administrative structures."

It was this scenario that focused our attention, at the Carolina Policy Studies Program, on the need for a symposium in which numerous players in the fields of child and family development and health care would come together to share visions of an integrated system of services. This volume is the representation of that symposium.

Child development and child health are completely interrelated. Jack Shonkoff challenges policy makers, as well as professionals, to radically reform the provision of services in order to capitalize on principles of normal, integrated development in children and families. Shonkoff notes the significant impact that such an approach would have on the training and development of professional service providers.

The environmental context has a significant impact on the services that are available. Many professional services are available neither in rural areas, nor in inner cities (U.S. Congress, Office of Technology Assessment, 1990). Phyllis Magrab focuses our attention on "Rural Issues in Planning Services for Children with Special Needs," as she notes the paucity of information available on children with special needs" and the significant effects of that deficit on planning and "providing family-centered, community-based, coordinated care in rural areas." The data that are available, Magrab notes, suggest that there is a greater incidence of infant mortality and chronic and disabling conditions in rural areas.

Deborah Klein Walker and Tom Kochanek each remind us that there is a long tradition of attention at the Federal level to the health and welfare of children and families. However, the support is of the "band-aid" application type and Walker says that there is "no systematic ongoing research or programmatic monitoring effort" of needs and capabilities that could make use of existing electronic technology, which Kochanek considers analogous "to the Star Wars initiative in the Department of Defense."

Gallagher comments on the difficulty of producing a vision of a comprehensive and coordinated system of service. In this instance, the vision would conceptualize (a) the ideal service system, (b) some strategies for getting from the status quo to the new system, and (c) some idea of how the resources can be found to support the new system.

The diversity of the target group of infants and toddlers with disabilities, the multitude of participating professionals and professional groups, and the range of service delivery settings all make the design of a single vision of service coordination very difficult. It may be helpful to think of a series of interrelated visions for rural, urban, and suburban systems.

Summary of conclusions and recommendations

A brief summary of the recommendations made by our policy analysts includes a future focus on the following areas: rigorous evaluation and analysis of the costs and benefits of existing programs; creation of model programs of services for children and families that are based on empirical evidence; and, full integration of family-centered care into all services. Moreover, all of this must be based on the interrelatedness of child and health development.

> **Evaluation and analysis**. The capacity to examine the current system of services and to build models of services based on that analysis is underutilized.

Empirical basis for systems of service. A new partnership must be forged between those who generate knowledge and those who apply it.

Integration of family-centered focus. In order to have a philosophy of family-centered care, there must develop a consensus and a vision; Guidelines for measurable indicators are necessary; accomplishment of this will occur as personnel preparation practices are modified.

Interrelated child health and development. Part H provides a window of opportunity for restructuring services to all young children and their families. The keystone of the structure must be the interrelation of health and other service areas for development in young children.

Future directions. The initiators of this law clearly had in mind more than merely providing some resources to the states for planning and development. The overall law has a variety of change and reform mechanisms built into it, among them family empowerment, multidisciplinary cooperation, and the initiation of an Individual Family Service Plan.

The health services become involved because the law requires a coordinated, multidisciplinary service system and the health services are clearly scheduled to play a significant role in that service system. The full portrait of such a coordinated system still escapes us, but strong implementation of the law includes the inductive building of a system from a type of backward-mapping–from the families up–in order to grasp the full design of the comprehensive system.

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