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Research Paper

How physicians support children with disabilities and their families: Roles, responsibilities and collaborative partnerships

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Abstract

Background: The American Association of Pediatricians (AAP), in collaboration with the Council for Children with Disabilities and the Council on School Health, recommends that physicians learn special education law and practices in order to increase their ability to work with schools to support children with disabilities and their families. However, there is limited research that examines how doctors perceive their role as collaborators with families and school personnel.

Objective: The purpose of this study was to explore the perceptions and collaborative experiences of doctors treating children with disabilities in order to develop an initial understanding of how doctors collaborate within the doctor/family/school triad.

Method: Semi-structured interviews with doctors ($n = 13$) from two states in the North Eastern United States were collected and analyzed using grounded theory methodology. Doctor specialty areas included general pediatrics, developmental pediatrics, rehabilitation pediatrics, and neurology.

Results: Analysis of the data revealed four key categories: (a) what doctors do with regard to children with disabilities and schools, (b) elements that interfere with doctor/family/school collaboration, (c) what doctors know and understand about topics related to special education, and (d) how doctors learned about topics related to special education. Doctors disclosed they learned about these topics through mentorship and on-the job training, not formally during medical school or residency.

Conclusions: This research presents powerful evidence in support of a paradigm shift with regard to infusing a focus on doctor/family/school collaboration for children with disabilities into the medical school curriculum. © 2016 Elsevier Inc. All rights reserved.

Keywords: Grounded theory; Qualitative interviews; Doctor/school/family collaboration; Doctor knowledge of special education

Recently in the field of pediatric medicine, there have been calls for increased support of children with disabilities and their families.[1,2] The American Association of Pediatrics (AAP) in collaboration with the Council for Children with Disabilities and the Council on School Health recommends that physicians learn special education law and practices in order to refer children who may need services and advise parents.[2] Additional recommendations to improve service include working collaboratively with other medical professionals[1,3] and school and community personnel.[2] However, there is limited research that examines what doctors currently do in their role as collaborators with families and schools, nor is there research that addresses how they perceive the collaboration. The goal of this study was to better understand the collaboration between physicians and schools from the perspective of doctors. The authors interviewed 13 physicians in the Eastern United States to determine answers to the following research questions. How do doctors perceive their role as collaborators within the doctor/family/school triad and how do they carry out that role?

Special education law and practice

In order for physicians to advise parents about special education referral, testing, and possibly services, they must have an understanding of the guiding laws and accepted practices in the field. Children with disabilities are protected under two Federal Laws, the Individuals with Disabilities Education Act (IDEA) and section 504 of the Rehabilitation Act of 1973. IDEA was established to ensure that students from ages birth to 21 identified with disabilities are provided with a free appropriate public education (FAPE) in the least restrictive environment (LRE) that ‘‘emphasizes special education and related

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services designed to meet their unique needs and prepare them for further education, employment, and independent living."[4] IDEA also includes a provision for Early Intervention (EI) services for children from birth to 3 years of age. Furthermore, each child classified with a disability that negatively impacts his or her academic progress must have an individualized education program (IEP), a written education plan that the school district and parents develop. This program is reviewed and revised, at a minimum, annually. Section 504 of the Rehabilitation Act of 1973 is a civil rights law that ensures access to the school curriculum and prohibits discriminating against a child due to his or her disability by providing the necessary accommodations. The document for ensuring access to the school curriculum for students with disabilities is known as a 504 Plan.[5]

The role of the physician

Within his or her role as health care provider for children with disabilities, the physician's duties are multifaceted and complex. Physicians are often the first to recognize, or hear parents' concerns about, developmental delays and disabilities in young children.[6,7] Physicians refer these children for additional medical testing and school evaluations and then, if a diagnosis is made, help families understand the implications.[6–8] In addition, many prescribe medicine for children with disabilities and need to monitor the effects through parent and school reports.[9]

Communication

Pediatricians may be the first person outside the family with whom parents discuss concerns about development.[6,7] In a study of parent satisfaction with physician communication, Street[10] found that parents highly valued physicians who provided information in the form of "explanation, instruction, description and advice" (p.1151). Worcester, Nesman, Raffaele, Mendez, and Keeler[11] found that parents of young children with challenging behavior reported it was important for physicians to be responsive to parental concerns and provide accurate information about the child's needs.

Treatment

Physicians conduct both well and sick child medical care from birth until 18 years of age. Pediatricians are often responsible for making referrals to Early Intervention (EI) for children from birth to 3 years of age. Once children are identified as having a disability, physicians are frequently called on to write prescriptions for medication intended to improve school performance[9] and for physical therapy,[12] and to advocate for adapted physical education programs.[3]

Collaboration

Collaboration is characterized by partners sharing decision-making responsibilities. The positive effects of parent/doctor collaboration have been demonstrated in several studies[6,13] and include improved parental satisfaction with services, fewer missed school days, less emergency care needed, and less financial strain on families.[3] Although numerous researchers have called for greater communication and collaboration between doctors and school personnel, very few have provided either evidence of this occurring or guidelines for the roles and responsibilities of the team members.[3,12,14] The studies that have examined family/school/physician collaboration are focused primarily on the treatment of children with chronic health care needs, such as asthma[14] and mental health needs.[15] In these studies, the collaboration is characterized by frequent communication and updates regarding current treatment and medication.[14,15]

Barriers to effective practice

Researchers have found that there were gaps in pediatricians' knowledge of special education practices[16] as well as working with individuals with intellectual disabilities[17] and those with physical disabilities.[12,18] These gaps were also evident in studies that examined Early Intervention (EI) referral.[19,20] The authors of those studies recommended that pediatricians become more familiar with the referral process in order to better guide families and to ensure that children receive needed therapeutic services as early as possible. Michaud and the Committee on Children with Disabilities[12] stated that when physicians are called on to write prescriptions for physical therapy, the requests are complicated by the fact that "many physicians have limited formal education about these formal interventions" (p.1836).

Although some studies have been conducted to examine what doctors know about special education and how prepared they feel to advise families of children with disabilities,[16,18] little to no qualitative research has been conducted to gain a deeper understanding of how doctors gained and utilized the knowledge they have about special education practices. In order to address these gaps in the research, this study was designed to determine how doctors perceive their role as collaborators with families of children with disabilities and schools and how doctors collaborate within the doctor/family/school triad.

Methods

Study design

The study was designed using the constant comparative method as described in grounded theory methodology.[21] This method is a way to develop an explanatory theory of