

The Primary Physician's Role in Care for Developmentally Handicapped Children

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Over the past ten years the needs and rights of handicapped persons have been widely emphasized, leading to major changes in their care. The primary physician has an important role in identification of handicapped children and in counseling and educating families. Training for physicians in these areas has only recently been introduced in some medical schools, residency programs, continuing medical education courses, and journals. The results of a survey of Arizona family physicians and pediatricians and parents of handicapped children confirm that primary physicians see handicapped children with regularity and generally have a clear perception of their role. Screening and counseling families about their child's disability appear to be major problem areas leading to parental dissatisfaction. The implications of these findings for future training efforts are discussed.

In the past ten years there has been considerable emphasis on the needs and rights of handicapped persons. Medical journals have published numerous articles on these subjects, new texts have appeared, continuing education courses and workshops have been offered, and medical training, especially in pediatric residencies, has included training in the diagnosis and management of children with chronic illnesses and handicaps.

Screening for metabolic diseases such as phenylketonuria and hypothyroidism has become routine and is mandated by law in most states. Developmental screening tests have been developed for use in physicians' offices, and most communities have implemented early intervention programs for preschool children. Special education services have greatly expanded in public schools, and supportive services to families have developed that include training in the home management of handicapped children, supportive counseling, and temporary respite care to enable families of severely handicapped children to enjoy vacations while knowing that their child is safely cared for. In addition, group homes and sheltered workshops have emerged that enable older handicapped children and adults to live in supervised settings independent of their families and to have jobs as alter-

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natives to institutionalization. As a result of these developments, most handicapped children are cared for at home, attend public school, and can look forward to much greater independent functioning, integrated into society.

When parents suspect that their child is not developing normally, they usually turn to their family physician or pediatrician. In the management of handicapped children and their families, it is impressive that parents often report dissatisfaction with what their physician said or did. A survey of family physicians and pediatricians in Arizona was recently conducted to ascertain the status of current health care practices to handicapped children and their families and to better understand the reasons for reported parental dissatisfaction.

Methods

Following preliminary interviews with several family physicians and pediatricians, a questionnaire was developed and sent to 270 primary care physicians in Phoenix and Tucson, Arizona, randomly chosen from the Arizona Medical Association Directory. One hundred twenty-five questionnaires were sent to pediatricians and 145 were sent to family physicians. Topics covered in the questionnaire included practice characteristics, time spent on well-child care, the use of developmental screening instruments, diagnostic workup strategies in children presenting with possible developmental disabilities, use of community resources, and comfort with counseling parents of developmentally handicapped children.

Information from parents of handicapped children came from interviews with ten sets of parents, from approximately 50 case evaluations in the Child Development Clinic, University of Arizona, and through four community workshops.

Results

Approximately 50 percent of the pediatricians (63/125) and 23 percent of the family physicians (33/145) completed and returned the questionnaire.

The pediatricians reported that 4.4 percent of their monthly pediatric encounters involved a child with developmental or behavioral problems, whereas the family physicians estimated that 7.3 percent of pediatric encounters involved such problems. Learning and behavior problems were seen most frequently (3 to 5 percent of pediatric encounters); mental retardation and cerebral palsy were less frequently seen (1 to 2 percent of pediatric encounters).

With regard to well-child care, both pediatricians and family physicians reported spending similar amounts of time for each encounter (10 to 20 minutes); however, the pediatricians appeared to spend a greater percentage of time dealing with developmental or behavioral concerns.

Although more than 90 percent of family physicians and pediatricians surveyed believe that developmental screening should be a routine part of well-child care, only 20 percent of the family physicians and 56 percent of the pediatricians report screening routinely. Of the screening instruments used, the vast majority (90 percent) of the physicians utilized the Denver Developmental Screening Test (DDST), whereas 7 percent used the Pre-screening Developmental Questionnaire (PDQ).

The four following areas were investigated to explore why physicians were not screening routinely:

1. Attitudes regarding value of early identification of handicapped children
2. Perception of sufficient training to perform screening
3. Perception of parental willingness to pay for screening
4. Practice setting

Physicians believing that early identification improves prognosis were more likely to perform routine developmental screening than those who disagreed. Approximately three fourths of the responding physicians felt they were sufficiently trained to perform developmental screening, yet more than one third expressed an interest in additional training in screening, were it available. Slightly over one half the respondents felt the parents were willing to pay for the time they spent screening or discussing developmental or behavioral concerns. Physicians who worked for health maintenance organizations were more likely to screen than those in other practice settings (85 percent vs 45 percent).

Physicians differ markedly in their approaches to evaluating children with common developmental problems, with 10 to 25 percent preferring to "wait and see" rather than refer for evaluation a 2½-year-old child who was not yet talking. Pediatricians in practice less than ten years were more likely to refer such a child for hearing and for speech evaluation early than were those in practice more than ten years (90 percent vs 50 percent). When presented with a 3-year-old child with unusual appearance, slow motor development, and two-word vocabulary, respondents differed markedly in the type of referral made. Fifty-five to 65 percent would refer to a developmental center, whereas the rest would utilize a variety of consultants. Family physicians and pediatricians appeared to utilize community treatment resources to different extents. Pediatricians in practice for less than ten years were most likely to refer to infant stimulation programs, to occupational and physical therapists, and to peer-support groups (such as Pilot Parents). Only 3 to 6 percent of family physician respondents had utilized infant stimulation or peer-support services.

Satisfaction with the role of counseling parents of handicapped children was reported by 48 percent of family physicians and by 84 percent of pediatricians. One third of the family physicians and one half of the pediatricians expressed an interest in additional training in parent counseling skills, were it available.

Discussion

The results of this survey indicate that primary care physicians in Phoenix and Tucson seem to be aware of childhood developmental problems and seem to be encountering them with a frequency similar to that reported elsewhere. Starfield et al¹ reported that in a variety of primary care settings 5 to 20 percent of pediatric encounters involved a primary developmental or behavioral concern.

Contacts with parents of handicapped children indicate that they fault their physicians in two areas: (1) for failing to detect problems early and acknowledge parental concerns that a developmental problem was present, and (2) for failing to offer appropriate information on diagnosis, prog-

nosis, and where to go for help. This survey of physicians suggests that there is some basis for these parental criticisms.

Only 50 percent of the pediatricians and 20 percent of the family physicians surveyed reported screening for developmental problems routinely, although more than 90 percent believe it should be performed as part of well-child care.

A major impediment to screening continues to be the time (and thereby cost) required to administer a screening test such as the DDST, which takes 20 minutes of staff time to administer. Most surveyed were apparently unfamiliar with the PDQ, a ten-item, parent-administered questionnaire that is reliable, accurate, and requires no staff time.² Although most respondents felt sufficiently trained in screening, one third requested additional training. A number continued to rely on "clinical judgment," based on history and physical examination alone. Bierman et al³ reported that more than 50 percent of mentally retarded children were missed when a screening test was not performed.

When a child is suspected of having a developmental problem, most physicians refer such a child for further developmental evaluation. However, there is wide variability in the types of referrals made. Less than one half of the physicians surveyed are referring to developmental pediatricians, despite their availability as the result of recent fellowship training programs. When faced with complex cases, where multiple consultants are needed, nearly one half of the family physicians and one third of the pediatricians would seek individual subspecialty consultations rather than refer to a developmental center. This approach may lead to parental confusion and dissatisfaction because fragmented information is received from each consultant, possibly with conflicting recommendations rather than a coordinated and comprehensive approach.

A disturbing number of physicians, particularly those out of training at least ten years, continue to wait for children to outgrow developmental problems. Such a practice leads only to a delay in making the diagnosis and intervening and erodes the family's confidence in their physician. When the child ultimately is found to have a problem, the parents then become angry at the physician for not acknowledging their concerns earlier and feel guilty that they had not sought a second opinion and begun treatment sooner.

In a review of the literature, Pulman⁴ found that 75 percent of parents of handicapped children were dissatisfied with the way in which the child's diagnosis was communicated to them. The main criticisms were that physicians provided misinformation and either minimized symptoms or exaggerated them into an inappropriately bleak prognostic picture.

Based on a hypothetical situation of counseling a family of a newborn with Down's syndrome, the present survey suggests that most physicians are both sensitive and appropriate, with several exceptions. Physicians who recommend immediate institutionalization are misleading families, as this is no longer an available option in Arizona. Physicians who wait until a family notices that their child appears unusual before informing them of the diagnosis appear to be insensitive to the issues that families of handicapped children face.

Others have pointed out the difficulties facing the physician who must counsel a family.⁵⁻⁷ The physician must be comfortable with the diagnostic information. Usually considerable doubt exists as to prognosis and, with many conditions, as to etiology. The physician must be aware of treatment services in the area. The physician must know the family, how they are apt to react to the information, and how to support them in grieving. The physician must also come to terms with his own feelings about the particular handicap and about having to deliver the bad news. A substantial number of physicians surveyed reported dissatisfaction with their role in counseling families and expressed an interest in further training.

At the present time the primary care physician who encounters a child with developmental handicaps has two reasonable options: to obtain appropriate training and perform the diagnostic workup himself utilizing appropriate consultations, or to refer the patient to a developmental pediatrician or developmental center for diagnosis, parent counseling, and initiation of treatment.

Primary care physicians may not be making optimal use of community treatment resources for handicapped children and their families. Given the frequency with which they are encountering handicapped children, the rates of referral for infant stimulation, developmental preschool, or peer support (Pilot Parents) appear relatively low. Previous studies suggested that many primary care physicians are unaware of local treatment re-

sources.^{8,9} Most of these programs are available at little or no cost to families. Use of a developmental center for diagnostic evaluation or consultation with a developmental pediatrician will usually provide to the primary care physician all needed information on available treatment programs.

The implications of these findings on the training of family physicians suggest three areas of focus. First, the family physician must be familiar with cost-effective screening instruments to identify the child with developmental problems early. Second, he must be familiar with local resources that offer comprehensive diagnostic assessment and access to community treatment. Finally, the family physician should gain experience and comfort in explaining diagnostic findings to families and, over time, helping them adjust to caring for their handicapped child. Such training may be best incorporated into ambulatory pediatric and behavioral science rotations and through conferences, seminars, and ongoing practice supervision.¹⁰

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