



## **Report to Congress**

# **The Pediatric Rheumatology Workforce: A Study of the Supply and Demand for Pediatric Rheumatologists**

MANDATED BY: PUBLIC LAW 106-310 CHILDREN'S  
HEALTH ACT OF 2000 (HR4365). AUTHORIZED AS  
SECTION 763 (b), PART E, TITLE VII OF THE PUBLIC  
HEALTH SERVICE ACT

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Administrator, HRSA

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## *Executive Summary*

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### **Legislative Charge**

The Public Health Service Act in Section 763, Pediatric Rheumatology states, “The Secretary, acting through the appropriate agencies, shall evaluate whether the number of pediatric rheumatologists is sufficient to address the health care needs of children with arthritis and related conditions, and, if the Secretary determines that the number is not sufficient shall develop strategies to address the shortfall.” (Public Law 106-310 authorized in the Public Health Service Act, Title VII, Part E, Subpart 1, Section 763). This report was prepared to fulfill that mandate by:

- Reviewing the existing literature on children’s access to pediatric rheumatology care in the United States in regard to pediatric rheumatologist supply and the role of other physician providers in treating these children;
- Analyzing available data to assess the supply of and demand for pediatric rheumatologists in the United States; and
- Determining if a shortage of pediatric rheumatologists exists and, if so, discussing those factors that would affect the shortage and describing possible options for ameliorating local and nationwide shortages.

The contract for this study, University of North Carolina at Chapel Hill (Dr. Michelle Mayer, Ph.D.), was awarded by the U.S. Department of Health and Human Services, Health Resources Services Administration (HRSA). HRSA staff was responsible for overseeing this study. In addition, staff of the American Board of Pediatrics, American Academy of Pediatrics, Arthritis Foundation, and the Pediatric Section of the American College of Rheumatology provided invaluable professional insight.

### **Pediatric Rheumatologist Specialty**

Pediatric rheumatologists care for children and adolescents with diseases characterized by inflammation of joints, muscles, and/or tendons. The most prevalent pediatric rheumatic diseases are juvenile rheumatoid arthritis (JRA) and systemic lupus erythematosus (SLE). These diseases, along with several other less common ones, affect approximately 285,000 children in the United States. Only pediatric rheumatologists have been trained as specialists to treat the complex, severe, and sometimes life-threatening rheumatic diseases of childhood. Given the potential for severe illness and disability associated with pediatric rheumatic diseases and the potential for a markedly improved outcome with optimal treatment, an adequate supply of pediatric rheumatologists is essential to provide children suffering from these diseases with access to expert care.

### **Key Findings**

- The evidence indicates that there is a shortage of pediatric rheumatologists in the United States.
- Pediatric rheumatology is characterized by a small number of providers concentrated in a limited number of areas in the United States; 13 States lack a pediatric rheumatologist, and throughout the Country provider to population ratios exceed practice capacity.
- Pediatric rheumatologists who were surveyed unanimously perceive a national shortage. Additionally, there is evidence of substantial reliance on internist rheumatologists (i.e.,

those that specialize in the care of adults with rheumatic diseases) to compensate for the lack of sufficient pediatric rheumatologists.

Contributing to the shortage, the majority of pediatric rheumatologists practice in academic medical settings where they function as patient care providers, medical educators, and researchers. These diverse roles compete for pediatric rheumatologists' limited time and decrease the availability of patient care they are able to provide. Efforts to increase the availability of clinical time for current pediatric rheumatologists and attempts to increase their numbers are warranted at this time.

## **Data Sources**

This report synthesizes the results of previously published studies identified by a systematic review of the pediatric subspecialty workforce literature. In addition to these published studies, analyses were conducted using data from a variety of sources. Slightly more recent data may be available by the time of publication, but the data presented in this report were the most up-to-date at the time of analysis. More detailed information about data analyzed for this report can be found in the appendices listed below:

- Appendix C describes 2003 data from the American Board of Pediatrics (ABP), which certifies pediatric rheumatologists and other pediatric subspecialists. Appendix C also contains 2001 and 2004 membership data from the American College of Rheumatology (ACR), the professional association of rheumatologists.
- Appendix D details data from the United States Bureau of the Census, the HRSA Bureau of Health Professions Area Resource File and the ABP that were combined to estimate distances to care.
- Appendix E provides detailed information on a 2004 survey of practicing pediatric and internist rheumatologists, performed by the Arthritis Foundation and the American College of Rheumatology.
- Appendix F describes the methodology for a 2004 survey of pediatric residency directors on the role of pediatric rheumatologists in the education of general pediatrics residents and how the current supply of these providers affects graduate medical education.

Additional information from the North Carolina Medicaid Program, American Academy of Pediatrics, the American College of Rheumatology, and the American Board of Pediatrics was used.

## **Chapter Summaries (Significant Findings Listed)**

*Chapter 1. Background on Pediatric Rheumatology and Pediatric Rheumatic Diseases* highlights the unique characteristics of pediatric rheumatology workforce in the United States and provides a brief introduction to childhood rheumatic diseases.

- Only pediatric rheumatologists have been trained as specialists to treat the complex, severe, and sometimes life-threatening rheumatic diseases of childhood.
- Pediatric rheumatic diseases affect nearly 300,000 children in the United States.
- The most common juvenile rheumatic disease, juvenile rheumatoid arthritis, is unique to children and can affect children as young as infants.
- As a group these conditions are among the most common chronic illnesses of childhood and involve considerable disease burden and disability.

- Pediatric rheumatic diseases require frequent and ongoing medical care: physician visits, laboratory work, infusion therapy, and physical and occupational therapy. Long travel distances between patient and caregiver can impede continuity of care and access to important ancillary healthcare services.

**Chapter 2. The Pediatric Rheumatology Workforce: Current Supply** describes the current status of the pediatric rheumatology workforce in the United States, including the number and distribution of pediatric rheumatologists, training requirements, and perceptions of supply.

- Fewer than 200 certified pediatric rheumatologists currently practice in the United States, making it one of the smallest pediatric subspecialties.
- Thirteen States, including heavily populated States such as Arizona, South Carolina, and Alabama, lack a pediatric rheumatology provider within their borders.
- On average, children in the United States travel 57 miles to reach the nearest pediatric rheumatologist. In contrast, children need to travel less than 25 miles to reach pediatric specialists in cardiology, endocrinology, and many other fields.
- Pediatric rheumatologists unanimously perceive that there is a national shortage of pediatric rheumatology providers; two-thirds also perceive a local shortage in their practice area.
- Pediatric rheumatologists attribute the current shortage to low salaries, inadequate reimbursement, and poor working conditions. At the assistant professor level, pediatric rheumatologists' annual salaries average \$115,022. In contrast, average salaries for pediatric cardiology, neonatal medicine, and pediatric critical care medicine at this academic rank are more than \$144,000.
- The limited supply of pediatric rheumatologists often results in long wait times for appointments, delayed diagnosis or treatment, and possibly leads to misdiagnosis and inappropriate treatment.
- One third of institutions housing pediatric residency programs would like to hire a pediatric rheumatologist but are unable to do so for financial or other reasons.
- The majority of pediatric rheumatologists work in a small number of academic medical centers where they are also responsible for performing basic and/or clinical research and educating medical students, residents, and fellows. Thus, other professional activities limit the time they have available to provide patient care.
- As many as one-third of pediatric rheumatology patients are insured through Medicaid, which reimburses physicians at levels below those of private insurers and Medicare. Low reimbursement rates limit clinical revenue for pediatric rheumatology practices and threaten their financial viability.

**Chapter 3. Estimating Pediatric Rheumatology Workforce Requirements** uses prevalence estimates, pediatric population data, and pediatric rheumatologist supply to estimate the demand for pediatric rheumatologists in the United States and presents data on available positions.

- In some States, demand models estimate that there are over 3,000 children with rheumatic diseases per pediatric rheumatologist, a number that far exceeds the average practice capacity of 443 children.
- Using State level population data, models developed for this report estimate that at least 337 pediatric rheumatologists are needed to meet patient care needs. Given the current number of pediatric rheumatologists, there needs to be a 75 percent increase in the number of pediatric rheumatologists.

- The majority of recently trained pediatric rheumatologists practice in a county that has another pediatric rheumatologist in practice. If maldistribution of supply continues, increases in supply may not ameliorate regional, statewide, or local shortages unless there are incentives to locate in areas that currently lack providers.
- While there were 23 advertised pediatric rheumatology positions in September 2004, only 10 pediatric rheumatology fellows completed training in the 2003-2004 academic year, suggesting that current training levels are not sufficient to fill vacant positions.

**Chapter 4. *Substitutes for Pediatric Rheumatologists? Primary Care Providers and Internist Rheumatologists Involvement in Pediatric Rheumatology Care as Evidence of a Shortage*** discusses the involvement of primary care providers and internist rheumatologists in caring for children with rheumatic diseases.

- Substitutes for pediatric rheumatologists are limited.
- Internist rheumatologists play a prominent role in the care of children with rheumatic diseases due, in part, to the limited availability of pediatric rheumatology care. Many internist rheumatologists limit their involvement to the care of adolescents and feel less comfortable than do their pediatric rheumatologist peers managing the care of children.
- By virtue of their training in the care of adults, internist rheumatologists may have limited experience with the rheumatic diseases common to childhood and lack an understanding of the unique clinical and psychological needs of pediatric patients.
- Primary care providers, like family practitioners and general pediatricians, play a limited role in the care of children with rheumatic diseases. Only one percent of primary care providers diagnose and treat juvenile rheumatoid arthritis independently and these providers generally feel uncomfortable caring for these children and refer them to pediatric or internist rheumatologists.
- There have not been investigations of differences in the quality of pediatric rheumatology care across physician types (i.e., pediatric rheumatologists, internist rheumatologists, or primary care providers).

**Chapter 5: *Important Issues Facing the Pediatric Rheumatology Workforce*** details the non-clinical roles of pediatric rheumatology providers and highlights their relevance to the shortage.

- One-third of medical schools and 40 percent of pediatric residency programs have no pediatric rheumatologist available to provide patient care or educate physicians in training.
- Many medical students and general pediatrics residents receive little training in the diagnosis and management of children with rheumatic disease, which may lead to unwillingness to care for these children and perpetuate low levels of interest in this field.
- While specific effects of the current shortage of pediatric rheumatologists on research activities are unknown, the pressures of meeting patient demand in the face of a provider shortage leaves limited time for research activities and may impede the advancement of medical science in this field and delay the development of treatments.

**Chapter 6. Potential Solutions** discusses the relative merits of various solutions to the access problems facing pediatric rheumatology. There are several approaches to increasing access to pediatric rheumatology care.

- The number of pediatric rheumatology fellows has increased in recent years; however, existing programs fail to fill all their available fellowship positions. Financing fellowship positions continues to be a challenge. Enhanced availability and financing of fellowship training will increase the number of trainees in the field.
- Efforts to increase the number of trainees should include incentives to practice in relatively underserved areas after completion of training.
- Increases in the number of trainees as well as increases in the number of pediatric rheumatologists locating in underserved areas will require reallocation of resources. Some potential areas for financial support include using existing programs, such as loan repayment programs, to target pediatric rheumatology.
- Improve the financial viability of pediatric rheumatology practice in academic settings.
- Enhance the ability of internist rheumatologists and primary care providers to provide care to children with rheumatic diseases through education and training.
  - Advocate for changes in the requirements for internist rheumatology fellowship training to include the care of adolescents (i.e., similar to requirements for endocrinology, diabetes, and metabolism fellowship).
  - Develop practice guidelines for juvenile rheumatoid arthritis to encourage internist rheumatologists to provide more care to children with juvenile rheumatoid arthritis.
  - Facilitate general pediatricians' exposure to pediatric rheumatology during residency through programs to encourage pediatric rheumatologist placement at centers that lack these providers and/or through telecommunications, like telemedicine and on-line training programs.
  - Augment programs like Pediatric Rheumatology Visiting Professorship Programs to increase exposure to pediatric rheumatology in medical schools and pediatric residencies.
  - Survey pediatric rheumatologists to determine their access to telecommunications and their willingness to provide training using these media. Survey training programs about their interest in using these media as part of physician training.
  - Pilot telecommunications-based educational programs that link pediatric rheumatology centers and residency programs without pediatric rheumatologists and evaluate their effectiveness at improving knowledge, skills, and comfort levels.
  - Pilot telecommunications-based patient care networks that link pediatric rheumatologists with distant providers and evaluate patient and providers outcomes.
- Use nurses, advanced-practice nurses, and physician assistants to extend pediatric rheumatologists. Delegation of certain tasks, such as referral coordination or telephone triage, to these providers allows pediatric rheumatologists more time to concentrate on patient care and other professional activities.

**Chapter 7. Conclusions** are that a pediatric rheumatology shortage exists and a 75 percent increase is needed.