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PERSPECTIVE

What Happens when Special Needs Children Grow Up?

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Medical care for special needs patients historically has been the domain of the pediatrician. However, now that people with a wide range of conditions are more often living into adulthood, internists need to assume care for an increasing number of special needs adults. In an effort to improve health outcomes for this vulnerable segment of the population, internal medicine residents need to have training content dedicated to the care of aging special needs patients.

The first step to address the disparities in care is to understand the term "special needs," which can be interpreted in a variety of ways. In the pediatric literature, the term "children with special healthcare needs" (CSHCN†) refers to a variety of conditions, including children with normal cognition but a range of chronic health conditions and systemic illnesses, such as cystic fibrosis, sickle cell disease, and even asthma, as well as physical limitations and emotional conditions. The term also includes young people with varying cognitive impairments such as autism spectrum disorders, Down syndrome, and many other forms of cognitive limitation. The terms "special needs" or "special healthcare needs" are non-specific, but for lack of better terminology, they will be used in the following discussion. Ideally, one would have precise definitions and an accurate count of all adults with special needs, but at the present time we must use proxies from the pediatric literature.

Little data exists on the care these patients receive once they age out of treatment by pediatricians. Some patients with rare health conditions continue to receive much of their healthcare from specialists after turning 18. Some stay with their pediatric specialists, while others find adult-oriented specialists; many of these specialists are highly qualified in their fields of expertise. But like other adults, these patients would benefit from knowledgeable and involved primary care physicians who can function as advocates and ensure the patients receive age appropriate preventive care.

The number of special needs patients is substantial. Newacheck et al. [1] used the National Health Interview Survey and Disability Survey of 1994 to estimate that 18 percent of children younger than 18 met the

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†Abbreviations: CSHCN, children with special healthcare needs.

definition of special healthcare needs; 6.5 percent to 31 percent of children are thought to have chronic conditions, depending on the exclusion criteria applied [2]. The various estimates translate to 500,000 children turning 18 each year [3], and these young adults need competent providers to assist them in navigating the complex world of adult care.

While a number of the chronic health conditions that fall under the label of CSHCN are well understood by internists, other conditions are less familiar. For many patients, specialists play a very active and critical role and having a primary care physician as an advocate and coordinator can improve access and utilization of healthcare. Internists must be prepared to manage these vulnerable and complex patients — especially cognitively limited adults. Creating a succinct, high impact training program that fits within an internal medicine residency curriculum is of great importance.

In 2002 and 2005, U.S. Surgeon General Richard H. Carmona identified a need for improving healthcare for those people with intellectual and physical disabilities [4,5]. These reports found that people with developmental and intellectual disabilities suffer from poorer health than the general population [6,7]. Dissatisfaction with healthcare may contribute to disparities in care for special needs adults. In their 2006 analysis of questions from the 2000 and 2002 Medical Expenditure Survey, Parish and Saville specifically looked at care satisfaction reports by women with cognitive limitations. This study indicated that these special needs adults were dissatisfied with their physicians and felt their physicians did not show them sufficient respect, when compared with women who have normal cognition [8]. It is unknown what proportion of special needs adults are dissatisfied with their physicians.

In an effort to understand if a physician's level of comfort and preparedness plays a role in delivery of care to special needs patients, we conducted a small survey at the Connecticut chapter of the American College of Physicians meeting. Although limited in its sample size and power, our survey indicated that attending physicians rated themselves higher than residents (median 6 vs. 5 on a 10 point scale, $p = 0.21$) in perceived preparedness. Attending physicians also were more likely than residents to state that they felt comfortable treating special needs patients (median 7 vs. 5.5 on a 10 point scale, $p = 0.05$). There are two possible explanations for the differences in attending and resident ratings: First, attendings have learned through experience; and second, they are more comfortable overall and there is a halo effect. We also contacted Connecticut's 13 internal medicine training programs to assess the presence of any formal training on the care of special needs adults. We found that in a three-year curriculum, only one program reported offering one lecture.

There appears to be a widespread lack of formal training for special needs care in internal medicine curricula. In the meantime, 500,000 children with special needs turn 18 each year and need care. By adapting training tools such as the materials provided by the Exceptional Children's Assistance Center in North Carolina, which initially were created for pediatricians and parents of special needs young adults, we can enhance internists' knowledge and communication skills. A first step to improving healthcare for special needs adults may be to develop, implement, and evaluate formal curricula.

REFERENCES

1. Newacheck P, Strickland B, Shonkoff J, et al. An epidemiologic profile of children with special health care needs. Pediatrics. 1998;102:117-23.
2. Scal P. Transition for youth with chronic conditions: primary care physicians' approaches. Pediatrics. 2002;110:1315-21.
3. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. Pediatrics. 2005;115:1562-8.
4. U.S. Department of Health and Human Services. Closing the gap: a national blueprint for improving the health of individuals with mental retardation. Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. Washington, D.C.: U.S. Department of Health and Human Services. Office of the Surgeon General; 2002. pp. 2-10.

5. U.S. Department of Health and Human Services. The Surgeon General's call to action to improve the health and wellness of persons with disabilities. Washington, D.C.: U.S. Department of Health and Human Services. Office of the Surgeon General; 2005. pp. 1-12.
6. Fisher K. Health disparities and mental retardation. J Nurs Scholarsh. 2004;36:48.
7. Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health access for people with intellectual disabilities. Ment Retard Dev Disabil Res Rev. 2006;12:70-82.
8. Parish S, Saville A. Women with Cognitive Limitations Living in the Community: Evidence of Disability-Based Disparities in Health Care. Ment Retard. 2006;44:249-59.