

# Residency Training in Transition of Youth With Childhood-Onset Chronic Disease

## abstract

**OBJECTIVE:** To assess the current medical school training of internal medicine and pediatric residents in transitioning youth with special health care needs from child-oriented to adult-oriented health care.

**METHODS:** We surveyed internal medicine and pediatric residents to assess their preparedness to transition youth with special health care needs to adult-oriented health care.

**RESULTS:** The survey results demonstrated that internal medicine residents felt unprepared to care for most patients with chronic childhood-onset illness; however, most pediatric residents were comfortable caring for such patients.

**CONCLUSION:** Training in chronic childhood-onset illness should be included in internal medicine training programs. *Pediatrics* 2010;126:S190–S193

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### KEY WORDS

pediatrics, internal medicine, children with special health care needs, medical education, internship and residency, graduate medical education

### ABBREVIATIONS

YSHCN—youth with special health care needs

WISHES—Working Initiative for Special Health Education Services

IMR—internal medicine resident

PEDR—pediatric resident

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Youth with special health care needs (YSHCN) have, or are at increased risk for, a chronic medical condition that requires services beyond those typically required by children.<sup>1</sup> Of children younger than 18 years, 12.8% have special health care needs, and 90% of these children will live into adulthood.<sup>2</sup> Many of their health needs, including mental and behavioral health problems, receive insufficient attention.<sup>3-6</sup> YSHCN remain a population at risk of being an underserved group of health care consumers, and YSHCN who live in poverty are even more likely than other YSHCN to report problems with access to care.<sup>2</sup>

YSHCN want to transition into adult roles, with adult roles and adult responsibilities,<sup>7</sup> but many never attain one of the milestones of adulthood: an adult-oriented health care team. The barriers to transitioning YSHCN include patient and family reluctance to transition to adult care, pediatricians' distrust of adult practitioners, and internists' discomfort with treating unfamiliar diseases.<sup>8</sup> When transitions do occur, they are often haphazard and lack sufficient planning or support.<sup>9</sup>

In 2002, the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians released a joint consensus statement on YSHCN.<sup>10</sup> The statement included a recommendation to train primary care providers in successfully transitioning YSHCN from pediatric to adult health systems. To address the consensus mandate, we created a novel transition curriculum, the Working Initiative for Special Health Education Services (WISHES), to educate internal medicine residents (IMRs), pediatric residents (PEDRs), and internal medicine/pediatric residents on health care transitions for YSHCN. In designing the curriculum, we first assessed the current exposure of IMRs and PEDRs to various childhood-onset

chronic illnesses and the concept of transitioning to adult care. In this article we report the results of that resident assessment.

## METHODS

In August 2007, an anonymous, Web-based survey was sent to all IMRs and PEDRs at an academic medical center. The 10-question survey assessed residents' training in 10 childhood-onset illnesses that represent a diverse array of disease processes: asthma; autism; cerebral palsy; congenital heart disease; cystic fibrosis; type 1 diabetes; Down syndrome; epilepsy; sickle cell disease; and spina bifida. Residents were asked about exposure to chronic childhood illness in inpatient versus outpatient settings and about their overall comfort in treating chronic childhood illness. In addition, residents were queried about their experiences transitioning patients with complex conditions from pediatric to adult care. Finally, residents were asked about their expected clinical roles after training.

For each survey question, participants responded on a 5-point scale (1 indicated strongly disagree/very uncomfortable, and 5 indicated strongly agree/comfortable). No incentives were provided for participation in the survey. Fisher's exact test was performed to detect group differences.

## RESULTS

The surveys ( $n = 220$ ) were distributed through the program directors' e-mail Listservs. A total of 107 residents responded to the survey, including 64 IMRs (59%), 30 PEDRs (28%), 5 residents in combined-degree programs (5%), and 8 in other specialties (7%). We included only categorical IMRs ( $n = 64$ ) and PEDRs ( $n = 30$ ) in the analysis. Residents from the combined internal medicine/pediatrics program were excluded from the final

analysis, because their training included a specific YSHCN curriculum.

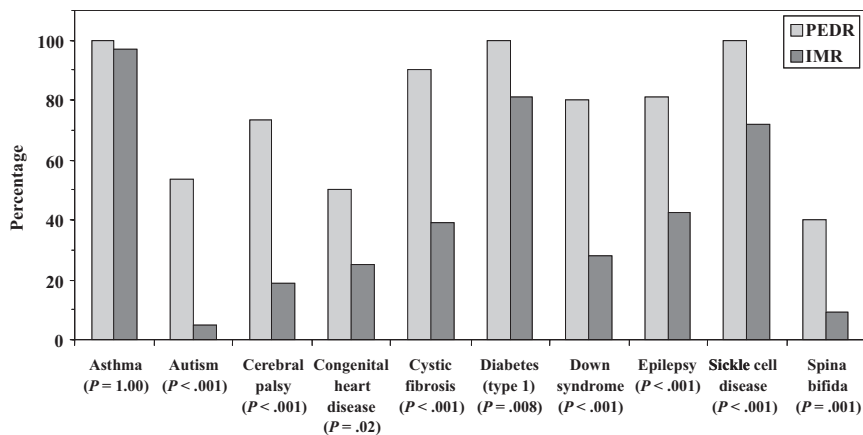
Most IMRs (73%) and PEDRs (83%) believed that the transition of YSHCN to adult-oriented care should occur at a specified age (mean age:  $18.3 \pm 1.4$  years). However, only 13.8% ( $n = 9$ ) of the IMRs, compared with 73% ( $n = 22$ ) of the PEDRs, had participated in an educational session dedicated to transition.

PEDRs were significantly more comfortable than their internal medicine colleagues in treating all childhood-onset chronic illnesses in inpatients except for asthma, for which the results showed no detectable difference between IMRs and PEDRs (Fig 1). In the outpatient setting, the results showed fewer significant differences between PEDRs and IMRs with respect to comfort in treating chronic illnesses (Fig 2).

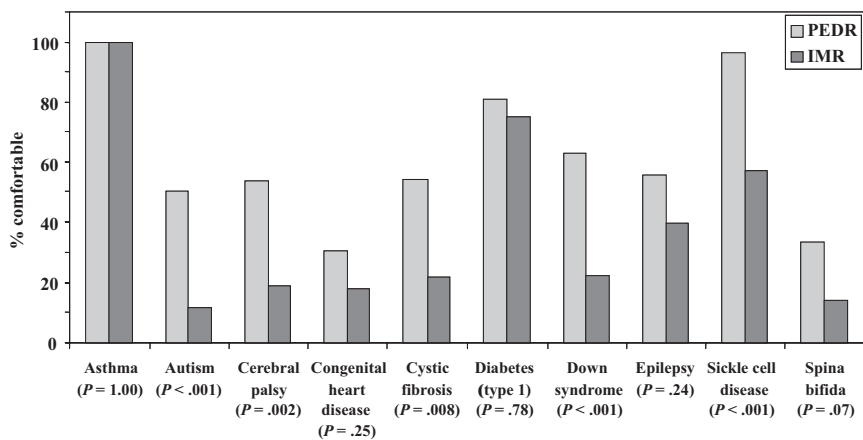
We found substantial variability between groups when we assessed their potential posttraining practice (Fig 3). The responses of IMRs and PEDRs indicated that they were equally likely to expect to care for patients with asthma, sickle cell disease, and epilepsy in their posttraining clinics. However, few IMRs thought that they would be likely to treat patients with autism, cerebral palsy, or spina bifida after completing their training.

## DISCUSSION

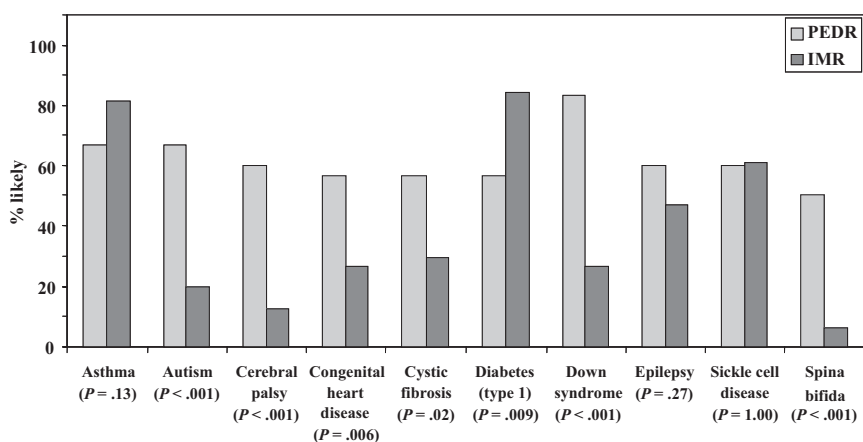
A growing number of YSHCN are transitioning into adult care. The 2002 joint consensus statement<sup>10</sup> recommended educating primary care providers about pediatric-onset chronic illnesses and effectively transitioning patients with these diseases from pediatric to adult care. Although most PEDRs and IMRs agreed that there should be an appropriate age for transition of care and that it should occur around the age of 18, most IMRs had received little or no formal training for how to transition these patients. We believe that most residents



**FIGURE 1** Proportion of PEDRs and IMRs who were comfortable with inpatient management of childhood-onset chronic disease.



**FIGURE 2** Proportion of PEDRs and IMRs who were comfortable with outpatient management of childhood-onset chronic disease.



**FIGURE 3** Proportion of PEDRs and IMRs who were likely to care for patients with specified childhood-onset chronic disease after the completion of residency.

chose the 18-year age as a transition point because it corresponds with the classic definition of the end of childhood

(ie, graduating high school), and it may also coincide with admission guidelines for adult versus pediatric facilities.

In addition, our survey of PEDRs and IMRs revealed striking inadequacies in training about various chronic childhood illnesses, which suggests that the trainees in the internal medicine program received little or no training about childhood-onset illness such as spina bifida. Discomfort with neurodevelopmental disorders such as autism spectrum disorders was particularly striking. Providers must, at a minimum, be educated in the disease process itself but should also be equipped with tools for facilitating the transition of care. They should be able to engage YSHCN in age-appropriate self-medical care.<sup>10-12</sup> The providers should also help YSHCN and their families anticipate developmental and psychosocial changes related to insurability, vocational readiness, and increasing medical management.<sup>13</sup> A lack of training in the disease process and how to transition care may significantly impede a provider's ability to guide and counsel patients on long-term anticipated morbidity inherent to the disease and its impact on psychosocial development.

As YSHCN transition into adult care, IMRs must be comfortable in both outpatient and inpatient management. IMRs, in particular, expressed a striking lack of comfort about providing care for hospitalized young adults with a variety of chronic illnesses. By increasing comfort in providing care for this patient population, providers will be more aware of potential morbidity and mortality specific to each chronic disease process. This awareness will empower providers to create long-term medical plans and provide disease-specific preventive counseling. IMRs need mentors to role-model effective care of YSHCN. Perhaps with better training and mentoring, IMRs might be more likely to accept YSHCN into their clinic practice. Likewise, as providing care to YSHCN within adult facilities becomes more accepted, the

impetus to train IMRs in childhood-onset chronic illnesses will continue to grow.

A clear need exists to mandate transition training for all IMRs and PEDRs. As exemplified by the American Academy of Pediatrics Community Pediatrics Initiative and the Adolescent Health Transition Project through the University of Washington, several models for resident-level transition training already exist.<sup>14,15</sup> These models should be used as the basis for developing a comprehensive national curriculum that training programs can implement. Committed faculty mentors are essential; residents should be instructed by providers with experience in transitioning YSHCN in all medical subspecialties and in general practice. Residency program directors should be cognizant of potential funding sources for resident advocacy projects related to transition. Also, because successful transitions are multidisciplinary, new physicians must be trained to work in health care teams to accomplish transition goals. Practitioners must be empow-

ered from early residency through continuing medical education with the knowledge and tools for coordinating these transitions.

Recognizing the dearth of residency training regarding YSHCN, we created a transition curriculum and advocacy project known as WISHES. WISHES is a model for providing comprehensive transition education to providers in a multidisciplinary manner. The 3 goals of the WISHES curriculum are to create and administer a health care curriculum pertinent to YSHCN, to train IMRs and PEDRs as care providers for YSHCN and educate health care professionals about the importance of transitions to adult care, and facilitate the transition of YSHCN from pediatric to adult medical providers. The WISHES program delivers disease-specific transition presentations through an internal medicine and pediatrics conference series, a medical school advocacy seminar as part of the core IMR and PEDR curriculum, and a training program for ancillary health care professionals. In addition, residents work directly with patients in inpatient and

outpatient settings. Future directions for WISHES include expanding and sustaining existing projects, evaluating the effectiveness of current initiatives, and working with national groups to improve transition services by improving provider education.

## CONCLUSIONS

In light of the striking deficiencies uncovered in our trainee survey, we believe that it is important to mandate transition and chronic illness training for both PEDRs and IMRs. By educating health care providers about the importance of a continuous and effective transition from pediatric to adult care, we can help decrease the morbidities experienced by this vulnerable and largely underserved population.

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