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Beyond the Stethoscope: Learning to Harness Our Collective Power to Advocate for Patients

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"You should see a doctor about why your child is so skinny," said a staff member to a young mother as the mother was leaving the immigration detention center in which she and her children had been held. A day after their arrival, her 2-year-old son, M.G., had developed a fever and a wet cough. With no medical attention, his symptoms progressed, and by the time the family was released from the center, M.G. had been vomiting and refusing to eat for almost 3 weeks. When he finally presented to our clinic, he was cachectic, severely dehydrated, and in respiratory distress from what was ultimately found to be an untreated bacterial pneumonia.

As trainees in our final year of pediatrics residency, we were well prepared to treat M.G.'s pneumonia and dehydration. We knew, however, that outside the hospital walls, he faced much bigger threats to his long-term health and well-being. This felt out of our reach as individual physicians. We discharged M.G. into a world in which his mother had to wear a tracking bracelet on her ankle and was required to present for deportation hearings, a world in which immigrant parents turn down much-needed health and nutrition benefits for their children out of fear that they will be deported or penalized in the immigration process,[1] a world in which leaders openly promote policies that detain children and tear families apart.

One in 4 children in the United States is a part of an immigrant family, and immigrant children represent the fastest-growing segment of the US population.[1] Many like M.G. arrive at the US border having experienced significant trauma, including abuse, exploitation, and threats to their lives. Recent policies that separate parents and children at the border intensify this trauma.[2] Adverse childhood experiences of this magnitude can have a detrimental effect on health into adulthood.[3]

Even among children who haven't crossed the border themselves, immigration policies have wide-ranging health impacts.[4] An estimated 5.5 million children (most of whom are US-born citizens) have unauthorized immigrant parents.[5] These children live in constant fear of losing family members to deportation or imprisonment. Children from mixed immigration status families report worse physical health compared with US citizens or legal permanent residents of the same ethnicity and socioeconomic status.[6]

Although we were able to cure M.G.'s respiratory illness, caring for him underscored how ill-equipped we were to address the complex social challenges facing his family. Initially overwhelmed at the enormity of these problems, the 4 of us came together to debrief about our shared experience. We realized that even though we claimed no expertise in immigration or health policy, we were experts in the health of our patients and uniquely entrusted with their stories. As respected voices in society, we are empowered to advocate on issues that affect the health of our communities and beyond.[7] The injustice we bear witness to compels us to leverage that expertise.

Physician advocacy is, of course, not new. Examples of advocacy within pediatrics date back to the field's inception in the mid 1800s. "It is not enough . . . to work at the individual bedside at the hospital," proclaimed Abraham Jacobi, MD, considered the founder of the field, "the pediatrician is to sit in and control school boards, health departments, and legislatures."[8] Embracing this paradigm, early pediatricians advocated for milk pasteurization when contamination contributed to the death of 1 in 5 children under the age of 5.[8] In the early 1900s, a group of pioneering New York women led by Sara Josephine Baker, MD, developed widely replicated midwife training programs, hygiene campaigns, and school-based health programs.[9] These historical examples of physician advocacy, included in our residency advocacy curriculum,[7] inspired our next steps.

Newly energized as advocates, we set out to share with lawmakers the human consequences of policies

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TABLE
Creating a Trainee-Led Advocacy Coalition and Institutional Culture

Goals	Actions
1. Formalize advocacy leadership within your institution	▪ Form an advocacy leadership council comprising trainees of all levels,[10] representatives from your institution's government relations and public relations offices, and faculty leadership with expertise in community medicine and policy. ▪ Schedule standing, virtual or in-person meetings to educate one another on the latest issues and to plan and delegate advocacy actions.
2. Foster an institutional culture of advocacy	▪ Dedicate trainee didactic sessions to current issues (eg, Medicaid policy, food insecurity) and advocacy skills training (eg, forming community partnerships, contacting legislators, op-ed writing, and social media advocacy). ▪ Incorporate hands-on projects into required advocacy experiences.[7,11] ▪ Promote your institution's advocacy training opportunities and initiatives during intern recruitment to attract diverse and public health–oriented trainees.[12] ▪ Invite grand rounds speakers who can educate about current policy issues and advocacy opportunities. ▪ Allocate time and funding[13] to send representatives on state or federal legislative visits, travel to professional conferences for advocacy training or presentations, and provide meals and supplies for educational sessions.
3. Expand your advocacy network beyond your institution[10,13]	▪ Join professional organization subgroups for advocacy or specific issues (eg, health care for the underserved, immigration). Send a delegate from your advocacy council to professional organization local chapter meetings. ▪ Establish relationships with local community organizations. ▪ Coordinate with advocacy contacts at other institutions within your region to share resources and to plan joint community interventions, advocacy campaigns, legislative visits, rallies, and educational conferences.
4. Rally your advocacy network to take action on specific issues[7,13]	▪ *Community advocacy:* partner with local organizations to establish shared short-term goals and to implement and evaluate interventions.[14] ▪ *Legislative advocacy:* call, write, and meet with legislators representing your region. Attend town halls and rallies, coordinate social media campaigns, and publish editorials. Register to receive state or federal bill updates to engage legislators, colleagues, and the public on specific legislation.

for which the full effects had not been considered. Most of us had no prior legislative advocacy experience, so we sought out mentors among our faculty. These mentors emphasized that advocacy is a learnable and essential skill for every physician, coaching us at every step.[9] With their support, we held events to recruit clinicians who were similarly frustrated by their patients' barriers to care. One year after what began as a clinical debrief among friends, we have built a coalition of more than 150 faculty, trainees, and staff who are committed to advocate for our patients.

We called our coalition an advocacy "rapid response team"—a reminder to remain nimble in a climate of ever-changing policies that affect health. With the infrastructure that we built, we can swiftly mobilize as changes arise at the state and national levels. For example, we distributed talking points and stamped postcards directly outside of immigration-related grand rounds, facilitating physician engagement in legislative advocacy. We led social media boot camps to enroll members in Twitter and to teach effective social media use. We organized groups of residents and faculty in white coats to attend legislator town halls and march for gun violence prevention. Our journey extended to the US Capitol, where we met with lawmakers in support of the Children's Health Insurance Program. To illustrate the human consequences of current and proposed policies, we created a bank of deidentified patient stories that can be drawn on at legislative visits. Throughout, we have collaborated with the larger network of physician advocates within our field's professional organization.

Our coalition has also aimed to directly empower children and families to advocate for themselves. For example, in the face of growing fears of deportation raids among immigrant clinic patients, we distributed "know your rights" wallet cards. We collaborated with parents of children with complex health care needs to advocate against proposed Medicaid cuts. We marched alongside families when they took the lead as advocates for issues affecting their health.

Now, at the end of our residency training, we leave behind a new generation of residents who will continue to build on our coalition's work. We hope

that trainees and educators at other institutions can learn from the experiences at our institutions and others to take steps toward building their own advocacy coalitions and culture (see the TABLE).[7,10–14] In this way, programs can position themselves to support residents who, like us, are moved by their patients' stories to engage in advocacy. As for ourselves, we realize that—as one of our mentors puts it—we have "caught the advocacy bug." We know we will integrate advocacy into our clinical and scholarly work as we transition into new academic or community settings. We will carry forward lessons learned from our mentors and from our experiences evolving into physician-advocates. We will remember that no action in the name of our patients is too big or too small; advocacy can be as big as organizing a statewide rally, or as close to home as making the clinic a safe place to discuss tough realities. It can be as involved as writing to a national newspaper or as quick as sending a tweet. Most important, we have learned that our voices grow exponentially when we collaborate with our colleagues to build a culture of advocacy. As we enter the next stage of our careers, we will continue learning and practicing advocacy for patients like M.G. as a foundational part of the role of the physician.

References

1. Council on Community Pediatrics. Providing care for immigrant, migrant, and border children. *Pediatrics*. 2013;131(6):e2028–e2034. doi:10.1542/peds.2013-1099.
2. Mendoza FS, Cueto V, Lawrence D, Sanders L, Weintraub D. Immigration policy: valuing children. *Acad Pediatr*. 2018;18(7):723–725. doi:10.1016/j.acap.2018.06.010.
3. Szilagyi M, Halfon N. Pediatric adverse childhood experiences: implications for life course health trajectories. *Acad Pediatr*. 2015;15(5):467–468. doi:10.1016/j.acap.2015.07.004.
4. Raymond-Flesch M. The negative health consequences of anti-immigration policies. *J Adolesc Health*. 2018;62(5):505–506. doi:10.1016/j.jadohealth.2018.03.001.
5. Chaudry A. Children in the aftermath of immigration enforcement. *J Hist Child Youth*. 2011;4(1):137–154. doi:10.1353/hcy.2011.0010.
6. Vargas ED, Ybarra VD. US citizen children of undocumented parents: the link between state immigration policy and the health of Latino children. *J Immigr Minor Health*. 2017;19(4):913–920. doi:10.1007/s10903-016-0463-6.
7. Chamberlain LJ, Kelly N. Child advocacy in the twenty-first century. *Adv Pediatr*. 2015;62(1):91–103. doi:10.1016/j.yapd.2015.04.010.
8. Burke EC. Abraham Jacobi, MD: the man and his legacy. *Pediatrics*. 1998;101(2):309–312. doi:10.1542/peds.101.2.309.
9. Changing the Face of Medicine. Dr. S. Josephine Baker. https://cfmedicine.nlm.nih.gov/physicians/biography_19.html. Accessed February 4, 2019.
10. Dharamsi S, Ho A, Spadafora SM, Woollard R. The physician as health advocate: translating the quest for social responsibility into medical education and practice. *Acad Med*. 2011;86(9):1108–1113. doi:10.1097/ACM.0b013e318226b43b.
11. Coria A, McKelvey TG, Charlton P, Woodworth M, Lahey T. The design of a medical school social justice curriculum. *Acad Med*. 2013;88(10):1442–1449. doi:10.1097/ACM.0b013e3182a325be.
12. Strelnick AH, Swiderski D, Fornari A, Gorski V, Korin E, Ozuah P, et al. The residency program in social medicine of Montefiore Medical Center: 37 years of mission-driven, interdisciplinary training in primary care, population health, and social medicine. *Acad Med*. 2008;83(4):378–389. doi:10.1097/ACM.0b013e31816684a4.
13. Earnest MA, Wong SL, Federico SG. Perspective: physician advocacy: what is it and how do we do it? *Acad Med*. 2010;85(1):63–67. doi:10.1097/ACM.0b013e3181c40d40.
14. Sanders LM, Robinson TN, Forster LQ, Plax K, Brosco JP, Brito A. Evidence-based community pediatrics: building a bridge from bedside to neighborhood. *Pediatrics*. 2005;115(suppl 3):1142–1147. doi:10.1542/peds.2004-2825H.

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