

Creating Healthy Opportunities: Conversations with Adolescent Health Experts



An Interview with Abigail English, JD, Conducted by Karen Brown

A PROJECT OF THE PARTNERS IN PROGRAM PLANNING FOR ADOLESCENT HEALTH (PIPPAH) INITIATIVE

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Karen Brown is a public radio reporter and freelance writer who specializes in health care. Her work frequently appears on NPR and in national magazines and newspapers. She has also produced several radio documentaries on mental health topics, including childhood bipolar disorder, siblings of the mentally ill, and post-traumatic stress disorder. She has won numerous national awards, including the Edward R. Murrow Award and Daniel Schorr Journalism Prize, as well as journalism fellowships, most recently the 2008-09 Kaiser Media Fellowship in Health. Her work is featured online at www.karenbrownreports.org.

ABIGAIL ENGLISH, JD

Abigail English is Director of the Center for Adolescent Health & the Law in Chapel Hill, North Carolina. The Center is a nonprofit legal and policy organization that works nationally to promote the health of adolescents and young adults and their access to comprehensive health services. Ms. English has worked on legal and policy issues affecting adolescents' access to health care for more than three decades. She has advocated for the legal rights of adolescents in the health care system, participated in major litigation affecting the legal rights of children and youth, authored numerous publications, taught courses in adolescent

health and the law, and lectured widely to youth-serving professionals. She has served on many boards and advisory groups and as President of the Society for Adolescent Medicine. Her research and policy interests focus on the barriers that affect adolescents' access to comprehensive health care and on strategies for overcoming those barriers. Her expertise includes key issues related to financial access to health care for adolescents and young adults, consent and confidentiality protections, HIV/AIDS services, sexual and reproductive health care, and the rights of vulnerable populations of young people.

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PROFILE:

Abigail English, JD

DIRECTOR OF THE CENTER FOR ADOLESCENT HEALTH & THE LAW



“Adolescents are neither like little children or like full adults... they are capable of acting at times in adult ways, but they also have very real vulnerabilities that are particular to their developmental stage, and their age.”

Long before she became a renowned legal advocate for adolescents, Abigail English had a deep empathy for children in peril. It started with the children of classic literature – think Charles Dickens’ David Copperfield – and expanded as she took jobs as camp counselors and tutors for poor, orphaned, or otherwise disadvantaged children.

“It somehow spoke to something in my heart and in my head, and appealed to my sense of justice, and my desire to be helpful,” says English, who now directs the Center for Adolescent Health & the Law in Chapel Hill, North Carolina.

And like the Dickens novel that first inspired her, English’s life path would go through a few plot twists before she settled down as a legal champion for vulnerable youth. She came of age during the 1960s, graduating from college at the height of the social justice movement and joining a non-profit that helped street youth. While writing a book on runaways, she met numerous social workers, judges, and probation officers who came into contact with her young subjects, as well as the runaway teens themselves and their parents. “That exposure to the way in which adolescents encountered the legal system when they ran away from home, made me very aware of the fact that there were serious deficiencies in how young people were treated by the law,” English says.

That experience catapulted her into law school, at a time when the U.S. legal system was just beginning to recognize the legal rights of children and adolescents – in the words of a 1967 Supreme Court case: “Neither the Fourteenth Amendment nor the Due Process Clause

is for adults alone.” While other lawyers focused on the needs of the very young, English was pulled to the older set.

“I think it had something to do with the fact that adolescents are neither like little children or like full adults,” English says. “They are capable of acting at times in adult ways, but they also have very real vulnerabilities that are particular to their developmental stage, and their age. So I think I found it both intellectually fascinating and emotionally compelling to think about how to make life better for these young people at that stage of their development.”

English says adolescents have a harder time attracting advocates, so she went where she was most needed. “They’re perceived as basically healthy and therefore not needing much, and as not very appealing because they act out, because they get involved in behaviors that we wish they didn’t get involved in – like sex, and drugs, and rock and roll,” she says.

English’s training was in law, not health, but she soon put the two together after meeting several young doctors who were leaders in the then-nascent field of adolescent health. They came to her for legal advice on issues facing their patients– issues around consent, confidentiality, and financial access, all of which were preventing adolescents from getting the care they needed. At that point a partnership was born.

“I very quickly realized that when teenagers can’t get health care, they don’t talk to lawyers. They don’t go to the legal aid office,” she says. “When they need health care, they either go to a clinic, or go to a doctor’s office, or

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Throughout English’s career – including 20 years at the National Center for Youth Law in San Francisco, 10 years at the Center for Adolescent Health & the Law, and a one-year term as president of the Society for Adolescent Medicine – she’s focused on distinct legal barriers that prevent adolescents from getting the health care they need.

One of her key areas is “consent and confidentiality.” In the 1960s and 70s, the first state and federal laws were passed to give adolescents some rights to confidential health care – without parental permission. English began her career in California, litigating for the rights of minors—all the way to the California Supreme Court—to receive confidential reproductive health care.

“I think that intuitively a lot of people say, ‘Well, I have to give permission for my daughter to get her ears pierced. Why shouldn’t I have to give permission for her to get health care services?’” says English. “Why shouldn’t I be able to know about all of the information concerning whatever health care services she gets?”

English’s response is that not giving teens some privacy around their health care has been shown, through research studies, to affect the ways in which they seek health care – sometimes delaying or avoiding it altogether. In some cases, teenagers fear punishment from their parents, or just don’t want to worry them, so they may not admit to risky health behaviors. Lack of privacy also influences how candidly teens interact with health care providers and disclose essential information to them about problems like substance use, mental health concerns, and sexual activity.

The consequences, she says, can be damaging to individual and public health. “If adolescents are discouraged from seeking health care that would allow them to be screened, diagnosed, and treated for sexually transmitted disease, that can have very serious consequences for their own health,” English says. “Untreated Chlamydia, a sexually transmitted disease that is very common in adolescents, can lead to infertility.” And if adolescents are unaware of their diagnosis, she adds, they could end up spreading the disease and contributing to a public health problem. Similarly, adolescents with untreated substance abuse problems may drink and drive, endangering themselves and others.

She does stress that the research shows most adolescents choose to involve parents in their health care decisions. But there are exceptions. “Adolescents at certain points in their development have a need for a greater sense of...autonomy and privacy. That’s a normal part of adolescent development.”

English also believes that most parents ultimately want their adolescents to be able to receive the health care they need. “Many parents support the possibility of confidential care for adolescents, in order to protect their health,” she says. “Also, many health care professionals are helpful in assisting adolescents to talk with their parents, even when it’s hard to do so.”

A related legal issue that evolved from English’s work on confidentiality is financial access to health care; if teenagers have no way to pay for their own health consultation, they’re unlikely to get it in private. Here, English has seen some creative approaches. For instance, sometimes health facilities agree to “write off” the bill for teens’ confidential care. In other cases, parents themselves have agreed to foot the bills of medical visits for their children, without insisting on knowing the details of what transpired on those visits.

But financial access to health care is a struggle that stretches beyond the issue



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of confidentiality. English has worked for years to expand Medicaid programs to include more low-income teenagers. In the 1990s, she helped push through the State Children’s Health Insurance Program (formerly S-CHIP, now CHIP), which provides health insurance to children and adolescents who do not meet the income requirements to qualify for standard Medicaid. CHIP was recently renewed in early 2009 and expanded to cover an additional 4.1 million children and adolescents.

Now, English is focusing on extending the age of eligibility for those programs – so that adolescents will no longer “fall off a cliff” at age 19, when they generally lose Medicaid or CHIP eligibility. She also wants to make sure public programs cover a comprehensive set of benefits that are particularly important for adolescents – including reproductive health, mental health, substance abuse, and dental care. She believes safety net programs should be easily accessible by the most vulnerable adolescents – for example, homeless youth who “may find it difficult or even impossible to enroll in a health insurance plan...simply because of the way the requirements are structured for who can sign an application, whether they have to have a fixed address, and what kind of documentation they need to provide for their income.” She also advocates for adolescents growing up in the foster care system, and those who have aged out of the foster care system with little or no family support. In the latter case, she wants all states to sign onto the option in the Foster Care Independence Act of 1999, which allows states to extend Medicaid coverage to former foster youth.

For the general adolescent population, English would like to see more attention directed toward preventive care – including vaccinations for teenag-



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ers. In recent years, more vaccinations have been developed and recommended for this age group – for instance, those that protect against HPV and cervical cancer, meningitis, Hepatitis B, and influenza. The challenge is letting families know these vaccinations exist and making them part of the annual health care routine.

English would also like the nation’s vision of preventive health care to include an annual physical for adolescents. “If they don’t get in and have a comprehensive health assessment, then there may be no recognition that they need some preventive mental health services,” says English. “There may be no recognition that they’re sexually active and need sexual and reproductive health services. There may be no acknowledgement until very far down the line that they are using substances and need some treatment services or counseling in that arena.”

The challenge does not stop at comprehensive benefits. Eligible adoles-

cents still need to find out about those programs and enroll in them. When CHIP was reauthorized in early 2009, more funds were included for outreach and enrollment. Finding ways to target the use of those funds to adolescents, especially the most vulnerable ones, is an important challenge. “I think there’s been much less attention to outreach to the adolescent age group so far than there needs to be in the future,” she says. “And I think social workers have a role to play, youth-serving programs where adolescents congregate have a role to play, schools have a role to play in disseminating information about the options and the services and the potential coverage that’s available.”

In this vein, she believes that different professional groups could work together better to combine their resources and reach their overlapping constituents – groups such as social workers, doctors, schools, families, and, of course, lawyers. “Whether by representing individual

adolescents (to get services they need), or advocating with state legislatures and the Congress to change laws in beneficial ways. Or whether it be health care professionals and social workers educating lawyers about what kinds of services adolescents really need and what can be provided to them that will promote their health. I think all those kinds of collaborative efforts could be very beneficial.”

But aside from the specifics of health care financing and legal rights for adolescents, what English would most like to see is a sea change in public attitudes towards health care – for adolescents and everyone else. “It’s really quite shocking that in the United States of America, in 2009, health care is not considered a guaranteed right,” says English. “I think we need to shift our perspective and recognize as a nation that health care is a human right, and a legal right, and I think we need to make sure that right is extended to adolescents, as well as other age groups in the population.” ■