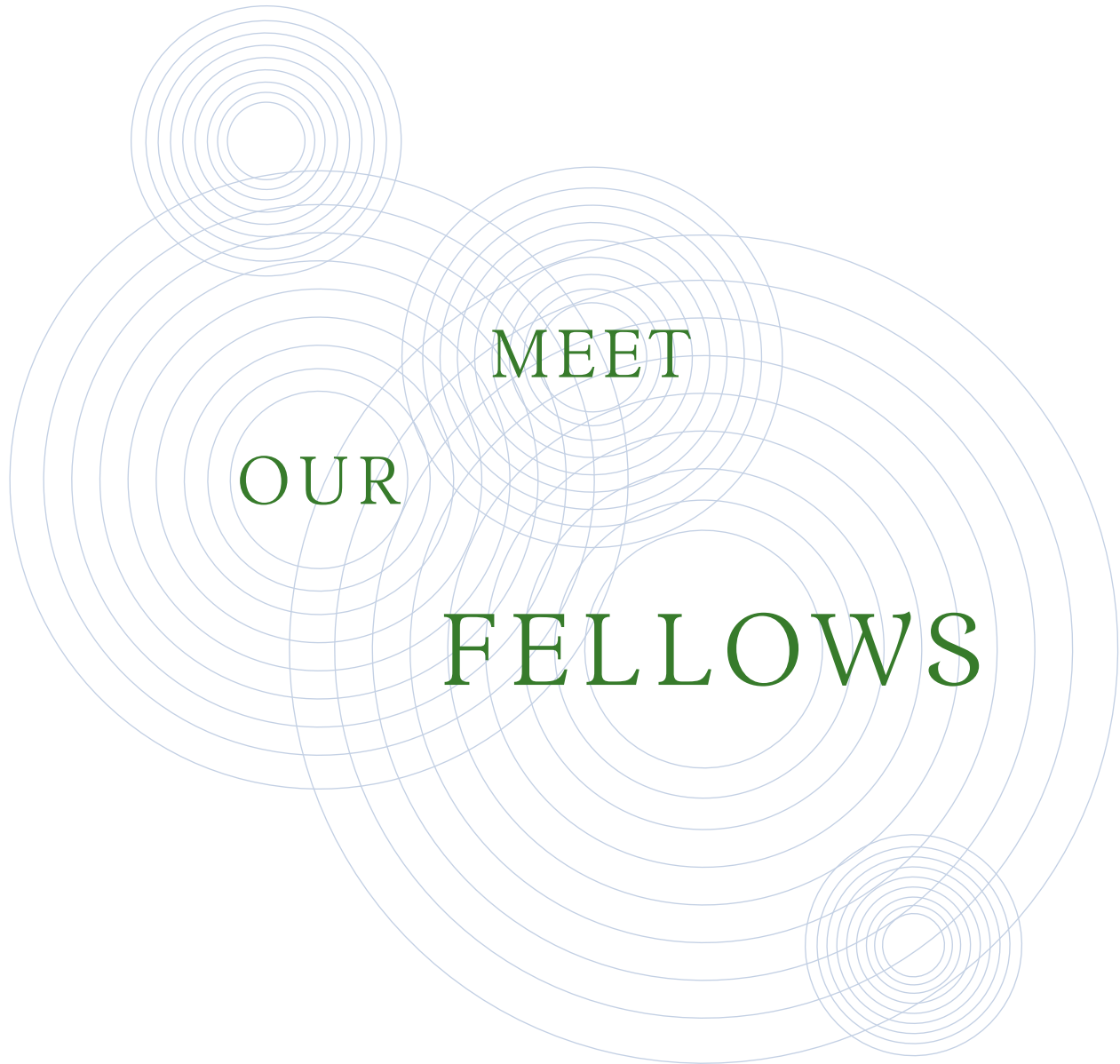




THE STONELEIGH FELLOWS PROGRAM



OUR

MEET

FELLOWS

DR. DAVID RUBIN

ACKNOWLEDGEMENTS

We acknowledge and thank Bernardine H. Watson, the author of this article, who tells an inspiring story about Dr. David Rubin. Ms. Watson interviewed Dr. Rubin and wrote this profile based on their conversations. This is the first in our series of “Meet the Fellows” profiles. The series is intended to provide readers with stories that describe our fellows’ motivation, goals and the philosophies that drive their work.

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DR. DAVID RUBIN


PEDIATRICIAN

Director of Research and Policy,

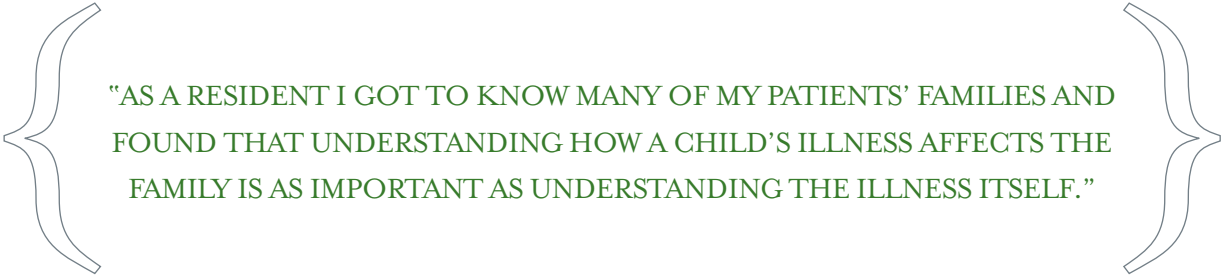
Safe Place: Center for Child Protection and Health

The Children's Hospital of Philadelphia

*Fellowship Project: The Children's Stability and Well-being
Longitudinal Study (CSAW)*



When you walk into pediatrician Dr. David Rubin's office at Children's Hospital of Philadelphia (CHOP), the first thing you notice are his oldest daughter Madeleine's big beautiful eyes. They follow you everywhere, looking out from the pictures of her that adorn the office. Some of the pictures are of the whole Rubin family—daughters Madeleine, Susannah and Phoebe, Rubin and his wife, Tigerlilly. Looking around the office you know that Dr. David Rubin is definitely a family man. On one July morning when I visited his office, between taking calls from Joe Kuna, deputy commissioner of Philadelphia's Department of Human Services (DHS), and answering questions from colleagues who popped in seeking his counsel, Rubin was on the phone with Philadelphia Electric Company (PECO), pressing them to get out to his family's home outside Philadelphia which had been without power since the night before. Family is clearly very important to Dr. Rubin. In fact, Rubin credits his mother, Eleanore, for his early interest in children. Rubin grew up in Wayne, New Jersey, a suburb about 20 miles outside of New York City. During his school breaks he would accompany his mother to her job as a first grade teacher in the New York's Hell's Kitchen neighborhood. "I would sit in my mom's classrooms and see kids who had a lot rougher life than I did," he recalls. "I never forgot my experiences or those kids."



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Rubin says he never considered any other profession besides medicine. “I always knew I didn’t want to sit behind a desk. Business or law never appealed to me.” Once in medical school, pediatrics was a natural progression. Rubin says the innocence of children touches him. “There’s something pure about a sick child. It motivates me.” Early on, Rubin realized he wasn’t just interested in children’s health—he was interested in their lives. “As a resident I got to know many of my patients’ families and found that understanding how a child’s illness affects the family is as important as understanding the illness itself.” In 1999 Rubin accepted a child maltreatment fellowship at CHOP and set his direction as a clinician, researcher and educator. Since that time his practice has focused on vulnerable populations, such as children in the child welfare system, his research on health policy and his role as educator helping produce pediatricians who are not afraid to think outside of the box.

Rubin’s approach to his work reflects clear, well-defined, personal values. For example, as a clinician he believes in learning from his patients. “I’ve had some very intense experiences with all types of families in my practice,” he says. “They ask questions and this helps inform my work.” Since his early training was in child maltreatment, Rubin participates on the child abuse team at CHOP and testifies in child-abuse cases. He also does general pediatrics. “I think seeing all kinds of kids helps keep me balanced,” he says.

Approximately 30 to 40 percent of Rubin’s patients are Medicaid recipients. He also sees a large number of children with serious medical problems and congenital syndromes that can be life-threatening and require complex medical treatment. Some of the families and children he sees have serious mental health issues; some are under significant stress and can appear hostile. But Rubin believes they sometimes just need someone who will listen. “I often get the families other doctors don’t want to deal with because they are always yelling at people. Once these families realize that someone in the system cares, most of them stop yelling,” he says.

Rubin can talk at length and with admiration about the families he’s gotten to know well over the years. He tells of a call he got at 2 a.m. from the family of child who was in respiratory failure and had to be admitted to CHOP. This was the first of many life-threatening admissions for the child. “I don’t always respond to calls at 2 a.m. because there is a great staff at CHOP to care for children in need,” Rubin says. “But the intensive care doctor didn’t know this family and this was their first crisis after the child’s diagnosis. Since I had been treating the child for a few months, I felt like the family needed to see my face that night. I was able to reduce some of their anxieties by helping them to understand what was happening to their child and by joking around—injecting occasional humor to help settle things down. This startled the nurses, because the child was in critical condition and the situation was so grave, but I had built up a deep relationship with the family and I believe my presence really helped. The child survived that hospitalization and many similar ones since, but that first admission and my being there was the cement that bonded that relationship.”

Rubin is clear about the limits of his role in working with families. He says the families he sees in his practice don’t always make the decisions he would make. Still he tries not to judge them. “It’s not my job to push my views on families, but to be there to help them make the decisions that are right for them. These families are extremely devoted to their children, often in the face of tremendous odds.”

What Rubin *does* see as part of his job is helping to get the best outcomes for the children and families he sees. He takes particular care in cases where child abuse is suspected. “Over the years,” he says, “I’ve come to depend on my clinical judgment about whether or not to call Child Protective Services (CPS) when an injured child is brought into the hospital.” That judgment is not just based on clinical experience. Rubin has conducted research that shows a level of bias in the amount of surveillance and reporting to CPS that black and poor families encounter when they bring their injured children into the hospital. “It’s often assumed that poor, African-American families

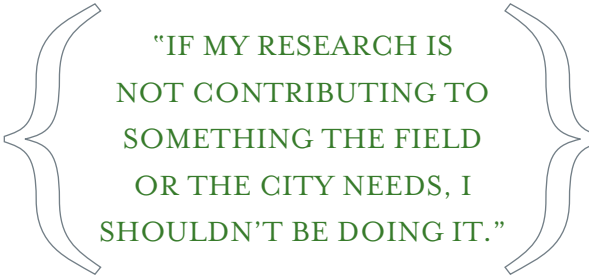


are harming their kids,” he says. “Surveillance may be good in that you catch people who are hurting children, but I’ve learned over the years there is a cost to a false positive, a cost in terms of stress to families, a cost to a system that doesn’t have the capacity to handle all these cases and a cost to the kids. Once you’ve reported a family to CPS and that ball starts rolling, suddenly the system is involved with its own issues of racial bias and you’ve removed a kid from a home who never should have been removed.”

Rubin says doctors need to be clear about what rises to the level of suspicion. For him, it’s all about how wide you cast the net. “If you cast the net wide enough to catch any kid you’re concerned about, you will likely pick up kids who are not being abused. I don’t cast my net as widely as some do, and I know at some point I’ll probably miss someone. But I’d rather try to prevent a kid from going into the system. If I’m at the bedside, I’ll get involved in encouraging a dialogue between the CPS worker and the family. If the child has to be removed from the parents due to safety concerns, I’ll ask the worker if they have spoken with the grandparents or if other kinship alternatives have been explored. I see my job as trying to keep children out of the system that truly don’t belong there.” Alternatively, he adds, “This unequal surveillance can also work to the detriment of white kids who may slip through the cracks with unidentified abuse. It is equally my responsibility to identify those children as it is to prevent a mistaken diagnosis of an African-American or Latino child.”

Rubin has also developed a specific approach to working with young pediatricians. As assistant professor of pediatrics at the University of Pennsylvania School of Medicine, Rubin challenges young doctors to go beyond the basic checkups they were taught to do in medical school and try to get to know and understand the children and their families. He tells them, “If all you’re doing is checking boxes about growth, immunizations, lead exposure etc., you’re not really helping your patients.” Rubin believes that a failure in the medical profession is that doctors often don’t think in terms of developing a long-term relationship with patients. He tells young doctors they don’t have to cover everything with a patient in a single visit. “If you’re developing a strong relationship with the kid and their family, you’ll see them again. Take some time and get to know the family. Give them a level of e-mail access to you. Try to listen more than you talk and remember to ask yourself if the family is getting what it needs out of the relationship with you.” He encourages medical students to remember who they are outside of school, to think back to what they wrote about themselves in their biographical statements when they applied to medical school and bring their personalities and interests to their work with children and families.

As a researcher, Rubin’s goal has always been to have “a seat at the table” where his work can have an impact on programs and policy. He calls it “being part of something bigger.” “I don’t believe in research that is done in the ivory tower and then just gets published in a journal.



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Research can die in journals,” he says. “If my research is not contributing to something the field or the city needs, I shouldn’t be doing it.” Rubin’s master’s thesis, *Occult Head Injury in High-Risk Abused Children (Pediatrics, 2002)*, was his first foray into what he calls “strategic research.” Using a sample of abused children admitted to CHOP, Rubin determined that one out of three of these children also had a head injury, even though they had normal neurological examinations. Today, because of Rubin’s work, children with evidence of physical maltreatment are routinely screened for head injury using CT scans or MRI’s.

Rubin’s subsequent research has moved toward attempts to understand the relationship between a child’s experience in the child welfare system and their health outcomes. “I wanted to reach a much wider audience of child welfare practitioners and policymakers and have a real opportunity to influence the system on behalf of the children and families I was seeing in my practice,” he says. Some of his most influential work involved exploring linkages between health care use and stability for children in Philadelphia’s child welfare system. “Based on the relationships with policymakers I had begun to develop in the city,” Rubin says, “I was able to get access to child welfare and Medicaid data. One critical question I was attempting to answer in this work was: “How is stability related to the magnitude of mental health care costs for children?” Among Rubin’s findings was a significant increase in mental health costs during the first year in foster care, particularly among children with increasing general health care costs, and among children who attempted to reunify with parents but were returned to the system in short order.

Another study using the same data looked at the magnitude of emergency room use by children in foster care. When Rubin talks about this work you can see in his face and hear in his voice the effect it still has on him. “The ER visits research took me back to why I went into child welfare work in the first place,” he says. “It’s 11 p.m. and

a foster family drops a kid off in the ER because the kid is out of control; they can’t deal with him anymore. The kid is sitting in the ER alone, waiting for a psych consult—sometimes for 12 to 24 hours. I saw this as the ultimate failure of the system. It was demoralizing for all of us that worked in the ER. I wanted to look at access to care for these children and how access relates to their stability in the system.”

Rubin’s research showed that 75 percent of ER visits for foster care children were occurring within three weeks of the time the child was moved to a new placement within the system. “This finding validated the experiences of every pediatrician around the country that works in the ER,” he says. “Children were frequenting the ER after placement changes because often the new foster parents didn’t know what meds the kid was on or the kid had tremendous adjustment-related issues and was acting out.”

The findings from these studies increased Rubin’s interest in policy and advocacy work on behalf of children in foster care, particularly regarding the issue of placement stability and the role of access to care. In 2005, Rubin was invited by Casey Family Programs to participate with other leading health policy experts from around the country in an analysis of the impact of pending Medicaid cuts on children in foster care. The resulting reports, which were widely circulated in policy and child welfare circles, cautioned that some proposed cuts would have serious consequences for children in foster care. Rubin and his co-authors urged Congress to protect foster families from having to pay premiums or co-pays for the children in their care; provide adequate funding for case management, rehabilitative and preventive services; preserve Medicaid’s “Early Periodic Screening, Detection and Treatment program”; guarantee continued Medicaid coverage until age 21 for adolescents leaving the system; encourage the development of integrated systems of care for children and families; and raise the quality of care received by children in the foster care system. Several of these recommendations were included in the final “2006 Medicaid Reform” legislation.

Clearly the issues of placement stability and access to care for children in foster care are subjects close to Rubin’s heart. If you want to hear him on his “soap box,” just bring up a related subject—health insurance. “It’s really

embarrassing that our country doesn't have national health insurance," he says. None of the health reform proposals currently being discussed go far enough as far as he's concerned. "Health care is something that needs to be financed through the federal government and financing is only part of it. Access to care is also critical. Patients should be able to walk into the doctor's office, present one card, a medical passport, and say—I am an American citizen and I need health care today. That would take care of a lot of the problems for kinship and foster parents who have difficulty accessing care for children or for teens who are left without insurance but have great needs after they have left the system. Currently there is way too much paperwork for families to navigate just to receive basic services. I'd like to see us get rid of all the billing requirements, all the administrators. We should have something like the Federal Reserve, but for health care—with doctors making decisions about what's best for patients rather than the administrators of HMO's that have to be concerned with the bottom line. This would be the most cost-effective approach because we wouldn't have to pay for the administrators of the various plans who make the system inefficient and who now outnumber the health care professionals who actually provide real services to patients and families."

In 2004 Rubin received a career development award from the National Institute of Child Health and Development (NICHD) to pursue his interest in placement stability for children in foster care. This award led to two studies, which used data from the *National Survey of Child and Adolescent Well-being* (NSCAW) to measure the impact of placement stability and kinship care on foster children's behavioral outcomes. In the first study, *The Impact of Placement Stability on Behavioral Well-being for Children in Foster Care* (*Pediatrics*, February 2007), Rubin was able to disentangle the relationship between a child's baseline health issues and his or her placement experience and outcomes. The study showed that children in foster care have placement instability



issues unrelated to their baseline health problems, and this instability alone has a significant impact on their behavioral well-being. The second study, *Impact of Kinship Care on Behavioral Well-being for Children in Out-of-Home Care* (*Archives of Pediatric Adolescent Medicine*, June 2008), determined that children placed into kinship care had fewer behavioral problems three years after placement than children who were placed in foster care.

These studies gave Rubin the opportunity to play another role he relishes: public advocate for foster care children and their families. On June 2, 2008, he presented findings from this study at a Congressional briefing held by the Child Welfare League of America, the American Academy of Pediatrics (AAP), the Children's Defense Fund, the Center for Law and Social Policy and Generations United. To bring the study's findings to life, Rubin took along grandparent caregiver Vern Mack who recently obtained custody of her grandson, and family therapist Joe Crumbley with whom he has often worked. "Vern lost her son to gang violence in Philly and is raising his son now." Rubin says. "You should see the transformation in this kid since he's been with grandmom. Having Vern there added credibility to the briefing. Congressional staffers were asking her how to structure the regs for kinship caregivers. It was democracy

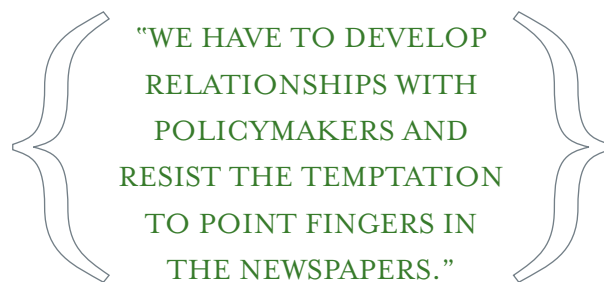
"HEALTH CARE IS SOMETHING THAT NEEDS TO BE FINANCED THROUGH THE FEDERAL GOVERNMENT AND FINANCING IS ONLY PART OF IT. ACCESS TO CARE IS ALSO CRITICAL. PATIENTS SHOULD BE ABLE TO WALK INTO THE DOCTOR'S OFFICE, PRESENT ONE CARD, A MEDICAL PASSPORT, AND SAY—I AM AN AMERICAN CITIZEN AND I NEED HEALTH CARE TODAY."

in action. And Joe was great too—telling personal stories about his work with kinship families and how important they’ve become in the growing attempts to provide a continuum of care for kids.” Rubin is clearly happy about the impact of the briefing. He says the response from Congress was very positive. Just three months later, the “Fostering Connections to Success Act” passed the House and Senate, including provisions adding guardianship benefits for kinship caregivers and new requirements for prompt notification of kin within 30 days of a child’s removal from their parents. The legislation also requires states to improve the coordination of health care services for children in foster care and promote placement of children with willing and available kin as means of improving outcomes for children in care. “We are proud that our data was useful to an incredibly dedicated group of advocates who had been working for some time to move the legislation along. Our studies weren’t responsible for the bill’s success but they helped,” Rubin says.

The results of the NSCAW studies convinced Rubin that real movement toward placement stability and health care access for children in foster care would require more cross-system research, evaluation and collaboration. In 2006, building on the NSCAW work and years of relationship-building with Philadelphia’s DHS, he began developing the “Children’s Stability and Well-being longitudinal study” (CSAW). The five-year study focuses on children age 3 to 8 entering foster care in Philadelphia. It was designed in close collaboration with DHS Deputy Commissioner Kuna and gives Rubin unprecedented access to Philadelphia’s child welfare and behavioral health systems. The overall goal of the study is to identify and understand the barriers that keep children from achieving stable and permanent placements early on and ultimately to help the city develop cross-system initiatives to improve both stability and outcomes for children as early as possible.

A critical component of CSAW is an analysis of the relationship between educational achievement and out-of-home placements. The study’s search for cross-system solutions reflects the Stoneleigh Center’s mission and is the primary reason Stoneleigh joined NICHD and the William Penn Foundation in funding the work.

For Rubin, this joint effort with DHS definitely represents having “a seat at the table,” and he takes the responsibility very seriously. “If medicine wants to help



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solve some of the critical problems we see in practice, we have to develop relationships with policymakers and resist the temptation to point fingers in the newspapers—you’re on a team and public leaders, whether they be administrators or policymakers, need to be able to trust you and see value from you. We can sit here all day and talk about all the things the city and DHS aren’t doing, but at the end of the day, while there are problems with the systems, I never question the sincerity of the people working in these systems. And yes, I’ve met some that I think are unqualified, but 99 percent of the people I’ve met in the child welfare system I’ve respected and think they are doing God’s work.” Rubin values the relationships he has developed with staff at DHS, from commissioners to front line workers to secretaries. “Starting back when I was a fellow, I saw part of my job as helping the line workers tell their stories,” he says. “In the CSAW project we now have contacts in 30 DHS agencies, and we see things the folks up top may not see. We can provide a level of advocacy and tell the higher-ups ... do you realize your workers are saying this?”

Rubin is hopeful that the CSAW study will help put Philadelphia on the track toward improving well-being for its most vulnerable children. So far nearly 450 children have been enrolled, and DHS providers have been updating the study team weekly about the placement moves of these children. But he has no illusions about what he is up against. According to Rubin, “In a large city like Philadelphia, the various youth-related systems operate in silos, and while for years there have been attempts to develop a continuity of care for vulnerable children, so far it hasn’t happened.” Rubin has no doubt that everyone involved agrees vulnerable children need stability from the people who are responsible for them. However, he also knows that DHS has a lot on its plate and it is difficult to get to the core of what really needs to be done to improve stability and access to care.

One early discovery of the CSAW study is that it is very difficult to obtain mental health services for a child early in placement. Rubin describes a situation he sees all too often: “A child comes into the clinic after being placed and has been identified with disruptive behaviors—what do we do? We tell the guardians to call Child Behavioral Health (CBH). Problem is—there is a long wait and they have to go to the back of the line. By the time a spot comes up, the kid may have been moved a few more times so they may never get seen.” Rubin shakes his head and continues. “Let’s say we’re able to get the child seen. Who’s communicating with whom? Is the doctor thinking he will ever see that child again? Are they going to treat the child’s symptoms or try to identify why the child isn’t stabilizing? This is a crisis of stability in the child’s life. Eventually the child gets disruptive enough that there is a recommendation for treatment foster care. To me we’ve already lost the game there. That child has maybe been in the system a year, 18 months, and what have we done for them?”

As far as Rubin is concerned, placing a child in treatment foster care often does not solve the problem. Long waiting lists make it difficult to get placements. “This means,” Rubin says, “kids continue to bounce around in regular care without the supports they need.” Also, according to Rubin, treatment foster care rarely provides the kind of permanency troubled kids need. “What if you are a treatment foster care parent and you’re successful with a kid and they start to get better? You love the kid, give them a firm hand, you’re able to get them in to see a psychiatrist. Are you going to adopt that kid and give them some stability? Probably not.” Rubin believes there are disincentives in the system that discourage adoption by treatment foster care parents. “First of all, treatment

foster care parents get paid more than twice as much monthly as regular foster care parents. The adoption benefits are not as good as that so most people think they are better off keeping a kid in the system. From the agency perspective, they don’t push these parents to adopt. Treatment foster care parents are not that plentiful. The agency needs them to take on other kids, and the agencies are also paid for placing kids in treatment foster care. So we can do all this great work with a kid and then put them right back in the regular system and reverse the gains they may have made in a treatment-level placement.”

Rubin reels off several more problems which he says result from a “silo” reality between agencies and systems. “Most treatment foster care providers in Philadelphia are not credentialed with the behavioral health system and don’t have ready access to mental health professionals,” Rubin says. “They have to go to the back of the line with everyone else in trying to get treatment for the children in their care. Also, there is no requirement to provide aftercare to children, leaving treatment foster care for home or regular out-of-home care. All these things lead me to believe that the fences between agencies in the system need to be a lot lower.” Rubin is attempting to respond to some of these issues by developing interventions that require collaboration between the foster care and behavioral health systems. And so far city leadership across the systems has been supportive. One such effort is a pilot program to test strategies for getting children with disruptive behaviors into treatment earlier; training foster parents, birth parents and kin caregivers to be able to handle some disruptive behaviors themselves; and co-locating CBH providers within foster care agencies.



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Pediatrician, researcher, teacher, family man, Rubin does seem to be everywhere. In addition to these roles he is also an active member of the American Academy of Pediatrics Task Force on Foster Care. How does he do it all? “I have a great team around me. The key is to delegate and to nurture other people so they can take on responsibility and act with autonomy. This frees me up to continue developing new projects.”

So what’s the next big challenge for Dr. Rubin? One very specific challenge for the CSAW project is building a stronger partnership with the Philadelphia School District to better understand the contribution the district can play in improving outcomes for children in the child welfare system. “Children spend more time in school than anyplace else, including their homes,” Rubin says. “Very rarely have researchers focused on school as an important source of strength for children in foster care. With the amount of time children spend in school, it would be crazy to not think they have an important role in substantive reforms.”

As Rubin works to develop this new component of his work, he knows progress won’t be easy. He sees his biggest challenge as getting traction on new ideas so there is a real movement for change in these public systems. “There is no doubt we’ve made progress,” Rubin says, “but I realize that the list of priorities facing the city and its leaders is daunting. For example, I’d like to see the development of an integrated data system to direct and track more intensive services to kids who aren’t stabilizing. But is that more important than the city’s current efforts to provide basic services and monitoring for all children in public systems?”

The issues David Rubin has taken on in his work are critical to the health and stability of the city’s vulnerable children and indeed to the city as a whole. Anyone who has worked with him will attest that he’s up to the job. Rubin’s energy, passion and dogged pursuit of system change in the face of formidable odds are the reasons he was selected by the Stoneleigh Center to take on this challenge. Dr. David Rubin has always wanted to be part of something bigger. Now he certainly is.

Stoneleigh Center is a Philadelphia-based foundation established to help improve the well-being of children and youth. Focused on work that promotes change in our country’s youth-serving systems, we meet our mission through fellowship awards that support outstanding individuals whose work unites research, policy and practice.

Learn more about our Fellowship Program and other work at www.stoneleighcenter.org

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