

RESEARCH REPORT

Impossible Choices

Teens and Food Insecurity in America

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IV ACKNOWLEDGMENTS

Executive Summary

The past couple of decades have been difficult for low-income families. Family poverty has increased, real wages have stagnated for low-income workers, and cash assistance has radically declined (Edin and Shaefer 2015). The Great Recession only exacerbated this hardship, causing the number of food insecure households—those without reliable access to a sufficient quantity of affordable, nutritious food—to spike and remain stubbornly high years into the recovery. Within these distressed households live an estimated 6.8 million food-insecure young people ages 10 through 17, including 2.9 million with very low food security and another 4 million living in marginally food-secure households. ²

Yet we know very little about how these young people experience hunger at this pivotal time in their lives. In this report, we present findings from a new study that uses qualitative methods to shed light on the unique ways that food insecurity affects teens (box 1). Though this study is small and exploratory, the stories we heard from youth who participated in the 20 focus groups across the 10 communities were remarkably consistent. The findings from this research paint a disturbing picture of ways that food insecurity may affect American youth and threaten their well-being.

In diverse settings, we heard many of the same themes:

- Teen food insecurity is widespread. Even in focus groups where participants had little direct experience with food insecurity, teens were aware of classmates and neighbors who regularly did not have enough to eat.
- Teens fear stigma around hunger and actively hide it. Consequently, many teens refuse to
 accept food or assistance in public settings or from people outside of a trusted circle of friends
 and family.
- Food-insecure teens strategize about how to mitigate their hunger and make food last longer for the whole family. They go over to friends' or relatives' houses to eat; they save their school lunch for the weekend.
- Parents try to protect teens from hunger and from bearing responsibility for providing for themselves or others. However, teens in food-insecure families routinely take on this role, going hungry so younger siblings can eat or finding ways to bring in food and money.

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- Teens would overwhelmingly prefer to earn money through a formal job. However, prospects for youth employment are extremely limited in most focus group communities—particularly in those with the highest rates of poverty—and teens often cannot make enough money with odd jobs to make a dent in family food insecurity.
- When faced with acute food insecurity, teens in all but two of the communities said that youth engage in criminal behavior, ranging from shoplifting food directly to selling drugs and stealing items to resell for cash. These behaviors were most common among young men in communities with the most-limited employment options.
- Teens in all 10 communities and in 13 of the 20 focus groups talked about some youth "selling their body" or engaging in "sex for money" as a strategy to make ends meet. However, these themes came out most strongly in high-poverty communities where teens also described sexually coercive environments (Popkin et al. 2016). Sexual exploitation most commonly took the form of transactional dating relationships with older adults.
- In a few communities, teens talked about going to jail or failing school as viable strategies for ensuring regular meals.

This exploratory research suggests that teen food insecurity is an issue that requires urgent action. The most risky behaviors are by no means typical of all teens, even in the most distressed places; however, the report illustrates the lengths to which some of the most desperate and food-insecure youth are willing to go to survive when there are few options available to them. It is important to remember that, throughout this report, we are talking about adolescents (those ages 13 through 18), who are extremely sensitive to the judgment of their peers. It also means that, realistically, their employment opportunities and earning power are limited. Because of their age and very real need, they are uniquely vulnerable to exploitation—from gangs or crews who want boys to sell drugs or girls to traffic or from adults who want to "date" teens.

The story that emerged from our conversations with these teens is one of limited options that leave them with impossible choices. In this report, we use teens' own words to tell this story and draw on our findings to make recommendations for policy and practice.

VI EXECUTIVE SUMMARY

Behind This Report

Work around teens and hunger emerged from the Urban Institute's work on the Housing Opportunity and Services Together (HOST) demonstration, a project that explores the potential for using housing as a platform for providing intensive, whole-family services to stabilize vulnerable families. We knew from a survey we conducted in the three HOST sites (Portland, OR; Chicago, IL; and Washington, DC) that rates of food insecurity were very high and rates of employment rates very low (Scott et al. 2013), but we also knew that these families received housing subsidies, and most also received Supplemental Nutrition Assistance Program (SNAP) benefits. However, our work in our DC HOST site, which included an effort to work with residents to co-design a program to address adolescent sexual health and safety, raised our awareness about the kinds of risky behaviors teens might be resorting to in order to cope with food insecurity.

Interested in further exploring how teens were experiencing food insecurity, the Urban Institute research team connected with the research team at Feeding America, the nationwide network of food banks. As an organization, Feeding America has long had a focus on ending child hunger, but the child hunger programs operated throughout its network tend to reach younger children better than they reach youth and adolescents.

With support from the ConAgra Foundation, Feeding America agreed to partner with the Urban Institute team to explore three key questions:

- 1. How do teens experience food insecurity in their families and communities?
- 2. What coping strategies, including risky behavior, do they use to survive?
- 3. What are barriers to teen participation in food assistance programs, and how could teens be better engaged?

We conducted the first phase of this research in 2014, holding six focus groups in the three HOST sites. Although the project originated from the adolescent sexual health and safety work in DC, we expanded the scope of our exploratory work to gain a broad understanding of all the ways food insecurity might be affecting teens and undermining their well-being, which in turn could be used to inform programs and strategies to better serve food-insecure teens. Findings from our first focus groups suggested that even these stably housed teens were painfully familiar with what it meant to not have enough food for themselves and their families. The teens spoke poignantly about the stigma of being food insecure and about feeling the weight of adult worries and responsibilities. They also talked about the ways that food insecurity can drive teens to desperate choices—skipping meals, working

under the table, dealing drugs, and engaging in exploitative sexual relationships with people who could provide needed resources.

In the second stage of this project, we took our research "beyond public housing," talking to teens in other types of low-income communities for several reasons. First, we hypothesized that these teens might experience even more acute food insecurity than those whose families receive a deep housing subsidy. Second, we wanted to make sure our exploratory research was more representative of the low-income teens and to avoid stigmatizing teens from public housing communities. We also wanted to further explore potential solutions that would reflect teens' special needs (see box 2 in Implications for Policy and Practice section).

Our continued partnership with Feeding America, as well as new funding from the ConAgra Foods Foundation and the Doris Duke Charitable Foundation, allowed us to expand our research in 2015 to seven more communities with strong service provider partnerships and capacity for organizing focus groups on teen food insecurity. The final mix of 10 communities reflected a substantial degree of diversity in terms of the communities themselves and the types of youth who shared their perspectives (see the Methodology section for an in-depth description).

With the additional support of the Ford Foundation, we present our findings in this report and in *Bringing Teens to the Table* (Waxman, Popkin, and Galvez 2016). *Bringing Teens to the Table* explores how teens view the food environment, their experiences with food insecurity in their households and communities, and the barriers to participating in food assistance programs. This report, *Impossible Choices*, provides a deeper look at the coping strategies teens use when faced with food insecurity, including those that may put them at long-term risk.

Methodology

In 10 communities across the country, we partnered with a housing authority/HOST service provider, clinic, community-based organization, or school to recruit participants ages 13–18 for two focus groups, one for girls and one for boys. To ensure that participating youth were likely to be able to speak to issues of food insecurity, they had to be receiving free or reduced-price lunch at their school or living with a family who had received SNAP benefits or charitable food assistance from a pantry or feeding site sometime in the past year. Partner organizations carefully screened for these criteria during the recruitment process. Participants' parents had to provide informed consent for their teens to participate in the groups; each youth participant also had to give verbal assent and each received a \$25 gift card to thank them for their time.

Table 1 provides an overview of the 10 communities where we held focus groups, including county-level information on child food insecurity from Feeding America's Map the Meal Gap project and zip code-level statistics on poverty, receipt of SNAP benefits, and unemployment.

The final mix of communities reflected a substantial degree of diversity, spanning five states, public and market-rate housing, large and small urban areas, and urbanized clusters located out in more rural parts of the country (table 1). Half of the communities were located within counties with child foodinsecurity rates at least 2 percentage points higher than the national average. Moreover, 9 out of 10 communities registered higher than average family poverty and unemployment rates. And all communities demonstrated relatively elevated rates of SNAP participation.

In all, 193 young people took part in the research team's conversations about teen food insecurity, across a total of 20 focus groups (table 2). We administered brief questionnaires after each group to gather information on basic demographics and food insecurity. As table 2 shows, our strategy resulted in a diverse set of teens participating in the groups; eight groups were majority African American, five were majority Latino, four were majority white, and the remaining three were mixed. Although all participants met the basic prescreening criteria, postgroup questionnaires also indicated significant variation in self-reported food insecurity using the six-item, 12-month US Department of Agriculture household food-security scale. Nearly half of the focus groups were conducted primarily with foodinsecure teens, five included a minority of food-insecure teens, and six consisted of a more mixed group of both food-secure and food-insecure participants.

The parents of all participants gave written consent for their teen to participate, and all teens gave their written assent after being informed of all the topics that would be discussed during the focus group and of the research team's protocols for ensuring the anonymity of participants. Participants also were advised that any information they shared would remain confidential except in cases where teens indicated imminent risk of harm to themselves or others.

During the focus group, trained researchers asked youth participants a number of questions about teen food insecurity in their communities (the focus group protocol is in appendix A). While some young people did share their own first-hand experiences, it is important to note that teens were not asked to share their personal experiences but rather their observations of teen food insecurity in their schools and neighborhoods. The focus group questions explored many topics like neighborhood context, how young people get food, use of SNAP and charitable feeding, barriers to food access, hunger and nutrition, the role of young people in their families, youth employment, and risky behaviors like stealing, dealing drugs, and inappropriate sexual relationships. In 18 of the focus groups, facilitators asked teens specifically about risky sexual behavior; in the remaining two, the issue surfaced organically from the teens themselves without direct questions.

Because of the sensitivity of the questions, the researchers tried to ensure the teens were in supportive environments that encouraged open discussion. For example, focus groups typically included at least one break to allow any emotions and tensions to settle, and facilitators were prepared to provide access to support for teens if the discussions triggered any feelings of trauma. The research team either identified these resources before going on site or had an established relationship with a practitioner who would assist in this regard.

Urban Institute researchers recorded all of the focus groups, and these recordings were professionally transcribed to provide the best-quality record of the conversations. Urban staff then used NVivo, a qualitative database package, to code major themes in the transcripts and classify focus groups by prominence of food security in the groups, gender, and location. These themes were then examined to identify subthemes and analyzed by the characteristics of the focus groups themselves. The major themes constitute the chapters of the report and the subthemes help structure each of the chapters.

Within the text, the authors relied heavily on the teen's own words, using quotes extensively to tell these stories as directly as possible. We employed standard conventions to edit the quotes in the most responsible way. Ellipses were used shorten quotes when intervening text was repetitive or went off topic. Brackets were used to clarify things that were said referencing earlier parts of the transcript (i.e. subjects of pronouns, times of day, unfamiliar local terms or slang), as well as to fix subject verb agreement and to indicate where we filled in our best guess where the audio recording was not

understandable. These edits helped make all quotes easier to understand while safeguarding the integrity of the teens' words.

TABLE 1

Overview of Communities

Community	Public/ subsidized housing	Туре	Child food insecurity rate ^a	Poverty rate for families with children ^b	SNAP receipt households with children ^b	Unemployment (age 16+) ^b
		Large				_
Chicago, Illinois	Yes	urban	Medium	High	High	High
Eastern Illinois	No	Urban cluster	Medium	Medium	Medium	Medium
Champaign metro (IL)	No	Small urban	Medium	Medium	Medium	Low
Los Angeles, California	No	Large urban	High	High	Medium	Medium
Greensboro metro (NC)	No	Small urban	High	Medium	Medium	Medium
Rural North Carolina	No	Urban cluster	High	Medium	Medium	Medium
Eastern Oregon	No	Urban cluster	Medium	Low	Medium	Medium
Portland, Oregon	Yes	Large urban	High	Medium	Medium	Medium
San Diego, California	No	Large urban	Medium	Medium	Medium	Medium
Washington, DC	Yes	Large urban	High	Medium	High	High

Note: We use stand-in names for some of the sites to minimize potential stigma for youth in smaller communities.

^a Based on county-level child food-insecurity statistics from Map the Meal Gap 2015. Communities rated "high" have rates exceeding the national average by 2 percentage points or more; communities rated "medium" have rates within (above or below) 2 percentage points of the national average. All data are estimated for 2013; in that year, the national child food insecurity rate was 21.4 percent.

^b Based on zip code-level 2010–14 American Community Survey five-year estimates. Communities rated "low" have rates lower than the national average, "medium" have rates less than two times the national average, and "high" have rates more than two times the national average. The national average for poverty among families with children was 18 percent, for SNAP receipt among households was 22 percent, and for unemployment (age 16 and older) was 9 percent.

TABLE 2

Overview of Teen Focus Groups and Participants

			Group Race/Ethnicity ^a		Group Food Insecurity ^b				
Community	Total youth	Total groups	Black	White	Latino	Mixed	Minority food insecure	Mixed food security status	Majority food insecure
All	193	20	8	4	5	3	5	6	9
Chicago	21	2	2	0	0	0	0	0	2
Eastern Illinois	14	2	0	0	1	1	1	0	1
Champaign metro (IL)	23	2	2	0	0	0	1	1	0
Los Angeles	20	2	0	0	2	0	1	1	0
Greensboro metro (NC)	23	2	2	0	0	0	1	1	0
Rural North Carolina	15	2	0	2	0	0	1	1	0
Eastern Oregon	17	2	0	2	0	0	0	1	1
Portland, Oregon	22	2	0	0	0	2	0	0	2
San Diego, California	20	2	0	0	2	0	0	1	1
Washington, DC	18	2	2	0	0	0	0	0	2

^a Groups were classified by what race/ethnicity constituted 50 percent or more of the focus group participants. Groups with no absolute majority were classified as "mixed."

BOX 1

The Research Experience

Teen food insecurity is a relatively new research area for the team, and the process of talking to vulnerable youth about food insecurity was often unsettling for both the teens and researchers.

It has been challenging to balance the goals of highlighting these troubling stories in order to bring awareness to teen food insecurity and of exercising caution to avoid appearing to generalize behaviors—particularly risky sexual behavior. It is often difficult to disentangle risky behavior specifically in response to food insecurity from that by teens in low-income settings generally. At the

^b All focus group participants answered a six-item set of questions to measure their food-security status over the past 12 months. Groups classified as "minority currently food insecure" were ones where a third or less of participants were food insecure, "mixed" a third to two-thirds, and "majority currently food insecure" more than two-thirds. The original three HOST community focus groups in Chicago, Portland, and Washington, DC, did not administer the official scale but were assigned "majority" values because of the highly elevated levels of family food insecurity identified in the HOST baseline survey.

same time, the team wondered the extent to which the teens underreported food insecurity and unhealthy behavior. Focus group facilitators were told troubling stories from teens after tape recorders were turned off or focus groups were over, and suspect that for each example like the ones noted below, others went unspoken.

This experience has led us to take great care to note frequently that results are not generalizable, that findings are exploratory, and that not all teens or all sites reported the same types or severity of food insecurity or behaviors. We also highlight the words of teens themselves as much as possible, to draw attention to this underresearched aspect of poverty through the teens' own lens. This work is an entry point into this research area, and not conclusive—as researchers, the team continues to develop the right tone and vocabulary to discuss this work. But these discussions with teens have left us with a new awareness of the need for additional work directly with teens and the challenges and limitations of our research approach.

Experiencing Food Insecurity as a Teen

"She [my friend] always beg for other people's stuff, but everybody push her away because like when I got chips, they like, 'Oh, here she go.' But I be feeling like she... always seems like she hungry because she don't ever have enough to eat."

Girl, Chicago

Despite their many differences, most study communities had one thing in common: poverty. The family poverty rate exceeded the national average of 11 percent in all but one community, and it registered at more than twice that rate in half of the focus group communities (table 1). In our discussions, teens expressed their belief that parents in these communities do their best to keep their families afloat, but many struggle to keep food on the table.

In many of the focus group communities, jobs are scarce and the jobs that are available often pay too little, offer too few hours, or require skills and education that struggling parents do not have. Wages and benefits together are often insufficient to pay rent, utilities, transportation, and food expenses for a given month, particularly for large families. "It's enough to survive, but it's not enough to live, basically," said one Portland girl. Unfortunately, federal safety-net benefits fail to fill the gap. In Los Angeles, with its large immigrant populations, the gap may be more about eligibility and enrollment: rates of SNAP receipt among families there are actually lower than family poverty rates. However, even in places like eastern Oregon or Washington, DC, where SNAP receipt is high relative to rates of family poverty, the benefit is not enough to stave off hunger.

As a result, many families start running out of food midmonth. Teens talked about the strategies that local families used to fend off hunger. In places like the Greensboro metropolitan area, families either do not have kitchen appliances or do not use them to save money on utilities. Families also stretch SNAP benefits as far as they can and meticulously ration low-cost and often low-quality food. One Chicago teen boy noted, "They're stretching the food, yeah. They eat one pack of noodles a day." Limited resources steer families toward less healthy options. "You can go to McDonalds," a teen girl in eastern Oregon explained, "and buy like a happy meal for a dollar or a few dollars and get a whole bunch of food. But you go to the grocery store and try to pick something healthy and it takes like \$5 for not very much because it's so expensive and they can't afford it."

Despite these efforts, families often start cutting the size of their meals and skipping meals altogether. A San Diego teen boy said, "There's a few people I know, they really struggle to get food. Or get money so they can buy the food. So they have to go through a starving period where they have to cut down on how much they eat." Teens in most groups agreed that parents were the ones who cut back their meals the most so that their children can eat. "Adults might think, well the kid needs it more, so they'll eat less" (Girl, eastern Illinois). However, teens in food-insecure families sometimes do the same thing to make sure there is food in the house for other family members, often younger siblings. "I will go without a meal if that's the case," said one girl in Chicago, "as long as my two young siblings is good, that's all that really matters to me."

Teens in many communities openly discussed strategies that they and their peers used to skip meals. One girl in Portland noted, "Breakfast really isn't, like I'd rather save my food so that I can eat, so I can actually sleep, because I can't sleep when I'm hungry." Other girls in places like eastern Oregon talked about holding on to their school lunch to get themselves through the weekend. "I don't always skip lunch, but if I don't have money or am almost out of money, I just don't eat lunch at all...because I don't have enough food at home and save it until after."

Teens often notice when their peers are hungry, particularly in communities with high rates of family poverty. A boy in rural North Carolina related how hunger affects young people's outward behavior, "By the end of the month you can tell by how the kids act. The kids might be aggravated. You can tell, they're depressed. You just know. It's hard to explain. You notice them going to the store a lot at the beginning of the month, but at the end of the month they get mad when you bring up food." Boys in Portland agreed that hungry teens often act out or are angry. As a girl in Los Angeles said, "You kind of have to go with the flow of it because you can't get through the day without eating because it totally throws your whole day off." In some cases, teen hunger is more obvious. "Some kids rush to the lunch line because they don't have food for breakfast" (Boy, San Diego).

However, many food-insecure teens may actually go unnoticed by peers and caring adults because of the great efforts they make to hide their hardship. A boy in eastern Illinois recounted how one of his friends covers up that he's hungry: "Some people don't show it. It's like it's their stuff. They don't want people to look at them. [My friend]'s the kind of person who's always bragging about he has this and he has that. He's like, 'Can you buy me something to eat?' And I'll just buy it because I know that he says stuff just to make himself feel good. But that's really not him." The boys in San Diego explained, "Teens feel more bad about [hunger] because they have more insecurities about themselves;" and "the poor kids are the outcasts basically... People [are] nasty to you. [They] look at you like you drunk." A girl in eastern Illinois also volunteered that some teens hide their hunger because they fear exposing their

family to child welfare involvement: "I've heard some people can get their families taken away if they can't afford to care for them, so you have to be careful."

Consequently, teens keep their problems under wraps. "We keep it quiet," said one Greensboro girl "It's a small town, and if anyone knows, everyone will know." Outside of a very small and trusted circle of family and close friends, hungry teens often turn down help. As a teen girl in eastern Illinois explained, "Sometimes the teens don't want to take the food from other people because they don't want to show that their family's struggling. ...They'll hide symptoms of not having enough to eat." This often includes forgoing offers of assistance from teachers, neighbors, and other well-meaning adults.

Other charitable feeding options may also not seem like an option for teens (Waxman, Popkin, and Galvez 2016). In addition to their reluctance to seek help because of the potential stigma they could experience, teens are often unaware of the places in the community they can get food. Sometimes teens also have misperceptions about their ability to access these services on their own, or they think that food programs are only for younger children. These misunderstandings prevent teens from getting food from feeding sites that potentially would serve them. Further complicating these perceptions is the lack of programs specifically tailored to teens. Only teens in rural North Carolina talked about a school-run pantry to help meet their needs.

Instead, hungry teens largely rely on a relatively close circle of family and friends. "I'm going to try to call my dad. If he says no," one girl from Chicago explained, "I'm going to try to call somebody else. And if that's not good enough, then, okay, well, then try my friends or something that live close by, see if I can get at least like two packs of noodles or something so we can all split it or something." Teens in multiple communities talked about showing up at a friend or neighbor's house to eat. Other young people ask trusted neighbors for basics they need to make food at home, like this girl in Los Angeles: "I actually remember when my mom started working ... [my siblings] would get hungry... and I would actually go to a neighbor and ask them for ingredients for a recipe I could borrow. And I would take it from them and make something at home for [my siblings]." In extreme cases, as one boy in Chicago described, "It gets so bad that some people that I know, like they send their kids to live with [their] relative that they know that had more."

Some teens also try to extend help to each other as much as they can. In addition to inviting friends over to their houses to eat, teens in many communities give away their own food to others who seem to need it more. A girl in Portland remembered, "I gave away at least 30 lunches last summer to some little kids that needed it... Like me, I can get by, barely get by, but I can get by, so sometimes I give away my lunches to littler kids that need it." But at the same time, teens often feel overwhelmed by the

responsibility. "One time my little brother woke me up and asked me fix something for his friend. I don't know how to feel about that. It made me feel really bad to have my brother tell me that the kid needed food," recounted a girl in the Champaign metro area. Another boy in eastern Oregon agreed, "If I see someone who kinda looks hungry I'll give them a little bit of food, but I won't sit with him and figure out what's going on, [because] there's never really a fix for the problem." And in all reality, teens and their families sometimes just do not have the resources to keep providing food for other hungry kids in the neighborhood, as one girl in Chicago explained, "[M]y friends, they're staying over here a long time...most of the time I'm like 'my mama will let you'...she be cooking and we be having a lot of food in the house. But there be sometimes we don't."

Bearing the Weight of Adult Responsibilities

"If a kid sees his own family struggling, they help out. They have to be the man or woman of the house" Boy, eastern Oregon

Teens in most of our focus groups across the 10 sites felt that parents do everything they can to try to shield their children from hunger. "With my neighbors, when they're running out of food," described one San Diego girl, "the mom's the one stressing, and she will ask the neighbors for money." Parents often try to hide family problems from their teens so that they will not be adversely affected. A girl in eastern Illinois related, "When my parents talk through it, they tell us to go upstairs. They worry that we'll stop eating, so try to hide it, so that we'll eat it." Other teens in other communities agreed: "Adults tend to not show it to not scare the kids or get them worked up about it. They would rather handle the situation themselves." (Boy, Champaign metro). At the end of the day, even parents in food-secure families do not want their children to worry about adult problems. A Chicago girl explained, "I'm at an age where I can work already, but my mom doesn't ask me to. Like my mom wants to concentrate on school, and she wants me to make it through high school. And my mom wants me to go to college, and that's like a dream for every parent."

However, a small number of youth talked about how struggling parents sometimes pressure their children to start taking on economic responsibility. "Basically [those parents] are saying, 'Get up and do something productive to help your family out, don't just watch [us] struggle,'" explained a young man in San Diego. This expectation can start as early as age 13, with parents suggesting that these youth look for a summer job, and it only intensifies as teens near adulthood. By the time they reach 18, some teens in food-insecure families feel they have little choice but to start supporting themselves and/or their families at home or move out on their own, which can be a terrifying prospect for a young person. One boy in rural North Carolina described being "scared that once we move into our apartment, a little while later food is going to be gone instantly because of bills." Nevertheless, in some places, "a lot of kids just live homeless and leave their families" (Boy, eastern Oregon).

Even when parents do not explicitly pressure their older children to help, many participants in our groups said that teens in poor families start helping to provide for themselves and their families on their

own initiative. Some young people do this as part of a growing sense of responsibility they feel as well as out of loyalty and appreciation for their parents. Others start observing, listening, and better understanding their families' material hardships and internalizing the stresses. As a teen boy in Portland confided, "Like you start to like get worried...like your family is in danger...they won't have enough food, or they won't have enough...to live. And they [teens] start to worry, and like they want to, they start to want to get jobs to provide for basic needs."

When faced with acute food insecurity, many teens begin to feel the weight of adult responsibilities. Teens who are the oldest in their families or have single parents, multiple siblings, or children of their own may be more motivated than their peers to find every way possible to help cover the cost of food, rent, and other basic expenses. One Chicago girl recounted the experiences of young girls in her neighborhood: "The[ir] parents [are] never home. They sacrifice to work all night, leave they kids in the house. They make sure they tell them, don't... let nobody in and all that stuff or whatever. But if you, if there is no food in the house... and [they] don't get off work until 12:00 in the morning... people going to have to do what they got to do."

Teens talk about their perceptions of their financial responsibilities in different ways. Most young people said teens often work to provide for their own needs, including basic food, clothes, and school supplies. In food-insecure households, their earnings free up resources for their families to spend on other essentials. Teens earn money, a Washington, DC, boy said, "...so they [parents] don't have to buy you nothing. You can buy your own stuff and...money they had they could spend on you, they can use for...the needs in the house, and they'd have more money for [them]." Regardless of the level of necessity, however, earning money also helps young people experiencing economic hardship acquire the things that make them feel "normal"—shoes, clothes, computers, and school activities.

Most food-insecure teens who take on early economic responsibility also explicitly share their resources with other important people in their lives. Often this includes buying or sharing food or clothes with siblings or friends who are also struggling. One teen boy from Portland told us about his experience: "I was like, okay, I'll buy myself some school clothes. So I went to the store, bought me some school clothes, and then I helped my little brother and sister, and I bought them some uniforms." Other times, teens pass money directly to their parents. A small number of teens talked about formal understandings about sharing all or a particular amount or portion of their earnings up front to pay for food, rent, utilities, gas, or other essentials. More commonly, teens said they address their own needs first when they have money in hand and then offer whatever is left to their parents.

Finding a Job

"It starts off trying to find a job and when that doesn't work out, you find a quick hustle like cutting grass..." Boy, rural North Carolina

Youth in all but two of the focus group communities—Chicago and Portland—brought up formal employment as teens' preferred way to help make ends meet. But the reality is that the kinds of jobs most teens can get are service-sector jobs that only offer minimum wage, like working in fast food restaurants, grocery stores, gas stations, drug stores, or clothing stores. And we know from youth unemployment statistics that it is difficult for teens in most of the communities to find a job at all. Unemployment for youth ages 16 to 19 exceeded the national average of 27 percent in all but eastern Illinois and Champaign. In four communities—Chicago; rural North Carolina; Greensboro, North Carolina; and Washington, DC—youth unemployment topped 50 percent. Given that context, it is not surprising that many of the participants in our focus groups in both large urban areas and smaller communities lamented the lack of opportunity in their neighborhoods, citing long-term disinvestment, and the closures of anchor businesses and, in one case, a nearby military base.

Further, in most communities, teens find themselves competing directly with older youth and adults for the same low-skill jobs. "Yeah, it can be difficult. People [employers] really wanted experience but we don't have experience. No one is willing to give it to us and it's hard to get a job when all they want is experience," volunteered a young man in Los Angeles. Teens also pointed out that state laws and child protection regulations can create additional hurdles, as one girl in eastern Oregon noted, "Most of the time you have to be 18 or 16. Legally you can get one at 14. But people don't want to hire 14 year-olds."

Trying to balance work with school can also make it more difficult for teens to compete with older workers for scarce jobs. Employers increasingly want maximum flexibility from workers to respond to flexible scheduling (Henly, Shaefer, and Waxman 2006; Lambert 2008). Young people who can find alternatives do, but when school-schedule friendly options are not available and families are in great need, some teens drop out of school altogether, at least temporarily. A girl in a Los Angeles told the story of a friend, "He would give enough to help out and save money. Once he saved enough [some time later] he was able to go back to school and just focus on school."

In addition, participants in a number of our groups thought that employment opportunities were particularly limited for young men. These low expectations may discourage boys from trying to find a

conventional job. As one San Diego teen boy put it, "Some managers are sexists and hire girls because they're prettier." Girls also saw boys as less likely to try to find work. One young woman in eastern Illinois bluntly stated, "Girls will put in multiple applications for jobs and call to follow up. Boys don't." Other girls in the rural North Carolina and Washington, DC, communities echoed this sentiment.

When they cannot find regular jobs, some youth work "under the table" for local restaurants, corner stores or swap meets (flea markets), or participate in subsidized youth employment programs run by the city or a local nonprofit. Portland boys worked at the community gardens, where they could take home food that they grew in exchange for the hours they put in cultivating the plants. In Washington, DC, girls participated in the summer employment program to find a placement, despite the fact that positions were short term and paid less than minimum wage.

Next, teens try odd jobs. We heard about a range of informal jobs. Boys were more likely to mention physical labor, like working on someone's lawn and outdoor area (e.g., mowing lawns, raking leaves), washing cars, carrying groceries, shoveling snow, taking out trash, and doing home maintenance. Girls were more likely to report doing hair, babysitting, dog walking, and sometimes getting paid to do homework for other people.

Young people in nearly half of the communities also talked about teens turning to hustles, like selling small items to neighbors and other children at school to make ends meet. For example, a girl in Washington, DC, told us, "I had to sell candy at the age of 11 just to provide for myself." Other youth in Los Angeles, the Champaign metropolitan area, and San Diego described how their peers sold everything from gum to fruit cups, spray-painted T-shirts, air fresheners, and music CDs to raise money for basics or extra things they needed at school.

And when families fall on really hard times, young people might even try to sell their own possessions. In the Chicago focus group with young men, one boy recounted the plight of one of his neighbors, "There's a dude who lives on my block, whatever, and I guess he was trading something ... his game... [to get] some money because, you know, they were struggling [and] ... could use some bread. ... [When it's hard young people] try to sell their game or their shoes or clothes or something."

Selling Drugs and Stealing

"People have to do other things, they do what they have to do to survive because not everyone can go out and get a job." Boy, eastern Illinois

When teens cannot find formal employment or make enough money from odd jobs, focus group participants across the sites told us about peers turning to dangerous and risky strategies to get the money they need to meet their basic needs. Notably, in the three focus groups with mostly African American young men, none of the participants shared stories about their own or their peers' formal work experiences. Neither did any of the teens—boys and girls—in two of the three public housing sites, where physical isolation and stigma may limit employment opportunities for youth. Instead, the discussions in these groups segued directly to odd jobs and hustles and then pivoted to illicit activities.

In the study communities with the highest poverty rates, desperation can drive both girls and boys to steal food and other basics from local stores for themselves or to share with their families. A young man in Chicago described it this way, "I ain't talking about robbing nobody. I'm just talking like going there and get what you need, just hurry up and walk out, which I do ... They didn't even know. If you need to do that, that's what you got to do, that's what you got to do." Other youth in San Diego described stealing in this way, but they also described a different strategy: going through the self-checkout and just not scanning all of the items.

In Portland, teens discussed stealing food and basics as a normalized behavior. According to our participants, some kids—both boys and girls—start doing it early, when they are as young as 7 or 8. And multiple local businesses accept it and work out ways for teens to work off the cost of what they steal. "It's like funny, because I know lots of people that got caught stealing," one teen girl remarked, "and they don't tell their parents, of course, because they [store staff] discuss with them, they're like 'why are you doing this?' And ... most of them are like because we need the food. I'm really hungry... [The store] just let them work there, and they're like, 'here,' and then sometimes they even give them like cans of food and stuff, like so they can take home if they really need it."

Some food-insecure youth also engage in other illegal behavior as a way to earn money. Regardless of the level of neighborhood poverty, teens in our focus groups said that strategies like selling drugs were common among food-insecure boys. "A lot of kids at a young age will sell drugs to get money for their families. People think it's good but it messes you up," confided a boy in Los Angeles. In part, selling

drugs is a relatively easy option, given the reported prominence of gangs and drug use among teens in most of the study communities. And it is not only young people in large urban areas who are affected; these issues came up even in the smaller communities. A girl in eastern Oregon explained, "Drugs, alcohol, gangs, and everything they bring from middle school, the elementary school, and they come to high school. And bad things people use to just do in high school has spread to the junior high and down to the elementary school. I've been watching it and seeing it and hearing it."

In about half of the study sites, teens in our groups also talked about boys stealing items they could then turn around and sell to get the cash they need. According to our participants, boys mainly steal things like phones, shoes, jewelry, or bikes from other youth. A girl in the Champaign metro area focus group related that she had been a victim of this kind of theft, but felt sympathetic to the boy who stole from her, "The kid who stole my phone, he'd been reported a bunch of times. He had so much pressure on him. That was the easiest way to get the money." In addition, in places like eastern Illinois and Washington, DC, teens talked about boys stealing items off the street like bikes, car parts, or radios to make money.

Gambling was another strategy that came up in the boys groups in eastern Illinois and Washington, DC, with participants describing young men in their communities who bet what money they have on sports games or shoot dice to try to make more. According to a boy in the group in the Champaign metro area, "Some gamble for their money, put in a dollar and try to get more, or they go out and take what they're not supposed to, just trying to make it by."

All of these behaviors—selling drugs, stealing, gambling, and shoplifting—pose substantial risks to teens, not only in terms of potential incarceration, but also in terms of how having an arrest record might affect their future employability. Girls in two of the communities with the highest concentrations of poverty pointed out that young people's experiences with the criminal justice system can make it nearly impossible for them to find traditional jobs. A teen girl in Portland described, "They're like, 'I need to get my stuff like back on track, I need to start doing stuff.' But after they want to start doing something, [the employer] won't hire them because they got arrested like when they were 14 [for shoplifting]."

Running the Risk of Sexual Exploitation

"It's really like selling yourself. Like you'll do whatever you need to do to get money or eat" Girl. Portland

Even under the best of circumstances, teens are under tremendous pressure to engage in sexual activity at an early age (Zweig et al. 2013). According to the most recent statistics, about 41 percent of all high school students report having had sexual intercourse (CDC 2015). Almost all teens in our focus groups talked about how the social climate at school and on social media raises the stakes. "Social media fuels it—Facebook, Snapchat," one boy from Greensboro said. Boys and girls are exchanging explicit pictures; and boys are pressuring girls to have sex and share nude photos; girls, whether they comply or refuse, are subject to public shaming. Boys call the girls *hoes*, *sluts*, and *bitches* and often repost pictures that were meant to be private. "Some girls get peer pressured into doing sex and stuff," a girl from rural North Carolina related, "and I know that for a fact because girls get peer pressured into anything. They get scared and then just do it."

Further, teen girls in the communities with the highest rates of family poverty, like San Diego, described highly coercive sexual environments, with men and boys actively approaching and harassing young women in their neighborhoods. One girl said, "It's a lot... there's... catcalling that goes on, and a lot of strange men that walk up to you." Another explained, "You can't even walk down the street to like Jack in the Box [restaurant] without like hearing something from somebody." Teen girls in Portland identified the same kind of behavior, including "guys... creeping in your window at like 11:00 [p.m.]" and stalking young girls. As a teen describes, "I remember one time I was outside doing chalk with my niece... and just like all these guys try to drive by... and just started whistling. And I'm like, you know, it's like pretty foul. It's like disgusting."

The toxic combination of peer pressures, social media, and coercive sexual environments may make hungry teens in a wide variety of communities vulnerable to sexual exploitation when their options are limited. Teens in all 10 communities and in 13 of the 20 focus groups talked about "some girls selling their body" or "sex for money." Teens often related these stories with distaste, but with a clear recognition of why teens—mostly girls—might feel pressed to go to these extremes to get the resources

they need to meet their basic needs. Reports of this behavior were much rarer among boys, only surfacing in the girls' focus groups in Chicago and Greensboro metro.

Although teens across the sites brought up sexual exploitation, their openness to discussing the topic as well as level of detail they were able to provide varied substantially across communities. In focus groups where a smaller proportion of the participating youth had recently experienced food insecurity, there was less frequent mention of these issues. This variation across the groups may well reflect a lower frequency or visibility of sexual exploitation, but there may be other reasons as well. In a more mixed group, youth who have witnessed these kinds of experiences might not have felt comfortable raising them in front of peers who might judge them. Further, youth who do not have firsthand knowledge of or experience with these matters may not be able to distinguish between more typical teen risky sexual behavior and sexual exploitation.

Identifying sex as a coping strategy for teen hunger may be particularly difficult because the great majority of teens talk about it in terms of ongoing, transactional *dating relationships*. As a teen boy in rural North Carolina explained, "When you're selling your body, it's more in disguise. Like if I had sex with you, you have to buy me dinner tonight... that's how girls deal with the struggle... That's better than taking money because if they take money, they will be labeled a prostitute." Despite the outward appearance of a dating relationship, youth in Portland were quick to point out, "You're not even dating... They'll be like... 'I don't really love him, but I'm going to do what I have to do.'" These kinds of relationships become a key survival strategy for some young women, particularly ones who already have kids of their own. As one girl in eastern Oregon explained, "[This girl I know] doesn't have a lot of money... so she goes out and mingles with the guys and that's how she feeds her family, by doing that."

Both boys and girls often commented on the age difference between the girls and the men with whom they have these transactional dating relationships. "Some young girls give sex to older guys to get things," volunteered a teen boy in the Champaign metro area. A girl in Washington, DC, gave the example of 17-year-old teen girl who was dating a 40-year-old, "He a[n] old man. He got money. So they, so she do what she got to do." Boys in San Diego unanimously agreed, though in other groups, like the girls in Portland, thought it was more about who has money and resources, including relatively young teen boys in the neighborhood who are selling drugs, stealing, or involved with gangs. One said, "[Girls] kick it with the boy...they're doing that stuff with them [because] this boy has money. I'm going to ask this boy because he has money..."

Despite the inherent risks, many girls in our groups apparently view these inappropriate dating relationships as more acceptable than their other last-ditch options for making ends meet. Stealing or

selling drugs are perceived as too risky; and, especially in high-poverty communities, these kinds of relationships between women and men may be highly normalized. A girl in San Diego told us: "It's one of those things that no one talks about, but everyone knows it goes on." Children see young teens doing it, and older teens see their mothers do it. "They be trying to hide it from their kids, but you know it's happening," one young woman in Portland explained.

Beyond these transactional dating relationships, in 7 of the 10 focus group communities, teens also related stories about girls exchanging sexual favors with strangers or stripping for money. They said these incidents occurred outside schools, in abandoned houses, at flea markets, and on the street. A girl in San Diego talked sadly about what happened to a friend from school, "Someone I knew dropped out of high school to make money for the family, she felt the need to step up, she started selling herself." And another girl in Chicago told a similar story, referring to an even younger girl who was only 11 when she dropped out of sixth grade to work in the sex trade. Boys in Los Angeles confirmed that this behavior may start at an early age in their community, with middle school girls putting up flyers in public places advertising their services.

Self-Sabotaging for Survival

"Some kids will pull a fire alarm to get a meal" Girl, Greensboro metro area

Selling, stealing, and engaging in survival sex all compromise teens' ability to be successful in school and may lead to life-altering experiences with criminal justice. However, underscoring the level of desperation facing too many of the youth we spoke to, teens in two of the communities shared stories of peers and neighbors who directly traded their futures to meet immediate needs.

Those in the Chicago teen boy group discussed the tactic of failing school or a class to be placed in summer school, where two meals a day are guaranteed. A teen noted that, "Some people...they'll be passing all these classes and just fail that one class just to make sure like...[they're] behind. If I fail this class, I've got to make it up next year and I'll fail the next class." When asked by the moderator if they deliberately failed to try to get food, the boy responded "Yeah."

In the Portland and Greensboro metro-area communities, teen girls said that some young people in their community view incarceration as a viable strategy to fend off hunger. In Portland, a girl told us that "a lot of people are choosing to be in jail rather than be on the street." Portland girls continued, "It might not be the best food, might not be the best place to be, but it's a roof over your head." And "every single day, they eat breakfast, lunch, and dinner." Girls in Greensboro Metro agreed, "Jail is a luxury, especially for people who live in a trailer. Some people, including teens, will commit a crime to get a place to stay, a meal."

These anecdotes are by no means typical of how teens cope, even in the most distressed places, but illustrate the lengths to which some of the most desperate and food-insecure youth are willing to go to survive when there are few options available to them.

Discussion

Although it generates less attention, material hardship—having to go without basic necessities—is more prevalent than poverty (Neckerman et al. 2016). Food insecurity is the most frequently reported kind of material hardship and one that often signals that the presence of many others, including housing instability, foregone medical care, and loss of essential services like water and heat (Gould-Werth and Seefeldt 2012; Feeding America 2014). In this sense, for many of the teens and families in our focus group communities, the difficulties they describe may not be just about food but also about daily struggles to meet their basic needs.

That said, food insecurity in particular takes a tremendous toll on young people at this important stage in their lives. Food-insecure youth have poor nutrition and inadequate physical activity, which may jeopardize their physical development (Fram et al. 2015). Moreover, food insecurity can have serious consequences for the mental health of young people. Food insecurity in youth is associated with increased mood, anxiety, and behavior disorders; substance abuse; dysthymia (persistent depressive disorder); and suicidal ideation (Alaimo, Olson, and Frongillo 2002; McLaughlin et al. 2012; Poole-Di Salvo, Silver, and Stein 2016). Episodes of food insecurity can also cause cognitive impairment that jeopardizes young people's educational outcomes (Gunderson and Ziliak 2014). However, hunger alone may not be causing these effects on the health and functioning of food-insecure teens: they may also be the result of the stress of broader material hardship and the different coping mechanisms that teens use to survive.

To date, there is little research on the role that youth play in making ends meet in their families. One small qualitative study documents that young people ages 9–16 in food-insecure households took on responsibility for helping to manage food resources, including participating in parental strategies, initiating their own strategies, and generating resources to provide food for the family (Fram et al. 2015). The authors also found that adults were not always aware of children's experiences. A recent longitudinal study of Baltimore public housing families who participated in the Moving to Opportunity Demonstration (Briggs, Popkin, and Goering 2010) also found youth stepping up early to take on economic responsibilities, calling this phenomenon "expedited adulthood" (DeLuca, Clampett-Lundquist, and Edin 2016). Youth who take on their economic role earliest, dropping out of high school and working, provide an average of 22 percent of their families' income (Scott, Zhang, and Koball 2015).

The findings from our focus groups signal that food-insecure teens overwhelming prefer employment over other ways to generate money. Earnings from youth employment can make a big

difference to low-income families, reducing the risk of very low food insecurity 50 percent (Hamersma and Kim 2015). However, taking on a substantial economic role too early can come at a high cost for young people. Many studies have documented that early youth employment may negatively affect high school graduation, particularly for low-income youth and those who work more than part time during the school year (Apel et al. 2008; Oettinger 2000; Rothstein 2001; Warren and Cataldi 2006). Moreover, once they drop out of school, teens who work early have little prospect of going on to college, work fewer hours, and earn less by age 25 than young people who stay in and graduate from high school by age 19 (Latham, Scott, and Koball 2016). The recent study of MTO youth in Baltimore also shows that "expedited adulthood" can trap even the most motivated young people in low-paying, dead-end jobs and push them toward low-quality postsecondary education that cannot provide the kind of career path necessary to escape poverty (DeLuca, Clampett-Lundquist, and Edin 2016).

When deprivation is severe and employment options limited, some youth —particularly young men—may turn to stealing or selling drugs. Research suggests that youth growing up in poor families in poor neighborhoods, like some of the ones in this study, experience a compounded risk of engaging in these kinds of delinquent behaviors (Hay et al. 2007). Youth unemployment rates and low wages are also associated with greater arrests for property crime (Allan and Steffensmeier 1989). Nevertheless, the literature on youth risk factors for criminal behavior generally does not mention food insecurity or the economic pressures that youth in our focus groups described (Shader 2001). Whatever the motivation, youth who engage in in criminal behavior at such young ages put themselves at great risk and undermine their long-term life chances. Young people who engage in criminal behavior are more likely to drop out of high school than their peers (Kirk and Sampson 2013; Latham, Scott, and Koball 2016) and if arrested are also more likely to be incarcerated as adults (Aizer and Doyle 2013).

Similar to other risky coping mechanisms, there is little research that explicitly connects food insecurity with sexual exploitation among youth. Most existing work documents that *adult* women—and men—sometimes resort to transactional sex to get money for food in poor communities in the United States and in other countries (Tsai et al. 2011; Weiser et al. 2007; Whittle et al. 2015). However, we know economic insecurity is one reason women and youth provide when describing why they might trade sex for things they need (see, for example, Dank et al. 2014, 2015; Silverman et al. 2015). And researchers have also found that *homeless youth*, especially lesbian, gay, bisexual, transgender, and queer teens, are at risk for sexual exploitation (Dank, Yu, and Yahner 2016).

What makes the findings from our focus groups particularly alarming is that the communities where the link between food insecurity and sexual exploitation was strongest were places where teens were stably housed and had deep housing subsidies to protect their families from extreme hardship. This

paradox aligns with existing literature on increased risk for young women living in neighborhoods with this kind of concentrated poverty. For example, the American Association of University Women reports that 56 percent of girls in middle and high school report sexual harassment (Hill and Kearl 2011). However, research suggests that women who grow up in chronically disadvantaged communities are even more vulnerable to sexual harassment, exploitation, victimization, and sexual assault (Cobbina, Miller, and Brunson 2008; Menard and Huzinga 2001; Popkin, Leventhal, and Weismann 2010; Smith et al. 2014; Mustaine et al. 2014; Popkin et al. 2016). Moreover, although some research estimates the rate of adolescents having ever exchanged sex or drugs for money as fairly small, at 4 percent (Edwards, Iritani, and Hallfors 2006), nearly one-third of a sample of African American youth living in urban public housing had traded sex for money (Nebbitt et al. 2014).

High levels of unemployment, chronic violence, and trauma in these communities are extreme, and adults sometimes know that these things are going on but do not feel empowered to intervene (Popkin et al. 2016). It is also possible that some of these stories reflect adult traffickers exploiting teens' vulnerabilities to force them into the sex trade, but without more information, we cannot know the extent to which this problem occurs in the focus group communities (Dank et al. 2014).

Regardless of where they live, sexually victimized youth struggle with posttraumatic stress, cognitive distortions, depression, and anxiety, and they are also more likely to engage in substance abuse, suicide, self-injury, binging and purging, and risky sexual behavior (Small and Zweig 2007). These young people may also have difficulty forming healthy relationships as adults.

The findings from this research advance our understanding of teen food insecurity and the kinds of coping mechanisms that youth may employ to survive. However, *quantitative* research is needed to better understand the prevalence of risky coping mechanisms and their relationship to food insecurity and other material hardship. Analysis of existing data, like the National Longitudinal Survey of Youth, on youth contributions to household income, employment patterns, and delinquency would be helpful in starting to understand these trends. However, new questions in nationally representative surveys of youth are also needed to link food insecurity and deprivation to coping mechanisms that may put youth at risk in both the short and long term.

Implications for Policy and Practice

The material hardships that young people endure as well as the options they use cope should not be seen as issues in isolation. Their experiences are shaped by multiple ecological factors, including prevailing mainstream expectations, the effects of racial and economic segregation, the resources and supports available in local communities and neighborhoods, and their families (Rawlings 2015; Popkin et al. 2015). This nested complexity makes addressing teen food insecurity an extremely complex issue to address.

In the short term, there are many teen-focused strategies that could help alleviate hunger and direct teens away from risky behavior, including the following:

- Improve SNAP adequacy: Teens' insight only confirm conventional wisdom that SNAP benefits, while valuable, are not sufficient to ward off food insecurity. Research has confirmed that benefit levels in SNAP are inadequate for many families who run out before the end of the month (Executive Office of the President of the United States 2015). Recalibrating the benefit has the potential to substantially ameliorate hardship; a recent report from the Institute of Medicine (Caswell and Yaktine 2013) examines the issues of benefit adequacy and explores alternatives in thoughtful detail.
- Strengthen teen nutrition programs: Expanding access to school-based meals for teens in the summer months and after classes could make a big difference. Likewise, innovative models such as the Summer Electronic Benefit Transfer for Children have shown promise in reducing food insecurity (Collins et al. 2016). Charitable feeding programs could also be adapted in many ways to make them more welcoming and accessible to young people. These strategies are discussed in more depth in the companion report (Waxman and Popkin 2016).
- <u>Create more and better youth job opportunities</u>: Under current economic conditions, many youth need to work and get paid. Many of the less-than-minimum-wage subsidized summer programs or unpaid internships available to low-income youth are insufficient. Some efforts in this area are already underway, through efforts like the 100,000 Opportunities Initiative, a coalition of businesses committed to providing apprenticeships, internships, and both part-time and full-time jobs to youth ages 16 to 24 who are not working and out of school. However, our focus groups indicate that there is a need to expand these types of initiatives to include *all* low-income youth; many youth struggling to make ends meet may be in school or working and still experience food insecurity and run the risk of dropping out and engaging in risky behavior. Jobs

- also need to be consistent with school schedules to make sure students who need to work can do so without sacrificing their education.
- Foster empowering youth environments: The Urban Institute and Feeding America are working with teens in Portland to design and pilot a new community-based approach to teen food insecurity (box 2). A teen advisory board and group of local service providers designed a new model that will include training programs for local kids as community health advocates, group activities around food, and teen-led food distribution. The team will be piloting this new approach throughout 2016, and we are excited about the opportunity to learn from a model that lets teens be agents of change. Not only may this model help alleviate food insecurity among teens and their families, it serves as the kind of "identify project" that scholars theorize helps provide especially low-income youth with a strong sense of self and motivation that can help them get through difficult patches during their transition from adolescence to adulthood (DeLuca, Clampett-Lundquist, and Edin 2016).
- Use trauma-informed approaches to help teens: Girls who are sexually exploited often get treated as status offenders and end up in the criminal justice system, where they do not get the help they need. Girls of color, especially those who live in deeply poor communities with coercive sexual environments are the most likely to have experienced trauma and to be treated as offenders rather than as children who need mental health and other supports. Advocates recommend training for educators and criminal justice officials in recognizing trauma as well as funding for gender-specific programs to provide prevention and trauma-informed interventions (Saar et al. 2015). Further, to interrupt the intergenerational cycle, many families require two-generational, trauma-informed care and counseling (Scott, Popkin, and Saxena 2016).

BOX 2

Addressing Teen Hunger: The Portland Teen Food Program

Families in the Portland, Oregon, HOST site experienced the highest levels of food insecurity among the three HOST communities included in the first round of focus groups: over 70 percent of households reported food insecurity (Scott et al. 2013). In contrast, the US Department of Agriculture reported that only 14 percent of households were food insecure at some time during 2014 (Coleman-Jensen et al. 2015). Focus groups conducted in 2014 underscored the severity of the problem and highlighted the risks that food insecurity creates for teens.

In response, in 2015 Urban and Feeding America launched a pilot program aimed at identifying ways to reduce teen food insecurity in the mixed-income New Columbia community, located in North Portland's Portsmouth neighborhood. New Columbia was redeveloped in 2005 with \$35 million in federal HOPE VI funds from the US Department of Housing and Urban Development to Home Forward, the housing authority for Portland and Multnomah County. New Columbia is relatively service rich, with a range of facilities and services located on site. Nevertheless, local food options are limited and the closest full-service grocery store is several miles away.

Building on the relationships developed through HOST, Urban mobilized a group of local service providers and a group of local teens to collaboratively design and then launch a new teen-focused food program. The service providers—Home Forward, Food Works (a youth leadership program), and the Oregon Food Bank—are the Portland Teen Food Collaborative. The collaborative worked closely with Urban to design and facilitate a series of discussion groups with teens to explore issues and solutions related to food insecurity in their community. A group of 12 young people ages 12 to 18 served as the Youth Community Advisory Board (YCAB). These teens participated in monthly discussion groups and committed to providing outreach and support for new services. Urban synthesized information gathered from each group to inform a teen-centered food-program model that reflects New Columbia's needs and resources.

By the end of the seven board sessions, the teens had identified several possible approaches to improving their local food resources, including providing a designated meeting space for teens to access food and services, coupling food distributions and supportive services with activities geared toward teens, and creating opportunities for youth leadership development and youth-led initiatives.

In early 2016, Urban, Home Forward, the Oregon Food Bank and Feeding America launched the new Portland Teen Food Program, based on the teens' recommendations. Monthly food deliveries are coordinated by teens with Food Bank and Home Forward staff, and a program manager was hired to work with teens and develop services related to food security. The food distributions serve an average of nearly 120 households at each event. Urban and the collaborative have also developed a 12-week youth empowerment program that will launch in fall 2016, intended to develop cohorts of teen leaders who are knowledgeable about their local food environment and can be resources for their peers.

Urban is evaluating the pilot program to understand the potential impact of new services on local teens and to develop guidance for other communities interested in a similar collaborative design process.

In the long term, teen food insecurity can only be eliminated by addressing its root cause—family poverty. Teens do not live alone and should not have to take on adult responsibilities prematurely, or face the kinds of impossible choices outlined in this report. To make sure teens are protected, we must create conditions that empower their parents:

- Basic employment opportunities and improved access to jobs: In many communities like those profiled in this report, there is an acute shortage of employment across the board. The public and private sectors together have to find more effective ways to create jobs (Edin and Shaefer 2015; Fieldhouse et al. 2011). Further, many adults—who themselves might have faced impossible choices during their own youth—have great difficulty accessing employment. Sometimes this is because of exclusions for criminal history that come with their own unique challenges, but in other cases, entry to the labor market is blocked by limited access to training, transportation, and child care that require greater workforce development and work support investments to surmount (Golden, Loprest, and Adams 2013). However, there is also important work with employers to be done to change the way they automate their searches, craft their job descriptions, and think about training to improve access, particularly for entry-level workers (Capelli 2012).
- Better quality jobs: Much of the hardship described in the focus groups comes about because low-income parents cannot find the kind of work that allows them to earn a decent living. Many cities and states are passing minimum-wage laws, mandatory sick leave, and scheduling regulations. However, at the end of the day, businesses have to recognize how investing in good jobs benefits not only workers but also the public good and their profitability. Government can help support this shift by increasing transparency and accountability around the public cost of private low-road business practices as well as aligning tax and regulatory regimes to cultivate the creation and maintenance of good jobs in local communities (Scott, Baylor, and Spaulding 2016).
- Cash assistance for families: When parents cannot earn enough, there should be ways to get the money they need to cover the costs of essentials, like rent, utilities, transportation, child care, and clothing. In recent years, direct cash assistance to families in need through the Temporary Assistance for Needy Families (TANF) program has dramatically decreased, as states tighten eligibility requirements and redirect TANF dollars for other purposes (Schott, Pavetti, and Finch 2012). Recalibrating TANF to maximize cash assistance and improving access to the program would take the pressure off parents to find alternative ways of making quick cash for necessities and may help youth in poor families avoid taking on adult economic roles in their households prematurely.
- Provide better access to opportunity neighborhoods for families with housing subsidy living in in concentrated poverty: There is clear evidence that helping deeply poor families move from distressed, high poverty communities to communities of opportunity has important benefits for

children. In particular, research shows that for girls, escaping the pressures of the coercive sexual environment associated with chronic disadvantage leads to improved mental health (Popkin et al. 2016; Popkin, Leventhal, and Weismann 2010; Popkin et al. 2015). And more recent findings from the Moving to Opportunity Demonstration show long-term economic benefits for children of both genders—gains that may help them truly escape poverty (Chetty, Hendren, and Katz 2015).

Expand housing assistance to help other low income families manage the largest cost in their family budget: Housing is usually the biggest cost for low-income families, yet only one in four eligible households are lucky enough to receive a deep federal subsidy. We know that housing assistance protects against homelessness and instability; we also know that it allows families to spend more on their children's needs. To address this problem, the Bipartisan Policy Center's Housing Commission has proposed both a significant expansion of the Housing Choice Voucher program along with an emergency fund that would serve less-deeply-poor families and help prevent them from slipping into homelessness (Turner, Cunningham, and Popkin 2015).

Another alternative is to enact a Federal Renters' Tax Credit for landlords that would help offset high housing costs for low-income renters (Sard and Fischer 2013). The earned income tax credit already uses the tax code to help provide support for low-income workers and has shown success in buffering some of the consequences of low-wages, however it alone is not enough to protect families from the kinds of serious hardship we have documented in this report (Edin and Schaefer 2015).

Addressing teen food insecurity is a great challenge, but the stakes are too high to ignore the problem. These young people are the future of our country. They and their families need real solutions.

Appendix A

Youth Focus Group Guide: Beyond Public Housing—Teen Food Insecurity

Introduction (10 minutes)

Hello. My name is	and this is my colleague	We work for the
Urban Institute, which is an independent	research organization in Washington, D	C. We do not work for
the federal government or any other publ	ic agency. We are here as part a team fu	unded by Feeding
America to figure out the challenges arou	nd food that you may face in your neigh	borhood.

INTERVIEW OBJECTIVES

- Lately, we've been hearing from people that not having enough food is an issue.
- We've talked to many people about this issue, but we want to hear what young people in your neighborhood think too.
- We aren't asking about your personal situations, but about what you think happens in your neighborhood or what you've seen happen.
- You are experts on [site] youth so we are here to hear your thoughts and opinions.
- Here are a few guidelines to help us have a good discussion that includes everyone.
 - This is an informal conversation about what you think—there are no right or wrong answers.
 - » Let's all respect what everyone in the room has to say.
 - You don't have to answer any question you don't want to. At any time, you can choose not to participate.
 - When we write about what we hear today, we will not associate your name with anything you say.
 - » Don't use any names when telling a story.
 - » Please keep what we discuss today in this room.

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- » Please keep in mind that we cannot control what participants in today's group say or do with the information you share. Guard what you say if you are concerned someone might repeat it.
- As a final note, if we hear anything that leads us to suspect or have reasons to believe you or someone else is in immediate danger of being mentally or physically abused or neglected, we are required by law to report it. (If teens ask to whom we report: "We will tell a program staff member, who can help directly and our own internal review board."

We would like to record the discussion today to make sure we have your thoughts recorded accurately. Nobody outside the research team will be allowed to listen to the tapes and they will be destroyed at the end of the study. May I record our conversation?

Consent/Assent Form

We have a consent form from each of your parents but before we begin, I want to give you the chance to agree to be part of this project. Let's review this assent form.

[Facilitate signing form]

Do you have any questions or comments before we continue?

I am going to begin recording our conversation now. Let's get started.

Intro

- What's this neighborhood like? (Or, "what is the neighborhood like where you live?", if participants don't live in the neighborhood where the focus group is held)
 - Type of housing (e.g., houses, apartments, other)
 - What is it like to live in this neighborhood?
 - What are some of the biggest challenges facing teens in your neighborhood?
 - » Do you think safety is an issue for teens in your neighborhood?

Where Are Teens Getting Food? (20 minutes)

Think about the stores near [site] that sell groceries.

- Tell me the first word that comes to mind to describe these places.
 - » Is this where most families get their food? (Probe: where do most families get their food?)
 - What kinds of food do people eat most (Probe: proteins? dairy? starches/carbs? vegetables? processed/fried foods? other junk food?)
 - What do you wish they sold that they don't?
- Where else do people in your neighborhood buy food? (Probe: think about grocery stores, vendors, food carts, restaurants, carry-outs, any place that sells food.)
- What do you think families in your neighborhood care about most when buying food? (Probe: nutrition, cost, convenience, taste.)
- Think about teens you know, are they involved in getting food for their families? Tell me about that? (Probe: where do they go and why?)
 - » Are teens providing meals for younger siblings?
 - » Are teens more likely to cook food or purchase ready-to-eat food?
- Some families might be able to get food stamps or EBT benefits. This means a family has a benefit card that looks like a credit or debit card that they can use to buy food. Do you think teens sometimes use their family's EBT card to get food? Have you heard teens say how they feel about doing that?

What Makes Getting Food Difficult? (35 minutes)

Now I would like to talk about some of the challenges young people around here face when getting food.

- Do you think young people in your neighborhood worry about not having enough food? Tell me about that. (Probe: Do you think this happens a lot or not so much around here?)
 - Is there a specific time of month when food runs low? Time of year?

- Do you think parents and other adults in your neighborhood are aware when teens do not have enough to eat? Do you think parents and other adults are aware that teens may worry about getting enough to eat?
- In your opinion, how do adults think of the problem of not having enough food compared to the way teens think about it?
 - » Do adults think it is a more serious problem than teens do? Do adults think it is a less serious problem than teens do? Or do adults and teens think the problem is equally serious?
- Do you think parents and other adults try to keep teens from worrying about food? If so, how so?
- Sometimes families have to rely on food that doesn't cost much money or eat the same things a lot because that is what they can afford. Do you think that happens around here? What do you think people eat most often?
- Do you think people in the community know when a family is having a hard time and food is low at home? Tell me about that. (Probe: how do people in the neighborhood treat families and teens who run out of food?)
- In your neighborhood, do most parents have jobs?
- When money is tight, where can families go for food?
 - What about places like food shelves, churches, or food pantries?
 - » Do teens go to these places or just adults?
 - When teens go, do you think their families ask them to go or they go on their own initiative?
 - What makes it hard for teens to go to a food pantry or other places that give out food? (Probe: think about teens you know, is this a big issue or a small one?)
- Are teens getting food from school? Tell me about that.
 - » (Probe: Ask separately about breakfast, lunch, school pantries, after school snacks, etc.)
 - » How do teens feel about getting free or reduced-cost food from school? Are there food backpacks or afterschool programs that provide snacks or dinner that teens use? What happens when there is no school (weekends, school vacations, summer vacation)?

- If there are any, what do you think the differences might be between a teen getting emergency food from places like school or a food pantry compared to a younger kid? Tell me about that.
- What kind of programs that help families get the food they need would teens be comfortable connecting with? (Probe: how could programs change to be better for teens to use or what kind of new programs could there be?)

Pressures and How Teens Are Coping (35 minutes)

We've been talking about where teens *go* in your neighborhood to get food for themselves and their families. Now we want to ask what you've seen teens *do* in order to get their needs met. We're not asking about your personal situations or activities but about what you think happens in your neighborhood. This is a good time to remind everyone not to mention anyone by name when answering these questions. Remember this is about what you observe teens doing, and you don't have to answer about what you do.

- Do you think teens feel like they have to help their parents pay for food and bills in their household? Tell me about that.
 - » How do the teens in your neighborhood help their families get what they need?
 - What kinds of things do girls do? What kinds of things do boys do?
 - Why do teens feel responsible? (Probe: families, adult neighbors, other kids and popular media)
 - » Do you think parents and other adults ask teens to do things to help their families? What do they ask them to do?
- If there isn't enough food at home, what do you think teens do to get food? (Probe: do they get jobs, trade favors, steal, borrow from friends?)
- There may be many things young people need besides food such as deodorant, beauty products, clothes, shoes. When their parents can't afford to buy these things, what do young people do to get the things they need?
- Do you know of teens in your neighborhood that have jobs?
 - What types of jobs do the teens in your neighborhood have?
 - Are there convention jobs for teens in your neighborhood? (Probe. Why are teens choosing to work, or choosing not to work?)

- » For instance, are they working at different businesses, babysitting, or doing odd jobs around the neighborhood?
 - What types of jobs do teen boys have?
 - What types of jobs do teen girls have?
- Do teens in your neighborhood typically work short or long hours at their jobs? Are they working these hours in the morning, at night, or over the weekend? Are there teens that miss school because of work?
- How do teens typically use the money they earn from their jobs? (Probe: do they spend it on their own needs/wants, or does it benefit the household?)
 - Does this differ by gender?
- Do you think teens around here sometimes date older youth or adults to get money or the things they need? Tell me about that.
- We have heard from teens in other neighborhoods that teens perform sexual acts to get money or the things they need. Do you think that happens around here? Tell me about that. (Probe: if such things happen, do you think this happens a lot or not so much around here)
 - » If so, are both girls and boys doing this?
 - What kinds of sexual things are girls doing to get what they need?
 - What kinds of sexual things are boys doing to get what they need?
 - Are there certain places in the neighborhood where this happens?
 - » Do you think adults in the neighborhood know this is going on?
- Why do you think teens feel like they need to do these things to get what they need? (Probe: are parents or other adults pressuring teens?)

Wrap Up (10 minutes)

It's important that youth are involved in decisions about services and programs that are available to other young people. Thank you for talking to us today.

- If you could talk to President Obama about food issues in [community], what would you say?
- If you could talk to your principal about the food programs in your school, what would you say?
- Is there anything else you think we need to know about the food issues we talked about today?

Thank you for sharing your thoughts and ideas.

Remind participants of services available to them and their families.

Distribute incentives and sign receipts.

Notes

- The US Department of Agriculture's Economic Research Service maintains national statistics on household food insecurity, and published figures described trends before and after the Great Recession. See "Interactive Chart: Food Security Trends," United States Department of Agriculture, accessed September 8, 2016, http://www.ers.usda.gov/data-products/food-security-in-the-united-states/interactive-chart-food-security-trends.aspx
- 2. These data are based on special calculations for Feeding America using the methodology for Map the Meal Gap, described here: "How We Got the Map Data," Feeding America, accessed September 9, 2016, http://www.feedingamerica.org/hunger-in-america/our-research/map-the-meal-gap/how-we-got-the-map-data.html. The US Department of Agriculture classifies households as marginally food secure if they answer affirmatively to one or two reported indications on the Core Food Security Module. This condition is described as one that typically reflects anxiety over food sufficiency or shortage of food in the house.
- 3. For information, see "HOST: Housing Opportunity and Services Together," Urban Institute, accessed April 28, 2016, http://www.urban.org/policy-centers/metropolitan-housing-and-communities-policy-center/projects/host-housing-opportunity-and-services-together.
- 4. The income threshold for SNAP benefits exceeds the federal poverty level in all states.
- For a detailed breakdown of 2015 youth employment by industry and occupation, see the Bureau of Labor Statistics' website: "Demographics," Bureau of Labor Statistics, accessed July 27, 2016, http://www.bls.gov/cps/demographics.htm.
- 6. 2010-14 American Community Survey five-year estimates.
- 7. In California, North Carolina, and Washington, DC, all minors have to get a work permit to get a job. Because of this barrier, young people in our focus groups in these states perceived that only less desirable employers are willing to hire them. In Oregon, the burden falls more solidly in the lap of the employers, which have to apply for permission to hire young people between the ages of 14 and 17. And in Illinois, the work-permit threshold is lower at age 16. However, the effect may be the same. See "Wage and Hour Division (WHD): Employment/Age Certificate," US Department of Labor, last modified January 2016, http://www.dol.gov/whd/state/certification.htm#2.
- 8. Literature has long documented the acute and unique barriers to employment that face young, African American men (Quane, Wilson, and Hwang 2015).
- 9. For more information, see "About the Initiative," 100,000 Opportunities Initiative, accessed July 27, 2016, http://www.100kopportunities.org/about-the-initiative/.

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UNFINISHED BUSINESS: More than 20 Million Children in U.S. Still Lack Sufficient Access to Essential Health Care



Children's Health Fund would like thank the national experts represented in this white paper. Each of these thought leaders and practitioners generously contributed to this report, as well as took time to review its contents and provide feedback.

Children's Health Fund is an organization committed to providing comprehensive health care to the nation's most medically underserved children through the development and support of innovative primary care medical programs and the promotion of guaranteed access to appropriate health care for all children. To learn more, visit www.childrenshealthfund.org

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EXECUTIVE SUMMARY

The extraordinary effort to provide health insurance coverage and access to care for all children in the United States has made significant strides over the last five decades. The development and expansions of Medicaid, the founding and reauthorization of the State Children's Health Insurance Program (CHIP), and the recent implementation of the Patient Protection and Affordable Care Act (ACA) have combined to insure more American children than have been covered at any other time in our country's history.

However, more than 50 years after passage of Medicaid (the federal health insurance program designed to support health care for poor children and people with disabilities), almost two decades following passage of the Children's Health Insurance Program, and six years after the introduction of the Affordable Care Act (Obamacare), approximately 28% of children in the U.S. still do not have full access to essential health services.

There are approximately 73 million children under the age of 18 years in the United States. The fact that 20.3 million children lack access to care that meets modern pediatric standards and expectations should be a call for immediate and focused attention to (a) identify the reasons for persistently poor levels of access to care and (b) develop strategies that can close the access gaps that have defied existing policies and programs.

Not only does failing to address health care access barriers threaten and undermine the health and wellbeing of children, but it also may have a direct impact on a child's ability to succeed academically and enter the workforce at their full potential. Loss of later productivity and the extraordinary costs of remediation will clearly have deleterious consequences for the future economic strength and vibrancy of the United States. The stakes could not be higher.

As described in this report, the methodology for arriving at the conclusions is based on the analysis of three key factors:

- Children who remain uninsured or incompletely insured, either persistently or intermittently;
- Children who are insured but who regularly miss primary care visits due to affordability issues or non-insurance related reasons such as living in severe health professional shortage communities, lack of affordable accessible transportation, cultural and language barriers; and,
- Children who are insured, but have inordinate difficulty getting access to essential subspecialty services (e.g. pediatric cardiology), when needed.

The first two considerations are derived from analyses of national data sets. The third is extrapolated from the clinical experiences and programmatic data of the Children's Health Fund's national network of programs that provide healthcare to underserved children in more than two dozen urban and rural programs around the U.S.

Conclusions derived from the analysis as stated above are as follows:

NUMBER AND PERCENT OF CHILDREN IN THE US WHO LACK SUFFICIENT ACCESS TO ESSENTIAL HEALTHCARE

Category	Number of children	% of all children
Uninsured	3.3 million	4.5%
Insured but missing timely, well child checks (indicative of lack of access to primary care)	10.3 million	14%
Children on Medicaid/CHIP who have access to primary care but have unmet needs for pediatric subspecialty care	6.7 million	9%
TOTAL	20.3 million	28%

At minimum, 20.3 million children (over 1 in 4) face barriers.

Based on the collective reach and impact of Medicaid, CHIP, and ACA, the child uninsurance rate fell from 13.9 percent in 1997 (9.6 million) to 4.5 percent (3.3 million) in 2015—a drop of more than 67%. But there is still much to be done. We need to find ways to cover that remaining 4.5 percent—some 3.3 million children, many of whom are from the most marginalized communities and regions in the United States. And while important, uninsurance figures often promote the false dichotomy of "insured" versus "uninsured" children, ignoring the millions of children who are counted as insured but go without coverage for some portion of the year. Such coverage gaps matter. Discontinuous health coverage can negatively impact timely receipt of preventative and other crucial health care services.

Beyond the issue of coverage is an equally important question: Do children who receive some form of coverage actually access the care that that coverage is supposed to provide? The answer is often no. Based on data and our analysis, Children's Health Fund believes that there are two main categories of barriers to obtaining health care: Financial and Non-financial.

Financial barriers refer to the costs imposed by a coverage plan that prevents children from accessing the care they need. Such barriers refer to costs such as high copays, high deductibles, and unaffordable prescription drug prices. CHF calculates that there are over 13.1 million children whose families report either having problems paying medical bills or being unable to pay medical bills. Provider-based barriers also contribute to the financial burden when clinics or providers won't accept certain forms of insurance or create environments that promote insurance stigma.

Non-financial barriers most often take the form of either geographic barriers or informational barriers. Geographic barriers include issues of transportation, such as a lack of a car or poor public transit options, and federal - designated Health Professional Shortage Areas (HPSAs) where the number of health professionals in a given geographical area is insufficient for that population's healthcare needs. CHF estimates that over 14 million children live in HSPAs. Informational barriers include parents' health illiteracy, dauntingly complex language used in information about coverage eligibility and accessing care, and parents' limited English proficiency.

Children's Health Fund believes that there are a number of concrete strategies and specific steps that can be developed and implemented to ensure true access to healthcare for all children. These include:

1. ELIMINATE FINANCIAL BARRIERS TO HEALTH CARE ACCESS

- a) Reduce or eliminate copayments: The ACA should be amended to reduce copayments, premiums, cost-sharing, and out of pocket payments for lower-income families, as well as increase subsidies and fix existing "glitches" that prevent families in need from gaining marketplace tax credits.
- b) Increase public insurance reimbursements: The ACA and federal/state policies should increase reimbursement rates for providers treating underserved communities. This can help draw providers to HPSAs and reduce insurance-based access barriers and stigma.

2. ELIMINATE NON-FINANCIAL BARRIERS TO HEALTH CARE ACCESS

- a) Send more health providers to poor communities: Policymakers must continue creating incentives that will draw providers to Health Professional Shortage Area and retain providers in those areas. An example of such an incentive is to provide tuition reimbursements for medical students agreeing to serve in shortage areas
- **b)** Create More Health Care Access Points: This can be done in three immediate ways:
 - i) Increase the number of Federally Qualified Health Centers and Rural Health Clinics
 - ii) Increase School-Based Health Services through more school-based health centers and more school nurses
 - iii) Increase the reimbursement allowability of telehealth for poor children and families
 - iv) Increase utilization of mobile healthcare systems
- c) End transportation barriers: Transportation services must be improved for low-income families seeking medical care. Targeted federal resources can help health clinics provide transportation services to augment public transit options; federal incentives can encourage states to facilitate improved coordination of federally subsidized transportation programs serving low-income communities. Federal health agencies can utilize quantitative measures of transportation disadvantage in low-income communities as criteria for enhanced reimbursement rate eligibility for community-based health providers. Interventions to increase families' access to cars and increasing reimbursements for travel can also be effective.
- d) Eliminate health illiteracy: Simpler and more widely available literature explaining public and private health plans can help parents ensure their children receive the care they need. Insurance representatives and healthcare professionals should be better sensitized to the health literacy needs of their patients; the number of staff dedicated solely to answering parents' questions should be increased; and programs to train parent mentors should be boosted.

e) Help parents with limited English proficiency: Increasing clinics' bilingual/multilingual capacity is key to serving parents with limited English proficiency. Reimbursement for translation and interpreter services should be increased, especially in areas with large immigrant populations. Telehealth services (phone or video) can also be used for provide remote language services for areas where on-site interpreters are not available

Children's Health Fund (CHF) estimates that, at minimum, 20.3 million children in the United States (28% of all children) face barriers to accessing essential health care. This estimate covers children who are a) uninsured; b) children who don't receive routine primary care; and c) publicly insured children who are connected to primary care but have unmet needs for pediatric subspecialty care when needed, such as pediatric cardiology or pediatric endocrinology.



I. INTRODUCTION

Children's Health Fund (CHF) estimates that, at minimum, 20.3 million children in the United States (28% of all children) face barriers to accessing essential health care. This estimate covers children who are a) uninsured; b) children who don't receive routine primary care; and c) publicly insured children who are connected to primary care but have unmet needs for pediatric subspecialty care when needed, such as pediatric cardiology or pediatric endocrinology.

NUMBER AND PERCENT OF CHILDREN IN THE US WHO LACK SUFFICIENT ACCESS TO ESSENTIAL HEALTHCARE¹

Category	Number of children	% of all children
Uninsured ²	3.3 million	4.5%
Insured but missing timely, well child checks (indicative of lack of access to primary care) ³	10.3 million	14%
Children on Medicaid/CHIP who have access to primary care but have unmet needs for pediatric subspecialty care ⁴	6.7 million	9%
TOTAL	20.3 million	28%

Note that this estimate may not fully represent large groups of children who face health care access barriers such as the over 14 million children living in Health Professional Shortage Areas (HPSAs)⁵ or the estimated 1 million undocumented children⁶ living in the US. Additionally, when not overlapping with the other access barriers detailed above, the estimate does not capture the many children with further unmet needs for dental and mental health services.

The Affordable Care Act has made important advances in extending health care coverage for children, but much remains to be done to increase coverage, make coverage continuous, and ensure that children who are covered receive the care they need. This white paper details the strides the United States had made in providing health care for children and examines the remaining coverage, financial, and non-financial barriers that must be addressed if all children are to access adequate health care.

Advances in Insurance Coverage and the Remaining Challenges

Insurance is key to giving our children the opportunity to become healthy, productive adults. Children covered by insurance are more likely to benefit from preventative healthcare services, more likely to receive necessary vaccinations, and more likely to receive early treatment for illnesses.⁷ Insurance is particularly crucial for children from low-income families, as this group is at a heightened risk for a wide range of chronic illnesses (such as asthma, obesity, and developmental disabilities) and serious injuries (such as those caused by poorly constructed home environments). Medicaid eligibility for low-income children in the 1980s and 1990s was associated with an 8 percent reduction in child mortality and a 22 percent decline in preventable hospitalizations.⁸ A study in 2016 found that expanding Medicaid eligibility for school-age children (beyond birth) was closely linked to long-term educational attainment in that it decreased high school drop-out, increased likelihood of college enrollment and increased likelihood of getting a college degree.⁹ Haboush-Deloye et al. (2014) found that between 1988 and 2005, over 16,000 child deaths might have been prevented by the provision of insurance.¹⁰

The movement to provide insurance for all American children has made significant strides over the last three decades. Expansions of Medicaid eligibility, the founding and reauthorization of the State Children's Health Insurance Program (CHIP), and the recent implementation of the Affordable Care Act (ACA) have combined to insure more American children than at any other time in our country's history. The child uninsurance rate fell from 13.9 percent in 1997 (9.6 million)¹¹ to 4.5 percent in 2015.¹² But there is still much to be done. We need to find ways to cover that remaining 4.5 percent—some 3.3 million children, many of whom are from the most marginalized communities and regions in the United States.

While important, uninsurance figures often promote the false dichotomy of "insured" versus "uninsured" children, ignoring the millions of children who are counted as insured but go without coverage for some portion of the year. For example, according to 2015 national survey data, a total of 3.3 million children (4.5%) were uninsured at the time of the survey. However, the number of children with any gap in insurance in the past year is much higher at 5.7 million children (7.7%). Such coverage gaps matter. Discontinuous health coverage can negatively impact timely receipt of specialty care, vaccinations, oral health care, asthma care, and important clinical preventative services. Even short periods of uninsurance make children less likely to have a usual source of care and more likely to experience delays in needed care than children with continuous insurance.

There are a wide range of causes for uninsurance and gaps in coverage,¹⁶ including: cut-off points for Medicaid and CHIP that exclude children from families that earn enough not to qualify for public coverage but too little to afford private insurance; citizenship requirements that exclude many immigrant children;¹⁷ waiting periods that leave children uninsured for a certain amount of time before they can gain or regain insurance;¹⁸ and other lacunas and "glitches" caused by law and policy structure.¹⁹ Obtaining continuous coverage for every child will only happen if we can comprehensively address such gaps.

Access Barriers

Beyond the issue of coverage is an equally important question: Do children who receive some form of coverage actually access the care that that coverage is supposed to provide? The answer is often no. For example, an estimated 10.3 million insured children don't receive timely, preventive care, i.e. 15% of insured children.²⁰ Beyond preventive care, many children don't receive the specialty care they may need, as illustrated by data from one of CHF's largest clinics serving Medicaid-enrolled children which showed that about 23% (just under 1 in 4 children) had unmet needs for specialty care.²¹ In this paper, we focus on some of the biggest barriers to accessing care, and break them down into two categories: financial and non-financial.

Financial barriers refer to the costs imposed by a coverage plan that prevent children from accessing the care they need. Such financial barriers plague low-income children covered by every type of plan, and refer to costs such as high copays, high deductibles, and unaffordable prescription drug prices. The impacts of these barriers are significant. Parents faced with financial barriers might seek to save money by calling their doctor for advice, rather than seeing that doctor in person; rather than fill expensive prescriptions, a parent might rely on a limited supply of pharmaceutical samples.²² The medical debt incurred by such costs has been linked to reduced access to care, creating a vicious cycle.²³

While financial barriers are largely caused by the structure of health care laws and insurance policies, non-financial barriers stem from a much wider set of factors. Some of these factors are geographical—families living in remote areas often have to travel long distances to access care for their children. Some are

personal—parents lack the health literacy or English language proficiency necessary for them to fully access care for their children. Non-financial barriers should not be understood as merely what's left over after financial barriers—non-financial barriers are powerful in their own right and can prevent families who do not experience financial barriers from obtaining care for their children.

We Must Act Now

Issues related to children are rarely central in discussions of health care reform. On the surface, this makes sense; the total cost of pediatric care in the United States is roughly \$300 billion per year, while adult costs can tally over \$2 trillion.²⁴ But when one considers that many of those adult costs could have been reduced—if not eliminated entirely—had those adults received adequate care when they were children, it becomes clear how counterproductive it is to prioritize adult health care over child health care.

Improving such access is not only a matter of sound health care policy; it is a vitally important means of strengthening America's economic outcomes. By the time children born into poverty reach age 50, they are 46 percent more likely to have asthma, 75 percent more likely to have high blood pressure, 83 percent more likely to have been diagnosed with diabetes, 125 percent more likely to have experienced a heart attack or stroke, and 40 percent more likely to have heart disease compared with people whose incomes are twice the poverty line or greater.²⁵ The national cost of asthma in school children alone is nearly \$2 billion annually and the national cost of childhood obesity is \$14.1 billion annually.²⁶ The beginning of a new presidential administration provides us with the opportunity to seriously improve our approach to improve healthcare accessibility for our children; we conclude this paper with concrete recommendations that can help guide the incoming administration and Congress do exactly that.

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II. FINANCIAL BARRIERS TO ACCESS

In spite of the considerable gains that have been made to subsidize the health care of low-income children, financial obstacles continue to force families to delay care, receive inadequate care, or go without care altogether. Data from the National Health Interview Survey show that even among children who are insured, there are about 13 million children whose families report either having problems paying medical bills or being unable to pay medical bills.²⁷ In a survey of parents seeking health care for their kindergarteners, 56.9 percent of those who indicated they experienced barriers cited a lack of financial resources.²⁸ Increased premiums are linked to lower-income children being disenrolled from insurance coverage.²⁹ And though the ACA has implemented measures to help reduce these costs—including removing copayments for preventive services and screenings—these measures have not been applied equally to all types of coverage. Further, wage growth continues to lag behind the cost of care:

The cost of employer-sponsored family coverage has climbed by 73 percent since 2003, while median family income has risen by only 16 percent. As a result, average annual premiums were 23 percent of median family income in 2013, up from 15 percent in 2003. Strikingly, average deductibles for an individual plan were 5 percent of median income in 2013, up from 2 percent in 2003.³⁰

Insurance Types

The type of insurance plan by which a low-income child is covered significantly influences the scale of financial barriers he/she will experience. Medicaid imposes the lowest costs for low-income families, with generally no premiums for children and individuals with income under 150 percent of the Federal Poverty Level (FPL), limited deductibles, and limited cost sharing.³¹ Medicaid enrollees have access to dental, vision, and developmental services under the Medicaid Early and Periodic Screening, Diagnostic, and Treatment program.³² Meanwhile, the coverage provided by CHIP programs varies substantially from state to state;³³ but when compared to private insurance, they do provide a relatively comprehensive set of benefits. The costs imposed by private insurance plans also vary widely, though tax credits and cost-sharing reductions are available for individuals and families who fall beneath certain income thresholds.³⁴

Yet cost burdens exist for children covered by every type of insurance, and low-income families often spend a high proportion of their income on care.³⁵ Though the financial burden of public insurance is capped at 5 percent of a family's income, researchers who modeled a scenario in which Medicaid and CHIP imposed no cost sharing or premiums found that 12.7% of families covered by those plans still spent more than 10 percent of their income on health services for all family members. Families below 100 percent of the FPL were likelier to have out of pocket costs and premiums exceeding 10 percent of family income than families at 200 percent of the FPL or above.

Meanwhile, in state exchanges created by the ACA to make coverage more affordable, families who miss the CHIP cutoffs can be faced with enormous burdens—in 36 states, children's premiums and cost sharing for CHIP averaged \$158, while children covered by a subsidized exchange plan on the silver level (second lowest) faced \$1,073 in annual out of pocket spending.³⁶ Overall, 77 percent of caregivers of privately insured children experience out of pocket costs, compared to 26 percent for Medicaid and 38 percent for CHIP.³⁷

Dental coverage for children has become a "loophole" for many families under the ACA. The law specifies that if a stand-alone dental plan exists in the Marketplace, qualified health plans are not required to offer dental benefits to children—families in turn are not required to purchase these plans, and many choose to go without them.³⁸ In a study of racial and ethnic disparities in care, 58 percent of white, 46 percent of

African-American, and 64 percent of Hispanic parents reported that the price of care was a major reason why their children have not received all the dental care they needed.³⁹ And while we report in this paper that 20.3 million children are not getting the services they need, this number does not include uniquely unmet dental needs of children.

The Effects of Financial Barriers

The effects of financial barriers can be significant. A 2010 study found that the most common reason for underinsurance was that costs not covered by insurance were either sometimes or always unreasonable, accounting for 12.1 million children.⁴⁰ Copayments have been found to reduce the number of health services used by low-income children; in Alabama, copayment increases of \$3 to \$5 per service significantly reduced the use of inpatient services and physician office visits.⁴¹ Premium increases are associated with significant reductions in public coverage enrollment, which in turn often leads to increased uninsurance for children.⁴² Cost-sharing at the point of service has been found to decrease access to certain services⁴³ while reducing the likelihood of receiving effective medical care and increasing out of pocket costs.⁴⁴ A recent survey of office-based pediatricians found that 51 percent of privately-insured patients covered by high-deductible health plans reduce or combine follow-up visits and use telephone consultations in lieu of office visits.⁴⁵

Families of children with special health needs are particularly affected by financial barriers. Publicly insured children with special needs spend more on premiums and care than other families—17.3 percent of families with special needs children have a 10 percent annual financial burden, compared to 10.5 percent of families without children with special needs. For example, higher cost sharing was associated with delaying care and borrowing money to pay for care for children with asthma. The cost sharing was associated with delaying care and borrowing money to pay for care for children with asthma.

Underinsurance is common among children with special health needs, which is likely because these children use the system more often than children without these needs and so are disproportionately affected by things like high deductibles and copayments. In addition, otherwise healthy children who experience an unexpected acute episode will incur significant jumps in health care spending—these economic shocks can knock families who are climbing out of poverty back into precarious financial positions. 49

Health Insurance Discrimination and Stigma

Families covered by Medicaid and CHIP are often faced with various forms of discrimination and stigma that stem from poor reimbursement and stereotypes attached to public insurance. Such stereotypes include: clinic administration's or providers' beliefs that these patients unreliably pay for the services they receive, beliefs that these patients are more litigious, and beliefs that these patients are unusually difficult to serve. Fourteen percent of Florida Medicaid beneficiaries were found to have experienced discrimination by health care providers because of their insurance coverage; the figure was 9.3 of all adults surveyed in Minnesota. In addition to refusal of care, these stereotypes can also lead patients and patients' families to feel unwelcome in medical environments—discomfort that can lead them to not be as forthcoming with their providers as they need to be.

One survey respondent explained that:

I'm very thankful that we have [public insurance] and thankful that the Oregon Health Plan gave us what we needed at that time when we couldn't get it for ourselves, but it's not something I would want to stay on just because every time you have to go up to that window and hand in your Oregon Health Plan card, it's like you saying, "I can't do this on my own."

Another survey respondent said:

The first time I went to the hospital for a follow-up, I had the security guard following me around. He asked, "Sir, can I help you?" and I told him I had an appointment. The guard asked "Where is it? I'll take you." Take me he did.⁵²

Such experiences can lead to negative health outcomes for children and their families. Lower uptake of Medicaid in conservative states may be linked to the high prevalence of negative opinions of public insurance.⁵³ Clinic staff's negative attitudes lead to inadequate care and a decline in health among stigmatized patients.⁵⁴ In a study of Latino immigrants in North Carolina, insurance-based discrimination was associated with an increased likelihood of going without needed care.⁵⁵

Poor reimbursement rates are a primary disincentive for clinics and health systems to accept patients with Medicaid, as the lower rates often can't compete with private insurance. Additionally, in a recent survey, 59 percent of pediatricians said they have a harder time collecting patients' shares of deductibles and copayments from families covered by private high-deductible health plans.⁵⁶

Xinxin et al. (2015) raise the possibility that stigma and discrimination against public plans might fade as the ACA expands the number of people with public coverage and reimbursement rates rise; but they also caution that that might just transfer the stigma to uninsured people. It's also conceivable that people who purchase the cheapest, least comprehensive forms of private insurance in the ACA market might also become increasingly subject to stigma and discrimination.

III. NON-FINANCIAL BARRIERS

The most common non-financial barriers can be grouped into two broad categories: Geographic Barriers and Informational Barriers. Below, we detail some of the most pressing examples of each type and the effects they have on children's access to health care.

GEOGRAPHIC BARRIERS

Transportation

As researchers from Children's Health Fund highlight in a recent study, access to a car or public transportation can often determine whether a child accesses healthcare. Some 1.6 million rural households do not own a car and 40 percent of rural communities lack public transportation services.⁵⁷ A study of 12 rural North Carolina counties found that households with people who have a driver's license are at least twice as likely to attend regular checkups and follow-up appointments than those without one,⁵⁸ while another North Carolina-based study of migrant farm workers found that 80 percent of workers cited lack of transportation as the primary reason their child had an unmet medical need.⁵⁹

Urban areas are by no means free of transportation barriers. Public transportation does not exist in many mid-sized and small American cities (which are often sprawled over large geographic areas) while low-income populations in even the biggest cities often live in areas that are poorly served by public transportation. A study of urban clinics found that 21 percent of missed pediatric primary care appointments were attributed to transportation problems. A study of urban children in Texas found that the use of a car increased the probability of keeping an appointment—respondents using non-car transportation had over three times the odds of not keeping their appointment as those who used a car. 61

Health Professional Shortage Areas

CHF estimates that over 14 million children live in Health Professional Shortage Areas, or HPSAs (see Annex 1). Due to issues like remote geographical locations, low reimbursement rates, and insurance discrimination (discussed in detail below), practitioners can be reluctant to locate their practices in certain areas, imposing time and financial burdens on children and their families.⁶² The ACA, by expanding the National Health Service Corps, seeks to reduce this trend, and yet many areas continue to be classified as HPSAs, defined as areas that either have a low ratio of providers to population or that demonstrate a high level of need (such as areas with high poverty rates). Sixty-five percent of rural areas have been designated as HPSAs.⁶³ Children in HPSAs are often forced to go without a usual source of care, which some researchers believe can be just as important as having insurance in facilitating the receipt of healthcare.⁶⁴ An Oregon parent living in an HPSA told researchers:

Even though my children are eligible for dental coverage under OHP [Oregon's Medicaid and SCHIP Program], it is impossible to find a dentist that will take OHP. The only one I could find is 3 hours and at least 2 mountain passes away making getting there almost impossible, especially in the winter.⁶⁵

Hospitals and clinics are also often scarce in these areas, especially in rural regions. 66

INFORMATION BARRIERS

Health Illiteracy

Low-income parents are often overwhelmed by the complexity of their children's health plans and find themselves ill-equipped to know what they should be getting from their plans or how access care. Families can also lack information or an understanding of the importance of preventative or follow-up care. Literacy rates are lower for low-income families, and yet the reading material that is necessary to understanding coverage is typically not written at a suitable reading level.⁶⁷ A lack of basic health literacy is cited as a major reason for why minority children who are eligible for public insurance do not receive coverage—one study found that over half of parents of uninsured children are unaware that their children are eligible for Medicaid/CHIP.⁶⁸

Limited English Proficiency

Obstacles surrounding language become even more complex for parents who lack basic English. It is daunting enough for immigrant parents to get their eligible children insured (and still more difficult if that child is an immigrant) and the struggles only continue as they try to access services. Ku (2007) gives a comprehensive view of the difficulties that limited English proficiency causes for both providers and patients:

It is harder to get medical histories or descriptions of symptoms, to make diagnoses, to discuss treatment options, or to ensure that patients or parents understand and can adhere to their treatment regimens. Moreover, patients with limited English proficiency may experience problems at many stages of a medical encounter, including interactions with the receptionist, nurse, physician, lab technician, pharmacist, and billing clerk.⁶⁹

Children whose parents have limited English proficiency are less likely to visit a doctor or emergency room, more likely to report lower satisfaction with their health care, have poorer health status, and are likelier to be misdiagnosed.⁷⁰

IV. CONCLUSION AND RECOMMENDATIONS

Reducing, and ultimately eliminating, barriers to access is a pressing task for federal and state governments, insurers and providers alike. Though we have separated the barriers into two broad categories, it is important to emphasize that efforts to reduce financial and non-financial barriers must go hand in hand. As Kullgren et al. (2012) note, if we only succeed in reducing financial barriers, there is a chance we will just create new disparities by further disadvantaging those who struggle with non-financial barriers.⁷¹

In addition to the measures we list below, it is important for policymakers to create ways to monitor efforts to eliminate barriers. Kullgren et al. (2012) raise the possibility that the Accountable Care Organizations created by the ACA could in time be held accountable for advancing access to care; state health insurance agencies could also create special mechanisms to reduce access barriers including contractual benchmarks for Medicaid managed care insurers. Tools for measuring patient health care experiences could enable consumers to identify the insurance plans that help remove those barriers, and periodic health surveys could include extra questions on non-financial barriers to access.⁷²

ELIMINATE FINANCIAL BARRIERS

Increase Public Insurance Reimbursements

To eliminate financial barriers, Jost and Pollack (2015) recommend amending the ACA to expand eligibility for cost-sharing reduction payments, reducing out-of-pocket limits for moderate-income individuals or families, and reducing or eliminating premiums for Medicaid ineligible families below 150% FPL. Additional recommendations include fixing the "family glitch" so that working families are no longer excluded from marketplace tax credits, increasing subsidies for families below 400% FPL, and providing subsidies to families falling above that threshold to reduce coverage costs to a fixed percentage of household income.⁷³

It is also important not to take the advances we have achieved for granted; funding for CHIP is set to expire in 2017 while the ACA's maintenance of effort provisions will end in 2019. These programs must be extended, or policymakers must otherwise ensure that replacement initiatives can provide comparable coverage.

Increase Public Insurance Reimbursements

A key means of reducing insurance-based discrimination/stigma and increasing the number of providers for publicly insured children is to support increased reimbursement rates for providers who participate in programs serving those children. Low provider reimbursement rates plague public insurance—especially Medicaid—leading many doctors to not accept publically insured patients.⁷⁴ The ACA has provided federal funding to increase Medicaid primary care reimbursement, but the increase has been relatively modest thus far.⁷⁵ These increases should utilize recent/current market rates and use electronic payment systems that ensure payments are delivered on time.⁷⁶ Increased reimbursement rates for providers treating underserved communities will help draw providers to HPSAs and reduce insurance-based discrimination and stigma.

ELIMINATE NON-FINANCIAL BARRIERS

Geographic Solutions

Policymakers must continue creating incentives that will draw providers to HSPAs and keep them in those areas. In addition to increasing loan repayment incentives and reimbursement rates, tax credits for capital projects and business tax abatements can help increase provider rates in HSPAs.⁷⁷ HPSAs are eligible to receive community health centers—Federally Qualified Health Centers (FQHCs) and Rural Health Clinics—that help make up for the health care services these areas lack.⁷⁸ Nearly half of these community health centers are located in rural areas and, taken together, serve one-third of children who live in poverty.⁷⁹ These centers have been found to reduce ambulatory care-sensitive inpatient admissions and emergency department visits, and patients who use them regularly incur significantly less in annual medical expenditures than non-users.⁸⁰ Community health centers show that to reduce financial barriers is to also reduce non-financial barriers: a study of patients who used these centers for the majority of their care incurred \$3,500 in annual medical expenditures, versus \$4,594 for nonusers.⁸¹

One particularly promising means of addressing HPSAs (as well as low-income children's' lack of a usual source of care) are School-Based Health Centers (SBHCs). SBHCs are health clinics located at schools or on school grounds that provide a wide range of preventative health services to students who live predominantly in underserved rural areas (28 percent of all SBHCs) and urban areas (54 percent). SBHCs reduce the various costs of health care for children in part by reducing the burden on parents to bring their children to a clinic. There are currently over 2,000 SBHCs in 41 States funded by a mix of private and public money. These centers have been found to have had significant impacts on minority children, including the reduction of teen birth rates by 3 percent.

Another recent development that holds significant potential for expansion of school-based services is the recent "Free Care" ruling enabling Medicaid reimbursement for school-based provision of health care services to Medicaid-eligible children. The ACA increased overall funding for these and other kinds of community health centers by \$11 billion and seeks to double their capacity by 2019. Additionally, mobile school-linked care services can increase providers' capacity with less capital investment in a fixed site.

In addition to further increasing the numbers of health professionals and healthcare centers in health provider shortage areas, there are also ways to improve what resources are already in them. Health professionals in these areas can be trained to provide a broader range of services—for example, since dentists are particularly scant in these areas (or often do not accept many plans used by low-income families) some researchers propose doctors be trained to provide basic oral health care.⁸⁴ HPSAs are often caused by geographic maldistribution, rather than a shortage of children's health care providers; in such cases, strategies to recruit and retain providers in areas can be more effective than trying to bring more short-term providers into an area.⁸⁵ Telehealth (see below) can also serve as a means of redistributing provider services and can also be based in schools.

As detailed in a 2016 CHF white paper,⁸⁶ telehealth is another potentially powerful avenue for addressing HPSAs. Advances in broadband coverage and affordable equipment are allowing more and more health care providers to use technologies such as videoconferencing and wireless communications to reach patients in remote and/or overburdened areas. Telehealth can help obviate transportation issues, difficulties in accessing remote communities, and shortages of health care providers, as well as the related costs.

Policymakers should continue providing support to pilot pediatric telehealth programs and appropriate reimbursement for telehealth services.

Reduce Transportation Barriers

There are several ways to improve transportation services for low-income families seeking medical care. Transportation planning officials can actively involve health sector officials to jointly plan ways to ensure that low-income parents are able to get to routine health care appointments. Increased or augmented Medicaid reimbursement can help health clinics to directly provide transportation services to supplement existing public transit infrastructure. With increased federal support, states can facilitate increased coordination of the federally subsidized transportation services that already serve low-income communities to expand transit options for those seeking medical care.⁸⁷

CHF strongly recommends that federal health and transportation agencies recognize and adopt a quantitative metric to assist in identification of "transportation-disadvantaged" communities. Designation as such should be a trigger for enhanced reimbursement to address transportation barriers to care. Additionally, telehealth services, interventions to increase families' access to cars and increasing reimbursements for travel may be effective.⁸⁸

Eliminate Health Illiteracy

Simpler and more widely available literature explaining the importance of preventative and follow-up care and also nuances of public and private health plans can help ease the process of accessing care for children, but devoting human resources to this effort will pay even better dividends.⁸⁹ This could mean making insurance representatives and healthcare professionals more sensitive to the health literacy needs of their patients. It could also mean adding or increasing the number of staff who are dedicated solely to answering parents' questions. Another possibility is to increase a specialized form of community health workers—parent mentors who themselves have children in the system. These mentors can be trained to assist and counsel parents of children who have similar conditions and risks. A study of mentors for minority children with asthma found that mentors are effective in reducing the various costs associated with the condition. For a cost of \$60 per patient a month for parent mentors, net cost savings reached \$597 per patient per asthma-exacerbation-free day that was gained.

Help Parents with Limited English Proficiency

Increasing clinics' bilingual/multilingual capacity is key to serving parents with limited English proficiency. Such services are becoming more common, especially in areas with large immigrant populations, but progress is being slowed by the lack of reimbursement for translation and interpreter services. This further highlights the need for many more community health centers, which on which immigrants often rely for assistance with language issues (community health centers have been found to be particularly important for Hispanic communities). As Call et al. (2014) write, "There is a need for more accessible and effective information (succinct and simplified mailings, help lines, navigators, and improved outreach) to facilitate understanding of available benefits." Telehealth services (phone or video) can also be used to provide remote language services for areas where on-site interpreters are not available.

ANNEX 1

NUMBER AND PERCENT OF CHILDREN IN THE US WHO LACK SUFFICIENT ACCESS TO ESSENTIAL HEALTHCARE

Category	Number of children	% of all children
Uninsured	3.3 million	4.5%
Insured but missing timely, well child checks (indicative of lack of access to primary care)	10.3 million	14%
Children on Medicaid/CHIP who have access to primary care but have unmet needs for pediatric subspecialty care	6.7 million	9%
TOTAL	20.3 million	28%

METHODOLOGY

- 1) **Uninsured**: Data on the number (3.3 million) and percent (4.5%) of uninsured children comes from 2015 National Health Interview Survey 2015 and is based on the category "Uninsured at the time of the Interview." This category does not fully capture those who may have been insured at the time of the interview but experienced a gap in insurance in the past year. About 7.7% (5.7 million) experienced a gap in insurance in the past year (either at the time of the interview and/or the year prior). We are choosing to use the measure "Uninsured at the time of the interview" versus "Uninsured for at least part of the past year" to avoid overlap with the second category "Insured & missing timely routine checkups" which is specific to those who are insured at the time of the interview.
- 2) **Insured & missing timely routine checkups**: This number was calculated by applying the percent of insured children who miss timely well child checks from the 2014 National Health Interview Survey (14.7%) to the number of insured children from the 2015 National Health Interview Survey (70,033,333). What follows is a description of the steps taken. We inferred that the rate of children insured at the time of the interview was 95.5%, based on 4.5% rate of children uninsured at the time of the interview from the 2015 NHIS. The overall population of civilian, noninstitutionalized children aged 0 to 17 was back-calculated as 73,333,333, based on 2015 NHIS uninsurance rate of 4.5% and 3.3 million uninsured children. The number of children insured at the time of the interview is 70,033,333 (95.5% of the 73,333,333). Therefore, the estimated number of insured children who miss timely well child checks is 10,294,900 (14.7% of 70,033,333 insured children or 14% of ALL 73,333,333 children).⁹⁴
- 3) Children on Medicaid/CHIP who have access to primary care but have unmet needs for pediatric subspecialty care: This number was calculated by extrapolating findings from a primarily Medicaid pediatric population served by a clinic in a high-poverty neighborhood in New York City to all Medicaid-enrolled children in the United States. This clinic is affiliated with Children's Health Fund and an academic children's hospital.

Findings from the clinic show that about 23% of pediatric patients (915 out of 1424 children) who are primarily enrolled in Medicaid have at least 1 unmet need for subspecialty care (such as pediatric cardiology, pediatric endocrinology, etc.). Dental and mental health needs are not included, though there is likely some degree of overlap. Given that this data comes from an urban clinic affiliated with an academic medical center that provides high quality primary care and has above-average access to pediatric

subspecialists, we believe that this percent likely under-estimates the level of unmet need for pediatric subspecialty care in Medicaid-enrolled children across the nation, particularly for children who live in rural areas and Health Professional Shortage Areas.

The 23% rate from the clinic is substantially higher than the national rate of 8% of publicly insured children with problems accessing specialist care when needed as reported by parents in the 2011-2012 National Children's Health Survey. Educate that the data reported by providers from the clinic is a better estimate of true level of need, versus data reported by parents, many of whom may not be fully aware of the child's medical specialty needs. The major caveat to this extrapolation is that findings from a small clinic sample of Medicaid-enrolled children may not be entirely generalizable to the entire population of Medicaid population.

Reviews of the literature on children's access to subspecialty care show that it is very difficult to estimate the number and percent of children who have unmet needs for subspecialty care due to considerable variation in methods across studies and lack of national data. Publicly available national data reported by providers could not be easily found.

We did not include children living in HPSAs in the equation, as they could overlap with all or some of the above categories. Per our calculations, the estimated number of children living in HPSAs (derived from 2015 US Census data and 2016 HRSA data) is more than 14 million.⁹⁷

ENDNOTES

- 1. For the full Technical Note and detailed description of Data Sources for this table, see ANNEX 1 TECHNICAL NOTE.
- 2. "Uninsured" category: Data on the number (3.3 million) and percent (4.5%) of uninsured children comes from 2015 National Health Interview Survey and is based on the category "Uninsured at the time of the Interview". This category does not fully capture those who may have been insured at the time of the interview but experienced a gap in insurance in the past year. About 7.7% (5.7 million) experienced a gap in insurance in the past year (either at the time of the interview and/or the year prior). We are choosing to use the measure "Uninsured at the time of the interview" versus "Uninsured for at least part of the past year" to avoid overlap with the second category "Insured & missing timely routine checkups" which is specific to those who are insured at the time of the interview.
- 3. "Insured & missing timely routine checkups": This number was calculated by applying the percent of insured children who miss timely well child checks from the 2014 National Health Interview Survey to the number of insured children from the 2015 National Health Interview Survey.
- "Children on Medicaid/CHIP who have access to primary care but have unmet needs for medical specialty care" category: This number was calculated by extrapolating findings from a primarily Medicaid pediatric population served by a clinic in a high-poverty neighborhood in New York City to all Medicaid-enrolled children in the United States. This clinic is affiliated with Children's Health Fund and an academic children's hospital. Findings from the clinic show that about 23% of pediatric patients who are primarily enrolled in Medicaid have at least 1 unmet need for pediatric subspecialty care (such as pediatric cardiology, pediatric endocrinology, etc.). Dental and mental health needs are not included. Given that this data comes from an urban clinic affiliated with an academic medical center that provides high quality primary care and has above-average access to pediatric subspecialists, we believe that this percent under-estimates the level of unmet need for subspecialty care in Medicaid-enrolled children across the nation, particularly children who live in rural areas and Health Professional Shortage Areas. Of note, the 23% rate from the clinic is substantially higher than the national rate of 8% of publicly insured children with problems accessing specialist care when needed as reported by parents in the 2011-2012 National Children's Health Survey. We believe that the data reported by providers from the clinic is a better estimate of true level of need, versus data reported by parents, many of whom may not be fully aware of the child's medical specialty needs. The major caveat to this extrapolation is that findings from a small clinic sample of Medicaid-enrolled children may not be generalizable to the entire population of Medicaid population. Reviews of the literature on children's access to subspecialty care show that it is very difficult to estimate the number and percent of children who have unmet needs for specialty care due to considerable variation in methods across studies and lack of national data. Publicly available national data reported from providers could not be easily found.
- 5. Estimated number is: 14,351,144. This estimate is based on the proportion of the US population under 18 years of age (23%) multiplied by the number of people living in Health Professional Shortage Areas for primary medical care (62,396,277 people). Sources: 1) US Census. Persons under 18 years, percent, July 1, 2015, 22.9%. Available at https://www.census.gov/quickfacts/table/PST045215/00. 2) Bureau of Health Workforce Health Resources and Services Administration. Designated HPSA Statistics. (See "Shortage Areas, Health Professional Shortage Area (HPSA) Basic Primary Medical Care" Available at: http://datawarehouse.hrsa.gov/tools/hdwreports/Reports.aspx.)
 Caveats: We do not know if the percentage of children in HPSAs is the same as in the national population.
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Caveat: We have assumed that the percentage of children in HPSAs is the same as in the national population.

Parker

At age 6, Parker Mable began attending her local public school in rural Indiana. During the first week of school, Parker's teacher referred her to someone in central office for medical attention. Parker had not seen a doctor in over a year, though she excitedly remembered going the emergency room twice.

After connecting with Parker's mother about the girl's medical history and obtaining consent to proceed, a school nurse conducted several screenings. Nurse Johanssen discovered that Parker needed vision correction, dental services and asthma. An additional telemedicine consultation helped to confirm Parker's need for speech pathology.

The nurse coordinated with Parker's family to assist with completing and submitting an application for Indiana Medicaid. The resulting coverage allowed the family to establish a medical home and start regular visits to a dentist. After conducting a home visit, Nurse Johanssen developed an asthma management plan for Parker that outlined strategies both the family and the school could use to reduce the risk of attack. The nurse hosted two sessions of health education with Denise Mable on asthma and nutrition; the nurse also conducted professional development on asthma management for Parker's teachers, recess coordinator and aftercare coordinator to assure continuity of her care.

Parker's teachers and specialized instructional support personnel, including Nurse Johanssen and a speech pathologist, worked with her mother to develop an Individualized Education Program. In addition to corrective lenses, Parker's IEP required that she regularly participate in speech therapy.

Nurse Johanssen continued to work closely with the Mable family and helped Parker's two younger siblings enroll in the district's early childhood program. The program screened the whole family and made connections to relevant healthcare providers. Denise was scheduled to use a telemedicine service to receive cognitive behavioral therapy for postpartum depression following the birth of her third child, though she struggled to consistently access the service due to internet connectivity challenges.

By third grade, Parker's standardized test scores suggested that her academic progress was just above the district average. Parker had learned to expertly wield her asthma inhaler when needed and to advocate for herself around new adults who may not be familiar with asthma. With more consistent access to a dentist, the Mable children had not visited an emergency room for dental care in three years and Parker's younger brother was doing well in the full-day kindergarten program.

Since enrolling Parker in kindergarten, Denise's salary has been fluctuating with a trend towards livable wages. She is concerned that her income may soon disqualify her family for Medicaid. At that point, without employer-based coverage, she will need to learn to navigate the insurance exchanges and associated providers.

Javon

When Javon entered a new high school in St. Louis, Missouri in the middle of a school year, his teachers and administrators quickly found that he struggled with his ninth grade courses. In the morning, Javon generally seemed disengaged from peers, coursework and educators. But after lunch, his boisterous behavior disrupted classes and activities. The school social worker took on Javon's case management.

Mr. Carroll's first talk with Javon revealed that his father had recently passed. Javon was added to the school's support group for bereaved students. Next, a behavioral health screening with the school psychologist identified Javon's attention deficit hyperactivity disorder.

After Mr. Carroll established contact with Javon's new guardian, his aunt, it became clear that Javon's prescription for Ritalin had not yet been filled in his transition. The school nurse helped the Jacksons establish a new medical home and set up a regular prescription. Nurse Willis also talked with Javon, which revealed that he was engaging in risky sexual behaviors and drug use. She referred him to the school-based health center at another city school to get a screening for sexually transmitted infections and receive health education. Despite several follow-up calls, Javon did not attend any of his appointments, likely because his aunt seemed opposed to completing consent forms, a first step in acknowledging his sexual activity.

Finally, while tracking Javon's grades carefully, Mr. Carroll suspected that Javon may have a learning disability. A screening revealed dyslexia. Javon's resulting Individualized Education Program entitled him to several accommodations during typical instruction as well as during assessments.

As Javon entered his sophomore year, he had become a peer leader in the Restorative Justice program, helping classmates to peacefully resolve conflicts. His grades better reflected his abilities, including his improved concentration during instruction.

Carter

Carter King is an outspoken high school junior. For the recent social justice unit of her social studies course, she conducted a project focused on food insecurity. She put in extra hours for the school's food donation drive and volunteered at a food pantry in the neighborhood. As she headed into the final quarter of the year, she became passionate about providing "just in time" strategies that directly address her classmates and peers, as well. Her work so far has been motivated by a few simple truths:

- Teen food insecurity is widespread in her community. While Carter hasn't had much direct experience with food insecurity, she is aware of classmates and neighbors who regularly do not have enough to eat.
- Teens fear stigma around hunger and actively hide it. Carter knows some of her classmates have refused to accept food or assistance in public settings or from people outside of a trusted circle of friends and family.
- Food-insecure teens strategize about how to mitigate their own hunger and how to make food last longer for the whole family. They go over to friends' or relatives' houses to eat; they save their school lunch for the weekend. Teens in food-insecure families have tried going hungry so younger siblings can eat.
- Teens would overwhelmingly prefer to earn money through a formal job. However, local prospects for youth employment are extremely limited for Carter's friends—and odd jobs don't usually offer enough in wages to make a dent for the family.
- Acute food insecurity has pushed some to criminal behavior. Boys tend to shoplift food
 directly, sell drugs or steal items to resell for cash. Girls are more likely to "sell their body" or
 engage in "sex for money" to make ends meet for Carter's friends, this most commonly looks
 like transactional dating relationships with older adults. Finally, some teens go to jail or fail
 school to ensure regular meals.

She's been working hard to work with local anti-hunger advocates to connect teens to programs for food security with less public visibility and stigma. One local hospital quickly became an ally and has been thinking about how they might expand the fresh fruit and vegetables referral program to teens. The program currently provides a dollar match for every dollar a referred patient spends at one of 6 area farmer's markets.

Excited about Carter's passion and creative ideas, the hospital asked her to join them in designing a program that raises awareness of psychological trauma and the research on adverse childhood experiences. They hope to ultimately decriminalize behaviors inspired by teen hunger among schools, small businesses and local law enforcement. Despite Carter's eagerness to help, she's unsure about how to work with the hospital while maintaining her grades and getting ready for college. So she's been to her school counselor several times asking about her own situation and other teens' opportunities for secure, consistent and flexible employment.