



**Children's Health Fund**

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

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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](http://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%                |
| <b>TOTAL</b>                                                                                                   | <b>20.3 million</b> | <b>28%</b>        |

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 to 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 HEALTHCARE<sup>1</sup>

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

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)<sup>5</sup> or the estimated 1 million undocumented children<sup>6</sup> 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.<sup>7</sup> 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.<sup>8</sup> 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.<sup>9</sup> 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.<sup>10</sup>

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)<sup>11</sup> to 4.5 percent in 2015.<sup>12</sup> 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%).<sup>13</sup> 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.<sup>14</sup> 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.<sup>15</sup>

There are a wide range of causes for uninsurance and gaps in coverage,<sup>16</sup> 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;<sup>17</sup> waiting periods that leave children uninsured for a certain amount of time before they can gain or regain insurance;<sup>18</sup> and other lacunas and “glitches” caused by law and policy structure.<sup>19</sup> 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.<sup>20</sup> 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.<sup>21</sup> 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.<sup>22</sup> The medical debt incurred by such costs has been linked to reduced access to care, creating a vicious cycle.<sup>23</sup>

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.<sup>24</sup> 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.<sup>25</sup> 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.<sup>26</sup> 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.

## 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.<sup>27</sup> 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.<sup>28</sup> Increased premiums are linked to lower-income children being disenrolled from insurance coverage.<sup>29</sup> 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.<sup>30</sup>

### *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.<sup>31</sup> Medicaid enrollees have access to dental, vision, and developmental services under the Medicaid Early and Periodic Screening, Diagnostic, and Treatment program.<sup>32</sup> Meanwhile, the coverage provided by CHIP programs varies substantially from state to state,<sup>33</sup> 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.<sup>34</sup>

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.<sup>35</sup> 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.<sup>36</sup> 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.<sup>37</sup>

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.<sup>38</sup> 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.<sup>39</sup> 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.<sup>40</sup> 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.<sup>41</sup> Premium increases are associated with significant reductions in public coverage enrollment, which in turn often leads to increased uninsurance for children.<sup>42</sup> Cost-sharing at the point of service has been found to decrease access to certain services<sup>43</sup> while reducing the likelihood of receiving effective medical care and increasing out of pocket costs.<sup>44</sup> 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.<sup>45</sup>

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.<sup>46</sup> For example, higher cost sharing was associated with delaying care and borrowing money to pay for care for children with asthma.<sup>47</sup>

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.<sup>48</sup> 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.<sup>49</sup>

### *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.<sup>50</sup> 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.<sup>51</sup> 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.<sup>52</sup>

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.<sup>53</sup> Clinic staff's negative attitudes lead to inadequate care and a decline in health among stigmatized patients.<sup>54</sup> In a study of Latino immigrants in North Carolina, insurance-based discrimination was associated with an increased likelihood of going without needed care.<sup>55</sup>

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.<sup>56</sup>

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.<sup>57</sup> 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,<sup>58</sup> 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.<sup>59</sup>

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.<sup>60</sup> 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.<sup>61</sup>

##### *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.<sup>62</sup> 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.<sup>63</sup> 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.<sup>64</sup> 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.<sup>65</sup>

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

## 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.<sup>67</sup> 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.<sup>68</sup>

### *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.<sup>69</sup>

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.<sup>70</sup>

## 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.<sup>71</sup>

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.<sup>72</sup>

### 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.<sup>73</sup>

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.<sup>74</sup> The ACA has provided federal funding to increase Medicaid primary care reimbursement, but the increase has been relatively modest thus far.<sup>75</sup> These increases should utilize recent/current market rates and use electronic payment systems that ensure payments are delivered on time.<sup>76</sup> 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.<sup>77</sup> 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.<sup>78</sup> Nearly half of these community health centers are located in rural areas and, taken together, serve one-third of children who live in poverty.<sup>79</sup> 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.<sup>80</sup> 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.<sup>81</sup>

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).<sup>82</sup> 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.<sup>83</sup>

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.<sup>84</sup> 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.<sup>85</sup> 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,<sup>86</sup> 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.<sup>87</sup>

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.<sup>88</sup>

### *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.<sup>89</sup> 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).<sup>90</sup> 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.”<sup>91</sup> 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%                |
| <b>TOTAL</b>                                                                                                   | <b>20.3 million</b> | <b>28%</b>        |

### 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.”<sup>92</sup> 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).<sup>93</sup> 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).<sup>94</sup>

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.<sup>95</sup> 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 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.<sup>96</sup> 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.<sup>97</sup>

## ENDNOTES

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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.
4. “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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97. Estimated number: 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>.)
- Caveat: We have assumed that the percentage of children in HPSAs is the same as in the national population.