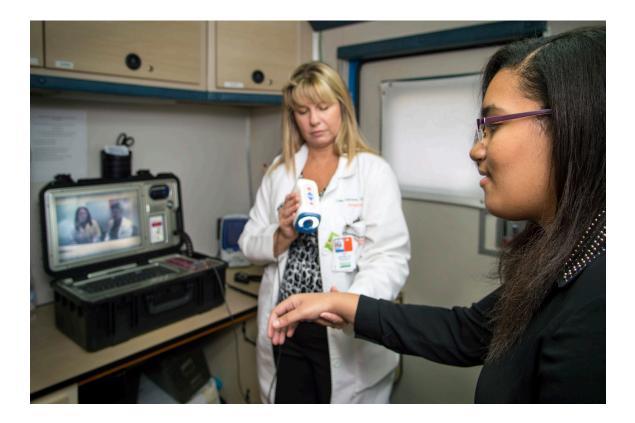


THE PERSISTENT HEALTH CARE ACCESS GAP FOR CHILDREN IN POVERTY

Will the Health Technology Revolution Level the Playing Field?



The First in a Series of White Papers on Technology and Child Health By the Samsung Innovation Center at Children's Health Fund This report was prepared by Children's Health Fund, under the auspices of the Samsung Innovation Center at Children's Health Fund.

Children's Health Fund is an organization commited 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 AND RECOMMENDATIONS

Across the globe, innovative technology has brought new health care access to some of the most remote and underserved populations in the world, to places where health care infrastructure was close to nonexistent. Funded by the United Nations, World Health Organization, and the World Bank, among others, these advancements have been transformative. In the United States, however, the promise of technological innovation is only now beginning to be leveraged to increase health care access and improve health care outcomes for the millions of children living in poverty.

While unprecedented advances in health care technology have produced radical changes for other population groups served by the American health care system, our nation's most vulnerable children have been largely left behind. Why is this and what can be done?

This white paper explores the need for, the potential of, and challenges to expanding the application and impact of innovative health care technology to ensure that all children can get the health care that they need and deserve. The Samsung Center for Innovation at Children's Health Fund was established to provide information and analysis about how advanced technology can help level the playing field and assure that all children have access to timely and quality health care. The conclusions and recommendations suggest immediate priorities for action.

From the broadest perspective, fulfillment of the promise of health reform depends in part upon innovation in health technology. By extending reach, efficiency, and continuity of care, technologies like telehealth, portable screening and diagnostic tools, and mobile follow-up communication between patient and doctor can increase access to health care and improve outcomes. The scale and impact of health care infrastructure investments must be amplified through these and other innovative technologies to serve millions of people newly insured under the Affordable Care Act of 2009. The drivers of health expenditures (largely the cumulative costs of poorly managed chronic conditions such as asthma, obesity, diabetes, etc.) need to be restrained to bend the arc of the "cost curve." Technology is providing tools to shape effective strategies to meet these goals for adults at a disruptive pace.

But what about children? Many continue to face extreme challenges in accessing health care...

Children living in poverty need a robust health system that understands and overcomes barriers of access to health care. Innovation and technology can be a major contributor if we marshal emerging technologies, clear a path for innovation with public policies that permit best practices while protecting patient privacy, and make investments – especially in prevention and wellness – with promising potential for high return on investment.

For many children, timely and appropriate access to needed medical care is a major challenge. Even for those vulnerable children with health insurance, the barriers to adequate health care can be insurmountable. Parents in minimum wage jobs often must take time off from work (and lose pay) to keep a doctor's appointment when their child is sick, let alone for preventive "well child" visits. Severe shortages of many pediatric specialists put necessary follow-up out of reach. Language barriers make it impossible for parents to communicate symptoms or understand a diagnosis. Deficits in health information contribute to choices that undermine wellness. Innovation in health technology can play a major role in overcoming these barriers. Healthy children are better learners, better positioned to achieve academically and grow into healthy adults more able to compete in a 21st century workforce. The numbers speak for themselves:

- Today in America there are at least 15 million children living in poverty, almost half of them in extreme poverty;
- At least 15 20 million children live in federally designated Health Professional Shortage Areas;
- Though the impact of full implementation of ACA provisions is yet to be determined, an estimated 5 million children still lack health insurance;
- Some 3 million children miss medical appointments because affordable transportation to medical facilities is not available.

But currently, the needs of these children are not driving technological advancement in health care in America. Instead, a robust consumer market has met the demand and provided the foundation for most progress. Innovating businesses have developed a rapidly growing, exciting portfolio of products tailored to their customer base. In many cases, these businesses are in sectors not traditionally thought of as health care – the data and electronics giants. They are focused on the immediate health needs of the largest segment of the American population, the aging boomers, as well as well-to-do "Gen-Xers" who turn to technology to provide solutions.

Now is the time to harness this accelerating change. We must leverage the technological advances that have already emerged and the progress that continues to transform how health care is delivered. We must ensure that these new opportunities are customized for all children and adapted for the particular needs of children in poverty.

That is the mission of the Samsung Innovation Center at Children's Health Fund. In the years ahead we hope to create a roadmap to help policymakers, health system planners/administrators, and health care providers find a way forward. We also plan to provide models for effective implementation of health care technology advancements that will reduce disparities in health care access and improve health outcomes for children in poverty.

The goal of this initial white paper is to understand current opportunities and deepen insights into their potential with respect to the unique sensitivities of underserved children. While technology has great capacity to improve care for all children, this demographic is traditionally treated as an afterthought in a consumer- and revenue-driven health care market. As a result, technologies (and/or their implementation) often do not fit the needs of children.

For marginalized children, technology can increase access to quality care. However, if not developed and implemented equitably, technology advancements could actually widen disparities in care as the "haves" get more and the "have-nots" are increasingly left behind.

- 1. New technologies must be designed for or adapted to the needs of children. Electronic health records, for example, have been in use for decades but commercially available electronic health records still often fail to be appropriate for child health care.
- 2. The federal Centers for Medicare and Medicaid Services (CMS) should create a special fund to incentivize the development of technologies to improve accessibility and quality of health care for medically underserved children.
- 3. Training curricula for health sciences students and providers should include education regarding the effective use of technology in improving health care for underserved pediatric populations.
- 4. Efforts should be made, supported by strategic public awareness and education campaigns, to ensure that families fully understand how new technologies can improve the quality and availability of health information relevant to their children.
- 5. Innovative ways to make health care more accessible and efficient, especially for underserved children, must be financially supported. Disruptive changes to the system mobile medical clinics, telehealth, mobile communication between doctor and patient (e.g., text messaging) have moved health care delivery beyond the doctor's office, but insurance reimbursement has not followed.

INTRODUCTION: CHILDREN, POVERTY, AND ACCESS TO HEALTH CARE

There are more than 75 million children in the United States, and nearly one in five (19.9%) live in a family with an income at or below the federal poverty level (\$23,550 for a family of 3). While children represent less than one-fourth of the nation's population, they comprise about one-third of people in poverty. Poverty is an even greater problem for children living in a single parent family – 45.8% live in poverty, many in extreme poverty (income less than half the federal poverty level). In 2013, at least 6.5 million children were living in extreme poverty.¹

Children in poor and low-income families experience an enormous health burden. Compared to other children, they have higher rates of acute and chronic disease, including asthma, obesity and developmental delay, and are often not ready to succeed academically when they start school. Children in poverty experience more severe symptoms and experience a lower quality of life than their economically-advantaged counterparts. Often lacking access to health care, they have higher rates of hospitalization and emergency room use. Especially for children in extreme poverty, food insecurity – not knowing where the next meal will come from – is a problem, and this may be associated with health issues that include under-nutrition, iron deficiency anemia (which can compromise the cognitive development of young children), and emotional and behavioral problems.² Timely access to pediatric care is essential for all children, but the consequences of failing to ensure access for poor children can be devastating.

Though the full impact of health reform implementation (the Affordable Care Act of 2009) is yet to be realized, more than 5 million children in families with incomes below 200% of poverty – that includes many children with parents working in low-wage jobs – remain uninsured.³ And there are other barriers to health care access. In a study of transportation barriers, Children's Health Fund found that 9% of children – at least 3 million – in families with incomes below 200% of poverty missed at least one health care appointment each year because transportation was not available.⁴ Some children have gaps in their insurance coverage, for example when their parent becomes unemployed, and they lose access to care during the year.⁵ In addition, about 15-20 million children live in federally designated Health Professional Shortage Areas where, even with health insurance, access to physician or clinic may be extremely challenging.⁶ When we include all children with limited access to care related to both underinsurance and other kinds of barriers, the number experiencing serious access difficulties is at least 15 million. (NB: categories of barriers overlap).



¹U.S. Census Bureau data for 2013.

² Health disparities are tracked by the U.S. Department of Health & Human Services, Agency for Healthcare Research & Quality (AHRQ) in their annual National Healthcare Quality & Disparities Reports. The most recent report (2013) was accessed at: http://www.ahrq.gov/research/find-ings/nhqrdr/nhqr13/2013nhqr.pdf.

³ U.S. Census Bureau data, average for 2010, 2011, and 2012.

⁴Grant, R., et al. JAMA Pediatrics. 2014; 168: 385-386.

⁵Short, P.F., et al. Medical Care Research & Review. 2012;69:721-736

⁶ HRSA Data Warehouse, U.S. Department of Health and Human Resources, April '15

THE PROMISE OF HEALTH TECHNOLOGY

Innovative use of technology can improve health care access and quality, and enhance quality of life. This white paper will focus on several important technological advances in health care delivery, and their potential to improve care for the most vulnerable in our society. The introduction of new technologies into the health care system is sometimes called "disruptive innovation" because it breaks down traditional models, creating opportunities for improved access, quality, and customization (see Disruption, Adaptation, and Innovation below). While the past several decades have seen unprecedented technological progress, advances have often moved at a slow pace. A notable exception has been the development of electronic health records (EHR), as we will discuss later, where federal legislation with financial incentives greatly accelerated adoption of the technology. The growth of EHRs, however, was initially concentrated in hospitals and large health care systems. Electronic recordkeeping in safety net health care programs generally, and in pediatrics specifically, lagged behind.⁷

There has been rapid development and expansion of mobile technologies in the consumer market. Tablets began to gain significant traction in 2010. Combined with improvements in mobile broadband speed and coverage, rapidly expanding app marketplaces and accessible development tools, and transitions from traditional print media to electronically distributed publications, a strong mobile information consumer economy solidified and set the groundwork for monumental disruption from outside of the health care technology industry.

In this white paper we will discuss four technologies that have enormous potential to enhance care for children in poverty. Two improve access to care, mobile clinics and telehealth; and two improve quality, electronic health records and mobile health ("mHealth") interventions. There are many aspects to mHealth; we will focus on the use of mobile communication such as text messaging in the context of health care delivery.

DISRUPTION, ADAPTATION, AND INNOVATION.

The way Americans get health care is radically changing, and traditional ways are now disrupted. In general, something is "disruptive" when it fundamentally redefines what we considered well known and established. The term "disruptive innovation" was coined in a 1995 article in Harvard Business Review [1]. Harvard Business School Professor Clayton Christenson has written extensively on the subject. In a 2009 New York Times article, he explained that the term "... refers to an unexpected new offering that through price or quality improvements turns a market on its head" [2]. In the business sense, the concept has been applied to everything from the Internet to transistor radios. One of the challenges with disruption is that it is difficult to recognize from inside the system being disrupted. Often we tend to experience innovation and adaptation from within, and disruption from without. Whether we recognize it or not, the health care system is being disrupted, largely due to outside consumer-driven forces. Where we get health care, whether we have to "go to the doctor" to be treated, how our health information is stored and our own access to our health records – all of this creating the potential for the health care system to evolve into a new one that is more efficient, more patient-centered, and more consumer-driven.

 Bower, J.L. & Christensen, C.M. Disruptive technologies: Catching the wave. Harvard Business Review. 1995 (January). Accessed at: https://hbr.org/1995/01/disruptive-technologies-catching-the-wave.
New York Times, January 31, 2009. Accessed at: http://www.nytimes.com/2009/02/01/business/01unbox.html?_r=0.

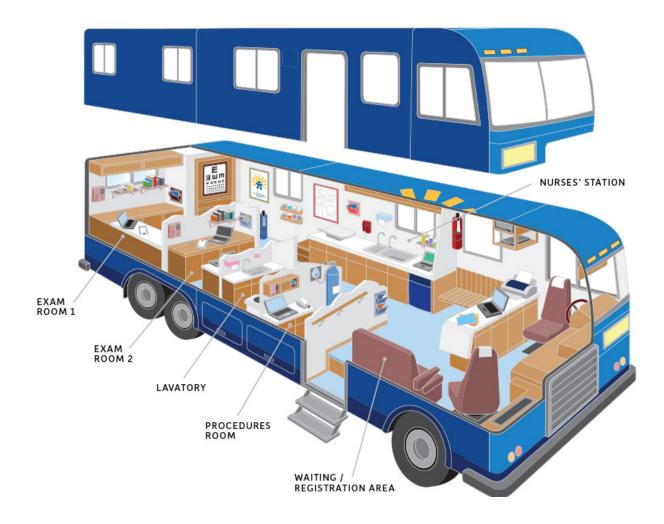
⁷Gracy, D., et al. Advances in Pediatrics. 2012; 59: 159–181

IMPROVING ACCESSS: MOBILE MEDICAL CLINICS

One of the earliest technologies at the junction of technology, mobility, patient access, and health care delivery has been the development of the mobile medical clinic (MMC or "mobile clinics"). Mobile clinics are literally doctor's offices on wheels, and bring health care to patients who otherwise could not get to the doctor. Mobile clinics also have the flexibility to relocate to keep pace with changing community needs, becoming dynamic and flexible additions to an area's health infrastructure.

Mobile medical clinics have existed in for decades but it wasn't until the late 1980s, when Children's Health Fund designed a pediatric clinic on wheels, that a real-world doctor's office entered daily public use in the United States. Designed to mirror every function of a fixed-site pediatric clinic – a full medical team, exam rooms, nurse's station, restroom, medication dispensing, even a waiting area – mobile clinics redefined the boundaries of space and functionality. (See Figure One.)

FIGURE ONE: A MOBILE MEDICAL CLINIC



These first MMCs were created to bring the health care to targeted patients: homeless children living in shelters and welfare hotels, who lacked access to routine health care. This is a rare instance where underserved populations, specifically vulnerable children, were the drivers of technological change, and the first to benefit from innovation.⁸ Mobile medical clinics—and later mobile dental, mental health, radiology, ophthalmology, and even mobile DNA testing clinics—now operate across the United States and the world. While many mobile clinic program models originally provided outreach and screening only, mobile units today are increasingly recognized as potential health care sites delivering high-quality, comprehensive health care. The federal agency responsible for funding and monitoring community health centers and rural health clinics now allows the purchase of a mobile clinic as an alternative to establishing a bricks-and-mortar clinic.⁹ As of 2014, there were at least 1,500 mobile clinics operating nationwide, providing 5 million visits per year.¹⁰

Despite the obstacles of often working in geographically remote areas, mobile clinics have been able to incorporate important advances in health technology, information systems, equipment miniaturization, and telecommunications; however, the success of mobile clinics in delivering quality health care to underserved and vulnerable populations has outpaced government regulations and policies. In 2008, Children's Health Fund surveyed state departments of health to ascertain their policies on reimbursing services at MMCs. Only 8 states reported that they allow Medicaid reimbursement at these locations, while 21 states could not report a clear reimbursement policy for care delivered on a mobile clinic.¹¹ Policy changes at the state and federal level are needed to allow this proven model to become sustainable and more broadly available.



⁸Redlener, I. Journal of Urban Health. 1998; 75: 724–731.

⁹US Department of Health & Human Services, Health Resources and Services Agency (HRSA). Starting a Rural Health Clinic - A How-To Manual. Accessed at: http://www.hrsa.gov/ruralhealth/pdf/rhcmanual1.pdf.

¹⁰ Hill, C.M., et al. American Journal of Managed Care. 2014; 20: 261-264.

¹¹ Overholt, S., et al. Presentation at 2008 Academy Health Annual Research Meeting. Accessed at:

http://www.childrenshealthfund.org/advocacy-and-research/conference-presentations.

The following are examples of mobile clinic successes:

- In a 2009 study conducted at Harvard Medical School, mobile medical clinics were found to save the health care system more than \$3 million in prevented emergency room visits against an annual operating cost of \$567,000. Additional savings were calculated based on patients' receipt of preventive care that they would not have otherwise received.¹²
- In Louisiana after Hurricane Katrina, mobile medical and mental health clinics demonstrated success in providing comprehensive pediatric care in an integrated medical home model to children and families. Mobile clinics are an effective model for post-disaster settings in which local health care infrastructure is devastated.¹³
- The American Academy of Pediatric Dentistry, responding to the workforce shortage that compromises oral health access for vulnerable children, cited international successes of mobile dental clinics in reaching underserved children in their policy statement, "Workforce Issues and Delivery of Oral Health Care Services in a Dental Home."¹⁴
- In a report on mobile clinic services to homeless adults and homeless families funded under the federal Health Care for Homeless Program, the role of technology was emphasized: wireless Internet access to download medical information and to enter intake information at visits; an electronic patient management system to check patient information in real time, and electronic health records to store information in the mobile clinic setting.¹⁵
- Mobile clinics have been recognized as an essential component of health reform in the post-ACA era, extending care to vulnerable populations. Nationally, 80% of mobile clinic users are non-White and/or Hispanic; 42% of visits are for pediatric patients; and services include preventive health screening, acute care, and chronic disease management. Access barriers successfully overcome through the mobile clinic model include transportation and geographic isolation, financial challenges (no insurance or copayment required), and mistrust between patient and provider addressed through culturally and linguistically appropriate communication.¹⁶

¹² Oriol, N.E., et al. *BMC Medicine*. 2009. 7:27; doi:10.1186/1741-7015-7-27.

¹³ Madrid, P., et al. Prehospital and Disaster Medicine. 2008; 23: 314-321

¹⁴ American Academy of Pediatric Dentistry. Accessed at: http://www.aapd.org/media/Policies_Guidelines/P_WorkforceIssues.pdf.

¹⁵ National Health Care for the Homeless Council. 2007. Accessed at: http://www.nhchc.org/wp-content/uploads/2012/02/mobilehealth.pdf. ¹⁶ Hill, C.F., et al. *American Journal of Managed Care*. 2014; 20: 261-264.

IMPROVING ACCESS: TELEHEALTH

The rapid rise of communications and computing technologies has converged with the potential to increase access to quality care through telemedicine, and more broadly, telehealth. (See Telemedicine and Telehealth on p.13 for a discussion of these terms). In this white paper, we will use the term telehealth, defined as the capacity to use telecommunications technologies to share clinical and allied information with a remote clinical resource such as a physician, nurse, or therapist, with the goal of providing direct health care services to a patient.

Telehealth has emerged as an important tool to improve access to pediatric specialists. There is a shortage of nearly all types of pediatric specialists, and this may worsen as older physicians retire.¹⁷ As new specialists begin to practice, they tend to settle in geographic areas where there is already a supply, so areas already facing shortages and inadequate access to specialist care continue to be underserved.¹⁸ This means that specialists will cluster in large cities with children's hospitals and teaching hospitals. The American Academy of Pediatrics reported that the average wait time for a pediatric specialist appointment is from 5 weeks to 3 months, clearly non-responsive to urgent needs. This is especially problematic in rural areas, where nearly two-thirds of primary care pediatricians rate the availability of specialists in their area as fair or poor.¹⁹

Evolving technology in communication linkages, and the equipment necessary to establish them, have facilitated the growth and improved quality of telehealth services. Relatively fast, secure, and stable communications links for the clinical environment have been facilitated by the advent of true 4G wireless broadband, its wide availability, and reduction in the costs of enabling technologies, e.g., 4G broadband modems. This has allowed the necessary equipment to be available in many clinical environments that previously could not achieve telehealth connections, including mobile clinics.

There has been unprecedented advancement and change in equipment in recent years. Earlier iterations of telehealth equipment were extremely bulky and required a lot of space in the clinical environment. Specialized cameras, for example, were at one time expensive to produce, expensive to use, and required specialized skills. Currently, as a result of advances in medical, diagnostic, laboratory and diagnostic technology, engineering, and consumer electronics fields, a dermatascope – a camera for examining the skin, sometimes controlled by the remotely located specialist – costs a few hundreds of dollars, rather than thousands. Operating the camera requires little more than plugging the device into a USB port on a computer and clicking a software application. Similar innovations and enhancements can be seen across the telehealth equipment spectrum.

There are different ways to accomplish a telehealth consultation. One possibility is real-time interaction, with the patient (often accompanied by a health care provider) in one site and the specialist in another. Communication is accomplished via video linkage. This is an appropriate way to accomplish behavioral health interventions, including case management and care coordination.

¹⁷ Jewett, E.A., et al. *Pediatrics*. 2005; 116; 1192-1202.

¹⁸ Mayer, M.L. & Skinner, A.C. Archives of Pediatrics and Adolescent Medicine. 2009; 163: 1087-1091.

¹⁹ American Academy of Pediatrics. America's Children Need Access to Pediatric Subspecialists. Accessed at: http://www2.aap.org/visit/Sec5203FactSheet.pdf.

Another method is "store and forward," in which a video or audio file or a photograph is obtained at the patient visit and electronically transmitted for review by a specialist at a later time in a remote site.

Telehealth can be an important link between primary care and behavioral health services, especially in light of the continuing shortage of child psychiatrists. The American Academy of Child and Adolescent Psychiatry issued a practice parameter in 2008 for telepsychiatry using interactive televideo communications.²⁰ A study of telehealth linkages over a two year period for behavioral health (mental health and child development) services found that the median distance that patients would have had to travel for a face-to-face visit was 63.8 miles.²¹

Another facet of telehealth is telementoring, an emerging model to help offset challenges that many impoverished communities face, especially those in rural areas who lack an adequate supply of specialists. In this model specialists remotely communicate with primary care doctors for general information, case conferencing, or other support in the care of complex patients. Over time, this will increase their knowledge base and improve the health care infrastructure in medically underserved communities.

The nature of the telehealth model – the patient and/or provider in one location and the specialist or consulting professional in another – presents policy issues in implementation. Questions that arise include, which health care provider will be reimbursed? Can both be reimbursed? What happens if the primary care provider and patient are in one state and the specialist in another (which often happens in rural areas near the border with another state)? Medicaid, for example, is a state-administered program and may not be available to reimburse physicians in another state. There are also problems that may arise when the patient is in a state in which the telehealth-linked specialist is not licensed to practice. Interstate reciprocity for licensure is uncommon. These issues have been raised in reports by the American Telemedicine Society and remain to be resolved.²²

Despite these potential barriers, there are important successes attributable to telehealth interventions. Spooner, writing for the American Academy of Pediatrics, outlined many areas where telehealth enhances pediatric practice. In teleradiology, the electronic communication of x-rays for reading by a remotely located health professionals is well established. A secure and relatively low-bandwidth connection is all that is needed. Store and forward technology is readily done for dermatology consultations, with the more limited detail available in commercial cameras replaced by dermatascopes which have the requisite level of resolution to allow remote diagnosis of skin lesions. Health professionals can use telehealth connections to monitor vital signs and other health indicators of home-bound patients.²³

Telecardiology services, in which heart murmurs and other sounds are remotely evaluated by a pediatric cardiologist, initially did not have optimal diagnostic validity, in part because of reduced bandwidth.²⁴

²⁰ AACAP Practice Parameter for Telepsychiatry With Children and Adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2008; 47: 1468-1483.

²¹ Soares, N.S., et al. *Telemedicine Journal and e-Health*. 2013; 19: 585-590.

²² American Telemedicine Association. State Telemedicine Gaps Analysis. September 2014. Accessed at:

http://www.americantelemed.org/policy/state-policy-resource-center#.VRTEdfnF_T9.

²³ Spooner, S.A., et al. *Pediatrics*. 2004; 113: e639-e643.

²⁴ Belmont, J.M., et al. *Telemedicine Journal*. 1995; 1: 133-149.

²⁵ Krishnan, A., et al. *Telemedicine and e-Health*. 2014; 20: 681-686.

This has changed with technological advances. In a review of remote transmissions of echocardiograms using Internet protocol technology over a 15 year period, investigators at Children's National Medical Center in Washington, DC found that the volume of patients served increased with no reduction in the quality of care.²⁵ More recently, the technology has become available to allow a specialist to hear heart sounds in real time via a digital stethoscope. This has greatly enhanced the accuracy of remote cardiac diagnostics.^{26 27}

Telehealth services have proven efficacy in treating conditions that disproportionately affect children in poverty, including weight management for children and adolescents who are obese.²⁸ Telehealth linkages with pediatric pulmonologists have effectively reduced asthma symptom severity and improved quality of life. The results were comparable in efficacy to those achieved in office visits with specialists.²⁹



TELEMEDICINE AND TELEHEALTH

The terms "telemedicine" and "telehealth" are sometimes used as if interchangeable: however, each has a somewhat different meaning. The US Health Resources Services Administration (HRSA) defines telehealth as "the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration. Technologies include videoconferencing, the internet, store-and-forward imaging, streaming media, and terrestrial and wireless communications" [1]. The Office of the National Coordinator of Health Information Technology adds, "Telehealth is different from telemedicine because it refers to a broader scope of remote healthcare services than telemedicine. While telemedicine refers specifically to remote clinical services, telehealth can refer to remote non-clinical services, such as provider training, administrative meetings, and continuing medical education, in addition to clinical services" [2]. Telemedicine is the more limited term, referring specifically to clinical services, generally in a distance communication that has a physician or other health care provider at both ends. Telehealth is the broader term, encompassing additional uses, e.g., patient health education and remote service delivery from allied health professionals (psychology, rehabilitation, nutrition counseling), case management, etc. Telehealth is the more commonly used term, including in federal policy. We will use the term "telehealth" throughout this document with the understanding that it includes the services referred to as "telemedicine" as well as other health-related services.

1. Accessed at: http://www.hrsa.gov/ruralhealth/ about/telehealth/. 2. Accessed at http://www.healthit.gov/providersprofessionals/faqs/what-telehealth-how-telehealthdifferent-telemedicine.

²⁶ Elawad, M. Digital Stethoscope Enables Remote Real Time Assessment of Heart and Lung Sounds. Accessed at: http://www.imedicalapps.com/2014/06/digital-stethoscope-lung-sounds/.

 ²⁷ Park, J. & Kyungtae, K. *Telemedicine and e-Health*. 2014; 20: 1069-1077.
²⁸ Lipana, L.S., et al. *Telemedicine and e-Health*. Epub 2013 Aug 27; doi: 10.1089/tmj.2012.0292.

²⁹ Romano, M.J., et al. *Telemedicine and e-Health*. 2001; 7: 281-286.

IMPROVING QUALITY: ELECTRONIC HEALTH RECORDS

Electronic health record (EHR) systems have been in use at least since the 1980s, with early systems having existed in computer labs and some academic hospitals. One of the first EHR systems to be used in a clinical setting was developed by Children's Health Fund in 1987 as a way to store patient information within the physical space restrictions posed by a mobile medical clinic. Having patient records on-site was essential for a patient population of medically underserved homeless children, who frequently presented with complex medical and psychosocial problems. They often had to be seen on a walk-in basis, so pre-delivering paper charts to the mobile clinic was not feasible. Currently, nearly 30 years later, there are hundreds if not thousands of EHR software systems available. Advances in 4G cellular broadband coverage, antennae systems, and connectivity have also allowed for more widespread and effective use of web-based EHRs in the mobile clinic environment.

The American Recovery and Reinvestment Act of 2009 and its HI-TECH provision sent billions of dollars in funding to health care providers and the health information technology industry. Federal "meaningful use" requirements were established through the Centers for Medicare and Medicaid Service (CMS), the agency that oversees public insurance reimbursement. This funding was made available to incentivize the use of EHRs to improve the quality, safety, and efficiency of health care delivery and to reduce health disparities.³⁰

These federal initiatives hastened the development and utilization of new technology, the uptake of which had previously been slow. A 2008 survey of physicians found that only 4% reported having a system they could describe as extensive and fully functioning and 13% had a basic system. Most likely to report using an EHR in their practice were physicians in large group practices or academic medical centers.³¹ A 2006 survey of EHR use among pediatricians found that 21.3% had some kind of electronic health record in their practice. The likelihood of having an EHR increased with the size of the practice, with pediatricians who were part of a large network or academic center more likely to have adopted the technology. Cost was a barrier, and issues were raised about pediatric-specific content and decision support in the commercially available products.³² Cost was also cited as a barrier to EHR use in community health centers, a major component of the safety net for medically underserved children.³³

There has been widespread adoption of EHR technology since 2009, illustrating the value that federal law and financial incentives can have in changing health care practice for the better.³⁴ Currently, survey data show that 80% of pediatricians use an EHR in their practice, although concerns remain about cost.³⁵

A unique advantage of health information technology is its capacity to allow comprehensive, computerized documentation of nearly every aspect of a person's health care interactions. All aspects of health care, including the doctor visit, lab tests and diagnostic imaging, and pharmaceutical information, can be and generally are now captured, stored, and accessed electronically when needed.

³⁰ Centers for Medicare and Medicaid Programs (CMS). EHR Incentive Programs. Accessed at:

http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/ehrincentiveprograms/. ³¹ DesRoches, C.M., et al. *New England Journal of Medicine*. 2008; 359(1): 50-60.

³² Kemper, A.R., et al. *Pediatrics*. 2006; 118: e20-e24.

³³ Miller, R.H. & West, C.E. Health Affairs. 2007; 26: 206-214

³⁴ Blumenthal, D. & Tavenner, M. *New England Journal of Medicine*. 2010; 363(6): 501-504.

³⁵ Lehmann, C.U., et al. *Pediatrics*. 2015; 135: e7-e15.

When used in a system of care, electronic health records facilitate care coordination by making information from one visit available to other providers involved with the care of that patient, so long as they have access to the electronic system. This is especially effective in hospital systems and primary care practices that are hospital affiliated. Electronically stored information may also be available to patients through Internet patient portals. It is possible to control the level of access to the health record based on "need to know" for each user. In this manner, each member of the health care team has real-time access to the patient's entire health record. Challenges remain regarding the software compatibility of different electronic systems that may be in use. There are also concerns about potential information breeches and compromised confidentiality of health information.

An important feature of EHRs, not sufficiently exploited in commercial software platforms, is the potential for computerized health records to be used to produce reports that describe patient characteristics, clinical needs, and treatment outcomes. Through electronically generated reports, registries can be created of patients with specific health conditions such as asthma or diabetes who may need more intensive follow-up. Patients with specific clinical needs can be flagged for the attention of the primary care provider, maximizing the efficiency of the visit.

Many physicians are frustrated, however, that their particular EHR is not customized for or able to capture the clinical elements most important for their patient population. In some large hospital systems, customization may be possible by an internal information systems team. In smaller practices, the vendor of the EHR system may have the ability to do certain kinds of customization, but this often is financially prohibitive.

Another limitation of the utility of EHRs is the lack of interoperability with other mobile technologies. For example, in many primary care settings, a tablet can be used to administer questionnaires or standardized screening for depression, child development, and psychosocial stressors while a patient is in the waiting room, improving efficiency and guiding treatment decisions. If the information collected on the tablet cannot be directly integrated with the EHR due to software incompatibility or firewalls, the advantages of the mobile technology over a paper survey are lost. Duplicate data entry would still be required. Alternatively, data could be scanned into the EHR, in which case it would not be integrated with other clinical content or extractible as an electronic report.

Additionally, as with many technologies, EHRs were not initially designed for children. Pediatricians across the nation are struggling with systems that often do not meet the unique needs of children, such as the support of weight-based medication dosing (that needs to be calculated in kilograms), growth tracking, age that needs to be recorded in months not years, and other child-specific issues.³⁶ A 2015 survey of Children's Hospital Association members found that there were still serious issues raised about suitability of available EHR platforms for use in pediatrics.³⁷

³⁶ Spooner, A.S., et al. Pediatrics. 2007; 119: 631-637.

³⁷Nakamura, N.N., et al. Journal of the American Medical Informatics Association (JAMIA). E-published ahead of print. 2015, March 9. pii: ocu045. doi: 10.1093/jamia/ocu045.

Despite the limitations of currently available EHR platforms, they have contributed to the quality of patient care in ways that have the potential to improve health outcomes for vulnerable children:

- Analysis of EHR data for immunization status at specific age points prior to 24 months of age has revealed indicators that children are at high risk of immunization delay. Interventions to promote up-to-date immunization status can be planned and implemented.³⁸
- In urban pediatric primary care settings, use of an EHR rather than paper charting improved the doctor's ability to focus on health promotion issues including nutrition, psychosocial risk such as domestic violence, lead exposure, and developmental milestones. This was, however, associated with a trend towards longer visits.³⁹
- Of particular importance for vulnerable children, clinical decision prompts in EHR platforms at the time of visit facilitated greater health provider compliance with best practice guidelines for children with asthma. The result was improved asthma symptom control.⁴⁰ Guidelines-based asthma treatment in primary care has been found to reduce health care costs by more than \$4,000 per patient with asthma per year in reduced hospital and emergency room use.⁴¹
- Electronic data extraction from EHRs was successfully used in a retrospective chart review methodology to evaluate the efficacy of a clinic-based family centered weight management program. Investigators analyzed changes in Body Mass Index (BMI) data over time. This type of study demonstrates the value of EHRs, when appropriately set up to run clinically meaningful reports. Such EHRs can generate data to assess the impact of interventions relevant to vulnerable children, in this case obesity intervention and weight management. ⁴²

IMPROVING QUALITY: mHEALTH

The term "mHealth" has several meanings. Its roots in the health care system are from the developing world, where it became a mechanism that leveraged the penetration of mobile phones into rural and medically underserved regions of India and Africa. Mobile devices support health service delivery in developing regions in many ways, including delivering health education, collecting health data, providing diagnostic services, and managing visits by health care providers. From this combination of technology (mobile devices) and need (health improvement), the term "mHealth" was coined. In the global health context, mHealth has become synonymous with telehealth.

In the US the term has come to describe a different way of using technology to enhance health care access and quality, through the use of mobile devices to "create, store, retrieve and transmit data in real time" via wireless technologies to improve the quality of health care.⁴³ The technology has promise especially to

³⁸ Fiks, A.G., et al. *Pediatrics*. 2006; 118: e1680-e1686.

³⁹ Adams, W.G., et al. *Pediatrics*. 2003; 113: 626-632.

⁴⁰ Bell, L.M., et al. *Pediatrics*. 2010; 125: e770-e777.

⁴¹ Grant, R., et al. Journal of Health Care for the Poor & Underserved. 2010; 21(Suppl 2): 82-92.

⁴² Brown, C.L., et al. Academic Pediatrics. 2015; 15:197-203

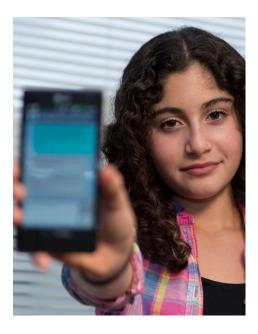
assist in the management of chronic conditions like asthma, diabetes, and epilepsy, with patients becoming able to independently generate health data on their own and communicate it with their doctors outside of the traditional health care setting.⁴⁴

The widespread use of mobile devices makes mHealth an especially powerful addition to the health care system. The National Institutes of Health reports that about two-thirds, 67.6%, of adults in the world own a mobile phone, with 285 million users of wireless communication services in the US. Among adolescents, three-fourths (75%) of high school students own a mobile phone. Unlike computers, where there has been a "digital divide" that kept lower income individuals from ownership, mobile phone use is ubiquitous across all socioeconomic sectors. This is indicative of the degree to which mobile phones have replaced land lines as the only telephone that individuals and families use. There are, however, geographic variations in mobile phone utility, with 99% of urban areas having wireless service compared to 82% of rural areas.⁴⁵

Not all mobile phones are smartphones, and penetration of smartphones into the telephone market is less extensive. Nonetheless, much of the use of mobile phones in health care have centered on smartphones. There are many sophisticated uses of smartphones within health care. An emerging technology likely to grow over the next few years, for example, is the use of smartphones for field or potentially home lab testing for certain conditions. Some mobile technologies use plug in accessories, microfluidic chips, or the phone's camera as part of the process. Systems like these have been piloted for the detection of certain kinds of cancers.⁴⁶ Smartphone apps are available for chronic disease management, physical fitness, and public health surveillance. Some apps make use of a Body Area Network with sensors; some use the phone's Global Positioning System (GPS) capabilities.⁴⁷

From the perspective of innovation, consumers have been adopting mHealth tools for information, self-monitoring, and self-management, as well as sharing with friends and family. This represents a significant shift from clinician-driven data management. Traditionally, in medical care, patients maintain a log or complete questionnaires supplied by a health care professional as part of wellness plans or chronic disease management.

In mHealth, health professionals are often by-passed, with the consumer independently acquiring health information including anthropometric data, calories consumed or burned, pulse oximetry information, diet and nutrition. When comprehensive personal health information is combined with a thoughtful health care provider's experience, health maintenance and the treatment of illness may be advanced.



⁴³ Akter, S. & Ray, P. *IMIA Yearbook of Informatics*. 2010; 75-81.

⁴⁴ Estrin, D. & Sim, I. *Science*. 2010; 330: 759-760.

⁴⁵ National Institutes of Health, Office of Behavioral and Social Sciences Research. mHealth - Mobile Health Technologies. Accessed at: http://obssr.od.nih.gov/scientific_areas/methodology/mhealth/.

⁴⁶ Business Wire. Detecting Disease with a Smartphone Accessory. Accessed at:

http://www.businesswire.com/news/home/20130604006318/en#.VJodrCrZA. ⁴⁷ Boulos, M.N.K., et al. *Biomedical Engineering Online*. 2011; 10: 24. Accessed at:

http://www.biomedical-engineering-online.com/content/10/1/24.

The use of mobile phones, particularly smartphones, to improve the quality of health care is the mHealth modality that is most generally available with the greatest potential to help vulnerable children and reduce health disparities. These are several examples:

- In an evaluative study of its use, short message service (SMS) text messages were well received at urban health centers by older pediatric patients and parents of patients. In the population, 94% of parents had mobile phones as did 75% of patients by 13 years of age. Nurses and allied health professionals were more comfortable using texts than were physicians. Texted appointment reminders were highly valued by parents.⁴⁸
- Communication by physicians to pediatric patients and their parents via smartphones contributed to comprehensiveness of care consistent with the medical home model. Examples are use of the technology for patient education, enhanced chronic disease management, and doctor-patient consultation.⁴⁹
- SMS texting has emerged as an effective tool in smoking cessation programs, including those directed at adolescents.⁵⁰
- In a weight management program, daily remotely communicated feedback improved patient adherence to diet and fitness protocols, resulting in improved outcomes.⁵¹
- SMS text messaging is an emerging tool in asthma management for high-risk patients, with the goal of improving medication adherence to reduce symptom severity, hospitalization and emergency room use. Some programs involve the pharmacist as well as the doctor, patient, and parent. For example, a smartphone app has been used successfully to communicate asthma action plan instructions to adolescents.⁵³ The American Lung Association lists seven mobile phone apps and games on its website. Each is aimed at helping the child with asthma self-monitor symptoms, improve mediation adherence, and follow his or her asthma action plan.⁵⁴

Despite a growing literature describing mHealth tools and interventions supporting the health needs of children and adolescents, the field is still very young. The rapidly changing technology landscape makes traditional long-term testing protocols difficult. By the time studies have been completed, new means of communication, interaction, and hardware technologies have come, gone, or changed substantially. It will take some time before we can prescribe the most effective mHealth tools and techniques. The answers will be drawn from across medicine, psychology, sociology, human factors engineering, and the health care and consumer technologies fields. However, it is clear that as with virtually every other aspect of the health care experience, mHealth will need to be one facet of a well-integrated and thoughtful program of care, guidance, and education.

⁴⁸ Mooney, J. *Telemedicine and e-Health*. 2012; 18: 454-458.

⁴⁹ Singh, Á., et al. *The Journal of Pediatrics*, 2014; 165: 606-610.

⁵⁰ Buller, D.B., et al. *Telemedicine and e-Health*. 2014; 20: 207-214.

⁵¹ Burke, L.E., et al. *American Journal of Preventive Medicine*. 2012; 43: 20–26.

⁵² De Vera, M.A., et al. *Trials*. 2014; 15: 10 pages. Accessed at: http://www.trialsjournal.com/content/15/1/488.

⁵³ Burbank, A.J., et al. *Journal of Asthma*. 2015. e-published ahead of print; DOI: 10.3109/02770903.2014.995307.

⁵⁴ American Lung Association. "Mobile Apps and Asthma Management: Why Educational Games Matter in Asthma Care. March 2014. Accessed at: http://www.lung.org/associations/charters/plains-gulf/news/mobile-apps-and-asthma.html.

CONCLUSION: NEW TECHNOLOGY DISRUPTS THE HEALTH CARE SYSTEM

The four technological advances we discussed have in common the potential to disrupt the way that health care services are traditionally delivered. Mobile medical clinics bring doctors directly to patients. They are service locations that move within communities to reach underserved patients, as opposed to fixed site clinics to which patients must travel. Telehealth and mHealth interventions involve doctor-patient interactions outside the health care visit at any location; communication is electronically facilitated. Electronic health records change the way that health information is stored and accessed. Some mHealth applications change the doctor-patient dynamics with respect to gathering, accessing, and communicating patient health information.

These are powerful approaches that together can make health care more accessible and efficient, more patient-centered, and potentially more effective than traditional delivery modalities. Regulation and policy, however, have not kept pace with innovation. Health care reimbursement – making sure that the doctor is paid by Medicaid or a commercial insurance plan – is built around a face-to-face visit in a doctor's office. When the same doctor-patient interaction can be accomplished by a video or text message, the patient need not travel to the doctor's office. Parents do not have to miss work, children do not miss school, geospatial access barriers do not interfere with timely health care, and the doctor's time may be better spent with a patient who needs to be examined.

We cannot predict with certainty where innovation and disruption will lead us in the future. New sensor technologies will allow parents and clinicians to anticipate children's health needs long before issues become serious enough to merit an emergency visit. Already computers are being trained to deliver diagnoses, leaving health care providers free to attend to complex and acute health needs. Smart devices and their rapidly escalating processor power may make truly portable, face-to-face and on-demand medical visits the norm, reading the patients' vital data as they speak, perhaps even dispensing medications and monitoring dosages. We see the beginnings of this today in activity monitors and clinical devices that now fit on a microchip but once required entire rooms to operate. Highly accurate lab tests requiring only a drop of blood have arrived and are on the threshold of availability across the country. Personalized medicine, optimized for each individual from the moment they are born, is not only possible, but likely.

Twenty years ago, we could not have imagined the extraordinary changes in our world enabled through the Internet and information technology that define our lives today. It is nearly certain that the same quantum changes will take place in the way health care is delivered over the next two decades. Children born today will certainly experience a world of health delivery and management vastly different than what we know.

For medically underserved children, health technologies available today and emerging tomorrow hold enormous promise to make health care more accessible, timely, and effective. For these innovative technologies to flourish in our health care system, however, federal and state policies must keep pace with technological innovation.

RECOMMENDATIONS

The Children's Health Fund makes the following recommendations to accelerate the use of new technologies to improve access and quality of health care for all children, especially for the most vulnerable.

- 1. New technologies must be designed for or adapted to the needs of children. Electronic health records, for example, have been in use for decades but commercially available electronic health records still often fail to be appropriate for child health care.
- 2. The federal Centers for Medicare and Medicaid Services (CMS) should create a special fund to incentivize the development of technologies to improve accessibility and quality of health care for medically underserved children.
- 3. Training curricula for health sciences students and providers should include education regarding the effective use of technology in improving health care in general and for underserved pediatric populations in general.
- 4. Efforts should be made, supported by strategic public awareness and education campaigns, to ensure that families fully understand how new technologies can improve the quality and availability of health information relevant to their children.
- 5. Innovative ways to make health care more accessible and efficient, especially for underserved children, must be financially supported. Disruptive changes to the system mobile medical clinics, telehealth, mobile communication between doctor and patient (e.g., text messaging), have moved health care delivery beyond the doctor's office, but insurance reimbursement has not followed.

