The Children's Partnership

PRESIDENTS
Wendy Lazarus & Laurie Lipper

CHILDREN'S HEALTH INFORMATION TECHNOLOGY ACTION PLAN:

Priorities for Federal Action to Modernize Health Care for Children through Health Information Technology

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The Children's Partnership (TCP) recommends a Children's Health Information Technology Action Plan that can modernize health care for America's children and model how these reforms can be effectively used to improve the health of broader populations while building greater fiscal efficiencies. TCP is a 15-year old nonprofit policy and strategy center, with offices in Washington, DC and California, working to improve the health of children and to improve their educational achievement and economic opportunities through effective use of the Internet and other technology tools.

Health Information Technology (HIT) can lay the groundwork for achieving the incoming Administration's health reform priorities of creating an accessible, patient-centered system that delivers effective, quality services, emphasizes preventive care, and functions with greater fiscal responsibility. With those goals in mind, there is no better place to focus HIT efforts than children. At this critical juncture, we would urge the 111th Congress to work with the new Administration to:

1. Prioritize children's needs and evaluate each HIT investment and policy change with an eye toward its potential to serve children;

2. Modernize Medicaid and SCHIP by providing funding and other incentives for states to increase administrative efficiency and the effectiveness of services delivered through those programs, which cover nearly 30% of America's children;

3. Promote three particular technology solutions that hold great promise for children: e-enrollment and retention to make sure that children have health coverage; electronic record systems to integrate information and services for particularly vulnerable children, such as those in foster care; and, telehealth applications to increase access to high quality care, especially for children living in medically underserved communities; and

4. Ensure that appropriate privacy protections are in place to promote children and families' trust in and use of health-promoting information technology.

1. PROMOTE CHILDREN'S HEALTH BY PRIORITIZING CHILDREN'S NEEDS IN THE DEVELOPMENT OF NEW HIT

For HIT to provide the fullest benefit to children, it must be designed for them.[1] Some HIT systems designed for adults may fit children as well, but that is not true for all HIT. For instance, an electronic health record that doesn't track a child's growth against a predicted curve is missing a key child health indicator.[2]

HIT is developing at a blistering pace in states and in the private sector. However, it requires the investment and involvement of the federal government to make sure that this opportunity occurs in a manner that benefits America's 74 million children, including children of all ages, those who are privately or publicly insured and those who are uninsured, children living in rural and urban areas, as well as children all along the spectrum from healthy to sick.

Federal policy-makers can prioritize children by:

- Directing agencies that currently conduct, regulate, guide, or provide funding and/or technical assistance for HIT to examine ways in which children's needs could be better met through administrative, clinical, and wellness applications of information and communications technologies; and
- Establishing and funding focused initiatives, such as those described below, to operationalize the findings of the inquiry.

2. PROMOTE CHILDREN'S HEALTH BY MODERNIZING MEDICAID AND SCHIP THROUGH HIT

Congress provided $150 million in Medicaid Transformation Grants that were awarded to 35 states, the District of Columbia, and Puerto Rico in 2007.[3] These funds have provided a strong and effective impetus for the development of HIT by state Medicaid programs, benefiting millions of children.[4] With the help of these funds, states have developed electronic health records for Medicaid recipients and e-prescribing capabilities, among other functions.[5] The grants have been successful because they were flexible and allowed states to design efforts that meet their specific needs.

A new federal funding initiative along the lines of the flexible Medicaid Transformation Grant would motivate and enable states to continue their progress in employing technology innovation. The 111th Congress should:

- Provide grant funding of <u>at least</u> $150 million for innovative HIT in Medicaid and SCHIP programs, giving preference to those system-transformative efforts benefiting children that promote a comprehensive, child-centered approach to care; and
- Structure the grants to allow states to develop technology that meets their unique needs.

[1] Richard Schiffman, et.al., "Information Technology for Children's Health and Health Care," *JAMIA*, Vol. 8, No. 6 (Nov.-Dec. 2001):546-551.
[2] S. Andrew Spooner and the Council on Clinical Information Technology, "Special Requirements of Electronic Health Record Systems in Pediatrics," *Pediatrics*, Vol. 119, No. 3 (March 2007): 631-637.
[3] See http://www.cms.hhs.gov/MedicaidTransGrants/ for further information.
[4] The Children's Partnership, *E-Health Snapshot: A Look at Emerging Health Information Technology for Children in Medicaid and SCHIP Programs* (Kaiser Commission on Medicaid and the Uninsured, Nov. 2008).
[5] Office of Inspector General, Department of Health and Human Services, *State Medicaid Agencies' Initiatives on Health Information Technology and Health Information Exchange* (August 2007).

3. PROMOTE CHILDREN'S HEALTH THROUGH THREE IDEAL TECHNOLOGY AVENUES

E-Enrollment and Retention that Increases Children's Access to Health Coverage
E-enrollment and retention use data-sharing and technology-enabled enrollment functions, like online applications and automated eligibility determinations, to make enrollment in public health insurance simpler and more efficient for families and the government while also making the system more accountable to the public.[6] In turn, stable health insurance coverage will improve the health and welfare of America's families.[7] Efficient enrollment and retention processes are also a logical precursor to efforts to increase or require coverage for all children.

The availability of enhanced funding for data retrieval and claims processing systems encourages HIT activity in Medicaid and SCHIP programs to improve those systems. However, states cannot receive enhanced funding for improvements made to Medicaid eligibility systems, though such systems are intricately linked to any substantive administrative overhaul to the public health care system.[8] To promote the modernization and efficiency of the IT that administers these critical programs, Congress should work with the new Administration to:

- Provide ongoing, targeted, enhanced financing that encourages states to invest in technology that improves cross-program coordination and data-driven enrollment systems;
- Remove the regulatory exclusion of eligibility systems[9] from the enhanced federal funding match given to the development and operation of Medicaid Management Information Systems if the eligibility systems are being revamped to connect more effectively with other programs' eligibility and data systems; and
- Offer bonus payments to states that reduce their population of eligible but uninsured children, which will help them fund eligibility system improvements.

A number of federal initiatives are underway that aim to promote cross-agency collaboration, including data-sharing. Most notable of these, for children's health, is the Medicaid Information Technology Architecture (MITA), which aims to provide states with the tools (and ultimately the financial pressure) to transform their Medicaid information systems into interoperable, beneficiary-centric systems.[10] It is critical that the 111th Congress work with the new Administration and direct the Department of Health and Human Services (HHS) to:

- Fund and support efforts like MITA;
- Provide targeted funding to support state HIT efforts that meet the criteria set by MITA; and
- Provide technical assistance and clarifying guidance to help state agencies overcome challenges to cross-agency data-sharing.

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[6] Op. cit. (4); The Children's Partnership, *E-Health Snapshot: Harnessing Technology to Improve Medicaid and SCHIP Enrollment and Retention Practices* (Kaiser Commission on Medicaid and the Uninsured, May 2007).
[7] Laura Summer and Cindy Mann, Georgetown University Health Policy Institute, *Instability of Public Health Insurance Coverage for Children and their Families: Causes, Consequences, and Remedies* (The Commonwealth Fund, June 2006).
[8] Shaun Alfreds, Eric Masters, and Jay Himmelstein, *Center for Health Policy and Research, Opportunities for Facilitating Electronic Health Information Exchange in Publicly Funded Programs: Findings from Key Information Interviews with Medicaid and SCHIP Leadership and Staff* (Shrewsbury, MA: U. Mass. Medical School, no date) 6.
[9] *42 CFR 433.112(c).*
[10] Richard Friedman, "Medicaid Information Technology Architecture: An Overview," *Health Care Financing Review* Vol. 28, No. 2 (Winter 2006-2007): 1-9.

Currently, Medicaid and SCHIP are required to collect and re-evaluate information even where another need-based program agency has already gathered that information, verified it, and found the family sufficiently low-income to qualify for its services. This procedure is inefficient and unnecessary in light of new technologies that allow for data-sharing and automation.[11] However, states will only be able to fully automate the eligibility and renewal process, add additional measures for verification and accountability, as well as reduce duplication and inefficiency if they are able to use another need-based program's income findings to determine eligibility without concern for minor differences in methodology. Congress should:

- Authorize states to determine eligibility for Medicaid and SCHIP based on the electronic data and findings of other need-based programs that are already in the state system (called "Express Lane Eligibility");
- Provide enhanced funding to states to make improvements to their eligibility systems that enable data-driven enrollment;
- Direct the Centers for Medicare and Medicaid Services (CMS) to issue guidance that clarifies the opportunity to use electronic signatures; and
- Give states this flexibility as part of SCHIP reauthorization.

The Deficit Reduction Act of 2005 (DRA) requires states to collect documentation of citizenship and identification for all Medicaid applicants and recipients. This documentation requirement has led to widespread declines in Medicaid enrollment and increased administrative costs (of $100 spent for every 14 cents in Medicaid savings).[12] It also presents a challenge to e-enrollment, retention, and other administrative streamlining. Congress should work with the new Administration and direct CMS to:

- Overturn the documentation requirement imposed by the DRA; and
- Allow states to use data-matching procedures to satisfy existing documentation requirements for Medicaid and SCHIP where doing so is at least as efficient and reliable as other options.

Electronic Record Systems that Improve Coordination and Continuity of Children's Care

Electronic record systems can help providers coordinate care for children through better information-sharing and, thereby, help ensure that appropriate, cost-effective services are delivered. Cross-sector coordination of care is a central element of a cost-effective health system that promotes health rather than focusing just on treating disease.[13] And, yet, a number of financial, legal, and structural barriers work against coordination and collaboration by public and private agencies—from siloed funding to conflicting missions to incompatible technology.[14]

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[11] The Children's Partnership and First Focus, *Modernizing Medicaid and SCHIP so They Work Better for Children and Taxpayers: The Case for Wise Investments in Health IT* (www.childrenspartnership.org).
[12] U.S. Government Accountability Office, *Medicaid: States Reported Citizenship Documentation Requirement Resulted in Enrollment Declines for Eligible Citizens and Posed Administrative Burdens* (GAO/07-889, July 2007).
[13] David Bergman, Paul Plsek, and Mara Saunders, *A High-Performing System for Well-Child Care: A Vision for the Future* (New York, NY: The Commonwealth Fund, Oct. 2006).
[14] U.S. General Accounting Office, *Managing for Results: Barriers to Interagency Coordination* (GAO/GGD-00-106, March 2000).

Such barriers are especially apparent in efforts to coordinate care for foster children, who need coordination across education, juvenile justice, mental health, health care, and foster care agencies, at a minimum.[15] These same impediments to actual collaboration interfere with the development of electronic record systems that can facilitate collaboration, whether in service of foster children or others.

In building an electronic record system that works for foster or other specific groups of vulnerable children, the new Administration could lead a systemic shift toward coordination and create a platform for electronic record systems that can later be scaled to benefit all children. To accomplish this goal, all relevant federal agencies should be directed to:

- Conduct a swift internal review of relevant programs to identify legal and structural barriers to coordination, rules that inhibit program funding from following the child receiving services, and federal funding restrictions in need-based public programs that result in program silos;
- Take administrative steps to remove these barriers to coordinated care for children and work with Congress to secure legislative change necessary to accomplish these systemic improvements;
- Adopt standards and guidelines that spur the adoption of HIT and provide explicit authority for the information-sharing that is necessary to accomplish this coordination through new HIT avenues;
- Provide incentives for states to develop and implement electronic record systems in their efforts to comply with the requirements for health care oversight and coordination for children in foster care under the Fostering Connections to Success and Increasing Adoptions Act of 2008 (HR 6893), and monitor compliance with the requirements; and
- Connect states to discuss best practices and share technology.

Telehealth and Telemedicine that can Increase Children's Access to Health Care Services, Especially for Children Living in Medically Underserved Communities

Telehealth uses technology supported by broadband—such as videoconferencing, Web-based applications, remote monitoring devices, and other innovative tools—to provide health care at a distance. It can increase access to health care, help children and families manage chronic diseases and conditions, facilitate coordination of children's care, and promote prevention and wellness. Through telehealth, providers can reach new populations with the exact care that they need, no matter where they are located.[16] Because there is a particular shortage of pediatric subspecialists across the nation, telehealth holds particular promise for children in medically underserved areas.[17]

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[15] The Children's Partnership, *Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems* (October 2008).
[16] The Children's Partnership, *Meeting the Health Care Needs of California's Children: The Role of Telemedicine, 2nd Ed.* (March 2008).
[17] Ethan. A. Jewett, et al., "The Pediatric Subspecialty Workforce: Public Policy and Forces for Change," *Pediatrics*, Vol. 116, No. 5 (2005): 1192-1202; Alan Gruskin, et al., "Final Report of the FOPE II Pediatric Subspecialists of the Future Workgroup," *Pediatrics*, Vol. 106, No. 5 (2000): 1224-1244.

In late 2007, the Federal Communications Commission awarded over $417 million for the construction of 69 statewide or regional broadband telehealth networks in 42 states and three U.S. territories under the Rural Health Care Pilot Program.[18] Because this funding supports only the telecommunications infrastructure for the networks, states will need support to develop and operate corresponding telemedicine and telehealth programs to deploy across the networks so that children, especially underserved children, can use the networks to meet their health care needs. Congress should work with the incoming Administration to:

- Invest operational dollars into the Rural Health Care Pilot Program so that the recently FCC-funded networks are used to their full potential.

Children in rural areas are enrolled in Medicaid at a higher rate than those in urban areas.[19] To increase their access to health care and improve their health outcomes through the use of telemedicine, the 111th Congress can make a big difference for children by working with the new Administration to:

- Create an incentive program under CMS to make maximum appropriate use of telemedicine and telehealth for children enrolled in Medicaid and SCHIP; and
- Design the incentive program such that funds are available only when a state identifies: health care needs of enrolled children that are not being met through traditional means, telemedicine and telehealth applications that are appropriate to meet the unserved needs, and a method for evaluating the application of telemedicine and telehealth tools to improve health outcomes.

The National Health Service Corps (NHSC) provides loan repayment programs to health providers who practice in underserved areas. Currently, the NHSC program requires participants to be physically located in the underserved area and provide full-time services. However, health providers in urban areas, today, now provide health care to patients in underserved rural areas via telemedicine and telehealth. Federal policy-makers could expand access for children and modernize the NHSC by:

- Piloting the use of the NHSC to fund the provision of care to underserved populations through telemedicine and telehealth instead of requiring participants to be located in the rural community they are serving full time.

4. CLARIFY AND ENFORCE PRIVACY PROTECTIONS TO ENSURE HEALTH-PROMOTING BENEFITS OF HIT ARE REALIZED

The success of any children's HIT effort that involves information exchange depends on having trustworthy, accurate information in the system and open communication between provider and family. Such communication is essential to quality pediatric care with positive outcomes.[20] While Congressional debate continues about the terms of future information privacy protections, federal authorities can provide clearer guidance and assistance to help

[18] Julie Schwartz, Progressive States Network, *Telehealth: Merging of Technology and Medicine Leads to Improved Healthcare* (May 2008).
[19] Kaiser Commission on Medicaid and the Uninsured, *Health Insurance Coverage in Rural America* (Washington, D.C.: The Henry J. Kaiser Family Foundation, 2003).
[20] Marie Mann, Michele Lloyd-Puryear, and Deborah Linzer, "Enhancing Communication in the 21st Century," *Pediatrics*, Vol. 117, No. 5 (May 2006): S315-319.

states incorporate appropriate privacy measures into their HIT efforts.[21] To enable this process, Congress and the new Administration should:

- Strengthen enforcement of the privacy protections that are already in place;
- Issue guidelines that clarify how existing privacy protections address unanticipated issues that have arisen since the protections were put in place (e.g., the emergence of personal health records hosted by organizations that are not covered entities under the Health Insurance Portability and Accountability Act (HIPAA);
- Identify privacy concerns and appropriate responses that are unique to caring for children;
- Develop compatible, model privacy policies that can be adopted by states and stakeholders; and
- Develop a process for awarding federal HIT privacy certification through the Office of the National Coordinator for Health Information Technology.

IN SUM, NOW IS THE TIME

Now is the time to make children's e-health a priority. Rapid advancements in HIT capability should benefit all children, especially those who are most vulnerable and currently served by Medicaid and SCHIP. States and the private sector will need to work in partnership with the federal government to make this happen. But, without the leadership and support of federal policy-makers, the resulting systems will remain fractured and may not reach the children in greatest need.

For further information, please contact:

Ken Kelly
Director, Washington D. C. Office, The Children's Partnership
kkelly@childrenspartnership.org
(202) 429-0033

[21] U. S. Government Accountability Office, *Health Information Technology: HHS Has Taken Important Steps to Address Privacy Principles and Challenges, Although More Work Remains* (GAO-08-1138).

For further information on E-Health for Children, see:

E-Health Snapshot: A Look at Emerging Health Information Technology for Children in Medicaid and SCHIP Programs (2008)
Available at: http://www.childrenspartnership.org
and http://www.kff.org/medicaid/7837.cfm

Improving Health Outcomes for Children in Foster Care: The Role of Electronic Record Systems (2008)
http://www.childrenspartnership.org/reports/fostercare

Meeting the Health Care Needs of California's Children: The Role of Telemedicine, 2nd Ed. (2008)
http://www.childrenspartnership.org/reports/telemedicine

Meeting the Needs of California's Children in Schools and Child Care: Telemedicine Can Help (2007)
http://www.childrenspartnership.org/schoolstelemedicine

E-Health Snapshot: Harnessing Technology to Improve Medicaid and SCHIP Enrollment and Retention Practices (2007)
Available at: http://www.childrenspartnership.org/reports/ehealthsnapshot
and http://www.kff.org/medicaid/7647.cfm