



Addressing the Health Needs of Children in the Child Welfare System

Recommendations to Improve Insurance Coverage, Access to Health Services, Screening, Prevention, Treatment, and Data Collection

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SUMMARY

Each year, over 5 million children come into contact with the child welfare system, including 800,000 children in foster care.² These children have a variety of unique health care needs and suffer from a higher incidence of physical and mental illness than children in the general population. However, the health care and child welfare systems frequently fail to meet their needs. This policy brief describes areas of need and proposes recommendations to improve insurance coverage, access to health services, screening, prevention, treatment, and data collection for these children.

The following four recommendations are of particular importance in protecting and improving children's health. Congress should pass legislation that:

- **Improves coordination of care delivery for children in the child welfare system.** All children should have a "medical home," a model of health care delivery that encourages coordination of services among providers, greater access to preventive care, and comprehensive disease management.
- **Increases federal funding for the implementation of abbreviated electronic medical records for foster children.** These records are known as "medical passports." They contain the most essential information about a child's health and follow the child from provider to provider. Pilot medical passport projects have begun in many states. Congress should continue to support these programs through increased funding.
- **Preserves funding for targeted case management and rehabilitative services within Medicaid.** In June 2008, Congress passed a moratorium delaying until 2009 the implementation of proposed CMS rules that would have greatly reduced the availability of targeted case management and rehabilitative services. Congress should permanently extend the moratoria on these rules.

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² U.S. Department of Health and Human Services, Administration for Children and Families. "Trends in Foster Care and Adoption – FY 2002-FY 2006," July 2008. Available online at: http://www.acf.hhs.gov/programs/cb/stats_research/afcars/trends.htm; Allen, K. "Medicaid Managed Care for Children in Child Welfare," Center for Health Care Strategies, April 2008. Available online at: http://www.chcs.org/publications3960/publications_show.htm?doc_id=683204

- **Ensures continuing Medicaid coverage for young people transitioning out of foster care.** This can be achieved by including foster alumni as a mandatory coverage category under Medicaid, by allowing youth to extend their stay in foster care beyond age 18, or by passing some form of universal health care coverage.

I. HEALTH NEEDS

The child welfare population can be broadly defined as children in protective services, children in out-of-home care, and children who are being adopted.³ Nearly 90 percent of children entering the child welfare system have physical health problems, and close to 40 percent need urgent medical referrals.⁴ Common physical conditions these children suffer include asthma, diabetes, vision and hearing problems, malnutrition, skin disease, severe allergies, manifestations of abuse, dental caries, and a high risk for HIV/AIDS.⁵

Children entering the child welfare system also have a higher incidence of problems requiring mental health intervention than children in the general population. Studies have estimated that up to 80 percent show signs of mental, behavioral, or developmental problems,⁶ compared to only 20 percent of children in the general population.⁷ Common mental health problems include attention deficit hyperactivity disorder (ADHD), depression, learning disabilities, speech or language impairment, post-traumatic stress disorder (PTSD), adjustment disorders, and substance abuse, among others.⁸

Furthermore, children in the child welfare system are far more likely than their counterparts to experience a chronic health condition or multiple health conditions.⁹ In fact, over 55 percent have two or more chronic illnesses.¹⁰

In some cases, children in the child welfare system receive more health services than other low-income children.¹¹ However, evidence indicates that at least a third of children in the system have an unmet

³ Child Welfare League of America. "Medicaid Targeted Case Management for the Child Welfare Population." July 2005. Available online at: <http://www.cwla.org/advocacy/tcm.htm>

⁴ Allen op. cit (2); Center for Health Care Strategies. "Children in Child Welfare Systems: Physical and Behavioral Health Needs." Available online at: http://www.chcs.org/usr_doc/Physical_and_Behavioral_Health_Needs.pdf; English, A. and Grasso, K. "The Foster Care Independence Act of 1999: Enhancing Youth Access to Health Care," *Journal of Poverty Law and Policy*, July-August 2000. Available online at: <http://www.abanet.org/child/englishgrasso.pdf>

⁵ CHCS op. cit (4); Allen op. cit (2); U.S. Department of Health and Human Services, Administration for Children and Families, Office of Planning, Research, and Evaluation. "Special Health Care Needs Among Children in Child Welfare," National Survey of Child and Adolescent Well-Being, Research Brief No. 7, July 2007. Available online at:

http://www.acf.hhs.gov/programs/opre/abuse_neglect/nscaw/reports/special_health/special_health.html

⁶ CHCS op. cit (4); Geen, R., et al. "Medicaid Spending on Foster Children." The Urban Institute Child Welfare Research Program, Brief No. 2, Aug. 2005. Available online at: http://www.urban.org/UploadedPDF/311221_medicaid_spending.pdf

⁷ U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*. Rockville, MD: HHS, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999. Available online at: http://www.surgeongeneral.gov/library/mentalhealth/chapter2/sec2_1.html

⁸ HHS op. cit (5); Allen op. cit (2); *Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV)*, cited in Austin, L. "Mental Health Needs of Youth in Foster Care: Challenges and Strategies." *The Connection* 20.4 (2004): 6-13. Available online at: <http://www.casenet.org/library/foster-care/mental-health-%5Bconnection-04%5D.pdf>; Troutman, B., et al. "The Effects of Foster Care Placement on Young Children's Mental Health." Report to the Iowa Consortium for Mental Health. Available online at:

http://www.medicine.uiowa.edu/ICMH/archives/reports/Foster_Care.pdf; Rosenbach, Margo. "Children in Foster Care: Challenges in Meeting Their Health Care Needs Through Medicaid." Mathematica Policy Research, Inc., March 2001. Available online at: <http://www.mathematica-mpr.com/PDFs/fostercarebrief.pdf>

⁹ CHCS op. cit (4); Simms, M., et al. "Health Care Needs of Children in the Foster Care System." *Pediatrics* 106.4 (2000): 909-918. Available online at: <http://pediatrics.aappublications.org/cgi/reprint/106/4/S1/909>; Szilagyi M. Extract from "The Pediatrician and the Child in Foster Care." *Pediatrics in Review* 19.2 (1998):39-50. Available online at:

<http://pedsinreview.aappublications.org/cgi/content/extract/19/2/39>

¹⁰ Allen op. cit (2)

¹¹ Rosenbach op. cit (8); Simms op. cit (9); Kortenkamp, K. and Ehrle, J. "The Well-Being of Children Involved with the Child Welfare System: A National Overview." The Urban Institute, New Federalism: National Survey of America's Families, Series B, No. B-43, January 2002. Available online at: http://www.urban.org/UploadedPDF/310413_anf_b43.pdf; dosReis, S., et al., "Mental Health Services for Foster Care and Disabled Youth," *American Journal of Public Health*, 91.7 (2001): 1094-1099. Available online at: <http://www.ajph.org/cgi/reprint/91/7/1094>; Stahmer, A., et al. "Developmental and Behavioral Needs and Service Use for Young

physical or mental health need,¹² 12 percent receive no routine medical care,¹³ and 37-70 percent of states fail to meet standards of consistency in the provision of health assessments, preventive health care, and mental health care.¹⁴ Even children who do receive health services often receive fragmented or inappropriate care.¹⁵ By expanding health insurance coverage; increasing access to health care services; improving screening, prevention, and treatment; and enhancing the collection of data on the child welfare population, the health of these vulnerable children can be dramatically improved.

II. INSURANCE COVERAGE

Studies show that people without health insurance coverage are less likely to access needed care, more likely to have delayed diagnoses, and have higher mortality rates.¹⁶ This problem is especially pressing for children in the child welfare system, who have greater health needs than children in the general population. Although most foster children are covered under Medicaid, most states do not extend Medicaid benefits to children aging out of foster care, and one third of children in kinship care do not have health insurance.¹⁷

Each year, over 20,000 adolescents age out of foster care.¹⁸ The Foster Care Independence Act of 1999 established these youth as an optional Medicaid coverage category eligible for federal matching funds, but only 17 states have extended Medicaid coverage to this population, with 5 more states planning to do so.¹⁹ Most of the remaining states use other programs to provide health coverage, but the overwhelming variety and differing eligibility rules for these programs present a significant obstacle to young people seeking health insurance coverage. The need for health services remains high among youth aging out of foster care, with nearly 55 percent experiencing one or more mental health disorders. PTSD and major depression are of particular concern.²⁰ Without health insurance, these young people will not be able to access the health services they need. Ensuring continuing coverage of health care needs is vital to improving the health of this population.

Like children aging out of foster care, children in kinship care also face difficulties obtaining health insurance. One third of children living in formal kinship care lack health insurance, and they are five times more likely to be uninsured than children in foster care.²¹ This gap in coverage between foster children

Children in Child Welfare." *Pediatrics* 116.4 (2005): 891-900. Available online at:

<http://pediatrics.aappublications.org/cgi/reprint/116/4/891>

¹² Kortenkamp op. cit (11); U.S. General Accounting Office. "Foster Care: Health Needs of Many Young Children are Unknown and Unmet." Report to the Ranking Minority Member, Subcommittee on Human Resources, Committee on Ways and Means, House of Representatives. GAO/HEHS 95-114, May 26, 1995. Available online at:

<http://citeseerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.42.5966>

¹³ U.S. GAO op. cit (12); American Academy of Pediatrics, Committee on Early Childhood, Adoption, and Dependent Care. "Health Care of Young Children in Foster Care." *Pediatrics* 109.3 (2002): 536-541. Available online at:

<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;109/3/536.pdf>

¹⁴ Percentages are based on states plus Puerto Rico and the District of Columbia that participated in the Federal Child and Family Services Review. See U.S. Department of Health and Human Services, Administration for Children and Families. "General Findings from the Federal Child and Family Services Review: I. State-Level Data Analyses." 2005. Available online at:

<http://www.acf.hhs.gov/programs/cb/cwmonitoring/results/genfindings04/ch1.htm>

¹⁵ Rosenbach op. cit (8); AAP op. cit (13); Halfon, N. et al. "A Guide to Developing Health Care Systems for Children in Foster Care." The UCLA Center for Healthier Children, Families and Communities. November 2001. Available online at:

<http://www.aap.org/advocacy/hfca/Foster%20Care%20Manual%20final.pdf> ; First Focus. "Addressing the Health Care Needs of Foster Care Children." Policy brief, May 2008. Available online at: <http://www.firstfocus.net/Download/FosterCareHealth.pdf>

¹⁶ English op. cit (4)

¹⁷ American Public Human Services Association. "Medicaid Access for Youth Aging Out of Foster Care." 2007. Available online at:

<http://www.aphsa.org/Home/Doc/Medicaid-Access-for-Youth-Aging-Out-of-Foster-Care-Rpt.pdf> ; Berman, S. and Carpenter, S.

"Children in Foster Care and Kinship Care at Risk for Inadequate Health Care Coverage and Access." Changes in Health Care Financing and Organization, Academy Health Findings Brief, Vol. VII, No. 4, July 2004. Available online at:

<http://www.hcfo.net/pdf/findings0704.pdf>

¹⁸ English op. cit (4)

¹⁹ APHSA op. cit (17)

²⁰ Rosenkranz, B. "Mental Health Care Issues for Children and Youth." National Resource Center for Family-Centered Practice and Permanency Planning. April 2006. Available online at:

http://hunter.cuny.edu/socwork/nrcfcpp/downloads/information_packets/Mental_Health.pdf

²¹ Berman and Carpenter op. cit (17)

and children in kinship care is partially due to caretakers' and caseworkers' insufficient knowledge about Medicaid eligibility. An Urban Institute report found that only 53 percent of children in kinship care were receiving the Medicaid benefits for which they were eligible.²² Eligibility rules for Medicaid and other public assistance programs such as Supplemental Security Income (SSI) can be confusing and complicated, and child welfare workers are all too often unfamiliar with the myriad programs available to children.²³ Furthermore, kinship families are often hard to reach and are frequently overlooked in Medicaid outreach activities.²⁴

Recommendations

- **Ensure continuing Medicaid coverage for young people transitioning out of foster care.** Two bills currently before Congress address this issue.
 - H.R. 1376, sponsored by Rep. Dennis Cardoza (D-CA), establishes independent foster care adolescents as a mandatory category of individuals for coverage under state Medicaid programs. Under this bill, all states would be required to extend Medicaid coverage to youth aging out of foster care up to age 21.
 - S. 1512, sponsored by Sen. Barbara Boxer (D-CA), gives states the option for youth to elect to remain in foster care up to age 21. Although the bill does not specifically mention Medicaid, it would automatically extend Medicaid coverage to this group by allowing them to remain in the foster care system up to the age limit specified by each state.

Congress should pass these bills and/or other health care reform bills that would expand coverage to young people transitioning out of foster care.

- **Improve outreach and education programs to help caregivers and caseworkers understand eligibility for Medicaid, SSI, and other benefits.** Kinship families should be targeted in Medicaid and SCHIP outreach activities, and Medicaid and SCHIP workers should receive training on eligibility rules. The Children's Defense Fund recommends the simplification of application forms and documentation requirements in order to facilitate the application process.²⁵

III. ACCESS TO HEALTH SERVICES

Expanding health insurance coverage addresses only part of the problem for children in the child welfare system. Being covered by Medicaid does not necessarily mean that these children (and other low-income children) will be able to access health services, primarily because of shortages of pediatric mental health providers and of health providers who accept Medicaid.

There is a general shortage of primary care providers in many areas of the country, especially pediatric mental health providers.²⁶ In a review of states' compliance with standards of provision of care for children in the child welfare system, HHS found a shortage of mental health services for children in 71 percent of states (see Chart 1 below).²⁷ An earlier study by HHS found that 25 states reported a lack of mental health services as a barrier to meeting the standards.²⁸

²² Ehrle, J., et al. "Children Cared for by Relatives: Who are They and How are They Faring?" The Urban Institute. February 2001. Available online at: <http://www.urban.org/publications/310270.html>

²³ English op. cit (4)

²⁴ First Focus op. cit (15).

²⁵ Bissell, M.K. and Allen, M.L. "Healthy Ties: Ensuring Health Coverage for Children Raised by Grandparents and Other Relatives." Children's Defense Fund. 2001. Available online at:

http://www.childrensdefense.org/site/DocServer/healthyties_fullreport.pdf?docID=638

²⁶ Allen op. cit (2); Data from HHS cited in Geen op. cit (6); Austin, L. "Mental Health Needs of Youth in Foster Care: Challenges and Strategies." *The Connection* 20.4 (2004): 6-13. Available online at: <http://www.casenet.org/library/foster-care/mental-health-%5Bconnection-04%5D.pdf>

²⁷ Percentages are based on states plus Puerto Rico and the District of Columbia that participated in the Federal Child and Family Services Review. See HHS op. cit (14).

²⁸ Rosenkranz op. cit (20)

Chart 1: Common Challenges with Child Well Being Indicators and Number of States for which Challenges were Relevant - 2002-2004

Challenge	# (%) of states*
The number of doctors/dentists in the State willing to accept Medicaid is not sufficient to meet the need.	27 (77)
The agency is not consistent in providing children with preventive health and/or dental services.	14 (40)
The agency is not consistent in conducting adequate, timely health assessments.	13 (37)
There is a lack of mental health services for children.	25 (71)
The agency is not consistent in conducting mental health assessments.	24 (69)

*Percentages are based on the number of states plus Puerto Rico and the District of Columbia that participated in the Federal Child and Family Services Review. 35 states participated.

Source: U.S. Department of Health and Human Services, Administration for Children and Families. "General Findings from the Federal Child and Family Services Review: I. State-Level Data Analyses." 2005. Available online at: <http://www.acf.hhs.gov/programs/cb/cwmonitoring/results/genfindings04/ch1.htm>

The shortage of health care providers willing to accept Medicaid patients has been well documented.²⁹ The U.S. Department of Health and Human Services (HHS) found in 2005 that in 77 percent of states, the number of doctors and/or dentists accepting Medicaid was too low to meet the needs of children in the child welfare system (see Chart 1).³⁰ A key factor in this shortage is a schedule of reimbursement rates that are generally perceived as too low for providers who contract with Medicaid on a fee-for-service (FFS) basis to stay financially solvent if they accept large numbers of Medicaid patients.³¹ Primary care providers are put at a particular disadvantage by low reimbursement rates: public and private fee structures already favor specialty over primary care, and Medicaid rates have not kept pace with payment rates in the private market.³² Although the number of specialists participating in Medicaid has increased in some places across the country, the rate of participation among general practitioners has declined in many areas, leaving Medicaid patients with few options for accessing health services on a FFS basis.³³

Another option for Medicaid patients is to enroll in a managed care plan. However, low reimbursement rates also impact children's enrollment in Medicaid managed care plans. States pay managed care plans a fixed per-child rate, called a capitation rate, and the plan assumes all costs for treating the child. Because of their large, integrated, multi-specialty practices, managed care plans have great potential to address the complex health needs of children in the child welfare system.³⁴ However, rates of participation vary widely across states, and reimbursement rates for children in these plans vary even more widely. Fourteen states reported they did not enroll any children in managed care as of June 2007; among those who did enroll children in managed care, the rates of enrollment ranged from 15.1 percent

²⁹ Allen op. cit (2); Geen op. cit (6)

³⁰ Percentages are based on states plus Puerto Rico and the District of Columbia that participated in the Federal Child and Family Services Review. See HHS op. cit (14).

³¹ The exception to this is Federally Qualified Health Centers, which receive more federal funding in return for their work with underserved populations. Despite seeing broad increases in funding since 2002 and subsequent increases in the number of patients served, these health centers do not exist in sufficient numbers to serve the entire Medicaid and uninsured population. (See U.S. Department of Health and Human Services, Health Resources and Services Administration. "Increasing Access to Health Care in the Nation's Neediest Communities." Available online at: <http://bphc.hrsa.gov/presidentsinitiative/>)

³² Holahan, J., et al. "Medicaid Managed Care Payment Methods and Capitation Rates: Results of a National Survey." The Urban Institute, Occasional Paper No. 26, May 1999. Available online at: <http://www.urban.org/UploadedPDF/occa26.pdf>

³³ *Medical News Today*. "More Nevada Specialists Participating in Medicaid Despite Reimbursement Cuts, Survey Finds." Aug. 15, 2008. Available online at: <http://www.medicalnewstoday.com/articles/118353.php> ; Center for Studying Health System Change.

"Medicaid Patients Increasingly Concentrated Among Physicians." News release, Aug. 17, 2006. Available online at: <http://www.hschange.org/CONTENT/867/>

³⁴ Allen op. cit (2)

in Illinois to 100 percent in South Dakota and Tennessee.³⁵ While some states benchmark their managed care capitation rates to statewide FFS rates, others pay significantly more or significantly less than their FFS rates.³⁶ In recent years, many states have moved toward using risk-adjusted capitation rates for children in the child welfare system. By increasing capitation rates for children in the child welfare system to account for the higher cost of serving them, risk-adjusted capitation protects managed care plans from incurring losses and encourages them to enroll more of these high-need children.³⁷ However, as of 2003, only 10 percent of states used risk-adjusted rates for children in the child welfare system.³⁸

Recommendations

- **Support efforts to increase the number of pediatric mental health providers and other general practitioners who provide services to children.**
- **Increase Medicaid reimbursement rates for primary care providers, pediatric dentists, and pediatric mental health providers. Expand the use of risk-adjusted capitation rates.**

Reimbursement rates are set by individual states under broad federal guidelines. Action in this area should take place at the state level. It is important to note that simply raising reimbursement rates is no guarantee that more providers will begin participating in Medicaid. Low-income patients will never be a lucrative population for providers, and many providers or practices do not have the resources or the experience to effectively manage their complex health needs.

IV. HEALTH SCREENING AND RECORD KEEPING

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)

Medicaid's EPSDT benefit was enacted in 1967 as part of an effort to improve the quality of child health care.³⁹ It is a central component of Medicaid's child health coverage and sets the broadest standard of pediatric coverage within Medicaid, emphasizing early intervention to prevent or ameliorate the full range of physical and mental health conditions that affect children.⁴⁰

EPSDT has five key components:

- a. Identifying problems early;
- b. Checking children's health at periodic intervals;
- c. Performing physical, mental, and other screening tests to detect potential health problems;
- d. Performing diagnostic tests to follow up on screening tests when necessary; and
- e. Treating the health problems found.⁴¹

Since its implementation, the EPSDT benefit has improved the detection and treatment of chronic illnesses and mitigated their effect on children's development.⁴² However, evidence suggests that many children in the child welfare system who are eligible for EPSDT do not receive the type of comprehensive

³⁵ American Academy of Pediatrics. "2007/08 Medicaid Reimbursement Reports." Available online at: <http://www.aap.org/research/medreim0708.htm>

³⁶ It is difficult to obtain comparative information on provider payment rates in states' managed care plans, as this has generally been classified as "confidential and proprietary" information by the states and the plans with which they contract. [AAP op cit. (35)]

³⁷ Holahan op. cit (32); Allen op. cit (2); Harman, J., et al. "Mental Health Care Utilization and Expenditures by Children in Foster Care." *Archives of Pediatric Adolescent Medicine*, Vol. 154 (2000): 1114-1117. Available online at: <http://archpedi.ama-assn.org/cgi/content/full/154/11/1114>

³⁸ Data from Health Care Reform Tracking Project, cited in Allen op. cit (2)

³⁹ Rosenbaum, S. "EPSDT at 40: Modernizing a Pediatric Health Policy to Reflect a Changing Health Care System." Center for Health Care Strategies Resource Paper, July 2008. Available online at: http://www.chcs.org/usr_doc/EPSDT_at_40.pdf

⁴⁰ Rosenbaum op. cit (39)

⁴¹ U.S. Department of Health and Human Services, Health Resources and Services Administration. "EPSDT Overview." Available online at: <http://www.hrsa.gov/epsdt/overview.htm>

⁴² Rosenbaum op. cit (39)

care that is covered under the benefit (see details in the following section). Moreover, the federal regulations governing EPSDT have not been modified since its enactment, nor has CMS issued guidelines for how the benefit can be used to support children's health services in a delivery system that has seen many changes during the last four decades. The advent of managed care, changes in performance measures, ongoing shortages of primary care physicians and pediatric specialty physicians, and recent revisions to coverage standards under the Deficit Reduction Act of 2005 (DRA), all present difficulties to states as they attempt to meet the level of care covered by EPSDT.⁴³ Despite these difficulties and some uncertainty as to the extent of the DRA changes, CMS, HHS, and Congressional leaders have repeatedly insisted that children on Medicaid must have continuing access to the benefits provided under EPSDT.⁴⁴ The primary challenge in EPSDT is for states to ensure that children will receive the benefits for which they are eligible.

Screening, Health Assessments, and Record Keeping

Regular health screenings and assessments are required benefits under EPSDT. Screenings and assessments are used to identify existing health problems or potential problems. Once a health problem has been identified, it goes into the patient's medical record, and the provider determines a course of treatment. Ideally, patients would have a stable medical provider, and their medical records would stay with them through all the health services they receive. However, consistent health screenings and accurate medical records are often lacking among children in the child welfare system (see Chart 1, p. 5).

In a paper outlining standards of care for children in the child welfare system, the American Academy of Pediatrics has stated that comprehensive mental and physical health assessments should be performed on an ongoing basis.⁴⁵ However, HHS found in 2005 that nearly 70 percent of states were not consistent in conducting mental health assessments (see Chart 1, p. 5).⁴⁶ At least 12 percent of foster children do not receive routine annual check-ups.⁴⁷

One reason for the sporadic nature of health care for the child welfare population is the environmental instability that often characterizes their lives. About half of foster children have more than one placement, three quarters have three or more placements,⁴⁸ and 35 percent re-enter the foster system after being returned to their birth parents.⁴⁹ Each placement change is usually accompanied by a change in physician.⁵⁰ In addition, there is high turnover among caseworkers and foster parents, the people who are best positioned to monitor and coordinate children's health care services.⁵¹

As a result of this environmental instability, most foster children receive episodic health care from multiple providers.⁵² It can be difficult to track down accurate past health information about the child, creating significant gaps in the medical history available to a child's providers and preventing them from getting a detailed picture of the child's health and health care needs.⁵³ A lack of comprehensive medical history information for foster children frequently results in incomplete or duplicate immunizations and a lack of quality ongoing primary care, including mental health care.⁵⁴

⁴³ Rosenbaum op. cit (39)

⁴⁴ Rosenbaum op. cit (39), Perkins, J. "The DRA Benefit Provisions and EPSDT." National Health Law Program. April 26, 2006. Available online at: www.healthlaw.org/library/attachment.81954

⁴⁵ AAP op. cit (13)

⁴⁶ Percentages are based on states plus Puerto Rico and the District of Columbia that participated in the Federal Child and Family Services Review. See HHS op. cit (14).

⁴⁷ First Focus op. cit (15)

⁴⁸ Halfon op. cit (15)

⁴⁹ AAP op. cit (13)

⁵⁰ AAP op. cit (13); Halfon op. cit (15); Rubin, D., et al. "Placement Stability and Mental Health Costs for Children in Foster Care." *Pediatrics* 113.5 (2004): 1336-1341. Available online at: <http://pediatrics.aappublications.org/cgi/content/full/113/5/1336>

⁵¹ Allen op. cit (2); Austin op. cit (26)

⁵² Halfon op. cit (15)

⁵³ AAP op. cit (13); Halfon op. cit (15)

⁵⁴ AAP op. cit (13)

Recommendations

- ***Increase federal funding for the implementation of electronic medical passports***

Several states and counties have dealt with the problem of incomplete medical histories by entering foster children's health information into an abbreviated electronic medical record, called a "medical passport," which follows the child wherever he or she goes. Medical passports address the lack of continuity of care by ensuring that each new provider will have access to the most important information about a child's health history. Most medical passport programs are relatively new, and their impacts have not been fully studied. However, preliminary research shows evidence of both improved outcomes and decreased costs to the state. For example, Wraparound Milwaukee has used electronic medical data to significantly reduce psychiatric hospital stays for the children it serves.⁵⁵ Programs in other states are expected to see similar improvements in health outcomes.

Initial funding for electronic medical passport programs has come from a variety of federal, state, and private sources. Federal funding sources include Medicaid Transformation Grants, grants from the Center for Mental Health Services, and Medicaid Administrative funds (especially Medicaid Management Information Systems funds).⁵⁶ Congress should enhance funding for Medicaid Transformation Grants and Medicaid Management Information Systems. Congress should also support funding for pilot programs and evaluation of existing programs to gather more evidence on the effectiveness of medical passports.

There are several caveats to consider in the implementation of electronic medical passports. Medical passports work best in the context of a fully digitized medical record system. Otherwise, information must be manually entered, leaving open the possibility for errors in the copying of data. Furthermore, making the information available does not guarantee that providers will use it. Additionally, many patient and consumer groups have expressed concerns about privacy issues involved with digitizing medical data. Existing medical passport programs have implemented a variety of privacy controls aimed at protecting children's personal health information, but there is no general consensus on the specific protections that should be in place, the groups and individuals (other than the child and the child's providers) that should have access to the information, and the liability of these groups or individuals when privacy violations occur. Discussions of privacy are vital in the implementation of any electronic medical record system.

V. PREVENTION

Consistent access to, and use of, preventive health care is of crucial importance in maintaining good health. Timely health intervention is especially important for children, who are still in their formative years when untreated health problems can have a significant impact on their future health and development.⁵⁷ Children in the child welfare system, even those who have health insurance and have had a visit with a provider in the last year, often do not receive adequate preventive health services. HHS found in 2005 that only 60 percent of states were consistent in providing children with preventive health and dental services.⁵⁸ Foster children receive fewer outpatient services than children in the general population and are more likely to receive a larger proportion of their care from the emergency room, an indicator of a lack of routine preventive care.⁵⁹

⁵⁵ Agency for Healthcare Research and Quality. "24-Hour Mobile Mental Health Crisis Team Reduces Hospitalization for Children with Complex Behavioral and Emotional Needs." Health Care Innovations Exchange: Innovation Profile. Available online at: <http://www.innovations.ahrq.gov/content.aspx?id=1719>

⁵⁶ Center for Health Transformation. "Best Practices in Texas Medicaid." Available online at: http://www.healthtransformation.net/cs/texas/best_practices_in_medicaid_texas; Milwaukee County. "Wraparound Milwaukee Background and History." Available online at: <http://www.milwaukeecounty.org/BackgroundandHistory10149.htm>

⁵⁷ Stahmer op. cit (11)

⁵⁸ Percentages are based on states plus Puerto Rico and the District of Columbia that participated in the Federal Child and Family Services Review. See HHS op. cit (14).

⁵⁹ Rubin, D., et al. "Placement Changes and Emergency Department Visits in the First Year of Foster Care." *Pediatrics* 114.3 (2004): e354-e360. Available online at: <http://pediatrics.aappublications.org/cgi/reprint/114/3/e354>

Without adequate preventive care, many children develop health problems that go untreated. Estimates of children who have been diagnosed with a mental, behavioral, or developmental disorder but did not receive treatment range from 23 percent to 75 percent.⁶⁰ The U.S. General Accounting Office reported in 1995 that 32 percent of foster children have unmet health needs.⁶¹

Recommendations

- **Preserve funding for case management and targeted case management within Medicaid.**

Medicaid contains the option for states to create case management and targeted case management (TCM) programs. Case management consists of services that assist Medicaid beneficiaries in identifying necessary health services, locating the services, identifying providers, and monitoring the provision of care.⁶² Targeted case management refers to case management services that are provided to a specific group of Medicaid enrollees.⁶³ TCM is an optional service program, meaning states can choose whether and at what level to fund it, and the federal government contributes an additional share. Thirty-eight states currently use TCM, and many have included foster children as a targeted class.⁶⁴

TCM is one of the highest sources of Medicaid spending on children (see Chart 2 below).⁶⁵ TCM recipients have been found to receive significantly more health services than those who are not in a TCM program.⁶⁶ Given the high level of need among children in the child welfare system, TCM can be a vital program in helping them access the health services they need.

Chart 2: Medicaid Expenditures over \$100 Million and Enrollment for Foster Children by Service Category

Category	Total spending (millions)	Percent of total spending	Enrollment	Percent of enrollees with spending	Spending per enrollee receiving
Other	\$ 628	16.7 %	241,178	27.8 %	\$ 2,605
Rehabilitative	493	13.1	102,166	11.8	4,823
Inpatient psychiatric	376	11.0	14,154	1.6	26,581
Inpatient hospital	354	9.4	37,342	4.3	9,473
Clinic	327	8.7	201,246	23.2	1,626
Prescription drug	290	7.7	437,104	50.3	664
Targeted case management	266	7.1	144,508	16.6	1,840
Health maintenance org.	193	5.1	198,369	22.8	975
Physician	170	4.5	416,360	47.9	409
Prepaid health plan	159	4.2	251,902	29.0	632
Outpatient hospital	129	3.4	269,065	31.0	479

Source: Geen, R., et al. "Medicaid Spending on Foster Children." The Urban Institute Child Welfare Research Program, Brief No. 2, Aug. 2005. Available online at: http://www.urban.org/UploadedPDF/311221_medicaid_spending.pdf

The Deficit Reduction Act of 2005 made many far-reaching changes to Medicaid, including changes that may affect the availability of case management services. CMS published an interim final rule to

⁶⁰ First Focus op. cit (15); Rosenkranz op. cit (20); Stahmer op. cit (11); Kortenkamp op. cit (11); Kaiser Daily Health Policy Report. "Foster Children Do Not Receive Adequate Health Care, Witnesses Tell House Panel." July 20, 2007. Available online at: http://www.kaisernetwork.org/Daily_reports/rep_index.cfm?DR_ID=46371

⁶¹ GAO op. cit (12)

⁶² Rosenbaum, S. "The CMS Medicaid Targeted Case Management Rule: Implications for Special Needs Service Providers and Programs." Center for Health Care Strategies Issue Brief, April 2008. Available online at: http://www.chcs.org/publications3960/publications_show.htm?doc_id=682815

⁶³ Rosenbaum op. cit (62)

⁶⁴ Geen op cit. (6)

⁶⁵ Geen op. cit (6)

⁶⁶ Geen op. cit (6); Allen op. cit (2); First Focus op. cit (15)

implement these changes, but many believe the rule goes far beyond the scope of the DRA, making eligibility for TCM too restrictive. A moratorium was put on this and six other proposed rule changes in the Supplemental Appropriations Act of 2008, delaying their implementation until April 1, 2009.

Congress should permanently enforce the current moratoria and preserve funding for case management and targeted case management.

VI. TREATMENT

Coordination of Care

Children in the child welfare system receive services from a number of different public and private agencies, organizations, and individuals. These multiple child-serving systems often have differing and conflicting interests, legal requirements, and rights.⁶⁷ Furthermore, they function independently and often lack systematized means of communication with one another.⁶⁸ The result is a lack of coordination among agencies, courts, families, health providers, and other institutions or individuals who are involved in the child welfare system. As Halfon, et al. write, “incremental policy changes over the past two decades have resulted in a patchwork of services to address the health needs of children in general... the result has been an uncoordinated layering of programs with sometimes redundant objectives and separate, even competing funding streams.”⁶⁹

Complicating this fragmentation are divisions within the health care sector, in which primary mental and physical health care are often provided in different settings, and care in either setting may be divided even more among different specialists or providers. This is a particular problem for children with chronic illnesses or other complex health conditions requiring care from many different providers.

The American Academy of Pediatrics recommends that states implement programs to coordinate and oversee children’s health care among all the different agencies. Federal legislation to this effect is now before Congress (see details below).

Recommendations

- ***Improve coordination of care delivery for children in the child welfare system***

H.R. 6893, “Fostering Connections to Success and Increasing Adoptions Act,” requires states to develop a plan for the ongoing oversight and coordination of health care services for any child in a foster care placement. The plan must ensure a coordinated strategy to identify and respond to the health care needs of children in foster care placements, including mental health and dental health needs. This bill became law in September 2008. Although it is a significant step forward, we must continue to monitor the coordination of health services for children in foster care to determine whether their needs are adequately met.

- ***Support the adoption of medical home programs***

Another model of care coordination compensates for the divisions within the health care sector by encouraging primary care providers to spend more time coordinating care for patients with complex health needs.⁷⁰ This model is known as the medical home, and it has been endorsed by the

⁶⁷ AAP op. cit (13); Allen op. cit (2); Austin op. cit (28)

⁶⁸ Halfon op. cit (15)

⁶⁹ Halfon op. cit (15)

⁷⁰ Under current payment structures, health care is paid for on a procedural basis, rewarding fragmented, high-volume, overspecialized, and inefficient care. Meanwhile, there is great need for better management of chronic/complex health conditions. Patients with complex health needs or chronic conditions often require care from many different specialists and sub-specialists who may prescribe an overwhelming variety of procedures and medications, and whose efforts are rarely coordinated with one another in

American Academy of Pediatrics as a way to improve the delivery of care to children.⁷¹ As with medical passports, there has been little evaluation of health outcomes in medical home programs to date. However, because of their emphasis on preventive care and care management, it is anticipated that medical homes will greatly reduce the development and worsening of poor health conditions.

Many states and private payers have begun experimenting with variations on the medical home concept. One common approach is to hire “care coordination” officers for each clinic who are responsible for helping patients manage their chronic conditions, following up with patients after visits, and helping to coordinate care among providers. Another common approach is to pay providers who meet certain criteria a fixed per-patient per-month fee, enabling them to spend more time with the follow-up or management of their patients’ health. North Carolina has implemented perhaps the most successful medical home program so far. Its pilot project began in 1999 with the state’s 750,000 Medicaid patients. The state soon began to see significant annual savings; in 2005 and 2006 savings were \$231 million.⁷² Other medical home pilot programs have begun around the country, sponsored by states, private insurers, and Medicare.

The Medicare Payment Advisory Commission has recommended that Medicare expand its plans for a medical home pilot project that is intended to start next year. The pilot is expected to pay primary care doctors in eight states an extra \$30-40 each month for every patient enrolled with a chronic illness.⁷³

Congress should support funding for the Medicare project and other medical home pilot projects, including studies on health outcomes and cost savings.

Training

Children in the child welfare system have unique physical and mental health needs. Unfortunately, the adults involved in caring for these children often lack the knowledge or training in how to properly care for them. Even among child health providers, there are limits to knowledge about the health needs of these children.⁷⁴ Foster parents often do not have enough knowledge or training about the health issues their foster children face or about how to access appropriate care in the medical system.⁷⁵ Social workers and caseworkers also frequently lack this knowledge, making them less effective as coordinators or overseers of children’s health care.⁷⁶ Studies show a need for special training and guidance for providers, families, and caseworkers, on how to identify and treat the special health problems of children in the child welfare system.⁷⁷

Recommendations

- **Improve training on the special health needs of children in child welfare.** Training programs should target child health providers, foster families, caseworkers, social workers, and other caregivers.

a comprehensive way. Primary care providers are in a natural place to act as a guide and care coordinator for patients with complex health needs.

⁷¹ American Academy of Pediatrics. “The Medical Home.” *Pediatrics* 110.1 (2002): 184-186. Available online at:

<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/1/184>

⁷² State of North Carolina, Office of the Governor. “Gov. Easley Announces Community Care Saves Taxpayers \$231 Million.” Press release, Sept. 25, 2007. Available online at: <http://www.communitycarenc.com/PDFDocs/InnovPress.pdf>

⁷³ Freudenheim, Milt. “Trying to Save By Increasing Doctors’ Fees.” *The New York Times*. July 21, 2008. Available online at:

<http://www.nytimes.com/2008/07/21/business/21medhome.html?partner=rssnyt>

⁷⁴ Halfon op. cit (15)

⁷⁵ AAP op. cit (13); Austin op. cit (26)

⁷⁶ AAP op. cit (13)

⁷⁷ AAP op. cit (13); Austin op. cit (26); Troutman op. cit (8)

Rehabilitative Services

Rehabilitative services account for the highest single expenditure category for foster children in Medicaid (see Chart 2, p. 9).⁷⁸ Twelve percent of foster children enrolled in Medicaid are the recipients of spending under the rehabilitative services category.⁷⁹ These services are intended to help children with specific physical and/or mental disabilities reach a better level of functioning.⁸⁰ They include crisis services, behavior management services, in-home services, respite services, and other services that are provided in a community setting rather than an institution.⁸¹ Like targeted case management, rehabilitative services are an optional coverage category under Medicaid, meaning states can choose whether and at what level to fund them. However, recent rule changes proposed by the Center for Medicare and Medicaid services may significantly restrict states' ability to provide these services.

Recommendations

- ***Preserve funding for rehabilitative services within Medicaid.***

The Deficit Reduction Act of 2005 made many far-reaching changes to Medicaid, including changes that may affect the availability of case management services. CMS published an interim final rule to implement these changes, but many believe the rule goes far beyond the scope of the DRA, greatly restricting the availability of rehabilitative services. A moratorium was put on this and six other proposed rule changes in the Supplemental Appropriations Act of 2008, delaying their implementation until April 1, 2009.

Congress should permanently enforce the current moratoria and preserve funding for rehabilitative services.

Psychotropic Medications

Psychotropic drugs are a class of medications affecting the mind, emotions, and behavior.⁸² They are commonly used to treat depression, anxiety, bipolar disorder, schizophrenia, attention deficit hyperactivity disorder, and other psychiatric disorders. While the safety and efficacy of psychotropic drugs have been well studied in adults, their effects in children are less well known.⁸³ Many researchers, physicians, and psychiatrists have expressed concern about the effects of these powerful drugs on the developing brain.⁸⁴ Other researchers and providers are strong proponents of their use. Overall, the use of psychotropic drugs in children has grown significantly over the last 20 years.⁸⁵

Foster children receive psychotropic medications at a rate two to three times higher than children who are not in foster care.⁸⁶ Of foster children receiving psychotropic medications, over 40 percent receive three or more psychotropic medications, and 16 percent receive four or more.⁸⁷ Use of multiple drugs increases the risk of adverse drug interaction. The American Academy of Pediatrics calls for the close monitoring of any child who is prescribed a psychotropic medication.⁸⁸ However, as previously noted, the close monitoring of any health condition in foster children is difficult due to placement instability, gaps in the medical record, and a frequent lack of routine check-ups (see p. 5-6).

⁷⁸ Geen op. cit (6)

⁷⁹ Geen op. cit (6)

⁸⁰ First Focus op. cit (15)

⁸¹ Allen op. cit (2); First Focus op. cit (15)

⁸² Definition from <http://www.medicinenet.com>

⁸³ Zito, J., et al. "Psychotropic Medication Patterns Among Youth in Foster Care." *Pediatrics* 121.1 (2008): e157-e163. Available online at: <http://pediatrics.aappublications.org/cgi/reprint/121/1/e157>

⁸⁴ First Focus op. cit (15); Zito op. cit (83)

⁸⁵ First Focus op. cit (15)

⁸⁶ First Focus op. cit (15); Zito op. cit (83)

⁸⁷ Zito op. cit (83)

⁸⁸ AAP op. cit (13)

Children in the child welfare system have a high incidence of mental illness and should have access to psychotropic drugs when circumstances warrant. However, there has been scant research on these drugs in children, and to date there is no substantive evidence proving their safety and efficacy in children.⁸⁹ Furthermore, several of the top psychiatrists pioneering the use of psychotropic drugs in children have been found to be the recipients of hundreds of thousands or even millions of dollars from the manufacturers of these drugs.⁹⁰ These potential conflicts of interest complicate the formulation of guidelines setting out appropriate and inappropriate uses of psychotropic drugs in children.⁹¹ While understanding the potential value of psychotropic drugs in treating children's mental illness, we must recognize the need for further research and oversight in this area.

Several states have begun projects to implement algorithms, or guidelines, regulating the use of psychotropic medications in children. The most promising effort is Texas' Children's Medication Algorithm Project (CMAP). However, the project has stalled due to an investigation into possible fraud after allegations of improper ties between researchers and pharmaceutical manufacturers.⁹²

Recommendations

- ***Establish guidelines and oversight for the use of psychotropic medications in children.***

H.R. 6893, the Fostering Connections to Success Act, includes a requirement for the creation of a prescription drug oversight plan. Congress passed this bill in September 2008. Congress should also support efforts to increase transparency in the pharmaceutical industry, especially the financial relationships between physicians, researchers, and drug manufacturers.

VII. DATA COLLECTION

Many researchers who study children in the child welfare system find that the available data is insufficient to allow for comprehensive findings on the health needs and well-being of this population. Knowing more about the health status and service use of all children in the child welfare system could help researchers and advocates gain a better understanding of how best to improve their health.

Medicaid claims have been the basis of many studies on the health of the child welfare population.⁹³ However, this claims data has several shortcomings. It is not linked to child welfare agencies' administrative data, leaving gaps in our knowledge of the links between a child's health and his or her activities or placements in the child welfare system.⁹⁴ Claims data cannot reveal diagnoses, health assessment results, or patterns of health usage.⁹⁵ Furthermore, it does not incorporate children who are enrolled in managed care.⁹⁶

Other studies have used expenditure information from the Medicaid Statistical Information System (MSIS) Annual Summary File.⁹⁷ This data provides more comprehensive information on Medicaid expenditures, but it shares the claims data limitations outlined above. Still other researchers have used information

⁸⁹ Zito op. cit (83)

⁹⁰ Carey, B. "Study Finds a Link of Drug Makers to Psychiatrists." *The New York Times*. April 20, 2006. Available online at: <http://www.nytimes.com/2006/04/20/health/20psych.html> ; Harris, G., and Carey, B. "Researchers Fail to Reveal Full Drug Pay." *The New York Times*. June 8, 2008. Available online at: <http://www.nytimes.com/2008/06/08/us/08conflict.html?partner=rssnyt> ; Harris, G. "Psychiatrists Top List in Drug Maker Gifts." *The New York Times*. June 27, 2007. Available online at: <http://www.nytimes.com/2007/06/27/health/psychology/27doctors.html> ;

⁹¹ Mental Health Weekly. "Delay in Drug Protocol Implementation in Texas Intrigues Outside Observers." 18.33 (2008): 1-3.

⁹² Mental Health Weekly op. cit (91)

⁹³ dosReis op. cit (11); Harman op. cit (37); Rosenbach op. cit (8)

⁹⁴ Rubin et al. were able to link Medicaid claims data with child welfare administrative data using a complicated three-step process [Rubin op. cit (50)]

⁹⁵ Geen op. cit (6)

⁹⁶ Geen op. cit (6)

⁹⁷ Geen op. cit (6)

from the National Survey of America's Families and the National Survey of Child and Adolescent Well-Being.⁹⁸ This is subject to the same limitations of all self-reported data.

Many researchers note the need for more detailed Medicaid claims data. One way to do this is by expanding Medicaid eligibility codes, which could illuminate important differences or similarities between foster children and other children in the child welfare population. Eligibility codes are used in medical billing to identify how patients are eligible for Medicaid. Eligibility codes can be studied in conjunction with the services charged to those codes in order to understand the health needs of specific groups of Medicaid enrollees. Currently, Medicaid eligibility codes do not distinguish between foster children and other children in the child welfare population, such as children in kinship care, children in protective services, and children who have entered the child welfare system but continue to live with their parents. Some research indicates that all children in the child welfare system have relatively equal health needs. However, only foster children have a distinct Medicaid eligibility code, making it difficult to study children in the child welfare population who are not in foster care.

Recommendations

- ***Make additions to Medicaid eligibility codes in order to distinguish between foster children, children in other types of out-of-home care, children living with their parents, and children in protective services.***

CONCLUSION

Health issues facing children in the child welfare system must be discussed within the broader context of health care reform. Health care consistently ranks as one of the top concerns voters want Congress and the president to address.⁹⁹ The cost of health insurance premiums is rising faster than inflation and workers' earnings,¹⁰⁰ and recent economic turmoil has added to voters' concerns about health care: in August 2008, nearly a quarter of Americans reported experiencing serious problems paying for health care and health insurance.¹⁰¹

In response to this widespread public concern about health care, both 2008 presidential candidates have announced proposals to reform the health care system, reduce total health care spending, and make health insurance more affordable. Barack Obama's plan creates subsidies to help low-income families purchase private insurance, establishes a public plan for people who cannot access any other coverage, requires businesses to pay a share of health care costs, and creates a National Health Insurance Exchange to evaluate plans and facilitate the purchasing of health insurance.¹⁰² In contrast, John McCain favors a more market-based approach, helping Americans make cost-conscious decisions about health services and deregulating insurance markets to allow purchasing of health insurance across state lines.¹⁰³

Despite the significant differences in their plans, both presidential candidates agree on some health reform measures. For example, both support increasing investment in electronic medical records. Both have voiced support for the concept of a patient-centered medical home. They also agree that information about cost and quality of health services should become more transparent and widely available.¹⁰⁴

⁹⁸ Kortenkamp op. cit (11); Stahmer op. cit (11); HHS op. cit (5)

⁹⁹ Saad, L. "Any Healthcare Reform Plan Will Do for Americans." Gallup. Oct. 25, 2007. Available online at: <http://www.gallup.com/poll/102349/Any-Healthcare-Reform-Plan-Will-Americans.aspx>; "Kaiser Health Tracking Poll: Election 2008." Issue 9, August 2008. Available online at: <http://www.kff.org/kaiserpolls/upload/7808.pdf>

¹⁰⁰ Kaiser Family Foundation. "Trends in Health Care Costs and Spending." September 2007. Available online at:

<http://www.kff.org/insurance/upload/7692.pdf>

¹⁰¹ Kaiser Health Tracking Poll op. cit (99)

¹⁰² Barack Obama's Plan, Obama for America. Available online at: <http://www.barackobama.com/issues/healthcare/>

¹⁰³ Laszewski, R. "An Analysis of John McCain's Health Care Reform Plan." *The Health Care Blog*, February 5, 2008. Available online at: http://www.thehealthcareblog.com/the_health_care_blog/2008/02/an-analysis-of.html

¹⁰⁴ Obama op. cit (102); McCain/Palin 2008, "Straight Talk on Health System Reform." Available online at: <http://www.johnmccain.com/Informing/Issues/19ba2f1c-c03f-4ac2-8cd5-5cf2edb527cf.htm>

Regardless of who wins the election in November, the new president will not be able to move forward on health reform without the support of key players in Congress. In the Senate, Senators Harry Reid (D-Nev.), Ted Kennedy (D-Mass.), and Max Baucus (D-Mont.) will have the most influence over any health care reform bill that comes before the Senate. Reid, the Senate Majority Leader, has taken past positions that generally indicate he would support the key components of Obama's health plan. Reid was also a strong proponent of the SCHIP reauthorization bills vetoed by President Bush in 2007.¹⁰⁵ Kennedy, chairman of the Committee on Health, Education, Labor, and Pensions (HELP), is planning to return to the Senate in January and take a leading role in health care reform. Members and staff of HELP have already begun discussions with Baucus, who is chairman of the Finance Committee, and others on getting a reform bill ready for the next session. Although Baucus has not always been a consistent supporter of health care reform efforts, his committee has been holding a series of hearings on the issue, and he has indicated he is serious about moving a health care reform bill through the Finance Committee.

In the House, Representatives Nancy Pelosi (D-Calif.), John Dingell (D-Mich.), and Pete Stark (D-Calif.) are likely to be the leaders on health care reform. Pelosi has not proposed her own health care reform plan, but supports general principles of reform such as covering the uninsured, reauthorization of SCHIP, and increased spending on preventive medicine, all components of Obama's plan.¹⁰⁶ Dingell is chairman of the House Energy and Commerce Committee and an avid supporter of a national single-payer reform plan. However, he has stated that he would also support any reform efforts that expand insurance coverage to more Americans, making him likely to support an Obama plan. Like Dingell, Stark believes covering the uninsured should be a priority. He has been outspoken in his criticism of private health insurance companies,¹⁰⁷ which could make him cautious about the aspects of Obama's plan that provide government subsidies for the purchase of private health insurance.

In order to push Congress to take action on health care reform, several national organizations have launched initiatives calling attention to the need for reform: Divided We Fail, Health Care for America Now!, Families USA, Whole Health Campaign, and the Patient Centered Primary Care Collaborative.

Divided We Fail is a disparate group of organizations that have historically been on opposite sides of many policy debates. Its leadership consists of AARP, the Business Roundtable, Service Employees Union, and the National Federation of Independent Business. The groups share a desire to bring health care reform to the forefront of national political debate, working from the premise that "all Americans should have access to affordable health care, including prescription drugs, and these costs should not burden future generations."¹⁰⁸ Though the coalition has enlisted a great deal of support from legislators and the public, it is not clear whether such a far-reaching alliance will hold together when the real work on health care reform begins.

Health Care for America Now! (HCAN) is a coalition of progressive organizations and unions that plans to spend \$40 million pushing for national health care reform legislation.¹⁰⁹ HCAN favors the Obama plan and is quite hostile to insurance companies.¹¹⁰ It has already used some of its money for a series of advertisements mocking insurance companies. HCAN has also taken advantage of MoveOn.org's

¹⁰⁵ Associated Press. "Reid: No Compromise on Health Plan," *USA Today*, October 4, 2007, http://www.usatoday.com/news/washington/2007-10-04-reid-health-plan_N.htm

¹⁰⁶ Nancy Pelosi official website. "Health Care." Available online at: <http://speaker.house.gov/issues?id=0004>; Keppler, B. "Nancy Pelosi's Health Care Address." *The Health Care Blog*. Available online at: http://www.thehealthcareblog.com/the_health_care_blog/2008/01/nancy-pelosi-he.html

¹⁰⁷ "Rep. Pete Stark: AHIP's Campaign for Health Reform Is a Sham," Health Care for America Now. Available online at: http://healthcareforamericanow.org/site/blog/rep_pete_stark_ahips_campaign_for_health_reform_is_a_sham/

¹⁰⁸ Divided We Fail. "Access to Health Care." Available online at: http://www.aarp.org/issues/dividedwefail/about_issues/access_to_health_care.html

¹⁰⁹ Bosman, J. "New Health Reform Group to Spend \$40 Million." *The New York Times*. July 2008. Available online at: <http://thecaucus.blogs.nytimes.com/2008/07/03/new-health-reform-group-to-spend-40-million/>

¹¹⁰ Bosman op. cit (109)

databases to send email to over 5 million households.¹¹¹ It has sent organizers to 52 cities across the country with the intention of organizing support for health care reform in the 2008 elections.¹¹²

Families USA has partnered with 19 groups in twelve swing states to call attention to the need for federal health care reform during the election season. It is also calling on McCain and Obama to make health care reform their first priority should they be elected president. Families USA has circulated a petition across the country calling for signatures to a letter urging McCain and Obama to focus on health care reform. Families USA has also coordinated a series of meetings between health care activists and key congressional and campaign staff to discuss ideas for health care reform and strategies for achieving it.

The Whole Health Campaign is a group working to call attention to the need for health care that covers the whole person, including mental health needs and substance abuse treatment. WHC was active at each party's convention, sponsoring "Recovery Rooms" to raise awareness of the need for mental health and addiction treatment services. Although the recovery rooms had mixed success, both parties' platforms do include an endorsement of the concept of mental health parity. Now that the conventions are over, WHC has turned its attention to formulating a strategy for working with both candidates to enact the language included in their party's platform.

The Patient Centered Primary Care Collaborative (PCPCC) is a coalition of over 200 employers, physician associations, labor unions, consumer groups, patient advocates, health plans, and others who have joined together to promote the concept of a medical home. The intent of the PCPCC is to foster discussions among the many stakeholder involved, develop model legislative language for incorporating the medical home into health care reform proposals, and to educate policymakers about this issue.¹¹³ Its nonpartisan, multi-stakeholder approach makes it uniquely situated to influence medical home initiatives.

In the context of this health care climate, there will be openings to move many of the recommendations in this report forward in 2009:

Insurance coverage: Covering the uninsured is central to Obama's health care reform platform and is supported by the major players in Congress as well as the national groups working to promote health care reform. However, there may be less room for movement on this issue under a McCain administration, given his past opposition to expansions of public health insurance programs.

Electronic medical records (EMRs): The adoption of EMRs is supported by both presidential candidates, Congress, national health organizations, and the public. Initiatives aimed at supporting EMR systems are almost certain to be a part of any health care reform proposals that come out of Congress in the next session.

Medical homes: Medical homes have been touted as a panacea to fix many problems in the health care system, but more research remains to be done on their cost effectiveness and quality outcomes.¹¹⁴ Several congressional committees have already held hearings on the medical home concept, and there will likely be significant support for increasing investment in medical home pilot projects.

Medicaid regulations on TCM and rehabilitative services: The moratoria on the CMS regulations restricting the availability of TCM and rehabilitative services are set to expire in April of 2009, virtually guaranteeing a debate on their continuation.

¹¹¹ Stein, S. "\$40 Million Health Care Campaign Will Target Some Dems." *Huffington Post*. Available online at: http://www.huffingtonpost.com/2008/07/08/40-million-health-care-ca_n_111295.html

¹¹² Stein op. cit (111).

¹¹³ Patient Centered Primary Care Collaborative brochure. Available online at: <http://www.pcpcc.net/files/PCPCCbrochure.pdf>

¹¹⁴ Berenson, R., et al. "A House is Not a Home: Keeping Patients at the Center of Practice Redesign." *Health Affairs* 27.5(2008): 1219-1230. ; Sidorov, J. "The Patient-Centered Medical Home for Chronic Illness: Is it Ready for Prime Time?" *Health Affairs* 27.5(2008): 1231-1234.