



## CoIN Framework Paper on Family-Centered Health Homes (FCHH) for Young Children

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*Children of color and their families are more likely to experience social and structural discrimination, marginalization and exclusion, and poverty, which are all detrimental to health development and learning. In response, the BUILD Initiative and the Child and Family Policy Center (CFPC) are developing a Learning Collaborative on Health Equity and Young Children. The Learning Collaborative will serve as a point of connection for state and community early childhood leaders and for health practitioners and champions to connect with and learn from one another, in order to further both the policy and practice of health equity for young children. One aspect of this work, led by CFPC, is to create a Collaborative Innovation Network (CoIN). This framework paper describes that work.*

This framework paper is a beginning description for developing: (1) a Collaborative Innovation Network (CoIN) of child health practitioner innovators to further develop exemplary practices within primary child health care in the early (birth through five) years; and (2) a broader Learning Community of both child health and early childhood leaders to inform the CoIN and to draw from the advances made by the CoIN to promote further diffusion of effective practices, including policy and financing changes. The approach begins with the primary care practitioner but extends beyond the provision of medical care to support healthy development of children in the context of their families and communities. In this paper, this practice approach is called a family-centered health home (FCHH) (but is subject to change). Below are brief definitions of these three key terms.

**Collaborative Innovation Network (CoIN):** An organized network of innovators developing core aspects of the family-centered health home for young children to further the knowledge base regarding effective FCHH practices and to diffuse evidenced-based practices. A CoIN stimulates the testing of innovations and sharing of results that are: (1) ahead of mainstream incentives structures and thus will not emerge and spread naturally; (2) too complex for any single innovative provider or system to develop themselves; or (3) represent key areas of need for innovation and practice development that network members then take action to address. A CoIN supports these innovators and innovations to further establish practices and protocols for use in the field. In this approach, these innovators actively design and test concepts that are not yet ready for wide implementation and share results of this work. The CoIN itself provides content and improvement expertise to innovators to both engage in innovation and to share results with the field and adapt findings and lessons learned for subsequent development.

**Family-Centered Health Home (FCHH) for Young Children:** A family-centered health home for young children is focused upon the primary health practitioner's role in ensuring that young children and their families secure the social and economic as well as medical services needed for healthy child development. Entailed in a family-centered home are three general components: (1) the health practitioner's leadership in screening and identification of children and families who are vulnerable to poor child health trajectories, (2) care coordination that links the family to resources and supports to address social as well as medical determinants of health, generally from a protective factors framework; and (3) community outreach and networking that identifies and connects available services and resources to the family-centered health home and its care coordination. The health practitioner often serves as a first responder and, depending upon the needs of the child and family, may or may not be the "health home leader" for subsequent engagement and work with the child and family, but remains part of the process. The first aspect of the family-centered health home applies specifically to the child health practitioner and that practitioner's office; the second and third components can exist within that practice but can be developed outside individual practices and at a community level as a broader community utility which may also be accessed by others outside the health system.

**Learning Community:** A community of leaders in health policy and early childhood policy, including representatives from the CoIN, that more broadly shares the CoIN findings and experiences and seek ways to diffuse effective innovations into the overall early childhood field. The learning community further works to develop and test broader policies and investments needed to diffuse evidenced-based innovations and ensure they are incorporated into mainstream financing and accountability systems. Both the learning community and the CoIN require strong facilitation and coordination, often on a virtual basis, that serves as a resource and repository for the findings and knowledge of the different members and participants.

The framework paper for developing a Collaborative Innovation Network (CoIN) and Learning Community on Family-Centered Health Homes (FCHH) for Young Children is based on the following:

- The science, across multiple disciplines (health, social science, economics, and family support) that the first years of life are absolutely foundational to young children's healthy growth and development;
- The knowledge that there are profound disparities (within and across all states) that exist in children's healthy development during the earliest years and a much larger share of the child population is affected than currently is being identified and effectively served. (These disparities disproportionately impact children of color and children in poor families and neighborhoods and, if not addressed during the earliest developmental years, produce and increase health, social, and economic inequities for children in subsequent years.);
- The particular potential role of the child health practitioner (family-centered health home for young children) during this period to serve as a "first responder" to those needs and a connector to both health services and social and community supports;
- The importance of responding to social determinants as well as child developmental and health conditions in promoting healthy development;
- The importance of supporting families' ability to provide a safe nurturing environment through using a strengthening families' framework.
- The presence of a growing array of exemplary and innovative programs and policy levers to guide changes in this primary child health policy and practice;
- The presence of a variety of champions and experts to support and guide work who can be part of a Collaborative Innovation Network to further develop effective strategies;

- The presence of a supportive, parallel community of early childhood systems builders who can become additional advocates for health's role in improving children healthy development and readiness for success in school and be part of a learning community;
- The ability to develop, at the state and community level, a critical mass of committed individuals to develop policy strategies and produce public will to enact and carryout policy changes; and
- The opportunities to partner with the Center for Medicaid and Medicare Services (CMS), the Center for Medicare and Medicaid Innovation (CMMI), and other federal offices for sustainable financing that can create legitimate incentives and reimbursement systems to promote diffusion of effective practices into more widespread and routine use.

This concept paper recognizes that there are multiple key groups of practitioners, leaders, and stakeholders who can contribute to this work.

First, the CoIN itself will bring together practitioner innovators and champions to further articulate the essential attributes of effective family-centered health homes (FCHHs) for young children and to continue to develop tools and strategies for the field, building a broader and deeper knowledge base of evidenced-based practice. This CoIN work is designed to contribute to the development of FCCHs for young children – whether in large or small practices, urban or rural areas, or serving general or very disinvested communities. This work is essential for a successful transition from exemplary to more mainstream and routine practice. CFPC/BUILD have identified a strong core group of such practitioner champions as a starting point for this work – who are leading innovations in their own practices. The CoIN will allow for greater connection and sharing of knowledge among them and for identifying areas for continued development and innovation. In many instances, the latter may be achieved through “plan, do, study, act” (PDSA) protocols and other methodologies to support innovation and learning within and then across cutting edge practices. This CoIN group also is key to subsequent work in policy development and program expansion with the larger Learning Center community.

Second, Learning Community will bring together health policy experts and advocates as well as practice champions to determine how FCHH practices and the evidence base from the CoIN work can be integrated into current health reform activities at the state and federal level (accountable care organizations, community health workers, State Innovations In Medicaid (SIM) grants, CHIPRA demonstration grants, EPSDT and private health financing of care coordination and other services) and further foster innovations, replication, and development of ecological approaches to healthy child development which address social determinants.

Third, the Learning Collaborative will draw upon the broader Learning Collaborative on Health Equity and Young Children focused upon early childhood systems building efforts, but largely representing early care and education, to provide for additional use of the CoIN and to promote overall early childhood systems building which responds to social determinants of health and requires increased or different responses from systems outside the health community.

While different current innovators and practitioner champions will have different foci, staffing structures, and organizations, the CoIN's focus will be upon how to foster innovation, learning, and diffusion related to three different underlying components of what the CoIN is defining as a Family-Centered Health Home.

- Broader surveillance and formal screening by the health practitioner and the health practitioner's office that includes family conditions as well as presenting child health conditions;

- Follow-up to this surveillance by a care coordinator/advocate (either within or outside the practice) that gains family trust and delves more deeply into family circumstances and moves beyond referring to service to scheduling and follow-up; and
- Community networking activity that identifies and reaches out to community resources which can respond to social as well as bio-medical determinants and better connects them with children and families from the FCHH who can benefit from their services.

Different exemplary pediatric initiatives address these three components in different ways, but each component must be structured to be effective within its own area of responsibility, resourced to be sufficient to meet that responsibility, and rigorous in collection of relevant information.

The CoIN is designed to better compile and organize current knowledge based upon exemplary practice, within and across these components. It also is designed to identify knowledge gaps and ways to further test approaches in moving toward replicable strategies and protocols.

These components of a Family-Centered Health Home are shown on the next page.

### **FCHH COMPONENTS**

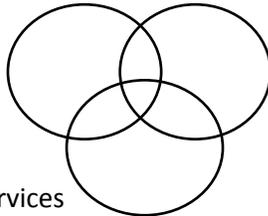
#### **Health Practitioner/First Responder**

Developmental/environmental surveillance and screening

Anticipatory guidance

Referral for “medically necessary” services

Referral for care coordination



#### **Care Coordinator/Family Advocate**

Engagement and whole child/family approach to identify needs and opportunities

Connection of families to services and supports to address social as well as clinical determinants of health (scheduling and follow-up)

#### **Community Service Maven/Networker**

Community networking and identification of services and supports

Continued connections with community services and supports to enhance capacity and alignment

A first step in developing the CoIN is to draw upon existing exemplary practices and their champions to more broadly enumerate the essential features of each of these components, to determine what currently is known about developing them and what needs to be done to find out more, and to assess what a CoIN can do to further test and develop effective protocols and practices. The following is a first iteration of topical areas within each of the three components that the CoIN might address and further define and develop effective protocols and structures.

### **Health Practitioner Component: Surveillance, Screening, and Referral to Care Coordination**

- Organization of the health practitioner office to gather pertinent information from families (resources and protocols in waiting room and/or information collection prior to well-child visit) and reliable and valid tools for that information collection
- Relevant information conveyed to practitioner from such information collection for practitioner visit with patient and anticipatory guidance to family
- Practitioner training and practitioner office training on surveillance and resources and connections
- Practitioner standard screening tools to identify need for referral to care coordination
  - Child development
  - Social determinants // family stress, including valid and reliable screening tools for identifying the 10 percent (or 20 percent) of families where social determinants cause the greatest risk to young children
- Protocols and priorities for referring for care coordination for identified child and family concerns
- Management information systems // electronic patient records that contain this relevant information
- Billing processes for Medicaid (and private coverage) to cover costs
  - Overall visit // levels of visits
  - Screening tools

### **Care Coordination Component: Identification of developmental, environmental, social determinant needs for child and family, referral/scheduling/linkage to someone who can help, follow-up and feedback**

- Job description and skill requirements
- Recruitment, selection, and training protocols
- Supervision/professional development structures and organizational support to perform functions
- Role and potential use of family advocates either in care coordination role or linked to ongoing services and supports
- Specialized roles and coordinators for different populations (language, culture, etc.)
- Within-practice versus outside-practice care coordination models
- Protocols for coordinator assessing child-specific needs and for assessing family/environmental concerns
- Protocols for coordinator accessing services and for scheduling appointments and follow-up with practitioner
- Management information systems for identifying concerns and providing follow-up services and connecting back to child health practitioner
- Billing processes for care coordination under Medicaid (and private coverage)

### **Community Outreach and Networking Component (Community Utility): continuous identification of community resources, networking across resources, further development of resources, and ensuring the best match of services to child and family needs**

- Job description, skill requirements, and recruitment and selection strategies for performing this function (community health liaison, community utility)
- Training and supervision

- Extent of interface/integration with other systems (2-1-1, home visiting) and possible development as a broader community utility for other service providers (e.g. home visiting, child protective services, early childhood education,
- Specific connections and relationships with home visiting and with Part B and Part C of IDEA
- Role in identification and development of peer support/mutual assistance groups within community, including family advocates
- Responses to care coordinator specific requests for assistance
- Outreach to and networking with resources in community to increase effective communication and referrals across services
- Specific connections with providers to meet needs for concrete services (e.g. housing, food, emergency assistance)
- Management information systems that maintain accurate and up-to-date information regarding resources
- Population-based analyses to identify resource needs and gaps, based upon experiences within neighborhoods and upon administrative data regarding current service availability
- Billing under Medicaid administrative claiming for community health liaison staff
- Billing processes for select services, with particularly respect to those eligible for payment under Medicaid/EPSDT for home visiting, Part C and Part B services, and other services which can be deemed “medically necessary.”

Note: CFPC/BUILD have identified a number of other CoINs and Learning Collaboratives that can contribute to this work. CFPC/BUILD also have initiated work and thinking around the issue of environmental screening and surveillance as a part of well-child visits and child health practice and have established a Kitchen Cabinet to guide this work (see below).

<p>KITCHEN CABINET for the Family-Center Health Home for Young Children Collaborative Innovation Network (CoIN)</p>
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The Kitchen Cabinet members for the CoIN are all long-time colleagues and collaborators with Charles Bruner and the Child and Family Policy Center and are nationally recognized in the field as thought leaders in promoting innovation in child health practice – particularly in responding more holistically to young children and their families. Most have done substantial work consulting and providing technical assistance at both the practice and policy levels and have contributed to advancing family-centered child health practice. They all have deep commitments to equity and inclusion. They provide a brain trust for the work of the Learning Collaborative in promoting practice innovation and its diffusion and incorporation into policy and widespread use.

The initial work of the Kitchen Cabinet is to finalize the framework paper for the CoIN, outline the core elements and features of the three components of a family-centered health neighborhood, further identify practitioner champions in the field, plan and participate in conducting an initial meeting of practitioner champions and health and early childhood leaders to introduce the CoIN, launch the CoIN, and oversee and consult, as warranted, on further CoIN and other Learning Collaborative work.

## KITCHEN CABINET BIOGRAPHY BRIEFS

Dr. **Paul Dworkin** is Executive Vice President for Community Child Health and Founding Director, Help Me Grow National Center at Connecticut Children's Medical Center, and Professor of Pediatrics, University of Connecticut School of Medicine. Dr. Dworkin's interests are at the interface among child development, child health services, and child health policy and his research has focused on the value of developmentally-oriented anticipated guidance, the role of developmental surveillance and screening in the early detection of at-risk children, and the value of care coordination in the linkage of children and families to programs and services. He was the editor of the Journal of Developmental and Behavioral Pediatrics from 1997 to 2002 and is currently editor emeritus. He is a past president of the Society for Developmental and Behavioral Pediatrics. Dr. Dworkin's vision led to the creation of Help Me Grow, a nationally-recognized and Connecticut statewide initiative to promote the early detection of children at risk for developmental and behavioral problems and their linkage to programs and services that is currently being replicated in more than 25 states with support from The Commonwealth Fund and the WK Kellogg Foundation.

**Amy Fine** serves as an Associate Director and Senior Fellow at the Center for the Study of Social Policy, where she helps shape CSSP's approach to integrating health, education, human services and other family supports at the community level, focusing on more preventive, developmentally-oriented service systems for children and families. With more than 25 years of experience working on issues related to maternal and child health, Fine has served as a consultant to federal and state health agencies, private philanthropies and national initiatives focused on improving results for children. Her previous work includes positions at the Association of Maternal and Child Health Programs, the Center on Budget and Policy Priorities, the Institute of Medicine and the University of North Carolina's Child Health Outcomes Project. She has degrees from The University of Michigan and University of California, San Francisco and earned her master's of public health from the University of North Carolina.

Dr. **Maxine Hayes** has dedicated her life to teaching and public service, focusing her efforts on disease prevention. She has received numerous awards for her accomplishments, including the prestigious public health award from American Medical Association, the 2002 Dr. Nathan Davis Award for Outstanding Government Service. In addition to her medical degrees, Dr. Hayes earned a Masters of Public Health degree at Harvard University. Dr. Hayes took a teaching position at the Department of Pediatrics of the University of Mississippi Medical Center in 1977 and practiced medicine there for nearly a decade. In 1985, she joined the faculty of the University of Washington School of Medicine, and began work for the Washington State Department of Health in 1988 as the State Health Officer. She continued that role until her retirement in 2014, working closely with local health officials and the medical community statewide, advising the governor and the state's Secretary of Health on health emergency responses, prevention of childhood diseases, and other public health issues.

**Kay Johnson**, MEd and MPH, has been actively involved in Medicaid policy development at the federal and state levels for the last thirty years, in policy advocacy, research, and technical assistance to states and communities. Her expertise encompasses a wide range of maternal and child health issues, including perinatal care, infant mortality, child development, oral health, and services for children with disabilities and special needs. She has provided technical assistance and consultation at the federal, state, and community levels on developing more integrated and family-focused services for low-income and vulnerable children, particularly in the first years of life. She started her career with ten years of providing direct services to low-income families, which is fundamental to her analytic work.

Dr. **Angela Sauaia** is Professor of Public Health, Medicine, and Surgery at the University of Colorado Denver. She has an MD degree from the University of S. Paulo, Brazil, and a PhD in Analytic Health Services from the University of Colorado Denver. Dr. Sauaia has more than 20 years of experience in health services and health outcomes research, and is internationally known for her research in post-injury care. She is a nationally-recognized expert in the area of health equity and her new book "The Quest for Health Equity" bears witness to the health inequities that plague our great nation, and brings hope that change is indeed possible and within reach. As a Latina immigrant herself, bicultural and multilingual, Dr. Sauaia brings her own personal history to the table and has gained the trust of the local underserved communities, based on a history of respect and candidness.

Dr. **Ed Schor** has held a number of positions in pediatric practice, academic pediatrics, health services research, and public health. He led Child Development and Preventive Care program at the Commonwealth Fund, and served as medical director for the Iowa Department of Public Health, Division of Family and Community *Health*. Dr. Schor has chaired both the Committee on Early Childhood, Adoption and Dependent care and the national Task Force on the Family for the American Academy of Pediatrics. He also has served on the Maternal and Child Health Bureau Child Health Survey Technical Panel and consulted for the National Center for Infancy and Early Childhood Health Policy.

**Judith Shaw**, RN, MPH, and Ed.D, is Associate Director of Nursing and Associate Director of Pediatrics at the University of Vermont and the Executive Director of the Vermont Child Health Improvement Partnership, which she established in 1988. She received the Vermont Medical Association Citizen of the Year Award in 2007 and the APA Health Delivery Award in 2015. Ms. Shaw established the National Improvement Partnership Network in 2008, a network of more than 25 states which have developed partnerships to advance quality and transform health care for children and families. She is a co-author of *Bright Futures*, the standard for well-child care practice in the United States.

