# The Integrated Care for Kids (InCK) Model and Family Engagement

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# InCK Marks

### Family Engagement, Medicaid, and InCK

- About InCK and InCK Marks
- Overview Family Engagement, Pediatrics, Medicaid, and the InCK Model
- What We Know Family Engagement for Children with Special Needs (and All Children)
- What Family Advocates Can Do Family Engagement in InCK Planning and Design
- 5. Next Steps for InCK Marks (and Family Engagement)

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### About InCK and InCK Marks

- The Integrated Care for Kids (InCK) Model is a \$128 million, 7-year federal initiative of the Center for Medicare and Medicaid Innovation (CMMI) designed specifically for children (prenatal to 21), with a competitive application process involving the state Médicaid agency and a Local Lead Partner and Partnership Council
- The InCK Marks Resource Network is a resource network providing state-of-the-field resources to child health advocates. experts, family and community leaders, practitioner innovators, Medicaid administrators, and policy makers in reviewing and developing strategies to improve child health through more integrated care for kids.

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### InCK Marks Partner Resource Network

SUPPORTING CHILD HEALTH CHAMPIONS ADVANCE MEDICAID TO IMPROVE CHILD HEALTH

















































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Family Engagement and Healthy Child Development

In Education, it is recognized that...

Parents are their child's first and most important teacher.



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### InCK Marks

Family Engagement and Healthy Child Development

In Health, it is recognized that...

Parents are their child's first and most important nurse and caregiver.



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### Family Engagement and Pediatrics

- Pediatrics has led in establishing the concept of a "patientcentered" medical home and has, for children (and particularly young children), expanded that to a "family-centered" medical home
- For children with special health care needs, "team-based" care has been emphasized, with parents as core part of that team
- Bright Futures represents a standard for well-child care that emphasizes parental engagement and responding to social as well as biomedical determinants of health

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# Family Engagement and Family-centered Approaches in Medicaid

- The EPSDT benefit requires parental guidance during well-child visits and coverage of interperiodic visits to address parental concerns.
- Medicaid can finance services provided to parents under child's coverage:
  - · maternal depression screening,
  - · child-parent mental health therapies,
  - advice/training for parents to provide health-related care for their children.
  - other services that rely upon parents as partners in their child's health care
- Medicaid has options to help children with disabilities and special needs stay in their homes and communities
  - · Home and community-based waivers/state plan options began through family advocacy (Katie Beckett) and the recognition that a child's best care can be provided in the homé
  - Medicaid eligibility linked to SSI disability determination and Family Opportunity Act option for states (Medicaid buy-in programs for children who have a family income of up to 300% of the FPL, and who meet SSI-eligibility requirements based on disability).

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### Family Engagement and the InCK Model

- THE core element of InCK (the practice change requirement) is to assess and "risk stratify" all children based upon health and healthrelated conditions, with those with complex health conditions and multi-system needs receiving care coordination that is "individualized, family- and child-driven, and ethnically, culturally, and linguistically appropriate"
- Preference is given to applicants who explicitly propose "two generation approaches" that work to strengthen families and their child's home environment
- Emphasis is placed upon reducing out-of-home placements and maintaining children with behavioral, substance abuse, and complex medical needs in their homes

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### InCK Marks

### Basics: Three Entities Must be Engaged

#### **Medicaid Agency**

- Partner with Lead Organization
- Responsible for Alternative Payment Model and data

#### Lead Organization

- Established entity
- Local convening of Partnership
- Coordination & accountability

### Partnership Council

- Represent core service areas
- Chartered, formal, engaged

All three entities will benefit from stressing family engagement and enlisting families and experts in family engagement in their work.

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Nora Wells, Executive Director



Partnering with Families: Why It's Important and What We've Learned from Families

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### A Multidimensional Framework For Patient And Family Engagement In Health And Health Care

Continuum and

In the health care system:

"Patient engagement has been called a critical part of a continuously learning health system, a necessary condition for the redesign of the health care system, the 'holy grail' of health care, and the next 'blockbuster drug of the century'."

Levels of Engagement			Shared Decision- Making
Provision of Direct Care and Services	Receive information	Asked about treatment preferences	Make decisions about treatment
Organizational Design and Governance	Surveyed about experiences	Involved in providing advice	Co-lead improvement activities
Policy Making & Accountability for Results	Part of focus groups	Sought for recommendations	Have voice and vote in decisions

Consultation

Carman K. L. et al. Health Affairs. 2013;32:223-231.

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Involvement

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Partnership &

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### Parent/family engagement

- Parent engagement is an overarching principle and approach for involving families in decisions about themselves, their children, services, and their communities. It includes:
  - · Direct relationships with service providers
  - · Mutual support shared among parents
  - · Advocacy by parents on behalf of their families
  - · Decision-making and advisory roles in agencies
  - · Leadership in the community
- The National Partnership for Patients (NPP) set 3 goals to engage patients and families:
  - All patients will be asked for feedback about their experience of care, and this information will be used by health care organizations and their staff to improve care.
  - All patients will have access to tools and support systems that enable them to effectively navigate and manage their care.
  - All patients will have access to information and assistance that enables them to make informed decisions about their treatment options.

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# The Power of Engaging Families in Improving Children's Health Lessons from Family Voices

### It takes Commitment



Families are included in all systems-level initiatives that impact the organization's policies, programs, services, and practices.

#### Key Criteria:

- Champion
- Win-Win
- Create opportunities
- Work together to create mission, strategic plan, other programmatic documents
- · Ensure support for partnership
- · Include budget for partners

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# The Power of Engaging Families in Improving Children's Health Lessons from Family Voices

### It is based on Transparency



Family leaders can easily access and understand the information they need to participate effectively.

#### **Key Criteria**

- Use data
- · Shared understanding of work
- Provides training & support
- Cultural awareness
- No jargon
- Convenient meetings

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The Power of Engaging Families in Improving Children's Health Lessons from Family Voices

### It depends on Representation



Family leaders reflect the diversity of the community served by the organization.

#### Key Criteria

- Partners with family-led or communitybased organizations to recruit and participating families
- · Race/ethnicity, Culture
- Language
- Age
- Gender
- Disability
- · Geographic Area

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The Power of Engaging Families in Improving Children's Health Lessons from Family Voices

### The Voices of Families Voices have an Impact



Family leaders' ideas are incorporated at the systems level to improve policies, programs, services, and practices.

#### Key Criteria

- · Choosing goals
- Involved in implementation
- Engaged in evaluation
- Influence programmatic options
- Engagement → improved services

Learn more: A Framework for Assessing Family Engagement in Systems
Change

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Shadi Houshyar
Director of Early Childhood and Child Welfare
Initiatives



THE VOICE FOR HEALTH CARE CONSUMERS

What We Know and How Family Leaders
Can Inform Actions on InCK in States

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### Families USA's Mission and Focus Areas

Families USA, a leading national voice for health care consumers, is dedicated to the achievement of high-quality, affordable health care and improved health for all.

We advance our mission through public policy analysis, advocacy, and collaboration with partners to promote a patient-and community centered health system.









We have worked at the national, state and community level for over 35 years.

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- Too often, the consumer voice is an afterthought in local, state, and national efforts to reshape our health care system.
- Families USA is working to address this problem by researching and giving broad voice to consumer perspectives, and exploring new ways that enable consumers to engage on health care issues. .
- This inclusion must span policy development, decisionmaking, implementation, and evaluation for it to be truly meaningful.

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- Families USA is committed to effective inclusion of the voices and priorities
  of communities of color and other disadvantaged groups. This is not only
  the right thing to do as a matter of equity, but it is also the smart thing to
  do, because the ultimate output will be of higher quality and more
  effective..
- Barriers, rooted in structural racism and bias that influence attitudes, behaviors, policies and practices of child and family serving systems prevent many families of color from being true partners and leaders in their child's healthy development.
- A great resource for how to make change: Manifesto for Race Equity and Parent Leadership in Early Childhood Systems developed by EC-LINC and CSSP available at <a href="https://cssp.org/wp-content/uploads/2018/11/Parent-Manifesto-FINAL.pdf">https://cssp.org/wp-content/uploads/2018/11/Parent-Manifesto-FINAL.pdf</a>

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What Family Advocates Can Do – InCK Planning and Design in States

Planning at the Practice Design Level





Planning at the Policy Development Level

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### Areas for Family Leadership in InCK

#### Community Planning/Implementation: Partnership Council

• Partnership Council must include "stakeholder representatives from families and caregivers living in the community."

#### Care Mapping and Service Design: Care Coordination

- Care mapping is "a family-driven, person-centered process that supports families and providers in coordinating care of children" (strategies can include peer support and community health workers).
- Care coordination required to "facilitate individualized, family- and childdriven, and ethnically, culturally, and linguistically appropriate care delivery"

#### • Two Generation Approaches: Young Children and Families

• For children 0-6, risk stratification can include parent risks and needs and preference given to applicants providing two-generation approaches

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### Areas for Family Leadership in InCK (cont.)

#### Alternative Payment Mechanisms (APMs): Goals

 State Medicaid agencies should consider that in achieving personcentered care, it is essential to empower individuals and their families/caregivers as partners in health care transformation – parents should be at the table

#### Root Cause Analysis:

- Applicants must identify health conditions that are root causes of outof-home placements
- Information sources can include child and caregiver interviews

Diverse and robust family engagement is key to achieving each of these goals.

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### Reasons to Engage Family Leaders

- Leaders with knowledge, experience, and expertise in family engagement are needed to ensure that opportunity is realized.
- Leaders in family engagement have roles at all levels of activity (Medicaid Agency, Lead Local Entity, Partnership Council).
- Leaders in family engagement have critical information on what works at service level, care coordination level, and planning and decision-making level.
- Leaders can help ensure that issues of diversity and equity are addressed.

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### InCK Marks

### Opportunities to Weigh In – Now to June 10, 2019

- Contact state Medicaid agency and encourage state to review InCK Model and give attention to family engagement at both the service delivery and the planning/design level.
- Offer to provide help and participate in InCK model review and planning to ensure diverse and robust participation from families.
- Provide information on opportunities for improving child health through family engagement.
- Focus on "what works" and provide state examples that are improving children's health through family engagement and leadership.
- Emphasize that opportunities exist whether or not the state applies for or receives InCK designation – all states can and should do something to integrate services and strengthen family engagement.

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### **Next Steps**

- Questions and Clarifications
- Future Webinars
- Next Steps for Champions
- Final Remarks

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### Next Steps: InCK Marks Webinar Series

- InCK Model Overview (March 5)
- InCK Model and the Medicaid EPSDT Benefit (March 19)
- InCK Model and Family Engagement (Now)
- InCK Model, Prevention, and Building a Culture of Health Root Causes and Risk Stratification (April 9)
- InCK Model and Health Equity (Coming)
- InCK Model and Alternative Payment Models and High Value Care (Coming)
- InCK Model and Foster Care (Coming)
- Both slides and recorded webinar available in webinar section of www.inckmarks.org

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### Next Steps: Champions

- Complete Survey on Webinar
- Sign Up for and Participate in Future Webinars
- Share State Experiences
- Provide Ideas for InCK Marks Activities



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