## InCK Marks

## Risk Stratification for Children in Medicaid: Achieving the Potential of Prevention

InCK Marks and Child and Adolescent Health Measurement Initiative (CAHMI) Resource Brief

> Charles Bruner and Kay Johnson, InCK Marks, and Christina Bethell, CAHMI

> > April, 2019

©2019



#### Preface

This InCK Marks resource brief is based on a larger body of work being developed by the Child and Adolescent Health Measurement Initiative (CAHMI) focused on identifying and responding to children for both biomedical and social determinants of health (SDOH). This brief draws upon and provides more detail about many of the points discussed in the InCK Marks April 9<sup>th</sup> webinar presentation on "The InCK Model, Prevention, and Building a Culture of Health."

The Integrated Care for Kids (InCK) Model and its Notice of Funding Opportunity (NOFO) provide guidelines to applicants that place strong emphasis upon conducting a "root cause analysis" for children's out-of-home placements and a "risk stratification" of children into service integration levels (SILs) based upon their risk. While screening for a child's own biomedical risks is well-understood by child health practitioners, screening for conditions around the child (social determinants of health) that impact healthy child development is an emerging field in child clinical practice.

This resource brief incorporates data from recent efforts to describe the child population overall, and the population of children on Medicaid specifically, by their health conditions and their home and community environment, in order to identify and respond to those who can benefit from increased attention and response. The InCK model emphasizes screening for risk stratification and integrated services as responses. InCK Marks work focuses on effective assessment of risks and approaches for responding earlier and to family and community as well as child specific concerns.

#### Acknowledgements and Disclaimer

This report was made possible with generous funding from the Robert Wood Johnson Foundation (RWJF) and the Perigee Fund for the establishment of InCK Marks. Support also came to CAHMI from the federal Health Resources and Services Administration and RWJF to lead the Maternal and Child Health Measurement Research Network (MCH/MRN), which is engaged in advancing the whole child and whole family screening methods discussed here. All opinions and views expressed are those of the authors and not necessarily of the funders. InCK Marks is not affiliated with the Center for Medicaid and Medicare Innovation nor should it be considered an authoritative source in addressing any issues or application requirements in the InCK Notice of Funding Opportunity (NOFO). The purpose of InCK Marks is to support child health champions – child advocates, practitioner leaders, family and community voices, health experts, Medicaid agency staff, and policy makers – in reviewing the InCK opportunity and to promote policies and practices that will advance child health. CAHMI is based in the Department of Population, Family and Reproductive Health within the Bloomberg School of Public Health at Johns Hopkins University. The mission of the CAHMI is to promote early and lifelong health of children, youth and families using family centered data and tools.

# Risk Stratification for Children in Medicaid: Achieving the Potential of Prevention

#### Introduction

Nationally, four in ten children now are covered under Medicaid, including half of all children birth to three. Medicaid has become the dominant source of health care financing for all children and an even larger share of those with special health care needs.

There is a growing and persuasive body of research that is broadening the definition of child health and health care from a treatment of injury and illness and the medical management of chronic health conditions to a more preventive, ecological, and developmental response through services and supports

that advance overall child well-being. The P.A.R.E.N.T.S. Science (Protective factors, Adverse childhood experiences, Resiliency, Epigenetics, Neurobiology, Toxic stress, and Social determinants of health) reinforce that healthy development in childhood is dependent upon much more than addressing the child's biomedical health concerns and requires responses that ensure safety, stability, and nurturing in the child's home and community environment. This is particularly true for the first years of life, where the child's brain is developing its basic architecture and intimate, serve-and-return interactions are key. Failures here to establish secure attachment and bonding can have profound adverse impacts that are difficult and costly to remediate later in life and which may never be fully corrected. This attention to the child's environment and family also is true in childhood and adolescence, as the child grows and all aspects of executive functioning continue to develop.

The role of the child health practitioner, starting with primary care and well-child visits, now is recognized as going beyond providing medical care. *Bright Futures*, recognized as the authoritative guide to the content of well-child Child health: "The extent to which an individual child or groups of children are able or enabled to a) develop and realize their potential; b) satisfy their needs and c) develop the capacities to allow them to interact successfully with their biological, physical and social environment" (National Research Council; Institute of Medicine, 2004). In other words, child and youth health is the "full range of health constructs, including physical health, developmental, social, emotional and behavioral health, oral health, nutrition, and physical activity" (U.S. DHHS; U.S. DE). – InCK Model Notice of Funding Opportunity (2019)

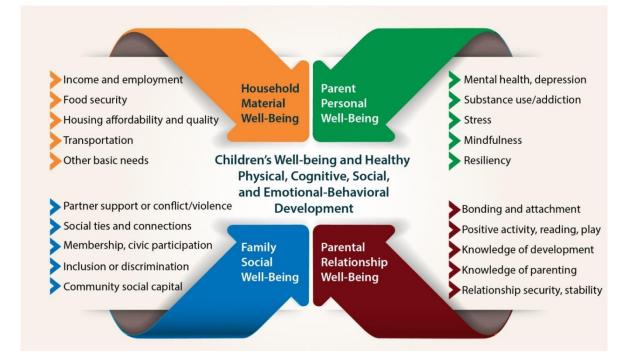
**Health equity** is achieving the highest level of health for all people. Health equity entails focused societal efforts to address avoidable inequalities by equalizing the conditions for health for all groups, especially for those who have experienced socioeconomic disadvantage or historical injustices.

- Healthy People 2020

visits, emphasizes the practitioner's role in providing guidance and direction to parents on much broader aspects of healthy development than responses to bio-medical concerns. The 4<sup>th</sup> edition of *Bright Futures*, released in 2018, has added an even broader range of topics for well-child visits around social determinants of health (SDOH). These include identifying and responding to concerns around household material well-being, parental personal well-being, family social well-being, and child-parent relational

well-being. As shown in Chart 1, both science and common sense recognize that healthy child development is dependent upon far more than providing child-specific medical care and treatment. The emphasis upon two-generation approaches to improve children's growth and development, stressed in the InCK model, is based upon this recognition that child well-being and parental well-being should not be considered as distinct and independent from one another.

#### CHART 1: HOME, FAMILY, AND FAMILY FACTORS (SOCIAL DETERMINANTS) IMPACTING CHILD HEALTH AND WELL-BEING



Source: Bruner C, Johnson K, Bethell C, et al. *Next steps in family-focused screening to address social determinants of health for young children in primary care. Report of the Social Determinants of Health Technical Working Group of the Maternal and Child Health Measurement Research Network*. Child and Adolescent Health Measurement Initiative, Johns Hopkins Bloomberg School of Public Health. 2018.

A variety of iterations of this chart have been developed to represent SDOHs, some broader than others in their range, but the different fields of research within the P.A.R.E.N.T.S. science are consistent with this representation.

While it does not take a medical degree for a primary health practitioner to recognize that a mother bringing in her sixth month-old is stressed and not picking up on her child's cues for attention or that a thirteen year-old is surly or withdrawn, practitioners cannot rely solely upon their own surveillance to identify children who require attention related to SDOHs. Moreover, the specific causes of that stress, surliness, or withdrawal may be very different for different children and families.

There now is a growing array of screening tools and guidance offered to both primary child health practitioners and families themselves to better identify ecological in addition to bio-medical factors placing child health at risk. Yet, few of these incorporate the full range of home and family factors shown above.

The federal InCK model recognizes the need to respond in an integrated way that extends beyond medical care and places a major emphasis upon developing "risk stratification" of children on Medicaid based upon a "root cause" analysis of current placements of children and youth, particularly for behavioral and substance abuse needs that currently result in out-of-home placements (e.g. foster care, residential treatment) or recurring hospitalizations or emergency room care. While a significant emphasis in the InCK model is to provide better alternatives to and therefore reduce placements and hospitalizations and their costs, any risk stratification tool should differentiate among different levels and types of risks, some of which may not, for most children, result in placement or hospitalization in the short run but will certainly impact healthy development and accumulate to increase risk for a multitude of adverse health outcomes over time.

This resource brief describes what currently is known about the population of children overall and those on Medicaid and the prevalence of risks that lead to health concerns, up to and including out-of-home placement. First, however, it provides a "root cause" analysis, based upon the Five Why's (referenced in InCK Notice of Funding Opportunity or NOFO) that starts at the point of imminent risk of placement and extends backward to prior causes for that risk. It then discusses the elements that are needed to assess risk, based upon the root cause analysis, recognizing that the InCK model requires a risk stratification into service integration levels (SILs) for all Medicaid children.

#### **Root Cause Analysis**

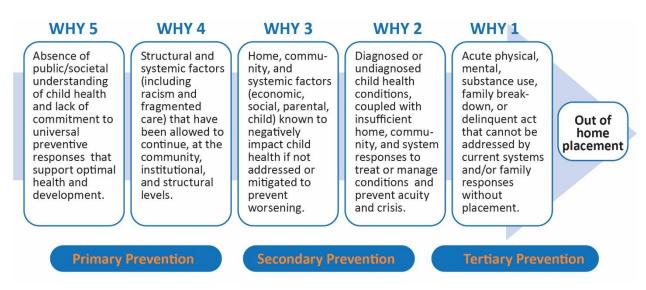
The InCK model requires that applicants provide a "root cause analysis" for placement of children into out-of-home care and, in doing so, employ methods like the Five Why's. The InCK model then requires that the risk stratification for all children be based upon this root cause analysis.

The Five Why's is a technique for moving backward (toward the roots) for the cause of a systemic breakdown or accident. It first looks at what was the immediate cause of that breakdown and then looks at what was the cause of that cause, and so on, generally to the point of getting at more underlying, or root causes, much like moving back from tertiary prevention to secondary prevention to primary prevention. Each of these why levels offers an opportunity for intervention to prevent the breakdown and, generally, to make the system operate more effectively overall. Often used in a review of the cause of mechanical accidents or medical errors, the Five Why's technique can be applied to human and social conditions.

As applied in the InCK model, these questions could go successively back to the antecedents of the prior root cause, as shown below:

- 1. Why are children with serious behavioral (i.e., mental health and substance abuse) issues, complex medical conditions, or other health conditions currently being placed in out-of-home placement, hospitals, or other facilities to address those conditions rather than kept at home?
- 2. Why do children who have such behavioral health conditions progress to the point of severity that they become at risk of out-of-home placement and hospitalization?
- 3. Why do children not receive services and supports early so that early interventions effectively treat the condition and, at least, prevent the condition from worsening?
- 4. Why do children experience trauma, separation, or lack of nurturing supports in the home, school, and community that result in (or exacerbate) such conditions?
- 5. Why is the home, school, and community life vulnerable to producing trauma, separation, or lack of nurturing?

In graphic form, as the InCK model starts with looking back to why children are placed into out-of-home care or hospitalized (particularly recurrent episodes), Chart 2 shows a root cause analysis based upon the Five Why's model and also shows how these why's fit into the designation of primary, secondary, and tertiary prevention.



#### CHART 2: THE FIVE WHY'S APPROACH TO A ROOT CAUSE ANALYSIS

Again, this root cause analysis is aligned with much medical, psychological, sociological, and child development research. It brings in causes from the perspective of the child or child's family as the subject of focus for intervention (which is largely the realm in which child health practitioners operate) and causes from the perspective of the community and society as the subject of focus (which includes public and population health). This root cause analysis also corresponds to the P.A.R.E.N.T.S. science, particularly related to early identification of child and family concerns related to the 3rd Why. This includes either (or both) the presence of risk factors and the absence of protective ones.

In terms of risk stratification at the point of the child health practitioner's contact with the child and family, it involves both health and development conditions in the child and conditions in the home and community that impact early and lifelong development and health.

#### Prevalence of Risk for Children Overall and in Medicaid

There currently are a small share of children with serious or profound disabilities or conditions or family situations that result in placement out-of-home or ongoing episodes requiring hospitalization or emergency room use. Fortunately, less than 1 percent (0.8 percent) of all children currently are in foster placements, and a much smaller percentage are in permanent out-of-home settings for profound physical, cognitive, or behavioral impairments (ICF-MRs, ICF-MIs, and other hospital or institutional/residential settings and group homes). There is a larger, but still small, percentage of children who are subject to multiple episodes of hospitalization for physical (hemophilia, asthma, etc.) conditions or behavioral (mental health crises, substance overdoses, or a combination of the two) ones. At a population level, an overall estimate of children who fit this category (generally the highest cost users of medical services) is 2

to 4 percent of the total population. This corresponds to the population in the First Why category and, for the purposes of the InCK Model, the Service Integration Level 3 (SIL3) of risk stratification.

Because of categorical Medicaid eligibility of children in the foster care system (e.g. even without regard for family income) and the additional eligibility provisions for children with complex medical needs (including children receiving supplemental security income (SSI) designation and through the Family Opportunity Act), a very high percentage of children either in out-of-home placement or receiving intensive and ongoing treatments in the home to prevent placement, are covered under Medicaid and its early, periodic, screening, diagnostic, and treatment (EPSDT) benefit. As will be described later, for the Medicaid population this represents 6 percent of children served.

The proportion of children vulnerable to or experiencing suboptimal health outcomes is, of course much larger. There are those who have identified or identifiable health concerns (particularly social, emotional, behavioral, and developmental) who currently are not being served in ways that optimize their health and development.

One way of categorizing these is as children with special health care needs (CSHCN). CSHCN have ongoing health conditions requiring a type or amount of services substantially greater than children generally need. Based on the validated parent-reported CSHCN Screener (used in several national surveys and performance measures), in 2016-2017, nearly one in five (18.8 percent) of all U.S. children met criteria for having a special health care need. Most meeting CSHCN criteria (60 percent) have multiple conditions and/or require multiple types of services and therefore are "more complex." Over one-quarter (23.8 percent) of children with Medicaid coverage are identified as CSHCN, which is one and a half times greater than the 15.6 percent of privately insured children. This may even be an understatement of the actual condition of children with health needs requiring some additional attention. The InCK Model's NOFO itself states that three in ten children on Medicaid have behavioral health or substance abuse needs, but only one-third receive any services to address them. This is the second Why group in Chart 2.

In addition to the groups of children with presenting conditions and potential diagnoses that can lead to treatment under Medicaid's EPSDT benefit – and particularly for young children – there is a third group whose home and family situations, absent strengthening, are very likely to result in those children developing health-threatening conditions and diagnoses as they grow and mature. Among very young children (birth to three), this population of children at-risk may be equal to or greater than the proportion of children with specific, diagnosed physical, social, or behavioral conditions – another 15 to 25 percent or more of the young child population in addition to the 15 percent in the above two categories.

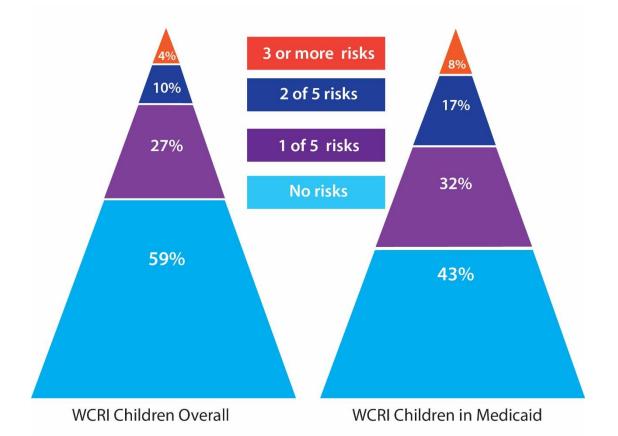
This totals to 30 to over 40 percent of children experiencing suboptimal health or on trajectories for adverse health outcomes throughout life. The rate of risk summarized here is consistent with other information about children and their cognitive, social, and behavioral development and their family and community environments. For the generally higher risk Medicaid population, these rates would grow to easily represent over 50 percent of children covered. Further, while illness or injury is the cause for some health adversities, the largest share of adversities comes from non-medical but health-related issues and not building protective factors into child's lives. Further, parents of children who do have special health care needs that are medical are likely to experience additional stresses and challenges and need additional support to be effective in their responses, as well.

This also corresponds to a Whole Child Risk Index (WCRI) Score developed by the CAHMI, using National Survey of Children's Health (NSCH) data (data provided here is from the higher bar standard which includes children with more complex special needs and multiple ACEs along with other social risk

factors) The WCRI score is based upon both child-specific special health needs and select indicators related to social environment (ACEs, food insufficiency, parent coping capacity, and family resilience). Chart 3 shows the breakout of U.S children age 0-17 by the presence of cumulative risk, these data are very consistent with the figures presented earlier.

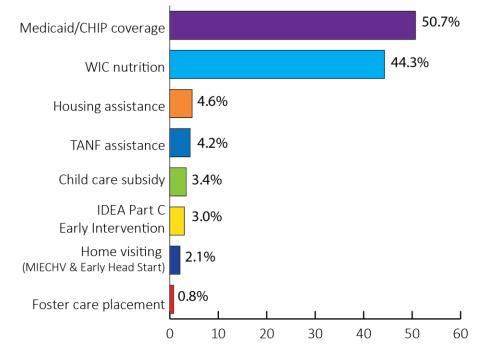
Higher rates of risk are found for those with Medicaid coverage and for younger children age 0-5. Findings using the CAHMI's Whole Child Risk Index (WRCI) show that 56.6% of children age 0-17 with Medicaid coverage have one or more of the five risks assessed and 7.6% have 3 or more risks. When social and family risks are stratified by special health care needs status and complexity, the WCRI identified 5.8% of children on Medicaid as having "more complex" special needs and 3-4 of the four social and family risks assessed.

### CHART 3: PERCENTAGE OF CHILDREN BY WHOLE CHILD RISK INDEX (WCRI) SCORES, US CHILDREN AGE 0-17



Source: Bethell, C. Overview of the Whole Child Risk Index: A summary measure to support statewide integrated systems of care innovations. April, 2109. Data: Author's analysis of the 2016 and 2017 combined National Survey of Children's Health data files. The WCRI identifies children with one of more of five risks: (1) more complex special health care needs; (2) 2 or more adverse childhood experiences/ACEs; (3) reported food insufficiency; (4) parental difficulties handling demands of parenting; (5) reduced resilience within the family.

The gap in receiving attention for any of these risks is greatest for the young child population. Once in school, children are subject to the Americans with Disability Education Act (IDEA) and attention to a range of needs for special education in inclusive settings, with 12 percent of school-aged children in special education (and an additional share receiving compensatory education or other counseling and school-based support, as well as others receiving behavioral health and other services outside the school setting). As shown in Chart 4, for children birth to 3, outside of health coverage and supports to meet household material needs (EITC, SNAP, and WIC), the percentage of young children and their families receiving supports from other federal and federal-state funding sources is in the single digits. The Individuals with Disabilities Education Act Part C Early Intervention program for children birth to three and Part B for children 3-5 each serve only 3 percent of the child population, one-quarter as many as are identified and served within special education for children 5-18. While there are many discrete programs that serve different populations of young children, their reach is generally quite small. While virtually all children of school-age receive educational assessments and a variety of screens and tests for their cognitive development, for a large share of young children, the only source for such initial surveillance and screening is in the child health practitioner's office. National and state data show, however, that rates of developmental screening by child health practitioners (one basis for risk stratification) are still less than 40 percent for young children and vary widely across states. Moreover, even when children are screened they often are not referred or receive follow up services.



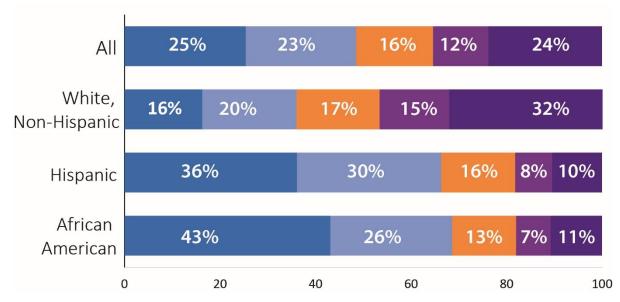
#### CHART 4: PERCENTAGE OF CHILDREN BY SERVED BY SELECT FEDERAL PROGRAMS

Source: Bruner C and Johnson K. *Federal Spending on Prenatal to Three: Developing a Public Response to Improving Developmental Trajectories and Preventing Inequities*. Center for the Study of Social Policy. 2018.

This estimate of 30 to 40 percent of children being at-risk also is also consistent with various, but related, measures of children's development and well-being than those outlined in the WCRI summary measure presented above. Analysis of data from Early Childhood Longitudinal Study (ECLS) indicates that one-half of children start school at some disadvantage due to some physical, social-emotional, or cognitive condition, and one-quarter are at high risk due to conditions across more than one of these dimensions. (This is similar to a new measure using NSCH data assessing if children age 3-5 are "healthy and ready to learn." Using the newer NSCH measure, even more young children were assessed as needing extra supports and attention in order to be ready for school.)

Testing at grades 4, 8, and 11 on both math and reading show that only half of students are fully proficient, and one-quarter to one-third are not even achieving at a basic level. One in four children do not complete high school with their class, and up to 60 percent are not considered to be fully ready for college or a career at that time. Further, those less prepared are more likely to have children as adolescents or as single young adults, with those children most likely to live in households struggling to make ends meet. For a majority of CSHCN, combined biomedical and social complexity often leads to less engagement and achievement in school.

If states want to move their child health systems to be more preventive and to respond early to signs of a developmental concern (physical, cognitive, social, and emotional), even a basic risk assessment and stratification approach like the CAHMI WCRI summary score will likely identify a large share of the population for response, with the majority with risks requiring two-generation approaches that address child, parent and family factors in an integrated manner.



### CHART 5: DISTRIBUTION OF THE YOUNG CHILD (0-5) POPULATION BY RACE AND POVERTY LEVEL, US, 2011-2013 CENSUS DATA

Source: Bruner C. ACE, Place, Race, and Poverty: Building Hope for Children. *Academic Pediatrics*. 2017;17(7S):S123-S129.

Finally, health and developmental risks and vulnerability do not exist evenly across or within states. They also vary by children's age, socio-economic status and racial, and ethnic identity. In particular, race, place, and poverty are intertwined and place and poverty relate back to and compound the discrimination (and marginalization) children and families of color can encounter. More detailed treatment of these different issues is provided elsewhere, but Chart 5 simply shows, again for young children, while the majority of white, non-Hispanic children live in relatively affluent households, at least two-thirds of Hispanic children and family risks, like food insufficiency, unmet needs for services and parenting stress. These stark differences, alone, require that a racial equity lens be applied to responding to child risk. In terms of the Five Why's, the fourth Why shows that population-level as well as individual-service level responses are needed to address the risks in marginalized, discriminated against, or segregated and excluded populations.

The need to address issues of race in the context of childhood and its impact upon both material well-being (both absolute and relative) and inclusion or marginalization and segregation (belongingness) remains one of America's greatest challenges and opportunities. *Neurons to Neighborhoods* offered that challenge in 2000, and it is even more relevant today.

#### Assessing Prevalence of Risk Using Medicaid Data

The InCK Model requires that states develop a risk stratification system for all children on Medicaid that covers both clinical and medical care needs (physical health) but also behavioral health and social service needs, including housing and nutrition needs. At least for children birth to 6, it gives preference to applicants that develop two-generation strategies which respond to parental and family issues (SDOHs) that impact child health and well-being. In previous sections of this brief, "Children of families of European origin soon will make up less than 50 percent of the population under 5. These demographic realities suggest both promising opportunities and sobering challenges. The opportunities offered by a multicultural society that is cohesive and inclusive are virtually limitless – including the richness that comes from a broad diversity of skills and talents, and the vitality that is fueled by a range of interests and perspectives. The challenges posed by a multicultural society that is fragmented and exclusive are daunting – including the wasted human capital that is undermined by prejudice and discrimination, and the threat of civil *disorder precipitated by bigotry and* hatred. From Neurons to Neighborhoods. Institute of Medicine, 2000.

information on the risk of all children, using parent-reported data available to states today, was presented. Findings show substantial risk for all children and markedly greater risk for children on Medicaid. It is to be expected that children on Medicaid have greater risk for poorer health outcomes, healthy development and health trajectories across life – both because eligibility for Medicaid for the most part is based upon household income level and, where it is not (e.g. when it is tied to the child's disability or foster care status), children are eligible because they have complex health problems or other substantial needs.

Medicaid administrative data is also an important source of data that can be used to give some picture of medical and social risk as well. State Medicaid data systems currently contain information on service utilization as well as the source for eligibility for recipients (e.g., based upon income; foster care; or disability status). Moreover, states also have claims and billing data that can identify children by services they receive (including behavioral health services) and the locus of services (including emergency room

and hospitalization). Child risk stratification using data currently in Medicaid administrative records is important. Yet, it is essential that efforts be made to identify information beyond medical diagnoses and care utilization. Additional information about the child's home and community environment may also be available in states that have sought to include such data.

#### Oregon's Medical Complexity and Social Complexity Framework.

The Oregon Pediatric Improvement Project (OPIP), in partnership with the Oregon Health Authority (Medicaid agency) Transformation Center, has developed a framework for identifying "health complexity" that is related to separate measures of "medical complexity" and "social complexity." It is conceptually similar to the CAHMI's WCRI. Chart 6 offers a schematic showing this formulation.

### CHART 6: HEALTH COMPLEXITY AS COMBINATION OF MEDICAL COMPLEXITY AND SOCIAL COMPLEXITY

### Risk Stratification: *Health Complexity* = Medical Complexity + Social Complexity



Source: Reuland. Health Complexity in Children: A Statewide Summary Report. Oregon Pediatric Improvement Partnership. November, 2018.

The Oregon Pediatric Improvement Partnership used this formulation to examine Oregon's Medicaid child population in terms of both medical complexity and social complexity, drawing upon Medicaid and other data sources linked to children's Medicaid records in order to identify social complexities with a focus on system documented adverse childhood experiences (ACEs). Each child was categorized as having 0, 1-2 or 3 or more social risks. Next, the Clinical Risk Groups (CRG) schema was used to classify children based on the complexity of their medical needs using Medicaid data. Each child was categorized within three levels – little or no chronic problems, non- complex chronic condition(s), and complex chronic conditions. Chart 7 shows the proportion of children enrolled in Oregon's child Medicaid population as they are placed into one of nine groups based on the 3 levels of social and 3 levels of medical complexity.

### CHART SEVEN: OREGON ANALYSIS OF MEDICAID POPULATION BY SOCIAL AND MEDICAL COMPLEXITY

Analysis of 12 factors	Medical Complexity – Non-Chronic Healthy	Medical Complexity – Non-Complex Chronic	Medical Complexity – Complex Chronic
Social Complexity: No factors	16.6%	1.7%	0.7%
Social Complexity: 1-2 factors	32.6%	<b>7.2%</b> ‡	2.4%
Social Complexity: <u>&gt;</u> 3 factors	<b>26.5%</b> ‡	9.5%†	3.0%*

\*most likely in preventable placement/imminent risk

<sup>+</sup>most likely experiencing multiple stresses and early intervention

+ most likely benefiting from enhanced prevention

Source: Reuland C et al. *Health Complexity in Children: A Statewide Summary Report*. Oregon Pediatric Improvement Partnership. November, 2018. See: <u>http://www.oregon-pip.org/projects/Packard.html</u> and <u>https://www.oregon.gov/oha/HPA/dsi-tc/Pages/Child-Health-Complexity-Data.aspx</u>

As can be seen, there is a relationship between medical complexity and social complexity, with more medically complex children also having greater social complexity. This was also found in the Whole Child Risk Index measure, where two-thirds of CSHCN with more complex needs also had 1 or more of the 4 social and family risks included in the WCRI. One explanation is that having a child with more complex needs place additional demands upon their families in their parenting roles, which can cause stress as well as added time, attention, and knowledge in responding to that medical complexity. It may also be the case the social complexity drives exacerbations in children's health problems and places them into a more medically complex category. A wide range of complexity exists across children with similar diagnoses and part of this variation is explained by family factors. (Note, that while similar proportions of children are identified as being at higher risk using the CAHMI's family-reported WCRI and OPIP's Medicaid data method – 5.8% for WCRI and 5.4% for OPIP – these may not represent the same children were methods to be compared.)

In fact, some medically complex conditions themselves are the result of social complexity during pregnancy and early life. Social complexity can result in child health conditions that become chronic and complex. Particularly from a health prevention and promotion perspective and for young children, identifying and responding to social complexity contributes to preventing or better managing medical complexity. A recent review of evidence on addressing ACEs reveals that children's health outcomes are improved when strategies that focus on child and parent connection and parent coping and parenting skills are used.

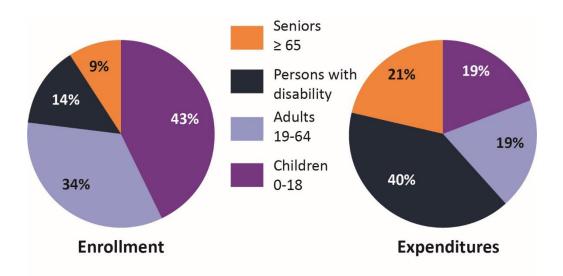
As Chart 7 shows, while the percentage of children identified as having complex chronic conditions is small (6.1 percent, and quite related to those in or at imminent risk of placement or episodes requiring hospitalization), 88 percent of these also are classified as having 1 or more social complexity factors that also may require attention. Further, nearly 60 percent of all children on Medicaid were identified as having some level of social complexity, which is much greater than for those with any level of medical complexity. This is also true for the WCRI measure.

Primary child health practitioners are trained and directed to screen for, diagnose, and treat medical complexity in the child. The frameworks illustrated here use a risk stratification process involving screening for social complexity as well medical complexity and are especially relevant to the goals of the InCK approach. However, they are not commonly used in clinical practice today.

#### The Child Medicaid Population Stratified by Type of Eligibility and Spending

In general, children are not a high cost group within the Medicaid population. While nearly one-half of the overall Medicaid population, they constitute less than 20 percent of Medicaid expenditures. As Chart 8 shows, while much smaller shares of the Medicaid population, persons eligible under the disability category or seniors (commonly for long-term care services, not covered by Medicare) represent the major costs, and cost drivers, for Medicaid. (Children may be eligible as children or under the disability designation; this chart includes children under the disability designation as part of the disability population and expenditures).

### CHART EIGHT: MEDICAID ENROLLMENT AND SPENDING BY ELIGIBILITY CATEGORY, US, FFY2013



Source: Johnson K, Bruner C. A sourcebook on Medicaid's role in early childhood: Advancing high-performing medical homes and improving lifelong health. Child and Family Policy Center, 2018. Based on data from CMS.

The Medicaid and CHIP Payment and Access Commission (MACPAC) provides reports to Congress that offer some of the most detailed analyses, at a national level, on Medicaid and CHIP spending and use. Its 2015 report to Congress included a chapter detailing the child Medicaid population according to its criteria for eligibility (disability, foster care, or regularly qualifying child) designation and whether or not the child had received some behavioral health service. MACPAC provided information on the number of children in the three categories and with or without a behavioral health conditions, along with the all Medicaid spending (including but not limited to behavioral services) on those children.

Chart 9 provides a summary of this information. It shows that a small share of the child population – particularly those in the disability category or in the child welfare category and with behavioral health concerns – produce the greatest Medicaid costs.

#### CHART NINE: MEDICAID CHILDREN BY ELIGIBLIITY CATEGORY AND BEHAVIORAL HEALTH USE AND MEDICAID COSTS, US, 2011

Medicaid Population	Number Children (millions )	Medicai d Costs (billions)	Annual per child cost	Percent of Medicaid Population	Percent of Medicaid Costs
All Children on Medicaid (including disability)	29.3 M	\$77.1 B	\$ 2,632	100%	100%
Disability (medically complex) & Behavioral Health	0.7 M	\$13.3 B	\$19,182	2.4%	17.3%
Disability(medically complex) & No Behavioral Health	0.7 M	\$ 7.9 B	\$ 11,399	2.4%	<b>10.2</b> %
Child Welfare & Behavioral Health	0.3 M	\$ 3.5 B	\$ 11,097	1.1%	4.6%
Other Populations – Behavioral Health	3.1 M	\$13.9 B	\$ 4,482	10.5%†	18.0%
All Other Children	24.5M	\$38.5 B	\$ 1,571	<b>83.7%</b> ‡	50.0%

\* most likely in preventable placement/imminent risk

<sup>+</sup> most likely experiencing multiple stresses and early intervention

<sup>‡</sup> most likely benefiting from enhanced prevention.

Source: MACPAC 2015 Report to Congress (2011 Medicaid data).

While representing 5.8 percent of the overall child population, children in the disability and child welfare with behavioral health condition categories generate 32.3 percent of overall child Medicaid expenditures. While children with some behavioral health conditions but without disability or child welfare involvement have a higher average rate of yearly Medicaid expenditures (averaging \$4,482), these are relatively small compared to other Medicaid populations and overall costs. Altogether, 13.5 percent of all children on Medicaid were identified as having some behavioral health services.

The InCK Model application notes that "Medicaid and CHIP cover some of the nation's most vulnerable children" and cites an estimate that more than one in three Medicaid-covered children have emotional or behavioral challenges but less than one-third currently receive behavioral health care. The 20 plus percent of children with emotional and behavioral health challenges not receiving care fall within the "other" population in this chart, with current annual per child Medicaid expenditures of \$1,571.

This MACPAC data is important in placing in the context of actual Medicaid spending a risk stratification which identifies children which go beyond the SIL3 level (which are the highest Medicaid cost children). It also provides spending information on children who have social complexities but at most emerging or

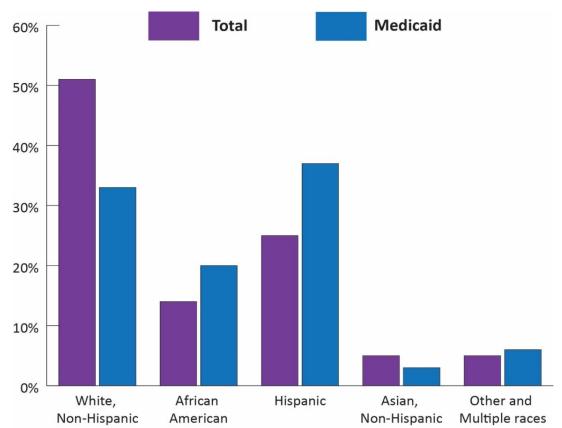
moderate levels of medical/behavioral complexity, showing these generally to be at moderate or low Medicaid costs (and therefore low to moderate current health responses to their health-related concerns and risks). The opportunity to improve health trajectories for this population through more preventive services may be substantial, but the expectation of doing so while reducing or maintaining current levels of Medicaid and other service expenditures is not.

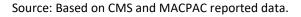
#### The Child Medicaid Population and Health Equity.

Finally, it is important to recognize that discrimination and racism (personal, institutional, and structural) affect child health and well-being (the Fourth Why in the root cause analysis). Children learn their own identity and how they are treated by others in the world. Being subject to discrimination, marginalization, and segregation causes stress, as well as affecting material well-being and access to health-related supports and services. Parental stress as a result of discrimination can affect parenting and even healthy pregnancy. Substantial disparities exist on most measures of child health by race and ethnicity, as well as by socio-economic status. While the two are intertwined, they both have impacts upon child health and well-being.

Medicaid has a substantial role to play in eliminating health disparities and inequities among children. As Chart 10 shows, while children are of color (not White and non-Hispanic) represent nearly half of the child population overall, two-thirds of children on Medicaid are of color.

### CHART TEN: TOTAL CHILD POPULATION AND MEDICAID CHILD POPULATION, BY RACE/ETHNICITY, U.S., 2016





This has very significant implications to how child health practitioners respond and connect to young children and their families, including combatting bias and ensuring culturally responsive care. Practices have the opportunity to model inclusive responses which acknowledge and recognize strengths, while not minimizing the impacts of discrimination and bias. Team-based care that itself includes a family advocate or community health worker culturally consonant with families can help to ensure that issues of dominant culture bias or insensitivity are addressed.

#### From Risk Stratification to Clinical Practice and Comprehensive Care

Identifying risk – both in terms of medical and social complexity – is only a step in the process of supporting healthier child development. Risk stratification, particularly around social risk and complexity, provides a starting point for engaging children and their families, but is neither an end in itself nor a simple hand-off referral for some discrete service.

Even when something like food insecurity is identified and the family currently is not enrolled in SNAP or WIC, there often is more going on in the family than access to nutritious foods (and many families are food insecure even though they already are enrolled in SNAP and WIC, and make use of food pantries and other resources in the community). A mother who indicates substantial stress in her life (or screens positive for depression) may, in fact, have a legal issue with respect to debt collection or a family crisis related to an abusive partner that is first on her list of issues to resolve.

Families are much more complicated in terms of their needs, hopes, strengths, and issues and opportunities in their lives than any risk screening and stratification can uncover, let alone pinpoint a single appropriate response. As such, screening is best conducted in the context of also engaging families in a process to identify their priorities, strengths and needs. One such emerging approach for doing this is through the CARE\_PATH for Kids project for children with medical complexity. The CAHMI's family driven, pre-visit Well-Visit Planner tools also integrate assessments and screening with opportunities for parents to identify strengths, needs and priorities at the individual, clinic and population level.

Overall, while risk stratification is used to discern likely levels of risk and need and some initial points for follow-up exploration, this is only the start of a process. It also is valuable to engage families in self-reflection and relationship building with practitioners. When conducted in a relationship-centered manner using parent and child responses to standardized questions, screening and risk stratification not only can be more precise in identifying children and families for additional attention than surveillance alone, it also can engage families in identifying resources and ways to address the needs and risks identified and foster trust and positive relationships with practitioners. Child health practitioners' observation-based surveillance of child or family risks and needs cannot replace the value of parent and child provided information. Meeting clinical goals for screening and stratification requires methods to closely engage families in the process and, ideally, integrate family and child reported information into medical records directly.

Engaging families and children in screening and stratification lays the groundwork for the more concerted and relational interaction that is required to properly respond to advance child health. Chart 11 offers a representation of where screening and risk stratification might fit into the identification of a child and family with needs and what subsequent responses both within the practitioner's office and through care coordination and linkages to community resources might result and produce.

#### CHART 11: FROM SURVEILLANCE AND SCREENING TO EFFECTIVE RESPONSE

#### Six Month Well-Child Visit

**Surveillance** – When she comes into the office, the mother appears stressed and does not pick up on her six month-old's cues for attention. Apple juice is in the child's bottle. The practitioner and office recognize the importance of carefully reviewing the screen.

**Screening/Risk Stratification** – A social determinants (SDOH) screen completed by the mother reveals no ACEs in the child (also no identified developmental/physical delays or concerns in the clinical screen). The SDOH screen indicates family has moved recently and is in temporary housing in a poor neighborhood in community. The mother reports food insecurity; as well as stress and social isolation.

**Practitioner activity in visit** – In the Reach Out and Read session, the mother reveals she did not know her baby liked listening to and looking at books. She indicates her infant has trouble breathing at times (first time following first cold/virus), and is fussy. The practitioner orders tests related to asthma/allergies and blood lead level and recommends an inter-periodic EPSDT visit in 2 weeks. Because of the SDOH screen (and surveillance), the practitioner also brings in/refers the family to care coordination.

**Care coordination further interview (and diagnosis)** – In a follow-up with a social worker/family advocate/community health worker/HMG call center, the mother indicates she has moved to new community to get out of unsafe home and neighborhood situation and is staying with a friend, working at a job where she is in trouble because she has missed work due to her baby's illness, and doesn't know where to go for help. The mother indicate she is receiving SNAP, WIC, and Medicaid for herself and child, but reports she doesn't have a crib at home and baby sleeps in her bed.

**Care Coordination actions (treatment)**: The care coordinator validates mother in her role (doing so much for her baby in stressful times) and helps, through Medical Legal Partnerships, to get her onto a subsidized housing list, links her to a church Stork's Nest program for a crib, and into a family development program at the local Community Action Agency (meetings and support group for new parents). She also gets the mother to make an additional visit with WIC to develop a food and nutrition plan. The care coordinator also sets up check-in times with the mother and shows interest in knowing how family is progressing.

**Practitioner clinical services (treatment)**: The practitioner identifies breathing/asthma as a concern, prescribes a home visit from a nurse to identify and address contaminants in home, provide training to the parent on early responses to episodes (as well as medication for the child); and mother enrolls in a family support program (e.g., CenteringParents, HealthySteps, DULCE, TripleP, home visiting, babies with asthma support group for responding to infant's special/general needs).

#### **Eighteen-Month Visit and Outcomes**

**Family**: Family is in own apartment, clean and without environmental hazards. The home has books and toys; mother and child are in a weekly family/library program; and mother has found employment that is more family-friendly. She has friends from work, church, and library program who can provide help (including child care) for unexpected needs.

**Child**: Child has no identified developmental delays, at normal weight, fewer episodes related to breathing/asthma, shows secure attachment with mother and grabs at new Reach Out and Read book and picks out pictures as mother reads and asks the questions.

In this example, the value of the formal screening is in further supporting the child health practitioner in ensuring responses to the family through that care coordination, which itself draws from the screen but also builds a connection with the family. The screen provides a reason for and the initial direction of the care coordinator's contact and relationship development with the family.

#### **Risk Stratification and Population Health**

In addition to use at the child and family level, using screening and risk stratification data collection methods that also provide information at the population level is important. With such population data, a picture of a practice's overall population or subgroups of its population by geographic area (neighborhood or community) or type of risk, need or strength can be identified. Knowing, for example, that a significant share of children and families served have concerns with the safety of housing for young children, the availability of fresh fruits and vegetables, the absence of young child activities and play areas in the neighborhood, child asthma or elevated blood lead levels, or absence of books and toys in the home, can suggest and motivate action to address broader community and public health needs. These then can lead to establishment of additional parenting support resources in the community, initiation within the practice of group-based programs or patient-support groups around specific topics, public education and messaging campaigns, or policy actions to establish recreational and educational opportunities in parks or through libraries.

Before children enter school, the most nearly universal point of contact with them is the health care system. The types of information gathered about children and families that are needed to respond to their health needs and concerns are also the types of information that provide a picture of how well young children are doing, how supportive their home and community environments are, and what gaps exist that deserve practice and community attention to fill.

#### Risk Stratification Tools – Medical and Social Complexity

One of the requirements of the InCK Model is to develop specific risk stratification screening tools for use throughout the local site (and for at least eighty percent of children served by Medicaid). The application indicates flexibility in developing or selecting tools but requires that common tools be employed at well-child visits. While these must be used for all children and cover issues of both-medical and social complexity, different specific questions or surveys are needed for different age groups.

There are many screening tools available to assess medical complexities – physical, mental, and developmental. Some screening methods are embedded in the WCRI risk measures discussed in this report and may underlie data included in Medicaid records data used in the OPIP Medicaid data focused method. Numerous standardized tools are available to engage parents and/or children in assessments of development, special needs, family risks, resilience and protective factors. ASQ and ASQ-SE offer developmental screenings by age. Other tools, such as those for autism, relate to specific medical conditions. CHADIS offers a wide array of such screening tools for use by practices. Child health practitioners generally are trained in screening for medical conditions and complexities and can also learn to screen for a broader array of factors relevant to clinical care, reduction of risks for out-of-home placement, and less than optimal development and health trajectories.

First, practitioners must see the value of broader assessments. Knowing a six-month old may have a developmental or physical concern but not knowing about the child's home environment and the parent's

nurturing and care is likely to lead to insufficient responses. Therefore, it is crucial that screening of young children extend to detailed and explicit screening of the child's family and home environment.

Screening for social complexity – in particular developing valid and comprehensive tools – is in an earlier stage of development than screening for medical complexity. This, however, is an area which now is receiving much attention, particularly as it relates to young children – both because the safety, stability, and nurturing in the home environment is so critical and because young children are less likely to have acquired diagnosable conditions than older children.

By the time a child has reached age 15, if the child has experienced trauma and ACEs or an absence of nurturing and the presence of other protective factors, the child is likely to have identifiable physical, social, emotional, or behavioral conditions that require attention. Moreover, unlike the six-month old, the child can speak for himself or herself and the child can be diagnosed for cognitive, social, emotional, and behavioral conditions, including those that stem from earlier family risks and experiences.

The latest edition of *Bright Futures* places much greater emphasis upon surveillance and anticipatory guidance related to social determinants of health, including positive determinants like positive family relationships. *Bright Futures* is sometimes viewed as a periodicity schedule with specific screening and examinations that must be incorporated into the well-child visit. That is one key part of *Bright Futures*, but the bulk of *Bright Futures* informs the content of well-child visits and the topics that should be discussed with the parents. Chart 12 shows on the left service categories related to specific screens and on the right describes the guidance for both the content and anticipatory guidance to be provided in the age-specific well-child visit. The examples here for the nine-month visit and eighteen-month visits.

As Chart 12 shows, the topics for well-child visits include safety in the home environment, parental risks and social supports, and parental knowledge about development and discipline (e.g., the elements in Chart 1).

In 2017-2018, CAHMI, through a Technical Work Group (TWG) established as a part of the Health Resources and Services Administration supported Maternal and Child Health Measurement Research Network (MCH/MRN), conducted a scan and systematic comparison of survey tools in use to measure social determinants of health for young children including factors related to household economic well-being, parental personal well-being, family social well-being, and child-parent relationship well-being. An initial report on this scan and a starting point set of items feasible for use in primary care practices as a screen was produced as a consensus document (see Appendix A). This starting-point short tool draws upon a variety of validated tools in use in the field by various initiatives and will continue to be developed and assessed for its value, validity and approaches to scoring and use. This and related work in the field offer the potential – along with already used medical and developmental screens – to establish more effective ways to initially screen children and their families for risk stratification (really "opportunity" stratification) and differentiated responses that can provide initial direction to staff when further engaging the child and family and coordinating with community based-resources they may need.

One of the strongest themes from the work of the CAHMI's MCH/MRN TWG was that such screening should seek to identify strengths as well as risks, in part because the screen is designed to engage and support families and in part because, even when risks are present, building upon family strengths often represents the most effective response to those risks.

#### CHART TWELVE: ELEMENTS OF BRIGHT FUTURES WELL-CHILD VISITS

#### SERVICE CATEGORY/PREVENTIVE SERVICE

Measurements Height and weight Head circumference Body mass index Blood pressure

Sensory screening Vision Hearing

#### **Developmental health**

Developmental screening Autism screening Behavioral assessment Drug use assessment Depression screening

#### **Physical examination Procedures** Tuberculosis testing Immunization

Anemia screening Lead risk assessment

**Oral health** Fluoride varnish Fluoride supplementation

#### **PRIORITIES FOR NINE-MONTH VISIT/TOPICS**

Social determinants of health Risks: Intimate partner violence Strengths and protective factors: family relationships and support (Six-month visit risk: living situation and food security; tobacco, alcohol and drugs; parental depression)

#### Infant behavior and development

Changing sleep pattern and schedule Developmental mobility and cognitive development Interactive learning and communication Media

**Discipline** Parent expectations of child's behavior

Nutrition and feeding Self-feeding, mealtime routines Transition to solid foods, cup drinking, plans for weaning

Safety Car safety Heatstroke prevention Firearm safety Safe home environment: burns, poisoning, drowning, falls

Bright Futures 4<sup>th</sup> Edition: Guidelines for Health Supervision Source: Bright Futures Periodicity Schedule In California Auditor March, 2019 Audit: "Millions of Children in Medi-Cal Are Not Receiving Preventive Care Services," Report 2018-111.

#### Developing a Risk Stratification and Response Strategy Within InCK (and Overall)

Risk stratification is required within the InCK Model, specifically to identify children at three levels of risk, as shown in Chart 13 (excerpted from more than four pages in the NOFO describing the SILs). Applicants then are required to respond with additional care coordination efforts at SIL2 and SIL3 levels of risk, and with team-based approaches at the SIL3 level. A general description of what qualifies as being at different levels of risk is provided, but it is expected that the first two years' planning will involve operationalization of these terms and development and refinement of tools and strategies to establish different risk levels. Since screens must be employed for all children on Medicaid that are part of the local effort, information gathered will provide for differentiating among children that extends beyond any specific categorization into SIL1, SIL2, and SIL3 categories.

#### CHART THIRTEEN: SERVICE INTEGRATION LEVELS AS DESCRIBED IN THE INCK MODEL NOFO

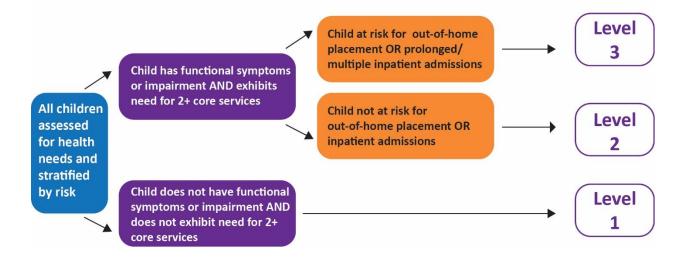
SILs consist of increasing intensity of integrated care coordination and case management appropriate for individual needs:

**Level 1**: Includes the entire target population. Focuses on basic, preventive care and active surveillance for developing needs and functional impairments.

**Level 2**: Includes children with needs involving more than one service type and who exhibit a functional symptom or impairment. [\*] Focuses on comprehensive needs assessments and integrated care coordination.

**Level 3**: Includes children who meet Level 2 criteria who are currently, or are at imminent risk of being, placed outside the home. Focuses on child-centered care planning, integrated case management, and home and community-based services. (NOFO, p. 20-21)

[\*] For young children from birth to age six, Lead Organizations should consider setting a policy allowing assessment of parent/guardian needs and stratifying the child based on the parent/guardian meeting these criteria. ... A similar approach should be considered for pregnant mothers. ... Preference will be given to applicants proposing two-generational strategies. ... [P]roviders may use tools that screen for Adverse Childhood Experiences (including domestic violence, child abuse, substance use), or other health determinants such as housing or food insecurity. (NOFO, p. 23)



Source: CMMI. InCK Model NOFO.

As applicants develop their strategies for conducting screens and assessments that lead to this risk stratification, they have significant flexibility in incorporating screening for social complexity in the family, particularly for young children and pregnant women – and including in their risk stratification and response children with social complexity and risk, as well as presenting child conditions and needs.

It is one thing to identify risk, however, and another thing to respond effectively to address that risk - and, in some instances - doing so in ways that prevent placement and/or reduce Medicaid costs for that child.

In addition to the example provided in Chart 11, the following examples offer a range of child and family conditions that child health practitioners are likely to encounter, discussed in terms of both risk stratification and response.

**Example One**. 2-year-old developing normally with mother and father both in graduate school and with limited income, but strong support system and grandparents who provide additional help, including financial assistance if needed.

Medicaid provides essential health coverage for many families currently with limited incomes, who need affordable health coverage, particularly for their children. A share of children on Medicaid are in households like Example One. They deserve high quality "basic preventive care and active surveillance for developing needs," but clearly represent SIL1, in terms of the InCK Model's risk stratification.

**Example Two**. 6-month-old of single mother working and living in a poor neighborhood, getting by but under very substantial stress and with limited support; infant has no identified medical conditions.

Similar to the detailed description of the child and family in Chart 11, if the local lead organization elects to do so, this child could be considered under SIL2 because of parental criteria and therefore receive additional care coordination. From a preventive and developmental perspective, if actions can be taken through care coordination and access to additional services that improve the child's home environment (safety, security, and nurturing), the child's health trajectory should be elevated. At the same time, current Medicaid expenditures on this child are likely to be quite low, so immediate cost benefits (particularly to Medicaid) are unlikely. The additional care coordination has a cost, and there may also be additional preventive and developmental service identified that involve Medicaid financing. As Chart 4 suggests, there are many more children in this category than there are publicly-provided services to address their needs. Providing care coordination and additional services represents much higher value care for the child (and therefore should be compensated for that in a value-based payment system), but it will not result in immediate cost savings.

**Example Three**. 3-year-old with some developmental delay (not enough to qualify for Part C but qualifying as a child with special health care needs) and 2 ACEs, living in temporary substandard housing. Mother may be depressed but is clearly stressed and struggling to hold it together.

This example may be the consequence of a specific child medical condition that has just been identified but not received attention; or it could be the result of the child in example two getting older without any actions that address the child's home environment. There is likely some level of medical complexity with the child as well as social complexity with the family. While the child likely can qualify for SIL2 based upon the developmental delay, the most effective responses are likely to involve two-generation approaches that seek to support and strengthen the mother and her relationship with the child. Care coordination in this instance is likely to be most effective if it is relational, helping to support the mother in her parenting and increase her agency in responding to her environment so that she has quality time with her child and receives answers to her questions and guidance about what she can do to support the child's development. Home visiting and peer networking can be very effective in improving the parent-child relationship and the child's development and should be eligible for reimbursement under Medicaid and its EPSDT benefit, if they are not provided through existing community services. The opportunities for improving child health (and receiving long-term returns-on-investment) are great, but actions are not likely to yield immediate Medicaid cost savings but to involve additional Medicaid investments.

**Example Four**. 8-year-old missing school because of asthma, living in house with mold and cockroach infestations, but doesn't have other health conditions. The family is poor, but goes to great lengths to ensure their children receive the care and supports they need.

The 1997 Jack Nicholson and Helen Hunt movie, "As Good As It Gets," could be this example; and Jonathan Kozol's 1987 Rachel and Her Children describes this health problem at almost an epidemic level within New York City. Unless housing remediation is identified as a service need, however, the child will not qualify as SIL2 as the child has only a physical health need and the family does not meet criteria for being at risk. At the same time, any risk stratification should identify this child and the likelihood the child will incur substantial medical costs due to asthma episodes – involving emergency room visits and hospitalizations. Moreover, there are costeffective actions that involve additional training and support to parents, household remediation for airborne contaminants (removal of home contaminants and triggers – cockroaches, mold, carpeting, cleaning with hepa vacuum cleaners) – that produce asthma attacks. In poor neighborhoods, attaching a pulmonary nurse practitioner to schools to reduce absences due to asthma has resulted in reductions to emergency room and hospitalizations, as well. In terms of opportunities to achieve the triple aim of improved health quality, improved population health, and reduced (Medicaid) health care expenditures, this represents a proven opportunity (e.g. lowhanging fruit) – one that often can contribute to the InCK Model's goal for cost savings, whether or not this is classified as SIL1 or SIL2.

**Example Five**. 12-year-old acting out in school and in special education for behavioral concerns, but does not have specific health diagnosis, mother has mental health issue and provides limited guidance or oversight for child.

Within the InCK model, this child may qualify under the SIL2 category as having needs in both the physical health system and in special education, but also may be too old to have the mother's condition considered. As differentiated from the first two examples, the child is in school and likely receiving significant additional attention there (in examples one and two, the child is not likely even to be in formal child care), so the role of the child health practitioner is more in the contributing realm to addressing the child's medical needs in the context of what also is being provided by the school (and any other involvement with child welfare, juvenile justice, or social service agencies and systems). The child health practitioner is in the position of diagnosing mental health issues and referring for treatment, as necessary. In general, such diagnosis and treatment is best when aligned with the school system's response, which involves sharing of information and alignment and integration of child case plans. Again, however, any mental health counseling or treatment provided the child as a result of the child health practitioner's involvement is likely to involve greater, rather than reduced, Medicaid expenditures. In addition, it may be that the child and parent are alienated from or overwhelmed by the school system and its responses to the child – and do not want information shared with the school about the child's treatment. The role of the child health practitioner and any referral to counseling or treatment is most effective when it strongly engages the child and family and then determines how best to work with what is going on in school (e.g. service integration is not always the answer).

**Example Six**. Woman in six-month of pregnancy comes in for prenatal visit, because of some spotting and abdominal pain, indicating she hadn't come in earlier because, for her first pregnancy, the "doctor just poked at my stomach and said everything was fine," and she didn't want to add to her stress in working and caring for her two-year old by taking time off from work she could not afford and taking two buses to get to the doctor's office. She is ambivalent about her pregnancy. Although she will love the child, she worries that she just will be too overwhelmed to meet both the infant's and her two-year old's needs.

Research shows the challenges to early entry into prenatal care to mothers who are struggling, risk being overwhelmed with their lives, and under substantial stress as a result. Research is also clear that fiscal, social, and emotional supports to those mothers are core to effective prenatal care and, in the case of otherwise medically-uncomplicated pregnancies, more important than the medical aspects of prenatal visits. Community health workers, promotores, doulas, and nurse midwives that provide enhanced care have been shown to both improve pregnancy outcomes and, as importantly, post-pregnancy nurturing and attachment. For the mother coming in at six months and potentially already facing some issues of malnourishment, the result of providing such enhanced care coordination may not be in reducing low-birthweight as much as reducing other stresses in the family and making her more eager and ready to provide for her children after she has her child. Risk stratification certainly can identify this mother as in the SIL2 category, and care coordination can help ensure greater fiscal, social, and emotional supports for the mother. This may even reduce the likelihood of c-sections (particularly if the enhanced care coordination is directed to this) and low birthweight and any neonatal intensive care unit (NICU) use, both with substantial costs. In addition, however, it also can reduce the likelihood of readmissions or emergency room use after the birth of the child. The birth of a child is one of the major medical costs incurred for most children, with much greater costs for c-sections than vaginal births and for the higher costs related to NICU use. Like the example 5, above, this is one where there are opportunities to provide higher-value care and reduce health care expenditures – although the major benefits from improved birth outcomes and a healthy start in life occur well beyond the neonatal period and in terms of life-course trajectories.

These examples were selected because they are representative of the types of children and families covered by Medicaid that do come into the child health practitioner's office for medical care. They are not particularly complex or unusual cases, but they are ones for which the current standard practice (even in example one, as to the comprehensiveness of screening) does not provide for the standard of high value care set out in *Bright Futures* and reflected in the most innovative and exemplary practices today.

They also point to increased roles that the child health practitioner and the Medicaid financing system can and need to play to improve child health and produce long-term benefits – for the child, the family, and society and with high returns on investment across health, education, social services, and the economy.

As the examples also show, screening and risk stratification are only a first step – the key to improving child outcomes is in the response, which requires more information than the screen itself is likely to provide and involves actions that respond to the child and family's unique conditions, needs, and strengths and hopes.

#### Conclusion

Risk stratification is important to more precisely identifying children and families who might benefit from additional or different service responses, starting from the visit with the child health practitioner. At the same time, this is only a starting point for subsequent identification of needs and responses to children and families. Effective screening responses almost always involve the child and family in providing support and encouragement to them, recognizing their own hopes and needs.

A top-down process for risk stratification runs its own risk of failing to recognize, value, and understand the child and family in meeting their health (physical, social, psychological, and developmental) needs. A ground-up process is needed to ensure that it also meets child, family, and health practitioner needs.

In terms of the InCK Model, much of the work to design and improve screening and its risk stratification process will be part of the two-year planning work. This does not need to start from scratch, however. As this resource paper suggests, such work deserves to look at the issue of health risk stratification or health complexity both in terms of the child's medical complexity and the child and family's social complexity. It needs to be viewed as a starting point for further inquiry and assessment of the child and family, in a way that engages and recognizes the child and family's needs and strengths and hopes and desires. It needs to result in a differentiated response that goes far beyond a simple three-level risk stratification process. And, it needs to examine the value of doing so in broader terms than immediate placement prevention or cost containment or savings.

#### Appendix A – Screening for Social Determinants of Child Health

The following is a set of eighteen questions designed as a core set for screening for social determinants of health (across material, personal, social, and parenting well-being). This could a separate screen or as a part of other screens (child health status, family medical history, parent concerns about child development, etc.). It is based upon and amalgamated from a review of a variety of screens in current use and provided as an appendix to a longer report that emphasizes that such screens represent only a starting point to engaging families and must be built into an overall strategy for engaging families and responding to their strengths, needs, and hopes.

Bruner, C., Johnson, K., Bethell, C., Dworkin, P., Kotelchuk, M., Perrin, E., Shaw, J., Trefz, M, & Whitaker, R. *Next Steps in Family-Focused Screening to Address Social Determinants of Health for Young Children. Report of the Social Determinants of Health Technical Working Group, Maternal and Child Health Measurement Research Network (MCH/MRN).* Child and Adolescent Health Measurement Initiative. 2018 Appendix.

#### Family Survey on Child's Home Environment and Health and Development Needs

The following questions are designed to help us better respond to you and your child and support you as you respond to your child's growth and health. Please respond to the following questions – all responses will be kept confidential. If you are uncomfortable responding to any of the questions, please feel free to skip them.

### Baseline Information on parent(s) (should be collected as general information about the child and family)

Age	Address [poor neighborhood]
Insurance status	Household membership
Work status	Health/disability status/condition
Race/ethnicity	Household income
Home language	Educational status

#### Questions (views of primary caregiver(s): Y (Yes) S (Somewhat) N (No)

- 1. Our household can manage itself financially and meet our children's needs, including books and toys and games and clothes for different occasions and a good home with play areas. Y/S/N
- We often find it hard to pay for the very basics like food, housing, medical care, and heating. Y/S/N
- 3. Generally, I am excited and confident, rather than stressed and worried, about my role as a parent. Y/S/N
- 4. Generally, I feel I know what I need to do to take care of my child(ren) and respond to their needs and the way they are growing and behaving. Y/S/N
- 5. Often, over the last two weeks, I have felt little interest or pleasure in doing things. Y/S/N
- 6. Often, over the last two weeks, I have felt down, depressed or hopeless. Y/S/N
- 7. [Stress is when someone feels tense, nervous, anxious, or can't sleep at night because their mind is troubled.] I am often stressed in my day-to-day life and activities. Y/S/N

- 8. I sometimes drink more than I feel I should. Y/S/N
- 9. Someone in my household smokes. Y/S/N
- 10. In the past year, I have used an illegal drug or a prescription medication for non-medical reasons, such as to feel better or get high. Y/S/N
- 11. I can solve most problems if I invest the necessary effort. Y/S/N
- 12. I can express my emotions, set limits for myself, and calm myself down. Y/S/N
- 13. I have good friends who provide me the emotional support I need and I can share my successes and my problems with them. Y/S/N
- 14. I can go to someone in my community if there is a sudden need for help financially (like an unexpected \$500 bill) or social support (taking care of a problem like emergency child care or transportation help). Y/S/N
- 15. I feel valued and accepted and included by my family and my community. Y/S/N
- 16. In the past month, I have felt emotionally upset (angry, sad, or frustrated) on how I was treated because of my race. Y/S/N
- 17. In the past year, I have at some time felt threatened in my home or been afraid of my partner or ex-partner (or someone who cares for me). Y/S/N
- 18. I have had a change in my family life (move to a new location, divorce or ending of relationship, new partner or new major interest in life, arrest or major illness of a family member, etc.) since my last visit that is affecting my role as a parent.Y/S/N

If yes, describe: \_\_\_\_

I would like to discuss the following concern or concerns (please circle the question number) about how it affects me and my young child and what I can do \_\_\_\_\_\_

Thank you for completing. Please feel free to ask the practitioner or staff about this survey or any of the questions on it.

#### Appendix B – Identifying Opportunities for Health Cost Savings

In general, children are not large users of health services nor large contributors to rising health care costs. These are more driven by increases in chronic health conditions, the aging of society and the proportion of the population with end-of-life conditions, and the costs of the medical interventions involved in treating chronic health conditions and responding to end-of-life diseases. At the same time, however, (and certainly as the takeaway message from the Adverse Childhood Experiences or ACEs research), many of these chronic health conditions are the result of compromises in development during childhood. The epidemic of childhood obesity and the rise in the level of opioid abuse have both short-term and much larger long-term implications to the nation's health status and health care costs.

The Center for Medicare and Medicaid Innovation (CMMI) and Integrated Care for Kids (InCK) model recognizes these threats, but it also has a mandate to advance innovations that can achieve the triple aim of improved health quality, improved population health, and reduced per capita health expenditures. While seeking to advance health, all of CMMI's initiatives have required applicants to develop innovations that can project overall cost savings in Medicare or Medicaid – and to advance these through alternative payment models and systems. That is the case with the InCK model.

At the same time, however, developing value-based payment systems and transforming health system responses is more than simply reducing health costs. The move to value-based care requires that systems determine what constitutes value (and higher value) and developing payment models that provide greater reimbursement for higher value care.

The challenge applicants for InCK face is in identifying where their work (and with what populations of children), new health system responses and payment models can achieve immediate health cost offsets – and ensuring that these are part of the model and used as an identified subset of the child population to project cost savings. The slide below provides some examples from the field that have shown promise in producing immediate health (or in some instances child welfare) cost offsets.

### InCK Marks

#### Potential Immediate Cost Savings in the First 1000 Days – Evidenced-Based Examples

- Address home environments that trigger respiratory distress and ER visits (e.g. asthma, allergy)
- Provide post-delivery neonatal supports, particularly for infants from NICUs, to prevent re-hospitalizations
- Offer brief home consultations within first three weeks at home (e.g. Family Connects) to reduce ER use and hospitalizations
- Provide family preservation services/family group decision-making/mobile crisis responses to infants at imminent risk of foster placement (may not reduce Medicaid spending, savings may be in IV-E)
- Reduce c-sections through greater use of doulas, nurse midwives, promotores, and/or other supports/provisions
- Support infant-toddler court teams to speed reunification and permanency from foster care removals (may not reduce Medicaid spending, savings may be in IV-E)

WWW.INCKMARKS.ORG

### Appendix C – Some Take-Away Messages on Risk Stratification and Healthy Child Development

- 1. The definition of child health has moved beyond medical treatment of disease or illness and clinical management of chronic health conditions to advancing healthy development across physical, social, emotional/behavioral, and cognitive development dimensions of health and wellbeing. While this extends beyond medical care, child health practitioners are in the position to identify and initiate interventions and responses that extend beyond clinical services. Children are growing and developing, and ensuring healthy trajectories in childhood is the foundation for lifelong health. Child health practitioners have a key role not only in providing clinical care but also in initiating responses to broader factors relating to child health.
- 2. Risk stratification for children, and particularly young children, involves both screening for the child's own health conditions and for the child's home and community environment (household material well-being, parenting personal well-being, family social well-being, and parent-child relationship well-being). A child's health complexity (and therefore need for additional responses beyond basic medical care) includes the child's medical complexity and the child and home's social complexity. Children need to be screened (and risk stratified) both in terms of their own health conditions and in terms of factors in their home environments that affect their healthy development.
- 3. In the overall population, 2 to 4 percent of the child population has health complexity that places that child at risk of (or in) placement and requiring sustained interventions and treatment. Another 10 to 15 percent of the child population has some child health condition that deserves attention, often also requiring responses to the home environment. Beyond this, an additional 15 to 20 percent of children are in home environments that need attention and, without greater safety, stability, and nurturing in the home and community, will result in compromises to the child's health. While the majority of children will develop along healthy trajectories, a very substantial share (at least 30 to 40 percent) has health conditions that need attention or are in a home environment that compromises that development.
- 4. In the child Medicaid population, the percentages of children requiring additional attention are higher, with 5-6 percent having health complexities that place the child at risk of (or in) placement, 20 to 30 percent having diagnosable health condition that deserves attention, and an additional 20 to 25 percent at risk of developing one, due to their home environment. Half or more children on Medicaid, are at significant risk of (or experiencing) compromised health trajectories.
- 5. Screening and risk stratification for children on Medicaid can produce a more accurate assessment of the child population requiring additional attention, but this is only a starting point for responding to need and risk or determining the level or type of response needed. Screening must be accompanied by practitioner surveillance and anticipatory guidance aligned with that screening, along with care coordination and services that are child-and-family centered for children determined at risk. Effective screening enables the practitioner, generally through relational care coordination, to engage and work with the child and family to respond to risks and needs in the context of the child and family's lives, strengths, hopes, and needs.
- 6. There are many established tools to screen for specific child health conditions and medical complexity. There is an emerging field to screen for home environments and social complexity, but these also need further development, with particular attention to the ability of the child health

practice conducting the screen to initiate responses to identified risks. The development of effective screening and risk stratification strategies needs to be undertaken from a learning and continuous improvement perspective, with strong ground-up and practice-level involvement and not just top-down screen development and imposition.

7. Practices, communities, and state Medicaid systems do not need to start from scratch. There is a growing array of evidenced-based models and approaches to screening, anticipatory guidance, detection, referral, response, and follow-up that can be built upon. In practice, these require differentiating among children and families and responding to them in individualized ways, with the screen only a starting point. For those at highest risk (e.g. in or at imminent risk of placement), there may be opportunities for cost savings (in Medicaid or in foster care) through tertiary prevention strategies that enable the child to remain in the home. In many instances, however, responding to and reducing child risk requires new or enhanced activity and investment. The biggest benefits from risk stratification and effective response is in terms of healthier overall trajectories (particularly starting early with vulnerable families) with high potential returns on investment over the child's life. High value practice changes that improve child health trajectories – from responding both to the child's health condition and the child's home environment – need to be recognized in alternative payment models and value-based payment system and reimbursed for the high value they have.

#### Appendix D – Selected References and Resources

- Agrawal R, Hall M, Cohen E, et al. Trends in health care spending for children in Medicaid with high resource use. *Pediatrics*. 2016;138(4). pii: e20160682.
- Antonelli RC, Turchi RM. Care Management for children with medical complexity: Integration is essential. *Pediatrics*. 2017 Dec;140(6). pii: e20172860.
- Beck AF, Klein MD. Moving from social risk assessment and identification to intervention and treatment. *Academic Pediatrics*. 2016;16(2):97-98.
- Beck AF, Sandel MT, Ryan PH, Kahn RS. Mapping neighborhood health geomarkers to clinical care decisions to promote equity in child health. *Health Affairs*. 2017;36(6):999-1005.
- Beck AF, Tschudy MM, Coker TR, et al. Determinants of health and pediatric primary care practices. *Pediatrics*. 2016;137(3):e20153673
- Berwick DM, Nolan TW, Whittington J. The triple aim: Care, health, and cost. Health Affairs. 2008;27(3):759-769.
- Bethell C, Carle A, Hudziak J, et al. Methods to assess adverse childhood experiences of children and families: Towards approaches to promote child well-being in policy and practice. *Academic Pediatrics*. 2017;17:S51–S69.
- Bethell CD, Newacheck P, Hawes E, Halfon N. Adverse Childhood Experiences: Assessing the impact on health and school engagement and the mitigating role of resilience. *Health Affairs*. 2017;33(12):2106-2115.
- Bethell C, Reuland CH, Halfon N, Schor EL. Measuring the quality of preventive and developmental services for young children: national estimates and patterns of clinicians' performance. *Pediatrics*. 2004;113(6 Suppl):1973-83
- Bethell CD, Solloway MR, Guinosso S, et al.al. Prioritizing possibilities for child and family health: An agenda to address adverse childhood experiences and foster the social and emotional roots of well-being in pediatrics. *Academic Pediatrics*. 2017;17(7S):S36-S50.
- Bruner C. ACE, Place, race, and poverty: Building hope for children. Academic Pediatrics. 2017;17(7S):S123-S129.
- Bruner, C. *The color of our future: Child well-being at the state and community levels.* Paper for Forum on Child Well-Being Measurement. Robert Wood Johnson Foundation and Doris Duke Charitable Foundation. 2018.
- Bruner C. Village building and school readiness: Closing opportunity gaps in a diverse society. State Early Childhood Policy Technical Assistance Network; 2007:13–14.
- Bruner C, Dworkin P, Fine A, et al. *Transforming young child primary health care practice: building upon evidence and innovation*. Child and Family Policy Center. 2016.
- Bruner C, Johnson K. *Federal spending on prenatal to three: Developing a public response to improving developmental trajectories and preventing disparities.* Center for the Study of Social Policy. 2018. Available at: <a href="https://cssp.org/resource/federal-spending-prenatal-to-three/">https://cssp.org/resource/federal-spending-prenatal-to-three/</a>. Accessed May 1, 2019.
- Bruner C, Johnson K, Bethell C, et al. Next steps in family-focused screening to address social determinants of health for young children in primary care. Report of the Social Determinants of Health Technical Working Group of the Maternal and Child Health Measurement Research Network. Child and Adolescent Health Measurement Initiative, Johns Hopkins Bloomberg School of Public Health. 2018. Available at: https://action.cahmi.org/docs/default-source/mch-mrn/sdoh\_twg\_consensus\_mch-mrn\_designv2\_072618.pdf?sfvrsn=9dc95b17\_2. Accessed May 1, 2019.
- Centers for Medicare and Medicaid Services (CMS). Center for Medicare and Medicaid Innovation (CMMI). Integrated Care for Kids. Website. Available at: <u>https://innovation.cms.gov/initiatives/integrated-care-for-kids-model/.</u> Accessed May 1, 2019.
- Centers for Medicare and Medicaid Services (CMS). Annual EPSDT Participation Report. Form CMS-416. Federal Fiscal Year (FFY) 2017. <u>https://www.medicaid.gov/medicaid/benefits/epsdt/index.html</u>. Accessed May 1, 2019.
- Centers for Medicare and Medicaid Services (CMS). Children's Health Care Quality Measures. Available at: <u>https://www.medicaid.gov/medicaid/quality-of-care/downloads/performance-measurement/2019-child-core-set.pdf</u>. Accessed May 1, 2019.
- Antonelli RC, Turchi RM. Care Management for children with medical complexity: Integration is essential. *Pediatrics*. 2017;140(6). pii:e20172860.
- Fierman AH, Beck AF, Chung EK, et al. Redesigning health care practices to address childhood poverty. *Academic Pediatrics*. 2016;16(3 Suppl):S136-S146.
- Garg A, Dworkin PH. Surveillance and screening for social determinants of health: The medical home and beyond. *JAMA Pediatrics*. 2016;170(3):189-90.

- Ghandour, R.M., Moore, K.A., Murphy, K. et al. School readiness among U.S. Children: Development of a pilot measure. *Child Indicators Research*. 2018. Available at: <u>https://doi.org/10.1007/s12187-018-9586-8</u>. Accessed May 1, 2019.
- Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*, 4th ed. American Academy of Pediatrics; 2017. Available at: https://brightfutures.aap.org/Pages/default.aspx. Accessed May 1, 2019.
- Hirai AH, Kogan MD, Kandasamy V, Reuland C, Bethell C. Prevalence and variation of developmental screening and surveillance in early childhood. *JAMA Pediatrics*. 2018;172(9):857-866.
- Howard C, Home C, Gillooly M, Vinci RJ, Bair-Merritt MH. School readiness: The next essential quality metric for children. *Health Affairs*. Online. July 18, 2018.
- Institute of Medicine and National Research Council Roundtable on Health Disparities. *Focusing on children's health: Community approaches to addressing health disparities: Workshop summary.* National Academies Press; 2009. Appendix E. Bruner CH and Shor EL. Clinical Health Care Practice and Community Building: Addressing Racial Disparities in Healthy Child Development. Available at: https://www.ncbi.nlm.nih.gov/books/NBK215345/. Accessed May 1, 2019.
- Johnson K, Bruner C. *A sourcebook on Medicaid's role in early childhood: Advancing high performing medical homes and improving lifelong health.* Child and Family Policy Center. 2018. Available at: <a href="https://www.cfpciowa.org/en/issues/health\_equity/sourcebook\_on\_medicaids\_role\_in\_early\_childhood/">https://www.cfpciowa.org/en/issues/health\_equity/sourcebook\_on\_medicaids\_role\_in\_early\_childhood/</a>. Accessed May 1, 2019.
- Kogan MD, Schuster MA, Yu SM, et al. Routine assessment of family and community health risks: parent views and what they receive. *Pediatrics*. 2004;113(6 Suppl):1934-1943.
- Kuo DZ, Melguizo-Castro M, Goudie A, Nick TG, Robbins JM, Casey PH. Variation in child health care utilization by medical complexity. *Maternal and Child Health Journal*. 2015;19(1):40-48.
- Masten AS, Monn AR. Child and family resilience: A call for integrated science, practice, and professional training. *Family Relations*. 2015;64:5-2.
- National Research Council and Institute of Medicine. *Strategies for scaling effective family-focused preventive interventions to promote children's cognitive, affective, and behavioral health: Workshop summary.* Washington, DC: The National Academies Press, 2014.
- Reuland C et al. *Health Complexity in Children: A Statewide Summary Report*. Oregon Pediatric Improvement Partnership. 2018. Available at: <u>http://www.oregon-pip.org/projects/Packard.html</u> and <u>https://www.oregon.gov/oha/HPA/dsi-tc/Pages/Child-Health-Complexity-Data.aspx.</u> Accessed May 1, 2019.
- Sege RD, Harper Browne C. Responding to ACEs with HOPE: Health outcomes from positive experiences. *Academic Pediatrics*. 2017;17(7s):S79-S85
- Shonkoff JP, Garner AS; Committee on Psychosocial Aspects of Child and Family Health; Committee on Early Childhood, Adoption, and Dependent Care; Section on Developmental and Behavioral Pediatrics. The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*. 2012;129(1):232-246.
- Shonkoff JP, Phillips DA. From Neurons to Neighborhoods: The science of early childhood development. National Academy Press. 2000.
- Shumskiy I, Richardson T, Brar S, at al. Well-child visits of Medicaid-insured children with medical complexity. *Journal of Pediatrics*. 2018;199:223-230.e2.
- Thomson J, Shah SS, Simmons JM, Sauers-Ford HS, et al. Financial and social hardships in families of children with medical complexity. *Journal of Pediatrics*. 2016;172:187-193
- Yoshikawa H, Aber JL, Beardslee WR. The effects of poverty on the mental, emotional, and behavioral health of children and youth: implications for prevention. *American Psychologist*. 2012;67(4):272-284.