

Scope and Scale:

Developing a Risk/Opportunity Strategy for Identifying Young Children and their Families to Achieve Gains in Population Health

InCK Marks

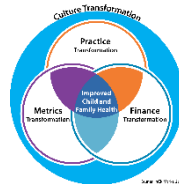
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Preface

This working paper tackles the question of the scope and scale required to transform health care for young children to achieve gains in child health and development at the population health level. Specifically, it provides estimates of the proportion of young children and their families who need and could benefit from a transformed child health care system that responds to both medical and social determinants of health. It builds upon a previous resource brief by InCK Marks and the Child and Adolescent Health Measurement Initiative (CAHMI), *Risk Stratification for Children on Medicaid: Achieving the Potential of Prevention*, which provides more background and detail on many of the statements in this report. Both of these InCK Marks reports draw upon the CAHMI Technical Working Group report on designing parent-administered screens to identify social risks among young children and their families.ⁱ Understanding the scope and scale of risks among families with young children points to the urgent need for advanced, team-based primary care, including relational care coordination.

The key takeaway messages from this resource brief and the related reports upon which they are based are provided in the chart on the next page.

Acknowledgements and Disclaimer

This report was made possible with generous funding from the Robert Wood Johnson Foundation, but all opinions and views expressed are those of the author and not necessarily the funder. 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 – to advance primary and preventive child health care transformation through integrated approaches that build upon evidence and science.

ⁱ Bruner, C., Johnson, K., Bethell, C., Dworkin, P., Kotelchuck, M., Perrin, E., Shaw, J., Trefz, M., & Whitaker, R. (2019). *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 (MCHMRN). Child and Adolescent Health Measurement Initiative

Take-Away Messages on Risk and Opportunity Screening

1. As children grow and mature, they develop health conditions (physical, cognitive, social, and emotional/behavioral) based both upon their own constitution and upon their experiences. Social determinants of health play a major role in healthy child development.
2. By age 18, approximately one-quarter of America's youth have significant adverse health conditions, and another one-third have a health status that is suboptimal. Many of these health conditions are preventable or could be much better mitigated if responded to earlier.
3. The first three years of life represent an opportunity for identification of children and their families who are most at risk of developing adverse health conditions as they grow into adulthood, but only a small part of such identification can be achieved through looking at the child and that child's health. Most must come from looking at the home and community environment in which the child lives.
4. To achieve population-level gains in children's health and development into adulthood through more preventive responses in the first three years of life requires different, and generally enhanced and more ecological, responses to a large share of the young child population. While high rates of return are possible through actions which reach 5 or even 10 percent of the young child population, significant gains at the population level require responses that reach 30 percent of all young children (and a much greater proportion in poor neighborhoods and communities).
5. Identification of this 30 percent of young children and their families requires screening tools that extend beyond children's developmental status to household and family conditions. Current efforts to do so by poverty, maternal depression, or the presence of trauma or adverse childhood experiences (ACEs) are imprecise in identifying this population and, at best, represent only elements in doing so. There is a growing array of specific questions and broader tools, based upon parental reporting, that can do so. These require rigorous application and testing in the field to further develop and perfect.
6. There are fundamentally different challenges and opportunities to achieving population-level impacts compared to demonstrating impacts at an individual child and family level. Achieving significant population-level impacts requires new or different responses for at least 30 percent of the young child population, which requires attention to community-building as well as individual service strategies. These also require different approaches to overall testing and evaluation.
7. Screening for such determinants requires engaging the family and is much more than gathering information from them. It is as much process as it is product. At the practice level, screening and surveillance should initiate and further a partnering with the family in advancing the child's health, recognizing and valuing the family and addressing its needs, hopes, and values. It involves building relationships and starting from where families are and building upon their hopes for the healthy development of their children.

Scope and Scale:

Developing a Risk/Opportunity Strategy for Identifying Young Children and their Families to Achieve Gains in Population Health

Introduction: Ensuring the Healthy Development of Young Children

Families and their communities assume the primary responsibility for the healthy development of young children, yet they cannot do it alone. Society has a role and responsibility to support children's healthy development, even when their parents do not have the resources and supports to do so. This includes some services and supports that are made universally available to children, such as public education (K-12). This includes some services, such as health care coverage and food and nutrition, that are seen as essential to healthy development, where public programs (Medicaid, CHIP, SNAP, and WIC) are established to ensure all children, regardless of the parents' income and resources, receive them. And, it includes some services required to ensure the safety of and a home for children in very vulnerable circumstances, such as child welfare and foster care and care for children with extensive medical care needs. There is growing recognition that, for young children, the opportunity for preschool experiences should extend to all four and even three year-olds and that government should support child care for working families to make it affordable and ensure quality.

Whether through private health insurance or through public coverage under Medicaid or CHIP, a standard for primary, preventive, and developmental health services has been established in federal law based upon *Bright Futures*. For Medicaid, the Early Periodic, Screening, Diagnosis, and Treatment benefit emphasizes prevention, promotion, and early intervention. The child health practitioner has the responsibility for screening, anticipatory guidance, and provision of care coordination for all children. The practitioner then has the responsibility to provide preventive and developmental services to respond to identified needs and concerns to advance healthy development. The term "targeted universalism" has been used to emphasize that all children should receive primary and preventive health services, but in that process children should be identified who require additional services and supports to address their developmental needs.

This resource brief provides a framework for assessing the size of the young children population for whom targeted as well as universal primary and preventive health care services are warranted. Such an assessment and response is essential if the child health care system is to contribute to making improvements and closing disparities in health at a population level.

The Scope of the Challenge: The Health and Well-Being of Youth

By age 18, one-quarter of youth in the United States don't graduate from high school with their peers and only one-third are either college- or career-ready. One in five is obese. One in five has a mental condition or drug involvement problem that significantly impairs functioning and up to one-half have some mental health concern. One in five engages in risky sexual behavior, sometimes leading to unplanned pregnancies and unprepared parenting. One in twenty is in jail or prison, homeless and on

the streets, experiencing long-term residential care, or graduating from foster care or other adolescent placement without a real permanency plan or opportunity.

In short, simply looking at the 18 year-old population, we can identify 5 percent who are subject to current and future chronic and high-cost episodic care for their health (physical, cognitive, social, and/or behavioral) conditions. We can identify another 20 percent experiencing some health conditions that are of significant costs to themselves and to society. We can identify another 30 to 40 percent who not only are on sub-optimal life course trajectories, but in many respects on less than satisfactory ones for their and society's future well-being.

While some of these health conditions are unavoidable, many are not – and most at least can be significantly mitigated and their severity lessened. Even when 18 year-olds are able to overcome such conditions, the time involved and the costs of doing so take a toll on the youth and on society. In short, the opportunity to reduce the incidence or severity of these conditions requires earlier identification of and response to children at risk of or in the beginning stages of developing these conditions.

At age 18, it is possible to determine a youth's position on this health continuum by directly assessing the youth. The cumulative nature of the youth's own constitution and experiences over eighteen years—safety, security, stability, nurturing, opportunity – is reflected in the youth's health status. For younger children, and particularly for very young children, however, this is not the case. Different screens, assessments, and actions are needed that respond much more to the child's home environment and social determinants of health than to child-specific health and health-related conditions.

Beginning Early: Assessing Health Conditions and Risks for Young Children

For some young children (birth to 3), health conditions at birth have lifelong consequences or require substantial interventions to treat and correct (e.g., heritable disorders, preterm birth, very low birthweight birth). This represents 2-4 percent of the infant population. Preterm birth and low birthweight are leading causes of infant mortality and child health problems, particularly for babies with the shortest gestation and lowest birthweight. Another 4-8 percent of young children have other physical, cognitive, or behavioral conditions or other special health care needs which can be identified in infancy. A share of this 6-12 percent of the population will correct or outgrow these conditions, but many of this population will still be within the 25 percent of 18 year-olds with adverse health conditions. The majority of that 25 percent of 18 year-olds, however, is not identifiable through assessment of their own health status in the earliest years.

The question is whether they can be identified and actions taken which can reduce the likelihood of serious, long-term health or developmental conditions. The growing P.A.R.E.N.T.S. Science (Protective factors, Adverse childhood experiences, Resiliency, Epigenetics, Neurobiology, Toxic Stress, and Social Determinants of Health) suggests they can, but this requires looking at social risks and then taking action to strengthen and support families. While doing so will not eliminate all adverse health conditions of 18 year-olds (and adults through their succeeding years), effective responses that strengthen the home and community environment can substantially reduce them and the severity of their impacts.

Importantly, the identification of these social determinants of health also is relevant to many of those in the 6-12 percent of children who can be identified with some child-specific health condition. For instance, addressing child specific infant health disparities (e.g. higher rates of low birthweight,

prematurity, and infant and maternal mortality among African Americans and native Americans) requires attention to social determinants and the impacts of discrimination, isolation or marginalization, and lack of predictable resources these populations disproportionately experience.

Necessary Scope and Scale: Identifying Young Children and Families at Risk of Future Adverse Health Conditions

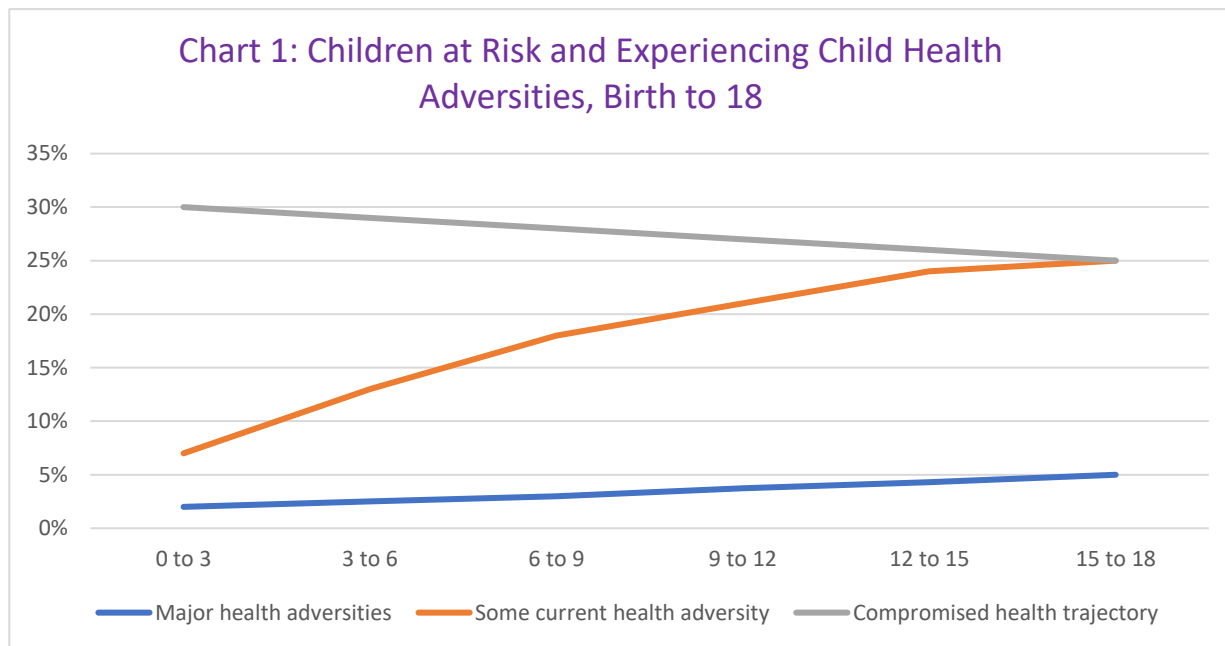
Identification from a preventive and early intervention perspective can never be precise and exact. Any prospective assessment will both over-identify and under-identify those who, over the course of future experiences and life, develop adverse health conditions. This is part of the nature and science of prevention. While today, one-quarter of 18 year-olds experience significant adverse child health outcomes, it is not possible to precisely identify those one-quarter of young children who will, by eighteen, have those outcomes.

One can reduce the amount of over-identification by very narrowly identifying children with highest levels of risk. A screen that identifies only 5 percent of the population at highest risk likely will have very limited over-identification, but consequently will only identify a small fraction of those for whom preventive services could reduce future health conditions. At best, if interventions on this 5 percent of young children were highly effective, they might reduce preventable adverse child health outcomes of 18 year-olds by a percent or two. To produce substantial population-level gains requires the identification of a much larger portion of the young child population.

Identifying the 30 percent of infants and toddlers most at risk is needed to make significant population-level reductions in adverse health outcomes by age 18. While there will be a greater over-identification of children (e.g. identification of children who will not experience major adverse child health outcomes at 18), the impact at a population level will be more substantial. Moreover, a large share of those who are over-identified for developing major adverse health outcomes at 18 still will be among those with suboptimal development, where gains from interventions will benefit both them and society.

As Chart 1 graphically shows, as children grow and mature it is possible to identify a growing share of the child population at risk by looking for child-specific health conditions. In the earliest years, however, the majority must be identified by looking at family environments and assessing social risks (i.e., home and community environment) to identify this population. The space between the grey line and the red line represents those children who must be identified based upon their social risk factors and not their specific health conditions, with initial actions to avert the development or severity of health conditions

focused upon strengthening the home environment. Those below the red line also may benefit from and need such family strengthening activities to address existing identified health conditions, as well as require child-specific responses to those conditions.



Beyond Poverty and ACEs: Identifying 30 Percent of Young Children by Home and Family Environment

In identifying families who are at risk and eligible for services, family economic circumstances are commonly employed, usually by some measure related to poverty. Increasingly, in screening young children in health care settings, other measures are being advanced, particularly around adverse childhood experiences and around maternal depression.

Currently, approximately one in five infants is born into a family at or around the poverty level, with more than twice that number below 200 percent of poverty, generally considered as a better measure for the ability of families to make ends meet.

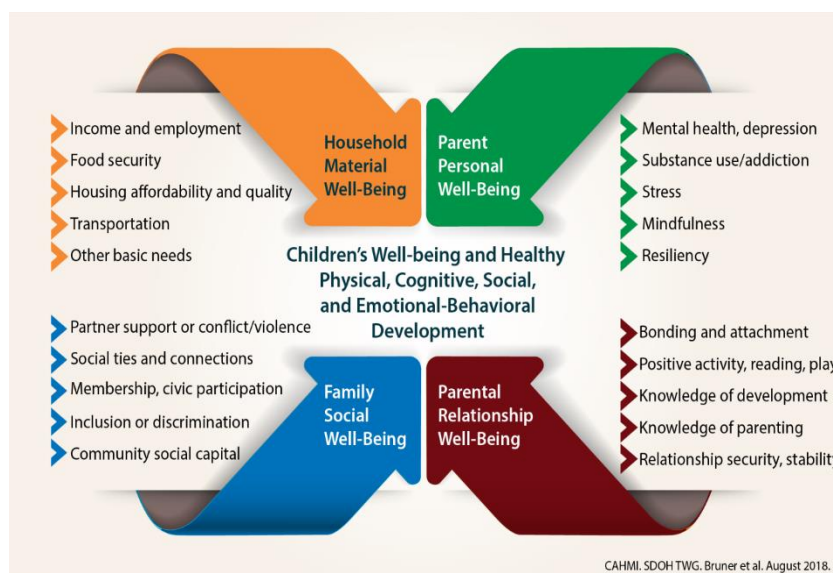
For a variety of reasons, however, poverty (or low-income) is not a sufficiently precise measure for discerning social (or even economic) risk among children. Families starting out and having their first child usually are on the low end of their earning trajectories and may be in school or choosing to stay at home, so their earned income may be temporarily below or just above poverty, even though they have sufficient means and access to resources through family and friends to get by. For instance, a couple in graduate school with a new baby, living in married student housing, likely has income below the poverty level, although their child likely is at minimal risk of a compromised health and developmental trajectory. While poverty may be one factor in determining risk related to economic security, stress, and safety and stability, other family factors (parental education level and single parenting), are equally if not more important.

Similarly, looking for adverse childhood experiences (ACEs) as a means to identify vulnerable children is unlikely to be a sufficient method for identifying children at risk. With respect to ACEs, young children have only a limited time period to acquire them. The National Survey of Children’s Health shows that the presence of ACEs increases with child age. While 15.7 percent of children 6 through 11 and 20.1 percent of children 12 through 17 have two or more ACEs, only 6.2 percent of children 0 through 5 do. Moreover, ACEs only cover a portion of what can affect the safety, stability, and nurturing in the home environment. Research is clear that children experiencing some adverse event can still thrive and that most children experience some adversity growing up. Where there are substantial protective factors, children generally develop along healthy trajectories, even if there is some adversity. Alternatively, without protective factors, children are vulnerable, even if there are no specific incidences of adversity.

A growing body of research has shown that maternal depression affects maternal-child relationships and nurturing and therefore healthy child development. This has been recognized within Medicaid, in the Center for Medicare and Medicaid Services (CMS) providing explicit guidance approving the coverage of maternal depression screening under a child’s Medicaid coverage. Maternal depression screens typically identify up to ten percent of mothers, although a smaller share may be indicated, through further assessment, for specific mental health treatments. As with poverty and ACEs, maternal depression represents a factor to consider in identifying young children and their families for prevention (and treatment) services to improve healthy child development. At the same time, none is a precise way to do so and ACEs and maternal depression screening alone will not begin to get to the 30 percent of young children most vulnerable to compromised healthy development. To get to that broader level and to reduce the over-identification of young children with low risk requires attention to multiple factors in the home and community environment, and multiple potential responses depending upon the specific conditions and risks. The Child and Adolescent Health Measurement Initiative’s (CAHMI’s) Technical Work Group (TWG) on identifying young children organized these into four broad categories, as shown in Chart 2.

Chart 2: Social Determinants of Healthy Young Child Development

As Chart 2 shows, in addition to responding to any child-specific conditions affecting the child’s health (physical, cognitive, social, and emotional-behavioral development), ensuring a safe, stable, and nurturing home environment may require attention to household material well-being, parent personal well-being, family social well-being, and parent-child relationship well-being. Again, the P.A.R.E.N.T.S.



Science, drawn from multiple academic disciplines, provides ample evidence of the centrality of

responding to and ensuring household and family well-being in order to ensure healthy child development.

The CAHMI TWG reviewed a range of screening questions and tools to identify young children and their families within and across each of these four domains, developing a composite tool of eighteen questions that could become an initial screen, with recommendations as to its or any screening tool's use in identifying young children most vulnerable to compromised developmental trajectories.

Moving Forward: Recognizing the Challenges and Opportunities to Improving Child Health at a Population Level

The next steps needed for the field include rigorous action research in using such tools to identify and respond to young children and their families with social risk factors and facing negative social determinants of health. Such rigorous field-based research is needed to continuously improve both the tools themselves and how they can be best used with young children and families both to identify concerns and engage families in responding to them.

Where the design is to identify and respond to 30 percent of the young child population and begin to impact population-level child health concerns, this presents challenges and opportunities that are different from identifying and responding to a much smaller percentage of families.

First, when tools identify 5 or even 10 percent of young children, they are likely to identify children who are among the children in that 30 percent category, although not necessarily those most vulnerable among those 30 percent. The problem of over-identifying young children at risk who can be helped is minimized. At the same time, however, even very successful actions with these young children and their families will at best have very modest impacts at a population level in reducing risk, particularly below the level of significant health concerns. Actions with this population may produce high rates-of-return on investment, but will have quite low impacts upon reducing the gaps and disparities in child health trajectories. For instance, a screen that identifies 5 percent of young children for intervention, with an intervention that is successful in improving their trajectory so, at age 18, one-quarter of those served are not among the 25 percent with significant health conditions who otherwise would have been (a very high level of success) would only reduce, at the population level, the percentage of 18 year-olds with such conditions from 25 percent down to 23.75 percent.

Second, when tools identify 5 or even 10 percent of young children, practitioners may be able to secure existing services and supports within the community to respond to family issues and concerns, simply by getting these young children and their families "first in line" for these limited available services (e.g., housing programs or home visiting services). When programs identify 30 percent of young children, they must come to grips with any shortages or gaps in the availability of these services and supports. They are a much truer test of whether the challenges young children and their families face are in: (1) finding existing available services and coordinating or integrating them; or (2) developing more services to meet young children and their families' needs at a population level.

Third, when programs or practices identify and respond to 5 to 10 percent of young children, particularly within poor and vulnerable neighborhoods (where those vulnerable to adverse health trajectories are more likely to be in the 50 to 60 percent or greater range than the overall 30 percent range), they can face challenges in singling out specific children and their families to offer opportunities that are not

available for their similarly at-risk friends, families, and neighbors. Providing help to a young child and family that enables them to grow but only by leaving their best friend, sister, and neighbor behind not only makes the likelihood of success smaller but also, when that choice is made, makes the neighborhood and community poorer by the loss of that more flourishing child and family. In such neighborhoods and communities, solutions to produce population-level gains likely require community-level as well as individual child and family interventions, particularly in advancing community safety and the social ties young children and their families need. Most research on program efficacy (and research methodologies employing randomized controlled trials) does not consider the potential for this “fallacy of composition” in assuming that individual success also produces collective gain – but considering this is essential when seeking to produce population impacts.

Conclusion

This discussion points to the need for the field to engage in more concerted efforts to identify and then respond to young children at a much more extensive level (scope and scale) than most efforts currently do. When the goal is to improve healthy child development at a population level – and close preventable gaps by race, place, and socio-economic status – it is necessary to expand the focus to a very substantial share of the young child population and to do so from a family strengthening and support perspective. The take-away messages below summarize the points made in this resource brief.

Appendix One:

Measuring Child Health Status and Social Factors Affecting It by Child Age

1. Measurable Conditions of a Child at Birth

Low birthweight/very low birthweight/high birthweight
Prematurity
Congenital abnormality

2. Measurable Conditions of a Youth at 18

On-time graduation from high school
Proficiency in math, reading, and science
Obesity
Risky sexual behavior
Mental health
Homelessness
Child welfare/juvenile justice/corrections placement

3. Different Health Conditions and Risk Factors by Child Age: National Survey of Children's Health: 2017-18

	0-2	3-5	6-11	12-17
0 ACEs	81.2		64.7	54.9
1 ACE	12.6		19.6	25.0
2+ ACEs	6.2		15.7	20.1
Special health care needs	10.6		20.6	24.2
Poor-fair maternal mental health	4.8		4.8	5.4

Appendix Two:

Applying this Resource Brief to the Early Childhood Comprehensive Services (ECCS) Initiative

Both the federal government (particularly through Early Comprehensive Service System (ECCS) Initiative and impact grantees) and foundations (through the Pritzker Children's Initiative and the multi-foundation Effective Parenting in Primary Care Initiative) have set goals for their work to dramatically improve the percentage of young children (birth to three) on target for healthy growth and development, including readiness for and success in school. They have similarly suggested that, by age 3, 30 percent of children are on compromised paths and have generally seen that reducing this number requires greater attention to improving child health, strengthening family and home environments, and providing high quality care arrangements and developmental supports and opportunities within the community.

The following is an outline for what it would take, within the ECCS Initiative, to meet the goal set out for that initiative, an improvement in young children being on track by age three for healthy development and success, based upon the framework presented in this resource brief.

ECCS Goal. Improve by one-quarter the percentage of young children (birth to three) on track for starting school healthy and prepared for success.

Logic Model. Do so through actions that better integrate and serve young children and their families to improve health, family stability and nurturing, and access to and use of quality early care and education services.

Based upon the goal and logic model and this resource brief, the following represent beginning estimates for what actions it will take to achieve the goal in terms of new or enhanced programs and practices at the community level – e.g. the scope and scale of activities that are needed to affect healthy child development at the population level.

Beginning Estimates for What It Will Take to Achieve Goal:

Percentage of young children (0-3) not now on track.

30% of all young children, higher in poor and vulnerable neighborhoods

Reasons for those children not being on track.

or substantial child health/development conditions that, in themselves, prevent their being on track (1/4 of above or 7.5%), although additional services and supports can produce gains in child outcomes and development

Home and community environments (safety, stability, nurturing and access to developmental opportunities) that provide insufficient supports and protective/developmental factors to leading to not being on track (1/2 of above or 15%)

Lack of quality early childhood experiences to ensure development and early response to delays or special needs (1/4 of above or 7.5%)

Promising actions that can improve the likelihood of children being on track.

Strengthening home environments/protective/developmental factors – Home visiting, parent education and support, peer networking, or family support designed to strengthening families at a relatively sustained level (if targeted to those with home environment concerns, may improve children being on track by 1/3)

Providing high quality early childhood experiences/developmental responses -- High quality early childhood experiences and Part C services (when needed) to enrich development outside the home (if targeted to those with lack of quality early childhood experience may improve children being on track by 1/2)

Current Reach of Existing Services to Improve Children Being on Track.

Responding to health/development conditions in the child – children with complex health needs (2-4 percent) are served, those with lesser developmental delays less likely to be served (Part C serves an average of 3 percent of population, some in the complex category), responses often do not address any home environment concerns that exist

Strengthening home environments – Home visiting, parenting education and support, Early Head Start, Healthy Steps, etc. currently serve 2-3% of population, and likely serve some families (due to imperfect targeting or those with complex health/development conditions) outside the 15% identified above.

Providing high quality early childhood environments – High quality early childhood experiences quite rare (subsidized child care for infants and toddlers serves 4% of population and not with high quality care – likely 1-2% of early childhood experiences, including Early Head Start and child care meet definition of high quality (developmentally enhancing) care, and Part C covers about 3 percent of children (but many of those are in the complex health/development conditions category).

Gap in Services to Improve Children Being on Track.

Strengthening home environments – Home visiting, parent education and support, peer networking, family support of relatively intensive nature (15% of young child population, recognizing imperfect nature of targeting).

High quality early childhood experiences and Part C as warranted additionally (8 percent of population, if targeted and including substantially full subsidization, although other children could also benefit from programs.)

Size for Addressing Gap in Services to Achieve Goal

Additional effective family strengthening services to 15%+ of population and additional high-quality early childhood environments for 8% of population, with specific targeting to highest opportunity children.

Results of Addressing Gap in Services

Potential 7.5% improvement in children being on track in the birth-three years (from 70% to 77.5%). Additional benefits to others participating (although not specifically by moving from not on track to on track)

Strategies for Addressing Gap in Services

Screening and risk/opportunity assessment through primary child health practitioner, along with initial care coordination and linkage to services strengthening home environments and to high quality early childhood and Part C services. It is possible (and beneficial) to employ Medicaid and leverage federal funding for a good share of the investments – in screening and risk/opportunity assessments, care coordination, and financing for some family strengthening home environments and some Part C services.