

**Key Measurement Issues in Screening, Referral,  
and Follow-Up Care for Young Children's  
Social and Emotional Development**

**April 2005**

*Prepared by Colleen Peck Reuland and Christina Bethell  
of the Child and Adolescent Health Measurement Initiative  
with support from The Commonwealth Fund*



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*The views presented here are those of the authors and not necessarily  
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## BACKGROUND AND PURPOSE

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Research demonstrates that children's healthy social and emotional development is essential to school readiness, academic success, and overall well-being.<sup>1</sup> In addition,

- Young children from low-income families are at higher risk for developmental delays than their more affluent peers. For example, one report found that first time kindergartners in the bottom fifth of the income distribution were less likely to exhibit social competence than those from families with higher incomes.<sup>2</sup>
- Early diagnosis and intervention increase the effectiveness and efficacy of services delivered to children with social risk factors.<sup>3</sup>
- Often children who could benefit from treatment are not identified as needing treatment. For example, physicians often do not identify young children with a clearly defined developmental problem, those who have a low intensity problem, or those who are at risk of substantive problems.<sup>4</sup>

Medicaid, which in 2003, covered about one in four of all children and about half of all low-income children<sup>5</sup> can do much to improve young children's healthy mental development, and a number of state Medicaid agencies have expressed interest in doing so. To assist states in these efforts, the National Academy for State Health Policy (NASHP), with funding from the Commonwealth Fund, administers the ABCD II initiative, a three-year project designed to build state capacity to deliver care that supports children's healthy mental development. Five states (California, Illinois, Iowa, Minnesota, and Utah) participate in the ABCD II Consortium which began its work in early 2004.

The **Assuring Better Child Health and Development initiative** (ABCD II), sponsored by the Commonwealth Fund, is designed to strengthen primary health care services and systems that support the social and emotional development of young children, 0-3. The program focuses on promoting the healthy mental development of children whose health care is covered by state programs, especially Medicaid.

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<sup>1</sup> Institute of Medicine. *From Neurons to Neighborhoods: The Science of Early Childhood Development* (Washington, DC: National Academy Press, 2000).

<sup>2</sup> Brett Brown, PhD, et al. *Early Child Development in Social Context: A Chartbook*, (New York, NY: The Commonwealth Fund, 2004). Retrieved February 4, 2005. [http://www.cmf.org/publications/publications\\_show.htm?doc\\_id=237483](http://www.cmf.org/publications/publications_show.htm?doc_id=237483).

<sup>3</sup> Institute of Medicine, *From Neurons to Neighborhoods*.

<sup>4</sup> Laura Sices, MD, et al. "How Do Primary Care Physicians Identify Young Children with Developmental Delays? A National Survey with an Experimental Design," *Pediatrics* 113, No.2 (Feb. 2004): 274-282.

<sup>5</sup> Kaiser Commission on Medicaid and the Uninsured. *Health Coverage for Low-Income Children, Fact Sheet* (Menlo Park, CA: The Henry J. Kaiser Family Foundation, 2004). Retrieved February 1, 2005. <http://www.kff.org/uninsured/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=46994>.

Many of the issues facing these five states as they seek to improve the delivery of care to young children will also be faced by other states attempting to address similar concerns. One early issue faced by the consortium states is how to measure the effectiveness of their efforts to improve the delivery of the services needed by very young children to ensure their healthy mental development. All five states need reliable and valid measures to inform program implementation efforts and guide improvements and ongoing program evaluation. Other states wishing to improve in this area will have a similar need.

***Mental development. Psychological development. Social development. Emotional development. Behavioral development. Psychosocial development.***

The literature on child development describes various aspects of childhood development using many different terms—often interchangeably. In this paper we have sought to be consistent and specific in our use of terminology.

In this paper, ***ensuring children's healthy mental development*** means identifying and addressing children's social and emotional development needs.

## Choosing the Measures

The first step taken by the consortium states as they sought to measure their projects' performance was to determine *what* should be measured. Each of the states involved in the collaborative is working to strengthen its Medicaid program's capacity to support young children's healthy mental development. Each proposed, as part of the ABCD II initiative, to develop and test new policies and procedures that, if effective, could be implemented statewide. Early in the development of their projects, the five states agreed that "strengthening Medicaid's capacity to support young children's healthy mental development" meant that they were striving to ensure that:

1. All children with social or emotional development issues are identified, and
2. All children identified with social or emotional development issues receive appropriate treatment—whether that treatment is delivered in the office of the primary care provider (PCP) or by another specialized provider.

Unfortunately, the states could not realistically measure the achievement of these goals. The treatment goal is particularly problematic as treatment delivered in the provider's office may not be reflected as a separate service in Medicaid administrative data, and it may not be possible to determine whether treatment by another provider resulted from the PCP's identification of a child as needing treatment, especially when some treatment may not qualify for Medicaid reimbursement. In that case, the Medicaid agency (the ABCD II lead agency) would be unlikely to have access to the information needed to produce the measure.

As a result, all five of the ABCD II states agreed that they would measure three aspects of their delivery of care:

1. The percent of children 0-3<sup>6</sup> screened to identify concerns related to social and emotional development;
2. The percent of children 0-3 referred for services to prevent or treat concerns related to delays in social and emotional development; and
3. The percent of children 0-3 treated for delays in social and emotional development, including treatment to prevent such delays. This third measure has been divided in two: one to capture treatment delivered by a PCP and a second to capture treatment delivered by another provider.

The five states believe that these three measures will help them determine if they are meeting their goals. The measures were chosen because they address the three key parts of the system that the states are seeking to improve: screening, referral for assessment/treatment, and treatment. In addition, the states believe that they will be able to achieve change in these areas within the three years of the collaborative and that their state agencies will have access to the information needed to measure performance in each of the three areas.

It is important at this point to note that Measures 2 and 3 are independent of each other.

- Measure 2 examines the number of referrals whether or not a referral results in the delivery of a service.
- Measure 3 examines whether treatment is delivered to a child whether or not that treatment results from a referral by the PCP.

Ideally, these measures would be related (e.g., Measure 3 would examine the number of children who received treatment as the result of a referral). But achieving this ideal is not possible because of the difficulty of accessing the data that is needed to relate the delivery of a specific service to a referral from the PCP.

## **Purpose of This Paper**

To assist the ABCD II states in their efforts to assess the effectiveness of their projects, NASHP contracted with the staff of the Child and Adolescent Health Measurement Initiative to prepare a paper outlining methods and issues for the states to consider as they developed and implemented the three common measures. This paper is an outgrowth of that earlier report and is meant to serve as a case study for other states interested in undertaking similar work and facing similar financial and data constraints.<sup>7</sup>

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<sup>6</sup> States implementing strategies focused on a different age group (e.g., 0-12 months, 0-5 years) will collect measures for that specific age group. Throughout, this discussion guide focuses on children age 0-3.

<sup>7</sup> It is important to note that although the ABCD II states are committed to implementing these measures, they all have limited financial and data resources. As a result, the measurement strategies outlined here take into account what is known about these constraints and represent what may be feasible in the short term, rather than strategies that might be more ideal (i.e., more valid and reliable) but less feasible to implement. The strategies and methods described here acknowledge that the measures are not being implemented in an ideal world, with ideal data sources and funding.

This paper is designed, first, to examine issues in performance measurement that apply to all measures of the health care delivered to children and, second, to examine each of the three specific measures developed by the ABCD II states as they have sought to strengthen mental health services for very young children. For each of the three specific measures, the authors present the following information:

- Their assumptions about the measure and how it will be used;
- An overview of the measure, including the questions that need to be clarified in order to implement the measure;
- Possible data sources, including which sources are and are not recommended for the measure—and why;
- Methodological issues to consider;
- Example(s) of possible measurement approaches; and
- Implementation tips for states.

Since this paper was originally developed for the five ABCD states, it is grounded in their specific goals, objectives, improvement strategies, and resources. The authors analyzed the following information in order to understand the context in which the three measures would be implemented and used in each of the five states:

1. All documents describing each project and reporting on project progress.<sup>8</sup>
2. The screening tool(s)<sup>9</sup> each state was considering using, including identifying how the tools would be administered, the number and characteristics of children identified by the tools, and the follow-up steps recommended for each child.
3. A review of existing measures to determine if any standardized measures were already in existence that could be adopted by the states. The initial review did not identify any standardized measures—with proven reliability and validity—to assess the implementation of screening, referral, and follow-up care for young children with delays related to social and emotional development.

Other state efforts would need to be similarly grounded.

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<sup>8</sup> Tables summarizing findings from this review are available upon request and were based on the information available about the ABCD II projects as of July 2004.

<sup>9</sup> Each ABCD II state has selected one or more standardized, documented screening tools to use in their projects. As will be discussed later, the specific tool selected will impact the resulting measures and strategies for measurement. For more information on screening tools that detect social and emotional development delays, please refer to David Bergman, *Screening for Behavioral Developmental Problems: Issues, Obstacles, and Opportunities for Change* (Portland, ME: National Academy for State Health Policy, 2004). Downloaded February 28, 2005.

[http://www.nashp.org/Files/Screening\\_Tools\\_Paper\\_publication\\_draft.PDF](http://www.nashp.org/Files/Screening_Tools_Paper_publication_draft.PDF)

Finally, because this paper is grounded in the specific needs and situations of the ABCD II states, it is important for readers to note some of the characteristics that are common to the five states, characteristics that may not be shared by other states involved in such efforts.

1. The strategies are designed to assess the performance of the ABCD II project pilot sites (intervention sites) not the Medicaid program as a whole.
2. This methodology assumes that the intervention sites are active partners in the measurement effort; they will collaborate with the state, share information, and, in some cases, implement new procedures designed to gather key information.
3. The strategies are designed to measure the use of standardized, validated screening tools and not to capture screenings that doctors and other health care providers may conduct without such a tool.

We recognize that these conditions may not exist in every measurement project. Nonetheless, we believe that the information presented in this paper will provide valuable information about possible approaches to measuring improvement in the delivery of appropriate social and emotional development services to young children.

## GLOBAL MEASUREMENT ISSUES

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Before presenting options and issues specific to the three measures, it is important to consider global issues related to quality measurement.

### A Concept is Not a Measure

A measure has the following attributes:

- A **denominator**: a specified group of children of interest who are eligible to be included in the measurement denominator.
- A **numerator**: a specified group of children included in the denominator who have received the specific aspect of health care of interest.
- A defined and **standardized strategy for data collection**: a standardized method for sampling, a defined unit of analysis, and a standardized method for data collection.
- A clearly specified **scoring methodology**.
- **Mechanisms for reporting and interpreting results**.

Note: The three ABCD II measures are percentages. A percentage is a proportion multiplied by 100.

### Child-Level Measurement

An ideal measurement system would allow information to be collected at a child level so that one could look across the multiple systems where the child received care to determine what services the child did and did not receive. It may be difficult for data systems within different departments and disciplines to share information about the same child (e.g., Medicaid, state mental health agencies, Title V/Maternal and Child Health programs, etc.).

Parent-reported surveys allow investigators to ask the parent about the multiple systems that the child may have encountered, providing information not easily obtained by administrative and electronic data systems and a child-level picture of the health care system.

### Measures Using Denominators Based on Informed Assumptions

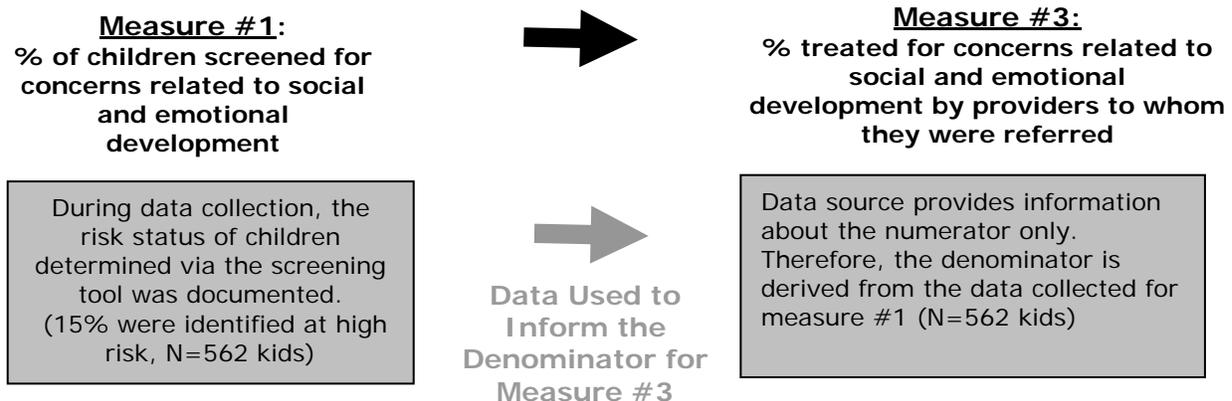
As was noted previously, a measure must have a numerator and a denominator. Given that data systems may not “talk” well to each other, it is sometimes difficult to identify both the numerator and denominator in the same data source for each eligible child. For example, encounter data can tell you whether a child received a treatment service outside the primary care office (the numerator for a measure). However, encounter data does not include information about children that should have received a treatment service (the denominator of the measure).

Therefore, for some measures it may be necessary to use prevalence data to make an informed estimate of what the denominator for the measure should be.

### Estimating a denominator based on data gathered

The following example illustrates how a state might take information gathered for Measure #1 (the percent of children screened) and Measure #2 (the percent of children referred for services) to make an informed assumption about the appropriate denominator for Measure #3 (the percent of children treated for delays in social and emotional development)

1. Measure #1: Practice A determines that in the last year it had 5,000 children aged 0–3 who had a well-child visit. Seventy-five percent of those children (3,750) were screened.
2. Measure #2: Of those 3,750 children, 15 percent (562 children) were identified as being at high risk and should have been referred.
3. Measure #3: Practice A then made an informed assumption by examining its billing code data to identify children who received treatment from Medicaid providers outside the primary care office.



Because Practice A's claims data only provide information about children who are referred and who receive services, no information is available from that data to determine who should have been referred and received services, which should be the denominator. Therefore, Practice A uses information gathered for Measure #1 to make an informed assumption about the number of children who should be included in the denominator for Measure #3. As was described above, 562 children were identified as being at high risk and should have been referred and received services. This serves as the denominator.

## **Measurement Strategies Need To Be Specified for Each Unit of Analysis**

Many of the state projects are being implemented in multiple settings. If the data are going to be summarized at the state level, standardized methodologies must be used to collect the data and to identify the numerator and denominator for each implementation setting. Separate sample sizes and data collection methodologies need to be clearly specified for each discrete unit of analysis or setting in which the efforts are being implemented.

## **Avoid Measures Based on Incomplete, Non-Valid Data Systems**

States should plan to conduct pilot tests before implementing a full measurement strategy in order to ensure that the data systems employ valid indicators for the aspects of care that are being measured.

States should avoid non-valid and/or incomplete data systems. For example, if the measure is whether or not children receive follow-up care, the data systems must include information about all the places where the child may receive such care. If the data systems are incomplete (e.g., only include medical providers and not other kinds of services in the community) then the data system is not a valid data source for the measure and will yield incomplete and inaccurate information.

## **Each of the Measures Are Tool-Specific**

The three measures adopted by the ABCD II projects are meant to be measured over time and used for longitudinal tracking of the states' efforts. The projects must be cautious of systematic variations in screening tools and follow-up activities and of the influence these changes will have on the measures and their comparability over time.

Throughout this paper, the measures are tied to the specific screening tools that are used by each state and to the follow-up care recommended for each identified risk group. If different screening tools are used, then tool-specific measures must be collected and then combined into the larger, more global measure of percent of children 0-3 screened to identify concerns related to social and emotional development.

If a state changes the screening tools it uses over the course of the project (e.g., in the first year it uses the Parents' Evaluation of Developmental Status (PEDS), in the second year it uses the Ages and Stages Questionnaire (ASQ), and in the third year it adopts the ASQ SE, then we recommend that the state first separately calculate measures for each screening tool and then compare the tool-specific findings at baseline versus intervention for each measure.

## **“Same Point in Time” Collection of Data**

An important step in measurement is ensuring that when data are collected they capture a number of variables at the child level and that they do so at the same point in time. In particular, the projects should collect the following variables for each child included in the measurement:

- Age of the child, in months: This is a powerful variable for analysis as it allows for targeted assessment of the quality of care provided for children in different age groups. In addition, recommendations for identifying a child with delays and for appropriate follow-up care are different based on the age of the child.
- Type of health insurance: The type of health insurance a child has may influence the kinds of services the child is eligible to receive and may influence the construction and/or interpretation of measure findings. In addition, for some measures, Medicaid data may be the only data available. It is critical to show the findings according to whether or not a child is enrolled in Medicaid.
- If billing/encounter data are used, states should collect information about the number and kinds of visits the child has had in the last 12 months. Specifically, information should be collected about the number of well-child visits the child has had during that same time period.
- If different sites participating in the project are allowed to use various screening tools, states need to document the screening tools that are being used. This will enable states to analyze whether screening, referral, and treatment are more likely to occur when a specific tool is used.

## **MEASURE #1: PERCENT OF CHILDREN AGE 0-3 SCREENED TO IDENTIFY CONCERNS RELATED TO SOCIAL AND EMOTIONAL DEVELOPMENT**

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**Screening** is the process by which a large number of individuals are tested for the presence of a particular trait. Standardized, validated screening tools offer a systematic approach to this process. Ideally, tools that screen for the mental development of young children should:

- Identify those children who may need social or emotional developmental care;
- Be accurate enough to avoid mislabeling many children;
- Differentiate between those in need and those not in need of follow-up;
- Be quick and inexpensive to administer; and
- Provide information that can lead to action.<sup>10</sup>

Early in the development of their individual projects, each collaborative state selected a menu of tools that they believed met these criteria. (As part of the technical assistance provided to collaborative states, NASHP staff prepared a paper discussing the use of screening tools and comparing some of the major tools on characteristics that states need to consider when selecting tools.<sup>11</sup>) Each intervention site may choose a tool from its state's menu. An individual site may not use more than one tool, but different sites within a state may select a different tool. In each state this first measure is keyed to the specific screen selected by the intervention site(s).

### **Measurement Assumptions**

- Only screening that is conducted with a standardized, documented tool or set of tools will be counted. The completed tools must be kept in the child's medical chart.
- Each intervention site in the ABCD II states will use a single screening tool, but different sites in the same state may choose a different tool. This is important because measurement findings should be stratified according to the tool used. This stratification is necessary because tools vary in terms of recommended periodicity schedules (how often they should be administered), modes of administration (interviewer vs. self-administered), the issues they identify, and the steps that should be taken for those children identified as being at risk. As a result, allowing the use of different tools decreases the standardization of the measures and compromises the ability to summarize the information at a state level.

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<sup>10</sup> David Bergman, *Screening for Behavioral Development Problems, Newsbrief*. (Portland, ME: National Academy for State Health Policy, 2004).

<sup>11</sup> For more information on screening tools that detect social and emotional development delays, please refer to David Bergman, *Screening for Behavioral Developmental Problems: Issues, Obstacles, and Opportunities for Change* (Portland, ME: National Academy for State Health Policy, 2004).

- It is **not** a goal of the ABCD II states to collect data that can be summarized across all five states. Therefore, similar measurement methodologies are not needed across the states.
- Only the intervention sites are being measured.

## Overview of the Measure

<i>Numerator:</i>	Children 0-3 screened to identify concerns related to social and emotional development.	<b>x 100</b>
<hr/>		
<i>Denominator:</i>	Children 0-3 who <i>should have</i> been screened to identify concerns related to social and emotional development and who had a visit at the intervention site during the intervention time period.	

It is important to clarify and define the numerator and denominator in order to determine reliable and valid data sources for this information.

## Examples of clarifying questions that should be asked

### *Numerator*

- What counts as a screen?
- How will you know if a screen occurred?
- When should the screening occur—every 12 months?

### *Denominator*

- Who should be included in the denominator?
- Should the denominator be only children who have had a well-child visit during the implementation period?
- Should non-well-child-care visits be included?

## Recommended Possible Data Sources for Measure #1

- Medical chart<sup>12</sup>
- Parent report

Table 1 on the following page provides a brief overview of possible data sources, examples of measurement strategies, and key methodological issues to consider in using these data sources.

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<sup>12</sup> Minnesota implemented a tracking form used by office staff to measure intervention efforts. For the state's site measurement project, it was assumed that this tracking form was part of the child's medical chart and that it would be included in the medical chart review. If the tracking form was not included as part of the medical chart, then the general measurement design parameters specified for the medical chart review applied to the use of the tracking form independently.

**Table 1 Possible data sources for measuring the percent of children age 0-3 screened to identify concerns related to social and emotional development**

Data Source	Numerator	Denominator	Issues to Consider	Issues Related to Data Collection	Discussion/Consensus Needed
<b>Medical Chart</b>	Number of children whose charts have a completed, standardized screener during the specified time period.	Number of eligible children who have received well-child care during the intervention time period whose charts were reviewed.	<ul style="list-style-type: none"> <li>• It is unclear whether providers keep screening forms in the medical chart. It is especially unclear whether providers keep completed tools in the chart for children <b>not</b> identified as being at risk.</li> <li>• The current denominator is specified to represent the children who have had a visit. This biases the findings to only represent those children who have accessed the health care system.</li> <li>• Existing measures to utilize: <i>Healthy Collaborative*</i> measure on whether the child was screened.</li> </ul>	<ul style="list-style-type: none"> <li>• Identify a random, representative number of charts.</li> <li>• May be best to pull all charts for a specific well-child visit at which the screener is recommended (e.g., 12 months, 24 months).</li> <li>• This methodology will <b>not</b> capture data on screening that occurs outside of the office/or public health setting.</li> <li>• Other states have explored the use of one-page checklists to guide well-child visits. A screener could be added to this checklist and used for measurement purposes.</li> </ul>	<ul style="list-style-type: none"> <li>• Eligibility for the chart review.</li> <li>• Recommended periodicity for when screening should occur. This will influence what charts should be pulled and the reference period used by the chart review staff to determine whether the child was screened during the appropriate time period.</li> <li>• Unit of analysis and sample size needed (e.g., different sample sizes needed to pull a statistically significant sample in larger vs. smaller office, public health centers, etc.).</li> </ul>
<b>Parent Report</b>	Number of children whose parents indicated their child had been screened through a series of items asking about processes that would indicate that screening had occurred.	Number of eligible children whose parents completed the survey and/or who were asked questions via an interviewer-administered survey. Eligible children are those who have had a visit during the intervention time period.	<ul style="list-style-type: none"> <li>• Use of parent report is ideal for screening tools that are completed by the parent.</li> <li>• Parent report is less valid for tools that providers or staff members complete.</li> <li>• Existing measures to utilize: CAHMI items in the PHDS** focused on whether or not the child was screened. Additional, tool-specific items will need to be developed.</li> </ul>	<ul style="list-style-type: none"> <li>• Survey can be administered by mail, telephone, online, or in the office. Survey questions can also be administered by an interviewer and included as part of a more general discussion such as those conducted by care coordinators.</li> <li>• Identify a random, representative population of parents. The parent who is most responsible for the child's health care should be chosen for survey administration.</li> <li>• If the items are worded appropriately, this approach can capture screening conducted in multiple settings.</li> <li>• One option may be to survey <u>only</u> children who have received well-child visits during the time period in which screening is recommended.</li> </ul>	<ul style="list-style-type: none"> <li>• Eligibility for the survey: Should it be only children who have had well-child visits or all enrolled children?</li> <li>• Recommended periodicity for when screening should occur. This will influence what should be reference period for the items in the parent survey.</li> <li>• Unit of analysis and sample size needed (e.g., different sample sizes needed to pull a statistically significant sample in larger vs. smaller office, public health centers, etc.).</li> </ul>

**Table 1 notes:**

\*The Healthy Collaborative project is funded by the Commonwealth Fund and directed by the University of Vermont (Judith Shaw, principal investigator) and University of North Carolina (Peter Margolis, principal investigator). More information will be available on the Commonwealth Fund's Web site ([www.cmf.org](http://www.cmf.org)) or can be obtained by contacting Dr. Margolis at [Peter\\_Margolis@med.unc.edu](mailto:Peter_Margolis@med.unc.edu).

\*\*The PHDS (Promoting Healthy Development Survey) was developed by the Child and Adolescent Health Measurement Initiative (CAHMI). More information about the PHDS is available on the CAHMI website at <http://www.cahmi.org>.

## Possible Data Sources for Measure #1 That Are Not Currently Recommended

- **Billing/encounter data:** To the CAHMI staff's knowledge, no specific billing/encounter claims codes are routinely used in the ABCD II states to indicate whether or not a child was screened using a standardized screening tool in a primary care setting.
- **DC:0-3 (Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood):** The DC:0-3 was not included in Table 1 because it is not a screening tool. Rather, it is our understanding, it allows providers to enter diagnostic data for children who—through a series of screens and examinations—have been identified with issues. It is unclear whether providers who used standardized screens would enter data into DC:0-3 for children with no significant issues or concerns. This issue requires further discussion to confirm assumptions and possible use of this code field.
- **Provider survey:** The measures identified by the ABCD II states are focused on the percent of children screened. Using a provider survey would determine the percent of providers who use a screen. And it should be noted that numerous studies demonstrate the poor validity of provider reports on care provided.

## Methodological Issues to Consider

### Important information to collect at the time of data collection

The results of the screen for each child must be collected at the time of measurement. This information is needed to determine the appropriate denominator for Measure #2 and Measure #3.

The following should be collected:

A categorical variable must be created for the data entry form that includes the following response options:

- a) *Child not currently at risk.*
- b) *Child at moderate risk.* Child should be watched and follow-up screening recommended by the providers who conducted the initial screening (therefore, external referrals not recommended).
- c) *Child at significant risk.* Child should be referred for services. This group will determine the relative number of children who should be represented in the denominator for Measure #2. This data will also be useful in providing the practice sites with descriptive data about their population.

## Example of a Possible Measurement Approach

*Practice A uses the ASQ-SE to screen children. Children are screened at the 12-month, 18-month, and 24-month well-child visit.*

*At time X, data collection begins. During this time period, all charts for children who are having their 12-, 18-, or 24-month well-child visit are flagged for the chart reviewer. At the end of each month, the chart reviewer examines each flagged chart. Children who were scheduled for well-child visits but who did not come in are excluded from the chart review. The chart reviewer counts the total number of eligible charts (denominator) and then looks for at least one completed ASQ-SE form in the last 12 months in the chart (numerator).*

## Implementation Tips for the States

Rather than providing detailed measurement specifications, this paper outlines measurement options the states may feasibly implement in a fairly short time frame. As such, we have not set forth the most ideal or the most valid approaches for measuring these aspects of care, which would require data and systems not currently in place. The tips below are offered within this context.

- Medical chart review is recommended as the most valid data source for this measure. This may not be the case for the other two measures, where a parent-reported survey is recommended in order to allow for the collection of information about all three measures as well as other information of high relevance to each state's project.
- A standardized and succinct chart review should be used that, at a minimum, includes the following:
  1. Description of the charts that should be selected. Specify which charts are eligible to be sampled (e.g., only children who have had a visit in the last 12 months) and specify the number of charts that need to be collected for each unit of analysis that is being examined. Assure that the chart review process does not create biases for more charts to be pulled for specific providers or for specific patients.
  2. Definition of what tool needs to be included in the chart. Specify whether the tool needs to be completed fully and whether it needs to be scored in order to be counted as a positive indicator that the child was screened.
  3. Define the periodicity for when the tool or how often the tool should have been administered. Given that this measurement effort is focused on children 0-3, age-specific algorithms will need to be specified to determine at what times a child should be screened and which time frame the measurement should examine (e.g., at the last well-child visit, in the last year, etc.). For example, if a medical chart review is used, it will need to be specified, for specific age groups, how many tools

should be included in the chart and by what ages the screening tools should be administered.

## MEASURE #2: THE PERCENT OF CHILDREN 0-3 REFERRED FOR SERVICES TO PREVENT OR TREAT CONCERNS RELATED TO SOCIAL AND EMOTIONAL DEVELOPMENT

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Once a child is identified as having or being at risk for a social or emotional developmental delay the child needs to be treated to prevent the development or deterioration of the condition. The recommended standard of care will not necessarily require that the child be served by a provider other than his or her primary care provider. When the standard of care does recommend external treatment, a referral from the primary care provider to a source of that care is an important first step to receiving treatment. This measure looks specifically at referrals to external sources of care.

### Measurement Assumptions

- Not all children identified at risk should be referred externally for services. The denominator for this measure will be specific to children identified at risk for whom the recommended standard of care is to refer to them to services external to the primary care provider's office.
- Given that pilot sites are using different tools, the denominator for this measure will be specific to the tools being used in each pilot and the standards recommended for the identified risk groups.
- It is **not** a goal of the ABCD II states to collect data for summary across all five states. Therefore, similar measurement methodologies are not needed.
- Only the intervention sites are being measured.

### Overview of the Measure

*Numerator:* Children age 0–3 referred for services to prevent or treat concerns related to social and emotional development.

**x 100**

*Denominator:* Children age 0–3 who had a visit during the intervention time period, who were *identified at significant risk*, and who should have been referred for services to prevent or treat concerns related to social and emotional development.

It is important to clarify and define the numerator and denominator in order to determine reliable and valid data sources for this information.

## Examples of clarifying questions that should be asked

### *Numerator*

- For the risk categories identified via the screening tool, what services should the child be referred to?
- What data systems have information about these referrals?

### *Denominator*

- Should the denominator represent only those screened and identified, or should it be based on the number of children who are expected to be identified as being at significant risk and who should have received a follow-up given the characteristics of the population of interest obtained via Measure #1? The first option is anchored to children who were screened and for whom it is known that they should have received follow-up care. The second option is based on the risk prevalence data derived from Measure #1 and would be based on the proportion of children identified at risk who should have received follow-up. The first option is a best-case scenario for Measure #2 and is focused on children who were screened. The second option is a worse case scenario as it is anchored to the population estimates about the number of children who are at risk.
- How will you identify children recognized at significant risk who should be referred for services to prevent or treat delays related to social and emotional development delays? Tool-specific definitions and criteria will need to be specified and specific referral services listed.
- What data systems have information about these referrals? If these data systems are incomplete, it may be impossible to collect valid/reliable information about referrals.

## Recommended Possible Data Sources for Measure #2

- Medical chart
- Parent report

Table 2 on the following page provides a brief overview of possible data sources, measurement strategies, and key methodological issues to consider.

**Table 2 Possible data sources for measuring the percent of children 0-3 referred for services to prevent or treat concerns related to social and emotional development**

Data Source	Numerator	Denominator	Issues to Consider	Issues Related to Data Collection	Discussion/ Consensus Needed
<b>Medical Chart</b>	Number of children whose charts have a completed screening tool identifying them at significant risk for which the provider indicated that the child would be referred for services.	Number of children who have received well-child care in the intervention time period whose charts were reviewed and who were identified at significant risk.	<ul style="list-style-type: none"> <li>• See issues listed in Table 1.</li> <li>• The level of completeness of the charts regarding the need for referrals may vary.</li> <li>• Existing measures to utilize: <i>Healthy Collaborative</i> measure on developmental assessment.</li> </ul>	<ul style="list-style-type: none"> <li>• See issues listed in Table 1.</li> </ul>	<ul style="list-style-type: none"> <li>• See items listed in Table 1.</li> <li>• Define what referrals should be identified for each risk group.</li> </ul>
<b>Parent Report</b>	Number of children whose parents answered items indicating that their child was identified at significant risk and who also reported that the child was referred for services.	Number of eligible children whose parents completed the survey and/or who were asked questions via an interviewer-administered survey whose child was identified at significant risk and who had a well-child visit during the intervention time period.	<ul style="list-style-type: none"> <li>• See issues listed in Table 1.</li> <li>• Child may be identified at significant risk by the survey, but was not screened in the office, and therefore the provider did not know the child was at risk.</li> <li>• Existing Measures to Utilize: CAHMI items in the PHDS focused on screening and whether a child received a referral. National Survey of Children with Special Health Care Needs* and the National Survey of Children's Health** include items on referral.</li> </ul>	<ul style="list-style-type: none"> <li>• See issues listed in Table 1.</li> </ul>	<ul style="list-style-type: none"> <li>• See items listed in Table 1.</li> <li>• Define what referrals should be identified for each risk group.</li> </ul>

**Table 2 notes:**

\* The National Survey of Children with Special Health Care Needs (CSHCN) provides information about children and youth with special health care needs in all 50 states and the District of Columbia. In each state, telephone interviewers screened at least 3,000 households with children to identify children and youth with special health care needs. In-depth interviews were conducted with the parents of 750 of these children in each state. More information about the National Survey of Children with Special Health Care Needs can be found at <http://www.cshcndata.org>.

\*\*The National Survey of Children's Health is sponsored by the Maternal and Child Health Bureau of the U.S. Department of Health & Human Services' Health Resources and Services Administration. The survey is designed to examine the physical and emotional health of children 0–17. Special emphasis is placed on factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. Data was collected in 2003, with national and state-level estimates available in late 2004. More information about the National Survey of Children's Health can be found at <http://www.cdc.gov/nchs/about/major/slait/nsch.htm>.

## Possible Data Sources for Measure #2 That Are Not Currently Recommended

- Billing/encounter data: Billing and encounter data are limited to visits and/or services that have been received. Therefore, it is not clear whether referrals alone can be found in the data systems.
- Provider survey: Measure #2 is anchored to the percent of children. Using a provider survey would determine the percent of providers who use a screening tool and would likely be based on a vague response from a provider about what he might do for a hypothetical child identified at risk. Survey items of this kind have not been shown to be valid measures of health care quality.

## Methodological Issues to Consider

Only those children who are screened and identified at a significant risk level for which a referral is the standard of care are included in the denominator. This excludes the children who are not screened and therefore were not referred to needed services. States should take this into consideration and understand that the findings are a best-case scenario and do not represent care for the children identified in Measure #1 who were not screened.

The chosen data source needs to be thoroughly examined for its validity for this type of measurement. Evidence exists in the literature to show that referrals may not be well-documented in the medical chart.

## Example of a Possible Measurement Approach

*Practice A used a medical chart review to collect data for Measure #1 and Measure #2. At the time of data collection for Measure #1, for each completed tool found in the chart, the practice identified children who were at significant risk. Practice A then reviewed ONLY the charts of those children who were identified at significant risk (denominator for Measure #2) and examined the charts for the presence of a referral to an external provider.*

## Implementation Tip for the States

Rather than providing detailed measurement specifications, this paper outlines measurement options the states may feasibly implement in a fairly short time frame. We have not set forth the most ideal or the most valid approaches for measuring these aspects of care which would require data and systems not currently in place. The tip below is offered within this context.

- Given the current data systems in place and the variety of appropriate referral services, the CAHMI has significant worries that the ABCD II states will not be able to collect

valid information to collect this measure. This is due to the lack of referral data in the medical chart and the fact that referrals do not appear in claims/encounter data unless the service has been received.

## **MEASURE #3: THE PERCENT OF CHILDREN 0–3 TREATED FOR CONCERNS RELATED TO SOCIAL AND EMOTIONAL DEVELOPMENT**

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The collaborative states recognize that, at times, the appropriate treatment for a child identified as at-risk for social or emotional development concerns can be provided by the primary provider. Therefore, they have produced a measure of “children treated” that accommodates treatment provided by the primary care provider, as well as by other providers.

### **Measurement Assumptions**

- Children who should have been treated for delays related to social and emotional development are those identified by selected standardized tools as having concerns related to social and emotional development.
- Treatment includes all services that address concerns identified via the screening tool, including anticipatory guidance and parent education, continued surveillance and re-testing according to the recommended periodicity in the primary office, enhanced testing and assessment of the child in the primary office, referral to another health care provider for enhanced testing and assessment of the child or follow-up care, and/or referral to resources in the community.
- Treatment can occur within and outside of the primary care provider’s office where the screening was conducted.
- Appropriate treatment steps will be identified based on the screening tools that were used and the risk groups identified by each tool. If the screening tools are different within/across states, then the measurement methodology will need to be adjusted for each tool, therefore decreasing the standardization of the measures and lowering the ability to summarize the information at the state level. If different tools are used, then the findings should be specifically stratified according to the tool used.
- It is not a goal of the ABCD II states to collect data that can be summarized across all five states. Therefore, similar measurement methodologies are not needed.
- Only the intervention sites are being measured.

## Overview of the Measure

*Numerator:* Children 0–3 who were *identified at significant risk* who were treated for concerns related to social and emotional development.

**x 100**

*Denominator:* Children 0–3 who had a visit during the intervention time period, who were *identified at significant risk*, and *who should have been treated* for concerns related to social and emotional development.

It is important to clarify and define the numerator and denominator in order to determine reliable and valid data sources for this information.

### Examples of clarifying questions that should be asked

#### *Numerator*

- What services will be considered “treating the child”? It is important to list and define the treatment that should be provided within the primary care provider’s office and what services should be provided outside the primary care provider’s office. It is important to remember that treatment includes all services that address the concern identified via the screening tool, including anticipatory guidance and parent education (or guidance), continued surveillance and re-testing according to the recommended periodicity in the primary office, enhanced testing and assessment of the child in the primary office, referral to another health care provider for enhanced testing and assessment of the child or follow-up care, and referral to resources in the community. The measurement team will need to define the appropriate indicators that will be used to capture information about each of the appropriate treatment categories. Depending on the tool, appropriate treatment steps need to be listed by the risk groups identified via the screening tool.
- What treatment services have reliable and valid data sources? While referral to community resources may be recommended, valid data sources may not exist to measure whether or not the child received appropriate care in the community.

#### *Denominator*

- Which children should receive treatment? This answer is most likely dependent on the screening tool, and findings will have to be stratified according to risk/concern categories, as the appropriate treatment will significantly vary depending on the level and type of risk/concern identified.
- Should there be multiple versions of this measure that are specific to the appropriate level of treatment?

## Two Possible Measures

Since treatment can occur within and outside of the primary care provider's office, two possible measurement approaches are explained below. The first addresses measurement of children 0-3 who are treated by their primary care provider for delays related to social and emotional development. The second addresses measurement of children 0-3 who are treated by persons other than their primary care provider for delays related to social and emotional development.

### *Measure 3A*

**Numerator:** Children who received treatment services from the primary care provider who conducted the screening (e.g., children who received in the primary office anticipatory guidance and parent education, continued surveillance and re-testing according to the recommended periodicity in the primary office, enhanced testing, and assessment of the child).

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**x 100**

**Denominator:** Children who were screened using a standardized tool and whose screening results indicated that they should receive treatment services that should be provided by the primary care provider.

### *Measure 3B*

**Numerator:** Children who received from a non-primary care provider treatment services such as enhanced testing and assessment of the child, follow-up care, or a referral to resources in the community.

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**x 100**

**Denominator:** Children who were screened using a standardized tool and whose screening results indicated that they should receive treatment services such as enhanced testing and assessment of the child, follow-up care, or a referral to resources in the community from a non-primary care provider.

## Recommended Possible Data Sources for Measure #3

- Medical chart,
- Parent report, and
- Billing/encounter data.

Tables 3A and 3B on the following page provide a brief overview of possible data sources, measurement strategies, and key methodological issues to consider relative to the two denominators specified above.

**Table 3A Possible data sources for measuring the percent of children 0-3 treated by their primary care provider for delays related to social and emotional development**

<b>Data Source</b>	<b>Numerator</b>	<b>Denominator</b>	<b>Issues to Consider</b>	<b>Issues Related to Data Collection</b>	<b>Discussion/Consensus Needed</b>
<b>Medical Chart</b>	Number of children whose charts have a completed screening tool identifying them at significant risk/concern and who received appropriate treatment services in the primary care provider's office.	Number of children whose charts have a completed screening tool identifying them at significant risk and who should have received treatment services in the primary care provider's office	<ul style="list-style-type: none"> <li>• See issues listed in Table 1.</li> <li>• It is unclear the level of specificity available in the chart.</li> <li>• The appropriate treatment services will have to be categorized according to the level and type of risk/concern identified in the child.</li> </ul>	<ul style="list-style-type: none"> <li>• See issues listed in Table 1.</li> <li>• Numerous studies have shown that anticipatory guidance and parental education are often not recorded in the chart.</li> </ul>	<ul style="list-style-type: none"> <li>• See items listed in Table 1.</li> <li>• Define the appropriate treatment services that should be provided by the primary care provider's office for each "risk group" identified via the screening tool.</li> </ul>
<b>Parent Report</b>	Number of children whose parents answered items indicating their child was at significant risk/concern and who answered positively to items indicating that their child received treatment services in the primary care provider's office.	Number of eligible children whose parents completed the survey and/or who were asked questions via an interviewer-administered survey and who were identified at significant risk/concern who should have received treatment services in the primary care provider's office.	<ul style="list-style-type: none"> <li>• See issues listed in Tables 1 and 2.</li> <li>• Existing measures to utilize: CAHMI items in the PHDS. The National Survey of Children with Special Health Care Needs and the National Survey of Children's Health include items on referral.</li> </ul>	<ul style="list-style-type: none"> <li>• See issues listed in Tables 1 and 2.</li> </ul>	<ul style="list-style-type: none"> <li>• Specify and define appropriate treatment by risk groups.</li> <li>• Identify appropriate survey items.</li> <li>• See topics listed in Tables 1 and 2.</li> </ul>

**Table 3B Possible data sources for measuring the percent of children 0-3 treated by persons other than their primary care provider for delays related to social and emotional development**

<b>Data Source</b>	<b>Numerator</b>	<b>Denominator</b>	<b>Issues to Consider</b>	<b>Issues Related to Data Collection</b>	<b>Discussion/Consensus Needed</b>
<b>Billing/ Encounter Data</b>	Number of children who are at significant risk who received treatment services outside the PCP office.	Number of children who have been diagnosed at significant risk and who should have received treatment services outside the PCP office.	<ul style="list-style-type: none"> <li>• It is unclear how the denominator (children at significant risk) for this measure will be identified via billing and encounter data when the DC:0-3 is not present. In the absence of the DC:0-3, many children at significant risk and/or who currently have social, emotional, and developmental delays will be missed.</li> <li>• This measure may have to be narrowed so that it is only for the treatment of services for which there is accurate billing/encounter data. Narrowed in this way, it would not include appropriate treatment through resources in the community. If the measures are narrowed, then the denominator and numerator would have to be adjusted accordingly.</li> </ul>	<ul style="list-style-type: none"> <li>• Validity of the billing and encounter data. Past experiences have shown that while some codes may be present, it is important to confirm that they are routinely used by health care providers.</li> <li>• Treatment services may be conducted in a variety of places for which the data are not integrated. If this is the case, these services will not be recorded in the billing and encounter data.</li> </ul>	<ul style="list-style-type: none"> <li>• An “additive” measure may be needed to identify the denominator for this measure.</li> <li>• Specify and define groups: by diagnostic categories, appropriate levels of treatment.</li> </ul>
<b>Parent Report</b>	Number of children whose parents answered items indicating their child was at significant risk/concern and who also responded positively to items about treatment services received outside the PCP office.	Number of eligible children whose parents completed the survey who were identified at significant risk and who should have received treatment services outside the PCP office.	<ul style="list-style-type: none"> <li>• See issues listed in Tables 1 and 2.</li> <li>• Existing measures to utilize: CAHMI items in the PHDS. National Survey of Children with Special Health Care Needs and the National Survey of Children’s Health include items on referral.</li> </ul>	<ul style="list-style-type: none"> <li>• See issues listed in Tables 1 and 2.</li> </ul>	<ul style="list-style-type: none"> <li>• Specify and define appropriate treatment by risk groups.</li> <li>• Identify appropriate survey items.</li> <li>• See topics listed in Tables 1 and 2.</li> </ul>

## Methodological Issues to Consider

If billing/encounter data are used, only those children who are identified by their health care provider and who received a service are included in the denominator. This excludes children who were not screened and therefore were not referred to needed services. ABCD II states should take this into consideration and understand that the findings are a “best-case scenario” and do not represent care for the children identified in Measure #1 who were not screened.

Although a primary component of the ABCD II initiative is integration and collaboration, state efforts will not necessarily lead to data system integration, and it is unclear that data systems will be fully coordinated in the time period of the grant. When using measurement methodology that relies on these data sources (claims/billing data that are not coordinated with Medicaid system), it is unlikely that the system can account for all children who receive services. The ABCD II states should explicitly articulate who is and who is not included in the numerator and denominator and assure that biases are the same across their state pilot sites.

## Example of a Possible Measurement Approach

### Example 1

*Health Plan X used the PEDS to screen children at risk in pediatric offices. It also used a parent survey to collect data for Measures #1-3. The Plan identified a random, representative sample of children 3–35 months who had at least one well-child visit during the intervention time period and administered the parent survey by telephone. The PEDS instrument was included in the survey. Parents whose children were identified at risk in the survey (denominator for Measure #3) were asked specific questions about the appropriate follow-up recommended via the PEDS diagnostic tool. Health Plan X determined which children received appropriate follow-up (numerator) based on the parents’ responses.*

### Example 2

*Public Health Office X decided to implement the DC:0-3. Medicaid identified children 0-3 who go to Office X for well-child care and who have diagnoses, via the DC:0-3, during the intervention time period. This group represents the denominator for this measure.*

*Diagnosis-specific groups were then created based on the kinds of services children identified with the specific diagnoses should receive. For each diagnostic group, for each child, billing and encounter data were examined for services the child should have received. Children who received these services are counted for the numerator of this measure.*

## Implementation Tips for the States

Rather than providing detailed measurement specifications, this paper outlines measurement options the states may feasibly implement in a fairly short time frame. We have not set forth the most ideal or the most valid approaches for measuring these aspects of care, approaches that would require data and systems not currently in place. The tips below are offered within this context.

- It is recommended that the ABCD II states create two measures to capture whether treatment was received: 1) treatment received in the primary care provider's office, and 2) treatment received in the non-primary care provider's office.

It appears that the measure related to treatment in the non-primary care provider's office would be limited to those services for which claims/billing data are available. The numerator and denominator will need to be adjusted accordingly, and the state projects should explicitly indicate which services are not being measured.

- Within each measure, multiple data sources may need to be used as different treatments are more reliably and validly captured via different data sources. For example, anticipatory guidance and parental education are most validly captured via parental report, whereas intensive screening and assessment can be validly captured in the medical chart. If only one data source can be used, then the states will need to explicitly state what kinds of treatment are and are not being measured, as one data source does not validly measure all the treatment options possible.

## NEXT STEPS FOR THE STATES IN DEVELOPING AND IMPLEMENTING A MEASUREMENT METHODOLOGY

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The planning phase of a measurement project is the most essential to creating a successful process that will gather meaningful, actionable, and valid information. It is important during the planning phase to consult with key stakeholders: policymakers, consumers, and providers. This consultation will help ensure that those who are most likely to be instrumental in changing policies or practices receive the information they need to implement changes and that they receive it in a form that they can easily use.

Below is a summary of the recommended planning steps for the ABCD II states to consider as they continue to implement their measurement project.

- **Confirm whether the assumptions listed for the overall measurement project and for each measure are true.** If not, note how these differences influence the measurement strategy. Some key assumptions that were true for the collaborative state projects, but that may not be true for others producing these measures include:
  - The measure is intended to assess performance at an intervention site, not within the Medicaid program as a whole.
  - The providers whose performance is being assessed will be active partners in the measurement project.
  - The measure of screening will be keyed to the use of a single standardized tool at each intervention site and that tool will be placed in the child's medical chart.
  
- **Identify the standardized tools for identifying young children with issues related to social and emotional development.** This step is imperative to the success of this project since the recommended measurement methodologies noted in this document are meant to be anchored to the tools and to the recommended standards of care derived from these tools.
  - **Identify** the screening tool(s) that you wish to be used as a standardized tool (and thus measured in Measure 1).
  - **Confirm** that the health care providers whose performance you plan to measure use one more or these tools. (If they do not use one then the result of the measure will be zero.)
  - **Confirm** with pilot sites that the completed screening tools will be included in the child's medical chart. This is a crucial component of the implementation phase of the process that will benefit the measurement of the work.
  - **Identify** the periodicity for administering the screening tools (e.g., at least one screen by the 24-month well-child visit).
  - For each screening tool, **specify** recommended follow up/treatment steps appropriate for each risk group of identified children.
  - For each of these groups, **specify the key treatment steps** recommended and the indicators that will be used to determine whether or not the child received an appropriate level of treatment.

- **Identify the data resources for the measurement project.** Examine whether the data sources have reliable, valid information about the topics that are of interest. Examples of possible data sources include:
  - Medical chart,
  - Parent report,
  - Provider survey,
  - Billing/encounter data
  
- **Identify the unit of analysis for the measure** or, in other words, define the “denominator” for each of the measures (e.g., practice-level, health plan level, county-level, patients seen by a public health nurse). This involves clarifying not only the setting of the intervention but also who should be eligible to be included in the denominator (e.g., all children enrolled, all children who have been continuously enrolled, only children who had a visit during the time period).
  
- **Define a standardized methodology** for what will be “counted” for the numerator for each measure.
  
- **Pilot test the measurement methodology.** This is a crucial step to assure that the measures being gathered are feasible and valid. Common problems found in the “pilot testing” phase are:
  - A billing/encounter code identified for screening and/or follow-up is not routinely used by providers.
  - Necessary indicators are not in the medical chart, even though program implementation experiences show that the practice and/or provider are implementing the intervention (e.g., screening tools for children not identified at risk may not be in the charts).
  - Data systems are unable to merge (e.g., it is not possible, using the Social Security Number of the child, to merge data from Medicaid, the Department of Health, and Part C).
  
- **Modify the measurement methodology** based on lessons learned from the pilot testing.
  
- **Implement a standardized methodology** for collecting the data.
  
- **Analyze and report the findings** to various stakeholders. Ideally, stakeholders will be consulted during the planning process to ensure that they receive the information they need in the format they need to allow them to decide what actions to take based on the results of the measurement effort.