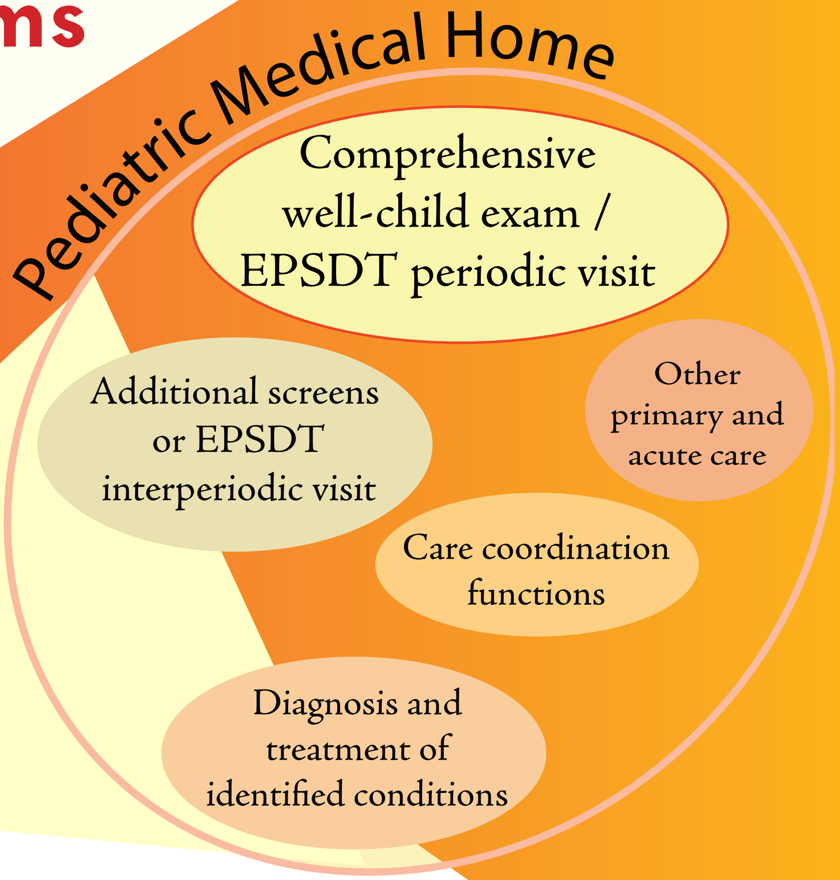
Collaboration and Action to Improve Child Health Systems

A Toolkit for State Leaders



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Welcome

A Toolkit for Mapping Child Health Systems

Evolution of the Toolkit

This document and the tools it contains are designed to help States achieve their goals for improving child health and well-being. By mapping a child health system, State leaders can better envision the experience of families, gaps in services, and connections among service systems.

The toolkit is based on the experience of 18 "State Leadership Workshops" conducted in 14 States and Puerto Rico between 2004-2009 with funding from the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). The purpose of these Workshops was to foster successful coordination and collaboration between State Maternal and Child Health (MCH) Programs and Medicaid agencies, as well as their sister agencies and private sector partners.

Through the Workshops, the discussion questions and diagrams contained in this toolkit evolved as a way to open communication, foster collaboration, remove ideologic stumbling blocks, and map existing and envisioned child health systems.

The toolkit was vetted by more than 50 child health leaders from across the country through a special pre-conference session at the 2008 annual meeting of the Association of Maternal and Child Health Programs (AMCHP). This led to major improvements in scope and design. The revised toolkit was pilot tested in 2009 in two States, Vermont and Colorado. Finally, peer review was done by four experts in Medicaid and maternal and child health systems.

A Child Health Perspective

This toolkit uses Medicaid child health benefits, as defined under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) policy, as a point of departure. The services defined under EPSDT law have direct impact on one-third of all U.S. children, through both Medicaid and the Children's Health Insurance Program (CHIP). EPSDT has indirect effects on providers, health plans, and systems of care for all children. But, the toolkit does not stop with EPSDT. Experience in State Leadership Workshops across the country demonstrated that the questions and diagrams in this toolkit can effectively increase understanding of the interaction among public programs, including public health, mental health, child welfare, education, special education, and early intervention. These questions and diagrams can illuminate the gaps among services and critical linkages across child health systems. The maps can illustrate the system as families experience it when they navigate through it.

Equally important, the toolkit is guided by evidence-based child health practice. It is informed by extensive review of the child health literature and Medicaid law. It is grounded in guidelines from professional organizations such as the American Academy of Pediatrics and American Academy of Pediatric Dentistry.

By design, this toolkit can be used by States to develop a "map" of their child health system and to advance the challenging work of improved coordination, integration, and management of services among providers, delivery mechanisms, and financing streams.

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Introduction

How to use this toolkit to map the child health system in your State

Multiple, Flexible Uses

This toolkit contains multiple system mapping diagrams and questions to guide discussion. It can be used by State leaders in several ways and to achieve multiple purposes. For example, it might be used as a guide to:

- Facilitate a one-to-two day State Leadership Workshop on Improving Child Health.
- Structure a year-long series of interagency staff meetings to improve management of EPSDT or child health services broadly.
- Assess the functioning of a care coordination or integrated services initiative.
- Review the operations and connections of a medical home project.

The State Leadership Workshops from which the toolkit evolved, often started with a system mapping exercise. The exercise began with drawing a circle to designate the primary care provider or medical home. Then, workshop participants discussed what might happen if a problem or risk was identified during an EPSDT comprehensive well-child visit, drawing the lines for referrals and linkages to partners.

The discussion and diagram helped to surface different views of how children and their families moved through the "system" of health services. The conversations typically focused on how system linkages currently compared to how the group would want things to work.

Workshop participants also discussed the intent and impact of current policies related to child health. Finally, these discussions nearly always generated ideas about how enhanced coordination and collaboration across programs and agencies could improve the delivery of child health services.

The questions raised and generated during the State Leadership Workshops form the basis for the discussion questions in this toolkit.

By "mapping" (i.e., drawing) a child health system, State leaders can better envision the flow of services and funding that support access to care for children and their families. The mapping exercise has been used to generate discussion about different populations, such as:

- all children or all children who have publicly subsidized health coverage;
- age groups that have particular needs, including young children 0-6 or adolescents; and
- children with special health care needs or those with mental health conditions.

In particular, experience in 14 States indicates that this toolkit and its approach to mapping can help a group of child health leaders from inside and outside of government see opportunities to improve: case management and care coordination; referral systems and linkages; and/or barriers that result from "siloed" funding or segmented thinking. In essence, it can help them see the system as it is and envision the system desire.

Organization of the Toolkit

Topic Sections

Each section of this toolkit contains background information, discussion questions, and diagrams related to a particular topic.

The section topics are guided by an assumption or principle about the child health system, Title V, and/or Medicaid. These principles are as follows:

1. Title V agencies have responsibility to assure access in MCH system that support families.
2. Medicaid's EPSDT mandates financing for child health services and supports to improve access to care.
3. Title V and Medicaid have legal obligations to collaborate and are required to have interagency agreements.
4. States' outreach and informing methods help families apply for coverage, understand their benefits, and find medical homes.
5. Implementing the medical home concept can improve child health quality and efficacy.
6. States play a central role in maximizing comprehensive EPSDT well-child screening visits.
7. Linkages, case management, and care coordination are critical to an efficient and effective child health system.
8. A dental home and appropriate dental care are essential to the health of every child.
9. Title V and Medicaid agencies together can support famiy-centered, coordinated care for children with special health care needs (CSHCN).
10. Effective Medicaid managed care arrangements depend on contracts appropriate to child health needs and systems.
11. Public-private and interagency collaboration are a foundation of child health quality efforts.
12. Practice scenarios on early childhood or adolescent health are contained in this section. For some groups one practice scenario could be the basis for a whole workshop.

Selected References

Selected references that support the content and concepts contained in each section can be found at the end of the toolkit.

Discussion questions

Each chapter offers background information and discussion questions related to a particular topic. As described above, the discussion questions are a composite of those raised in 14 State Leadership Workshops. They can serve as a point of departure for discussions of the child health system in other States. The questions provided can be used to spark conversation, clarify differing understandings of common situations, and point toward needed action.

In most instances, discussions will move from these general questions to a more detailed exploration of State-specific structures and issues. Any one chapter and its set of questions might take from an hour to a day to explore in detail.

System map diagrams

In addition to discussion questions, most sections of the toolkit contain diagrams that are part of the larger child health "system map" shown at right. These are composite diagrams based on those created in State Workshops.

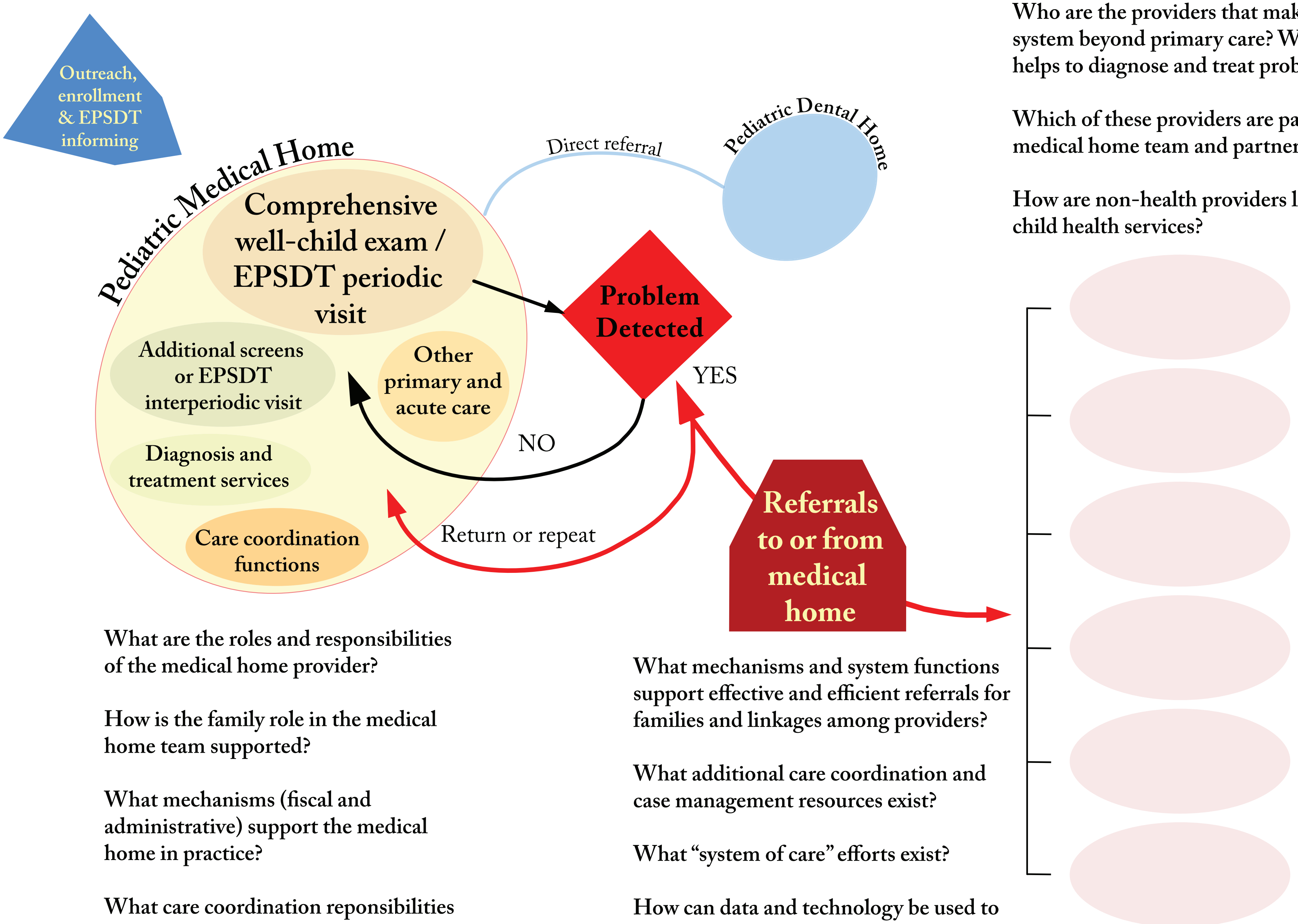
The system map is a visual representation of the core elements of a child health system, starting from a primary care provider (or medical home) and including an array of other service providers and resources that a child and their family may need. It is the child and family, as users of the system, that are moving between providers and services, so they are not drawn on the map.

Using this "idealized" version of a child health system, State leaders might draw both a map of current structures and of the system they would like to create in the future. Envisioning the system map together helps to stimulate further discussion.

Convening a Workshop

For State leaders that wish to convene their own leadership workshop on child health, sample agendas and a guide for facilitators can be found in Appendix A (page 30) at the end of the toolkit.

An Example of Systems Thinking to Improve Child Health



Outreach, enrollment & EPSDT informing

Pediatric Medical Home

Comprehensive well-child exam / EPSDT periodic visit

Additional screens or EPSDT interperiodic visit

Other primary and acute care

Diagnosis and treatment services

Care coordination functions

Direct referral

Pediatric Dental Home

Problem Detected

YES

NO

Return or repeat

Referrals to or from medical home

Who are the providers that make up the system beyond primary care? Who helps to diagnose and treat problems?

Which of these providers are part of the medical home team and partnership?

How are non-health providers linked to child health services?

What are the roles and responsibilities of the medical home provider?

How is the family role in the medical home team supported?

What mechanisms (fiscal and administrative) support the medical home in practice?

What care coordination reponsibilities are assigned to the medical home?

What mechanisms and system functions support effective and efficient referrals for families and linkages among providers?

What additional care coordination and case management resources exist?

What “system of care” efforts exist?

How can data and technology be used to improve integration and coordination?

* Start where you are

You may choose to start from the beginning and work sequentially through the toolkit and its discussion questions and diagrams.

Alternatively, you may wish to begin with a more specific identified challenge that currently exists in your State. For example, one of the following core questions may be at the center of your current situation.

- Does your State's Title V and Title XIX Medicaid interagency agreement need to be updated? (See Section 3, pages 4-5.)
- Do you need better outreach for enrollment and informing? (See Section 4, pages 6-8.)
- Are you aiming to assure a medical home for every child? (See Section 5, pages 9-10.)
- Does the State's EPSDT periodic visit schedule conform to professional guidelines? (See Section 6, pages 11-12.)
- Do you want more reliable and completed referrals? Are there too many overlapping care coordination and case management structures? (See Section 7, pages 13-14.)
- Are children just not getting to the dentist for prevention and treatment? (See Section 8, pages 15-16.)
- Is the scope and reach of the CSHCN program too narrow? (See Section 9, pages 17-18.)
- Do you need to think about the structure of Medicaid managed care contracts? (See Section 10, pages 19-20.)
- Is your state undertaking a new child health quality initiative? (See Section 11, pages 21-22.)
- Is the issue how to serve young children at risk, to assure early intervention before the need for a more serious diagnosis? (See Section 12, pages 24-25.)
- Is adolescent health the weakest part of your child health system? (See Section 12 pages 26-27.)

These questions and diagrams have been used with State leaders to begin the conversation on each of these topics. Experience has shown that asking questions through a structured process and mapping your child health system helps to move from discussion to action.

The questions contained in this toolkit are a starter set. They will help leader in your State develop a system map and define issues for further discussion.

Whether you focus only on one topic such as medical home or care coordination or tackle a system overhaul, we recommend that you start with a current challenge.

It is helpful to read the through the questions in this booklet as you begin to map your child health system, but most of all start where you are and work from your strengths and challenges.

1 Title V agencies have responsibility to assure access in MCH systems that support families.

Title V agencies unique role in assuring child health

Title V is the only Federal program with responsibility for assuring and promoting the health of all of America's mothers and children. Created in 1935, Title V has operated as a Federal-State partnership for 75 years.

As currently defined in Title V of the Social Security Act, dollars allocated to States under the Maternal and Child Health Services Block Grant are "for the purpose of enabling each State (A) to provide and to assure mothers and children (particularly those with low income or with limited availability of health services) access to quality maternal and child health services;..." SSA § 501(1)(A).

As State Title V agencies work to improve the health of all mothers and children, they assess needs, plan for programs to fill gaps, and provide services as necessary. The framework for Title V services includes efforts to:

- Provide direct services as needed to fill gaps.
- Develop and provide enabling services that help families to use appropriate health care and resources.
- Provide population-based services needed to protect public health and assure optimal health.
- Build an infrastructure of planning, evaluation, research, and training that supports effective and efficient delivery of services to women, children, and families.

The Title V law also States that MCHB is responsible for "assisting States in the development of care coordination services." SSA § 509(7). The terms care coordination and case management are defined as "services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services" and "to assure access to quality preventive and primary care services." SSA § 501(3) and (4).

Title V agencies based their work on key principles and values. Efforts are aimed at improving the health of all mothers and children. They aim to provide and promote family-centered, community-based, coordinated care. Populations at higher risk (e.g., low income) and with special health needs or disabilities are the focus of many direct and enabling services.

To work effectively and achieve their goals, State Title V agencies need to "see the big picture" of the health system and how children and families are served within it. This toolkit focuses on the big picture for children served under Medicaid and Children's Health Insurance Programs (CHIP). Users of this toolkit can explore how children and their families are served in Medicaid, EPSDT, and Title V programs.

Every State Title V program has activities to both address maternal and child health (MCH) generally and a unit dedicated to serving Children with Special Health Care Needs (CSHCN) and their families. In most States two separate units operate under the same agency umbrella, which might be a family health bureau or division within the health department.

The Title V MCH Block Grant funds are allocated to the States based on a matching formula that requires a $3.00 State match for every $4.00 in Federal funds. Some States appropriate more than this level of matching funds.

At least 30 percent of each State's allocation must be spent on preventive and primary care services for children. An additional 30 percent is to be dedicated to services for CSHCN. SSA § 505(3). This creates opportunities to make targeted investments in child health.

States are required to prepare and submit reports on Title V activities annually and to complete needs assessments at least every 5 years. Annual reports include progress on a set of Title V national performance measures.

Access to Primary Care

Title V also requires reporting on the numbers of obstetricians, family practitioners, family nurse practitioners, certified nurse midwives, pediatricians, and certified pediatric nurse practitioners licensed to practice in the State. SSA § 506(2)(E).

Beyond reporting, Title V State agencies play a larger role in monitoring and assuring access to primary care for women and children. They provide professional training, purchase direct services, and help to maximize the existing workforce.

Virtually every State has medically underserved areas, often in the most rural and urban communities. Such medically underserved areas do not have publicly subsidized health clinics, private physician practices, or other health providers in sufficient number to serve the resident population. The recently enacted Affordable Care Act of 2010 provides for a major expansion of community health centers that will help to fill current gaps.

The Affordable Care Act also provides additional support for community health teams, health professions loan and repayment incentives to serve in primary care and/or medically underserved areas, and other new funding to address and eliminate disparities.

In terms of primary care, some specific actions have been found to reduce gaps in the availability of services. Child health leaders can encourage improvements to primary care and adoption of best practices.

Discussion questions

- Do Title V, Medicaid, and other agencies work together to monitor access to primary care?
- Is the State maximizing the available pool of pediatricians, family physicians, nurse practitioners, and others who provide primary care?
- Do the laws and rules covering professional scope of practice enable or inhibit the roles of "mid-level" providers such as nurse practitioners and physician assistants?
- Have all medically underserved areas made attempts to launch a community health center? Has the State studied opportunities under the Affordable Care Act to expand the number of community health centers?
- Is the State supporting development of Accountable Care Organizations (ACOs), which are encouraged by the Affordable Care Act?
- Does the State use scholarship, loan repayment, or similar incentives for individuals who will serve in medical underserved areas?
- Has the State studied opportunities under the Affordable Care Act to provide incentives for primary care providers, particularly under Medicaid?

2 Medicaid's EPSDT mandates financing for child health services and supports to improve access to care.

EPSDT defines the child health benefits in Medicaid

The Medicaid child health benefits are primarily defined under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program.

As describe by the Centers for Medicare & Medicaid Services (CMS), EPSDT:

"*consists of two mutually supportive, operational components: (1) assuring the availability and accessibility of required health care resources; and (2) helping Medicaid recipients and their parents or guardians effectively use these resources*." (www.cms.gov)

The first component involves coverage of and payment for "medical assistance" services. The second is linked to a series of administrative obligations, such as: informing; supportive services to assure that care is secured (e.g. transportation, case management); and reporting.

Medicaid law requires that States provide for "providing or arranging for the provision of such [EPSDT] screening services" and "arranging for corrective treatment." SSA § 1902(a)(43).

The elements of EPSDT, as defined by law, include the following.

Benefits and services:

- Periodic and "as needed" screening services
- Vision, hearing, and dental services
- All medically necessary diagnosis and treatment needed to "ameliorate" conditions
- Prevention-focused standard of medical necessity

Administrative services:

- Outreach to and informing of families
- Transportation and scheduling assistance
- Linkages to Title V and other agencies
- Data collection and reporting.

SSA § 1902(a)(43).

Discussion questions

- Who administers EPSDT in your State?
- If more than one agency is involved, how do they work together to assure access to care?
- What are the mechanisms to provide appointment scheduling and transportation assistance to children and their families?
- What EPSDT data are collected and publicly reported by the state or health plans?

This toolkit is designed to help child health leaders in Title V , Medicaid, and related agencies understand how child health services are functioning in their State. EPSDT is the focal point for the guided discussions described on the following pages. The comprehensive approach, broad-based benefits, and structure of well-child visits under EPSDT make it an ideal basis for envisioning a quality child health system.

3 Title V and Medicaid have legal obligations to collaborate and are required to have interagency agreements.

EPSDT requires Title V and Medicaid collaboration

Since 1967, Medicaid has included the special child health benefits package known as EPSDT benefit. From its beginning EPSDT has been linked in mission and policy to Title V.

For more than 40 years, State Medicaid agencies, which generally focus on financing health care, have faced ongoing challenges in fulfilling their statutory obligations to provide outreach, informing, scheduling and transportation assistance under EPSDT. Title V programs can assist in carrying out these obligations. Title V also plays other roles in administering EPSDT.

Collaboration between State Title V and Medicaid agencies is facilitated by their required cooperative agreements. Such agreements have taken various forms. Effective agreements are based on a solid understanding of factors such as: the functioning of EPSDT, the availability of providers, and the community supports available to families.

Federal Medicaid law requires that State Medicaid agencies enter into cooperative agreements with State Title V agencies. Specifically, the law says these agreements are to address the following:

1. "Providing for utilizing such (Title V) agency... in furnishing such care and services which are available;" and
2. "Making such payment as may be appropriate for reimbursing (Title V) agency... for the cost of any such care and services furnished for any individual for which payment would otherwise be made [under Medicaid]..." SSA § 1902(a)(11).

Title V law also assigns responsibilities to the HRSA/MCHB and State Title V agencies to promote coordination of activities between Title V and Title XIX Medicaid, especially child health benefits under EPSDT. SSA § 509(2).

Such interagency agreements provide a formal structure to guide agencies respective fiscal, program, and administrative responsibilities. Whether the activity is paying for services, providing clinical services, conducting outreach, providing care coordination, setting standards of care, analyzing data, or conducting utilization review, Medicaid and Title V can increase efficiency and effectiveness through interagency efforts.

Under contract with HRSA/MCHB, the Maternal and Child Health Library at the Georgetown University has a published a report: *State MCH-Medicaid Coordination: A review of Title V and Title XIX Interagency Agreements*. Visit <www. mchlibrary.infor/iaa/toolkit.html> to find model agreements, search for ideas, and learn more.

Discussion questions

The following questions may stimulate your discussion on this topic.

Interagency agreements

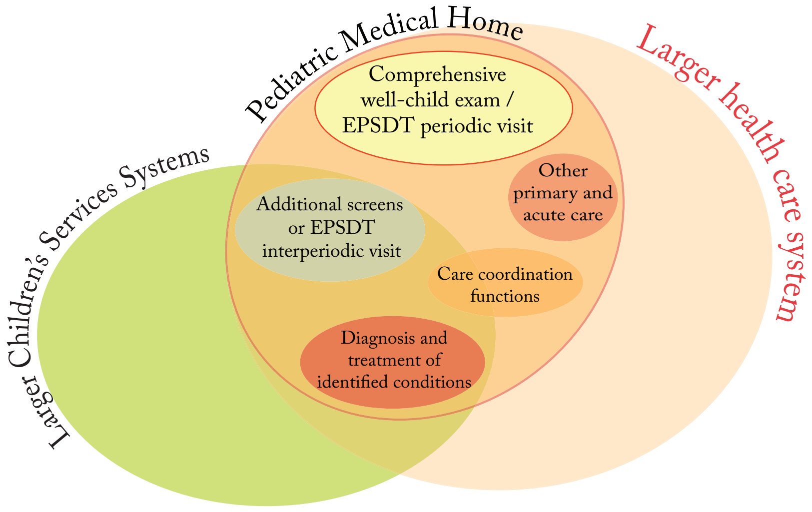
- Is there a Medicaid-Title V interagency agreement in effect? Is it up to date?
- Does the State's interagency agreement cover current activities, initiatives, and approaches? For example, does the agreement take into account the State's current Medicaid managed care contracts?

Opportunities for coordination that may be reflected in interagency agreements

- Does Title V assist with financing for services not covered by Medicaid?
- Do Title V and Medicaid work jointly to develop EPSDT guidelines, periodicity schedules, and standards of care?
- Does Title V assist with data analysis? Are data sharing issues reflected in such agreements in order to maximize the State's ability to measure and monitor child health?
- Does Medicaid reimburse for direct, clinical services provided by State and local programs that are financed by Title V?
- Does Medicaid reimburse local health departments for staff time spent in assisting families in appropriate use of children's health services under the EPSDT benefit (i.e., outreach, informing, care coordination, transportation scheduling)?
- Does Title V assist in recruiting Medicaid pediatric providers both for primary care and special needs?
- Does Title V collaborate with Medicaid in providing care coordination/case management. For example, do both agencies support local EPSDT coordinators? (See discussion below in Section 7.)
- Have Title V and Medicaid developed a common definition for CSHCN? Is this definition reflected in the interagency agreement?
- How does Title V help Medicaid fulfill the requirement for lead screening of children ages 12-24 months (with "catch up" testing between ages 36-72 months)?
- What is the role of Title V in development of Medicaid managed care contracts?
- Does the interagency agreement define interagency fund transfers that are or should be in place?

Other interagency coordination

- What relationships exist with early care and education programs such as Head Start and child care? Head Start has obligations to connect eligible children to EPSDT well-child visits. How are these activities supported and encouraged?
- How do Medicaid, Title V, and mental health agencies work together to assure that mental and behavioral health risks and conditions are identified early and treated appropriately?



- What is the role of schools in assuring child health? Does Medicaid and/or Title V finance school health activities?
- How do Medicaid and Title V work jointly to assure the efficiency and effectiveness of the State's newborn screening program?
- What interagency agreements support the Individuals with Disabilities Education Act (IDEA) programs—Part C Early Intervention, Part B Preschool Special Education, and Part B Special Education? Are Medicaid financing arrangements with special education programs effective and efficient?
- How do Medicaid and Title V work together with child welfare agencies? Do interagency agreements facilitate access to EPSDT for children in foster care?

4 Outreach and informing help families apply for coverage, understand their benefits, and find a medical home.

States obligations to provide outreach and informing

States must inform all eligible Medicaid recipients under age 21 about EPSDT services. Medicaid has responsibility for EPSDT informing and outreach. Many State Title V agencies assist in fulfilling these obligations. At a minimum, Title V can help to assess the adequacy of current efforts.

Federal regulations allow flexibility about the process, so long as the outcome is effective informing and informing is achieved in a timely manner (generally within 60 days of eligibility determination and annually thereafter).

States are expected to use a combination of informing methods. A combination of face-to-face, oral, and written informing activities is most effective and productive. Communication should be clear and easily understood (e.g., lower literary reading level, not full of agency jargon) so that families gain the information they need to use EPSDT services.

While the State has responsibility to inform all eligible those eligible for EPSDT, special approaches may be used to reach particular subgroups of Medicaid beneficiaries (e.g., pregnant women, adolescents, families of children with special health care needs, foster care families).

Through more than 40 years of experience with EPSDT and a decade of CHIP, lessons have been learned about effective informing. The summary below and diagrams with questions that follow can help State leaders review and improve their EPSDT outreach and informing methods.

Health literacy matters

The Institute of Medicine and Healthy People 2010 define health literacy as: "*The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*." National surveys indicate that more than one third of the overall U.S. adult population and more than one half of those covered by Medicaid have health literacy at or below basic levels.

Health literacy is not simply the ability to read. It requires a group of reading, listening, analytical, and decision-making skills combined with the ability to apply these skills to health related situations.

When information provided is dense, technical, and/or filled with jargon, families will not be well informed. For example, parents with "below basic" health literacy would not be able to determine from a written pamphlet how often a person might have a specified medical test. Persons with "basic" level health literacy would have trouble providing two reasons why their child's condition might call for a specified test, even when they use information from a pamphlet.

The American Medical Association (AMA) reports that low (basic and below basic) health literacy is a stronger predictor of health than age, income, or socioeconomic status. Without support, individuals with low health literacy have been found to be less likely to use preventive care, comply with prescribed treatment regimens, and effectively navigate the health care system.

Crafting effective messages

Messages should convey the benefits of preventive health care, coverage of diagnostic and treatment services, where services are available, and that transportation and scheduling assistance is available. Just telling families their children have coverage for well-child check ups is insufficient.

In States using managed care, effective informing would also include information about how to enroll in a plan and the obligations of the managed care organization to provide EPSDT services.

A mix of EPSDT informing methods

Face-to-face informing methods

With streamlined eligibility and less frequent face-to-face eligibility determinations in many States, alternate approaches have emerged for face-to-face informing. Face-to-face informing might be provided by eligibility workers, community health workers, and/or managed care plan staff, for example. Using nutrition programs, schools, community-based organizations, and safety net providers to inform families about EPSDT are other commonly used approaches.

Other oral informing methods

Public service announcements, community awareness campaigns, or videos in might be used. These provide general information and do not replace specific, individualized informing.

Written informing methods

Written reminders (e.g., through letters, postcards, birthday cards) are one tool but inadequate for populations with high mobility or for groups of children with low participation rates. Similarly, written materials handed out at the time families are completing the cash assistance eligibility process are not highly effective. Making information available on the Internet may be helpful for some families, but many low-income families do not have access to on-line information.

Outreach for enrollment

The importance of outreach to enroll eligible children, while not an obligation under Medicaid, has become clear. Such outreach may include information about the benefits of EPSDT but does not substitute for informing families about EPSDT benefits following eligibility determinations.

A variety of reports have described methods for reducing the number of eligible but unenrolled children. Many strategies that use community-based organizations and services have shown impact, including approaches through schools, employers, and nutrition programs.

For State agencies, a select set strategies designed to increase enrollment of eligible children have been shown to be effective, particularly when carried out in combination.

These include:

- adopting continuous and presumptive eligibility options;
- eliminating asset tests and in-person interview requirements;
- using streamlined and joint applications procedures; and
- exercising the new option to use Express Lane eligibility for CHIP and Medicaid.

Changing the "culture" of agencies and training staff to support the goal of enrollment is another method being used by States.

States also have used partnerships, public awareness campaigns (marketing), and data sharing strategies to increase the number of eligible children who are enrolled in Medicaid and CHIP.

The Children's Health Insurance Program Reauthorization Act (CHIPRA) provides bonuses for States that enroll children in Medicaid and CHIP above target levels.

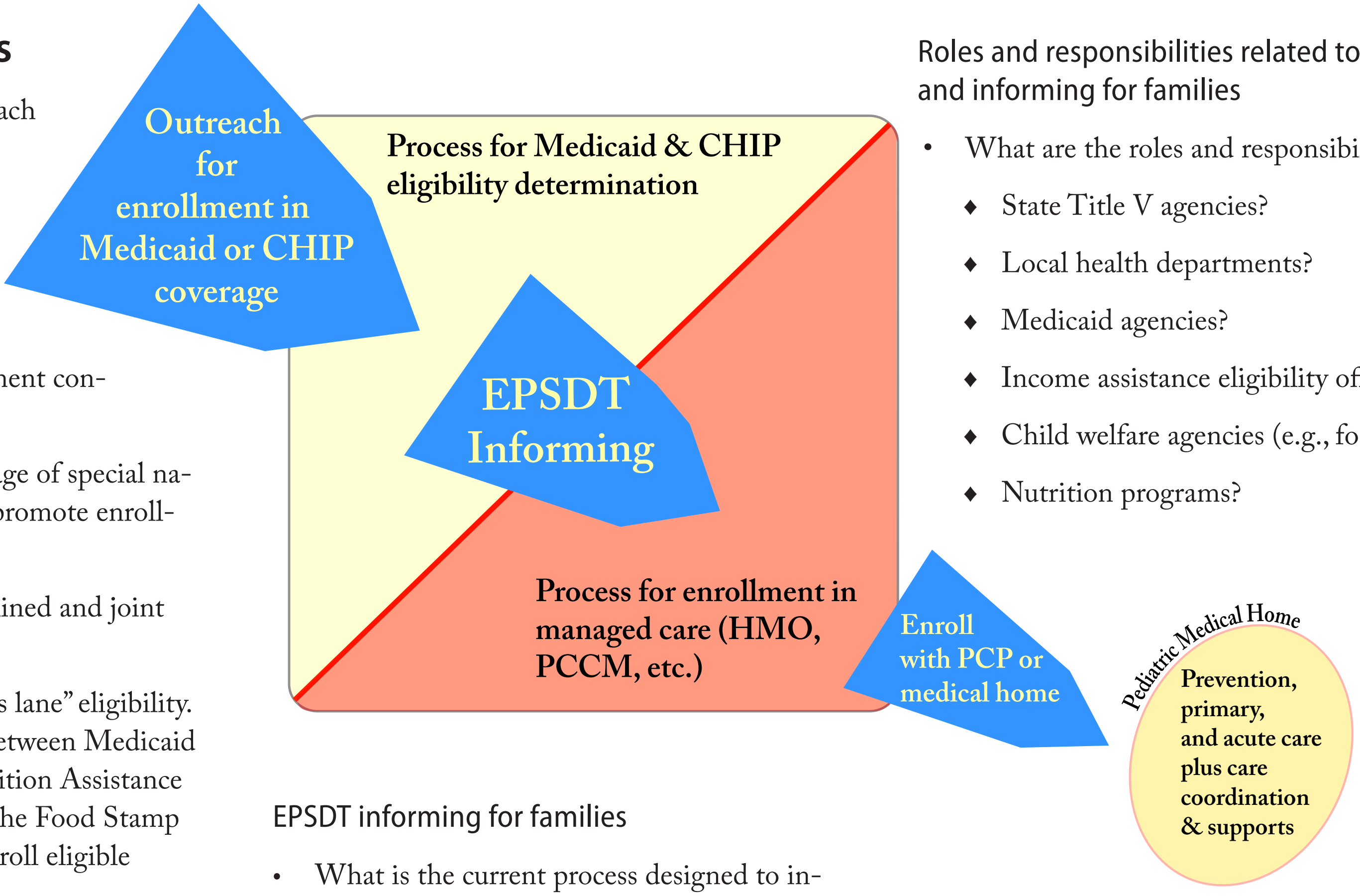
Federal law and court decisions call for methods that will effectively inform Medicaid recipients about EPSDT, including: the schedule for well-child screening visits , the range of covered services, the benefit of preventive care, that the services are free of charge, how to locate a provider, and that transportation assistance is available. Written information alone is insufficient. A combination of oral and written methods that can reinforce one another has been shown in studies to be most effective.

Discussion questions

To start the discussion on outreach and informing, follow the blue triangles in the sample diagram and consider the following questions.

Outreach for Enrollment

- How is outreach for enrollment conducted?
- Does the State take advantage of special national projects designed to promote enrollment?
- Does your State use streamlined and joint applications procedures?
- Does your State use “express lane” eligibility. For example, linking data between Medicaid and the Supplemental Nutrition Assistance Program (SNAP, formerly the Food Stamp program) to identify and enroll eligible children?
- Do the methods to reach out to eligible but unenrolled children include both Medicaid and CHIP?
- Is the State aiming to improve their enrollment procedures and increase enrollment of these children above the Federal target level in order to receive a Federal bonus payment for each extra child enrolled?
- How might improved data and information sharing increase the efficiency and effectiveness of outreach and informing?



EPSDT informing for families

- What is the current process designed to inform families and help them understand and use EPSDT? What combination of face-to-face, oral, and written methods are used?
- Are families effectively informed about both EPSDT screening and treatment services?
- Who is responsible for outreach and informing that helps families understand and effectively use EPSDT?
- What mechanisms are in place to assure that eligible families are enrolled, get connected to a provider, and receive visits on schedule? How could they be improved or augmented?

Roles and responsibilities related to outreach and informing for families

- What are the roles and responsibilities of:
  - ♦ State Title V agencies?
  - ♦ Local health departments?
  - ♦ Medicaid agencies?
  - ♦ Income assistance eligibility offices?
  - ♦ Child welfare agencies (e.g., foster care)?
  - ♦ Nutrition programs?
- What are the roles and responsibilities of:
  - ♦ Medical home providers?
  - ♦ Managed care organizations (MCOs)?
  - ♦ Primary care case managers (PCCM) contracting with Medicaid?
  - ♦ Other Medicaid contract entities?

5 Implementing the medical home concept can improve child health quality and efficacy.

The Evolving Medical Home

The American Academy of Pediatrics (AAP) and HRSA/MCHB have promoted the concept of a medical home for decades. The AAP first advanced the concept to emphasize the importance of having a provider who accepts responsibility for overall management and coordination of health services.

Generally, the term "medical home" is used to describe an enhanced model of primary care in which teams deliver comprehensive, coordinated, and patient-centered care. In 2007, a group of leading primary care professional organizations issued joint principles in support of the "patient-centered medical home" with a physician team that coordinates and integrates all aspects of preventive, acute, and chronic needs of patients.

Having a patient-centered medical home has been shown across a number of studies to improve access to care, increase quality of care, and reduce racial-ethnic disparities. Some studies report improved child health outcomes.

The consensus is that a pediatric medical home includes processes to provide care that is: accessible, continous, comprehensive, family-centered, coordinated, and compassionate. The approach aims to assure that: all providers of a child's care operate as a team; families are critical members of that team; and all team members understand the importance of quality care.

The work of a medical home is a dynamic process driven by the health and developmental status of a child and the ability of the family and other professionals to provide care and care coordination. (See Section 7 for more on care coordination in the medical home.) Appropriate care plans, centralized records, effective linkages among providers, and strong communication mechanisms are important to the success of a medical home.

States role in implementing the medical home concept

Both Title V MCH programs and Medicaid have an important role to play in advancing the medical home concept. Through partnerships and enhanced financing more pediatric medical homes are being developed.

Virtually all State Title V MCH programs have medical home initiatives or projects. Some operate on a small scale, involving only a small number of practices or targeted groups of children.

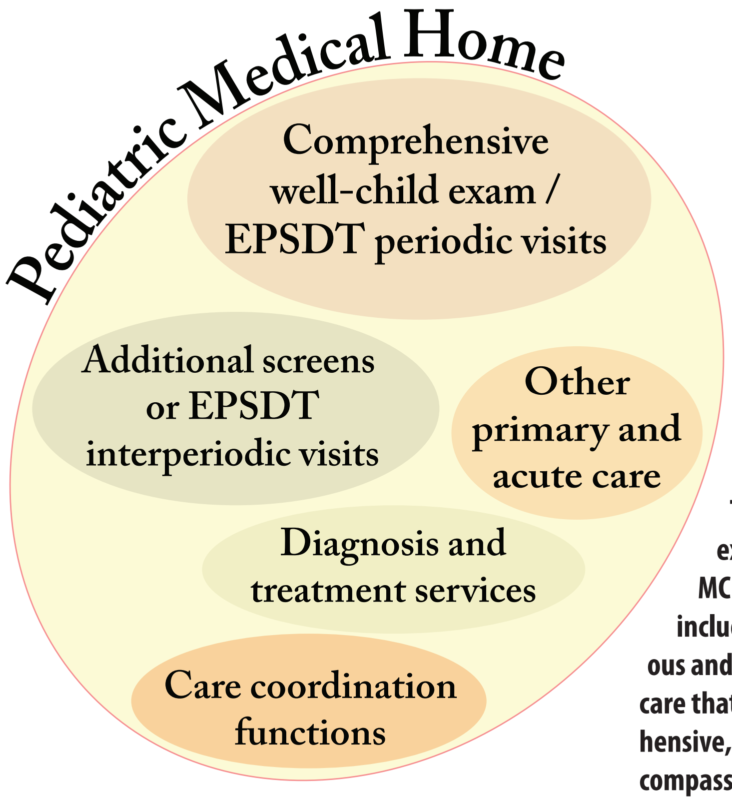
Through broader partnerships, other States have aimed to operationalize the concept of the medical home statewide. Family advocates, pediatric primary care providers, and health plans may be involved in such efforts.

Some States are using Medicaid managed care as a means to develop medical homes for a greater share of children. One approach is the use primary care case management (PCCM) as the basis for increasing the number of medical homes. This and other approaches are being used by States as means to train, certify, monitor, and compensate medical home providers.

Discussion questions

If your State would like to advance the medical home concept, consider the following questions.

- How many providers are involved?
- How much of the child population currently has a medical home provider?
- Is your State's medical home effort focused only or primarily on improving services for CSHCN?
- Is your State's medical home initiative managed by or connected to Title V and the health department?
- What is the role of the State Chapter of the American Academy of Pediatrics (AAP)? Of the American Academy of Family Physicians? Of other professional organizations?
- How are families and their advocates (e.g., Family Voices, Voices for Children) involved in efforts to increase the number of medical homes for children?
- Is your State's primary care association representing community health centers and federally qualified health centers actively developing medical homes?
- Have Medicaid agency staff been involved in development of medical home efforts?
- What about private health plans and managed care organizations? Could they be more involved?



- If your State has Medicaid managed care contracts, are the managed care organizations assisting with efforts to assure medical homes for children? How might they be more involved?
- Does your State use primary care case management (PCCM) arrangements to organize and finance care for children? How could the PCCM program be better used to advance the medical home concept?

The term medical home has many meanings in today's health system. The consensus among child health experts (including the AAP and HRSA/MCHB) is that a pediatric medical home includes processes to providing continuous and comprehensive pediatric primary care that is accessible, continuous, comprehensive, family-centered, coordinated, and compassionate. The approach to care aims to assure that all providers of a child's health care operate as a team; that families are critical members of that team; and that all team members understand the importance of quality, coordinated medical, mental and oral health care. Thus, the pediatric primary care medical home coordinates services beyond those provided inside a medical practice to include systemic services such as patient registries, planned co-management with specialists, patient advocacy, and parent education.

6 States play a central role in maximizing the impact of EPSDT comprehensive well-child screening visits.

EPSDT comprehensive well-child screening visits

EPSDT "screens" or "screening" visits are at the core of the preventive nature of this service. Originally, it was envisioned that local health departments would identify problems through screens and then link children with sources of health care and related services to diagnose and treat the problems. Over the past 40 years, EPSDT has evolved to keep pace with changes in the health care system and in pediatric guidelines.

Today, although they are still called screening visits, comprehensive EPSDT well-child visits replace the minimal screens conducted in the 1960s. The general expectation is that visits will conform not only to Federal rules, but also to the American Academy of Pediatrics (AAP) *Bright Futures* Guidelines for Health Supervision.

EPSDT is designed to address physical, oral, mental, and developmental needs. In turn, the content of the well-child visits screening for various types of risks and delays. For example, AAP recommended physical screening includes not only an unclothed physical exam but also vision and hearing, as well as calculation of the body mass index (BMI) starting at age 2 In addition, the AAP and an increasing number of States recommend general developmental screening with an objective tool at ages 9, 18, and 30 months.

Periodic visit schedules

Each State is required to establish a periodic visit schedule (as known as a periodicity schedule) showing the visits and components due by age. Schedules for screening in the context of comprehensive well-child visits, as well as schedules for vision, hearing, and dental services must meet reasonable standards of medical and dental practice.

States must consult with recognized medical organizations involved in child health care in developing schedules and standards. The AAP has a model periodicity schedule, recommended for use by States. The American Academy of Pediatric Dentistry has a recommended schedule for dental services.

Screening visit components

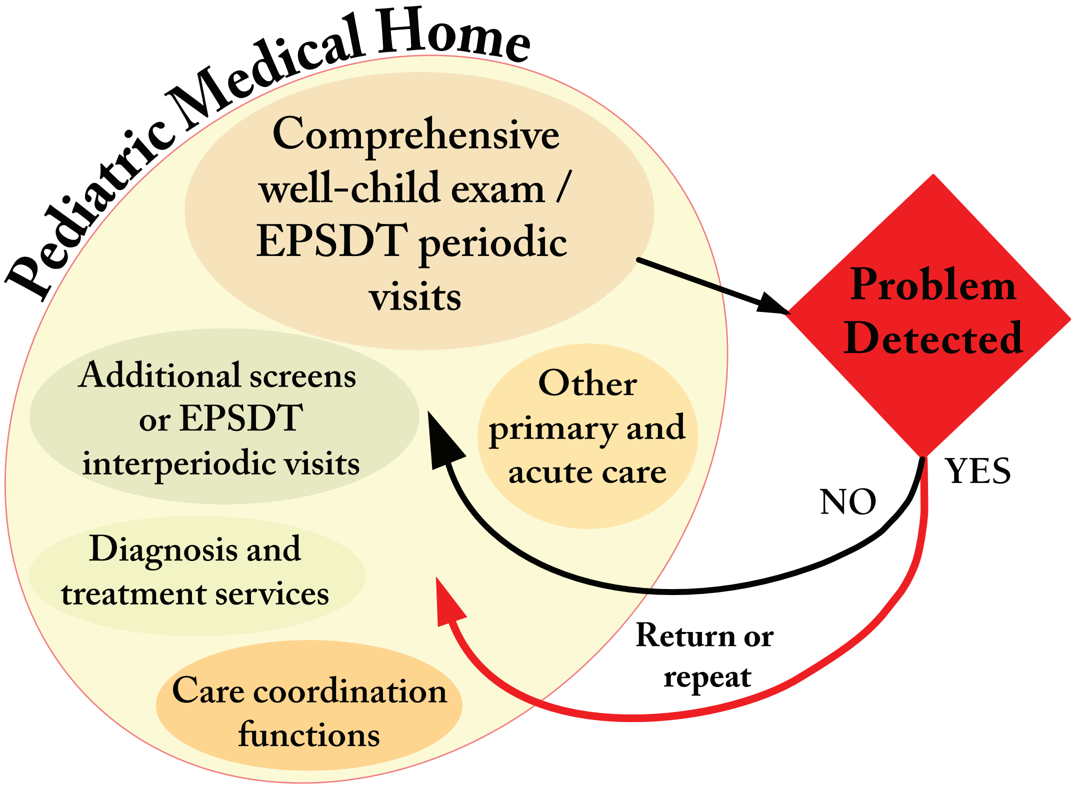
Based on Federal law. ***SSA § 1905(r)*** ,the CMS lists the following required components for an EPSDT comprehensive well-child screening visit: *www.cms.hhs.gov/medicaidearlyperiod-scrn/02_benefits.asp*

- *Comprehensive unclothed physical examination.*
- *Comprehensive health and developmental history.* This includes assessment of both physical and mental health development.
- *Appropriate immunizations.* To be provided according to the schedule for pediatric vaccines established by the Advisory Committee on Immunization Practices (ACIP).
- *Laboratory tests.* States define the minimum to be provided for a particular age group/ visit, including blood lead tests at appropriate ages.
- *Health education.* This includes health education and anticipatory guidance for parents.
- *Vision, hearing, and dental services*.

Discussion questions

Discuss your State's periodicity schedule.

- Does the State's periodicity schedule conform to AAP Guidelines for Health Supervision as written in Bright Futures?
- Are there clear (i.e., separate) periodicity schedules for dental, vision, and hearing services?
- What steps are required to update the periodicity schedule? Does it automatically change when AAP guidelines are revised?
- How is the periodicity schedule shared with or communicated to families? To providers?
- Are studies done to determine the level of compliance to periodicity schedules and visit content for EPSDT eligible children?



Interperiodic screening visits

Many conditions identified through EPSDT well-child screening visits can be managed by the medical home/pediatric primary care provider (PCP). This may be through in office treatment.

In other instances, a medical home/PCP recommends repeat screening visit, while at other times they are eqipped to provide treatment to address identified problems (shown by the "return/repeat" line in the diagram).

Medicaid covers a repeated EPSDT screening visit that is indicated but not on the EPSDT visit schedule. (Note: This is sometimes referred to as an "interperiodic" screen.) Interperiodic screens may be requested by providers or families as a result of a concern or suspected condition.

Discussion questions

- How are parents informed that they can request interperiodic screening visits when they have a concern?
- Are primary care/medical home providers encouraged to use this approach to care? If so, are there particular circumstances (e.g., for developmental screening visits) which are promoted as appropriate uses of such visits?
- Do provider rules vary? Does it matter whether it is a private practitioner, a health department clinic, or a federally qualified health center?
- Are there separate billing codes for interperiodic visits? Does the provider manual clearly explain how to bill for such visits?
- Would Medicaid pay for a partial exam or standalone screening test (sometimes referred to as "unbundling")?

7 Linkages, case management, and care coordination are critical to an efficient and effective child health system.

Medicaid financing for case management services

Care coordination and case management are terms used interchangeably to describe an array of activities designed to: link families to clinical, social, and other services that affect overall health and well-being; strengthen communication between families and providers; avoid duplication of effort; and improve health outcomes.

While the term "care coordination" is sometimes used to describe similar activities, Medicaid agencies generally finance only "case management" services. In Federal Medicaid law, case management is a reimbursable set of activities defined across sections of the law. These can be categorized as: (1) program administration activities associated with case management practice; (2) case management as a distinct class of medical assistance; and (3) case management as a component of covered professional, clinical, or institutional services (such as within the medical home) or as a component of managed care.

Generally, Federal Medicaid Assistance Percentages (FMAP) (i.e., Federal financial participation) for case management is set at: 1) a fixed 50 percent for an administrative activity; 2) at the State's medical assistance matching rate for medical assistance (also known as targeted) case management; and 3) at 75 percent for case management performed by skilled medical personnel.

Case management and care coordination in the medical home

Some case management/care coordination activities are among the functions of a medical home. The National Committee for Quality Assurance (NCQA) set nine standards, which define the characteristics of the patient-centered medical home and align with the joint principles of the AAP and other provider organizations. The National Quality Forum (NQF) framework for quality improvement defines care coordination and describes five key dimensions: health care (medical) home; proactive plan of care and follow-up; communication; information systems; and transitions or hand-offs.

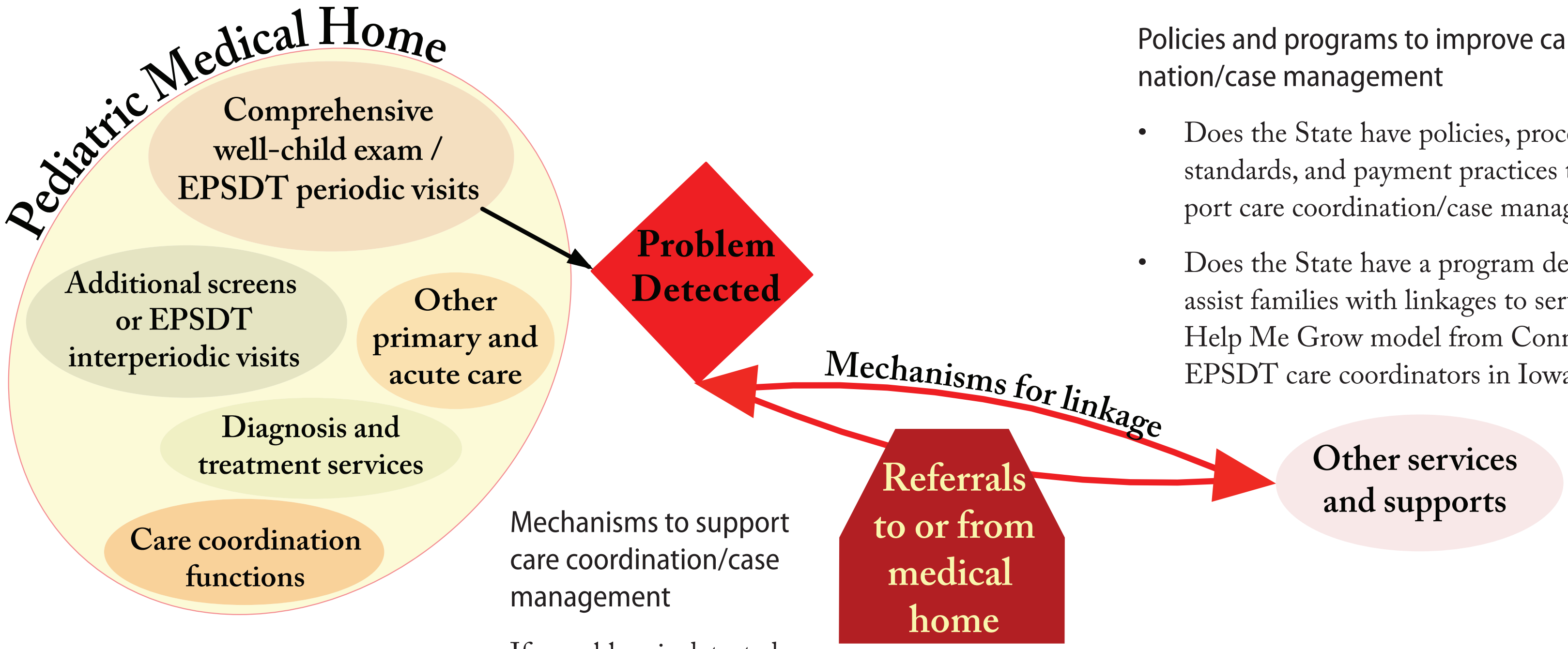
Discussion questions

States can assess their efforts against core competencies defined for practice-based pediatric care coordination. Does your State's strategy:

1. Adhere to family-centered principles?
2. Foster communication?
3. Support care planning processes?
4. Integrate information?
5. Promote systems of care and knowledge of community-based resources?
6. Maximize technology resources?
7. Foster quality improvement skills?
8. Promote positive attitude and outlook?

Adapted with permission from Antonelli and MacAllister, 2009.

More examples and information about child health linkages, care coordination, and case management can be found in references: Fine and Hicks, 2008; Johnson and Rosenthal, 2009; and Kaye et al, 2009.



Discussion questions

Roles and responsibilities for care coordination/case management

Who provides the care coordination/case management that supports families obtain access?

What are the roles and responsibilities of:

- ♦ Medical home/primary care providers?
- ♦ State Title V agencies?
- ♦ Local health departments?
- ♦ Medicaid agencies?
- ♦ Managed care organizations (MCOs)?
- ♦ Other Medicaid contract entities?

Mechanisms to support care coordination/case management

If a problem is detected, what mechanisms and structures support effective linkages and referrals to diagnostic and treatment services?

What are the mechanisms and structures that support referrals from and feedback to the primary care or medical home provider? Does your State have:

- Referral forms for use by pediatric primary care providers (i.e., same form used by many or required to be used by all)?
- Case managers who follow up on referrals (e.g., staff working in public health or managed care)?
- Other systematic ways to document or track referrals and follow-up (e.g., linked datasets, or electronic health records)?

Policies and programs to improve care coordination/case management

- Does the State have policies, procedures, standards, and payment practices that support care coordination/case management?
- Does the State have a program designed to assist families with linkages to services (e.g., Help Me Grow model from Connecticut, EPSDT care coordinators in Iowa)?

Improving the quality of care coordination/case management

- Does the State use quality improvement initiatives to promote and augment linkages and care coordination?
- Does the State monitor the quality of care coordination? What about in managed care arrangements?
- Is there a child health “improvement partnership” or quality initiative that connects payers, providers, families, and State agencies for practice improvement?
- Are technical assistance and training available to care coordinators/case managers?

8 A dental home and appropriate dental services are essential to the health of every child.

The importance of having a pediatric dental home

The American Academy of Pediatric Dentistry (AAPD), American Dental Association, and American Academy of Pediatrics recommend a dental home for each child, starting with visits in the first year. Medicaid guidance formerly called for dental visits to begin no later than age 3, and some States continue with this approach.

Primary pediatric oral health care is best delivered in a "dental home" where competent oral health /dental professionals provide continuous and comprehensive services. Ideally a dental home should be established at a young age (i.e., by 12 months of age in most high-risk populations) so that dental caries (causing tooth decay that makes "cavities") and other disease processes can be effectively managed with minimal or no restorative or surgical treatment.

Other providers also play a role in assuring oral health. Dental assistants and hygienists may provide components of routine preventive exams and certain treatments when in compliance with State practice acts. Pediatric medical providers provide education, identify high risk children, administer fluoride, and initiate dental referrals.

EPSDT's role in eliminating disparities in oral health

Disparities in children's oral health continue despite increases in children's health coverage, community water fluoridation, and parent education on behaviors that promote oral health. While differences in oral health behaviors in play a role, appropriate care from dental professionals is essential to closing the gaps.

Low-income children are significantly more likely to experience dental caries and to have untreated dental problems. The problem begins in early childhood, with 30 percent of poor children ages 2-5 having untreated decayed teeth. Medicaid and EPSDT have a central role to play in eliminating oral health disparities.

EPSDT and dental services

Medicaid dental services under EPSDT are required to be:

1. Provided at intervals that meet reasonable standards of dental practice, as determined by the State through consultation with recognized dental organizations involved in child health care;
2. Provided at other intervals, indicated as medically necessary, to determine the existence of a suspected illness or condition; and
3. At a minimum include relief of pain and infections, restoration of teeth, and maintenance of dental health.

Section 1905(r)(3)

Separate dental periodicity schedules

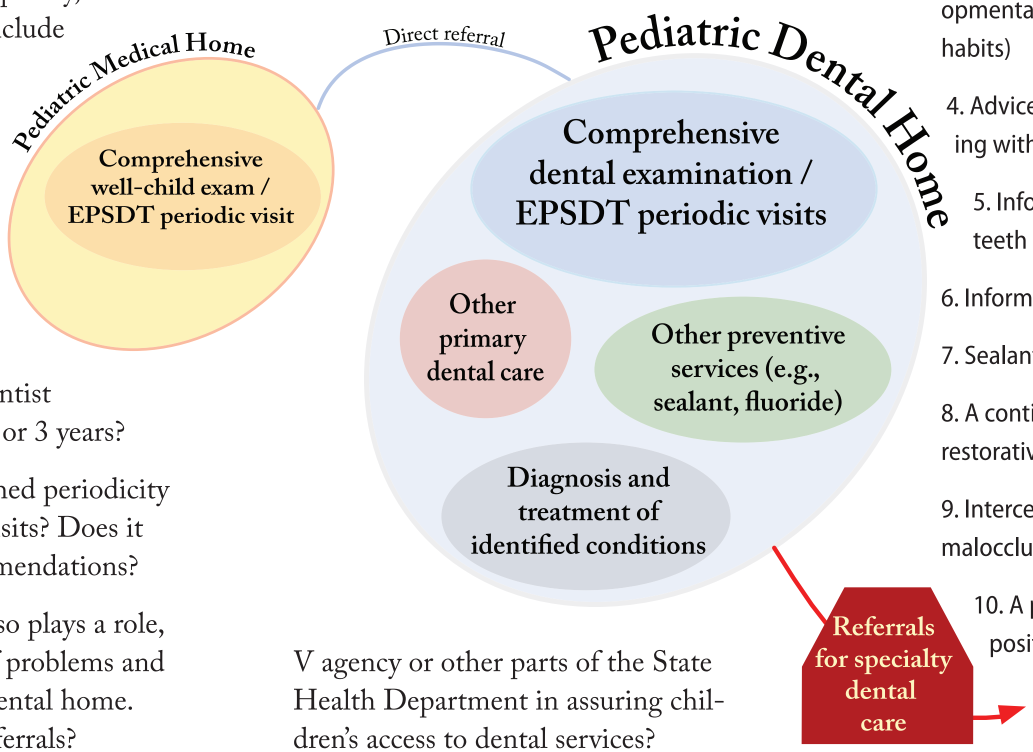
EPSDT periodic visit schedules for dental services should be distinct. The AAPD has a recommended periodicity schedule that outlines the content and frequency of assessments, examinations, diagnostic tests, and prevention activities. The recommendations generally call for procedures to be repeated at 6-month intervals or as indicated by needs or risks.

A broad range of dental services covered

Professional guidelines (and Medicaid statutory requirements) for pediatric dental services call for early and periodic clinical examinations to assess oral health status, diagnoses to determine treatment needs, and follow-up care for any conditions requiring treatment. Typically, such periodic dental "check-up" visits include both oral assessments and routine preventive services (self-care instructions, dental sealant application, etc.).

Discussion questions

- Does Medicaid guidance for providers emphasize the importance of referrals to a dentist in early childhood by age 1, 2, or 3 years?
- Does your State have a published periodicity schedule for EPSDT dental visits? Does it align with professional recommendations?
- The medical home provider also plays a role, through early identification of problems and assistance with referrals to a dental home. What mechanisms support referrals?
- Does your State have an oral health access initiative? Does it focus on children?
- Is there an overall lack of capacity or a shortage of dental providers? A shortage of dentists who participate in Medicaid?
- Are there particular shortages in dental provider capacity for young children? For children with special health care needs?
- Could barriers related to dental practice laws or Medicaid qualifications be addressed?
- What is the role and capacity of the Title V agency or other parts of the State Health Department in assuring children's access to dental services?
- What is the role of WIC agencies in screening and making referrals for dental services?
- What is the role of Head Start and other early care and education providers?
- Do school health programs include oral health education and fluoride treatments?



A dental home should provide children with:

1. An accurate examination and risk assessment
2. An individualized preventive dental health program based upon examination and risk assessment
3. Anticipatory guidance about growth and developmental issues (e.g., teething, thumb or pacifier habits)
4. Advice for injury prevention and a plan for dealing with dental emergencies
5. Information about proper care of the child's teeth and supporting structures
6. Information about proper diet and nutrition
7. Sealants on pit and fissure areas of teeth
8. A continuing care provider that accomplishes restorative and surgical dental care as needed
9. Interceptive orthodontic care for developing malocclusions
10. A place for the child and parent to establish a positive attitude about dental health
11. Referrals to dental specialists such as endodontists, oral surgeons, orthodontists, pediatric dentists and periodontists when care cannot be directly provided within the dental home, and
12. Coordination with the primary care medical provider.

Source: Guide to Children's Dental Care in Medicaid, CMS, 2004.

9 Title V and Medicaid agencies together can support family-centered, coordinated care for CSHCN.

Defining CSHCN is a first step

National survey data indicate that 1 in 7 children under age 18 has a special health need. The prevalence of chronic illness, disability and other special health needs among children has increased, and the distribution of the disease burden contributes to disparities in child health status by race/ethnicity and by income.

In the context of Title V, children with special health care needs (CSHCN) are defined as: "*Children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally*." While this definition conceptually includes a wide array of conditions and more than 10 million children, not all States consistently define and serve this group.

Each State Title V CSHCN program defines the categories of children eligible for services and supports. Typically, States include children with chronic illnesses, genetic conditions, and physical disabilities, but often not those with mental health or developmental conditions. Moreover, the definition of CSHCN used in a given state may be unique to the Title V program and not used by Medicaid, IDEA, mental health or other programs. This may result in barriers to access and additional costs. Studies show that better identification and management of chronic conditions can reduce costs and improve child outcomes.

Many CSCHN have multiple conditions that interact. In addition, CSHCN are at greater risk for unmet health needs, poorer oral health, and behavioral problems. Their health expenditures are three times greater than their peers.

Screening for Special Health Needs

The CSHCN Screener© is a five item, parent-reported tool designed to reflect the HRSA/MCHB definition of CSHCN. It is a five-item, parent-based tool that provides a standardized method for identifying CSHCN. This tool can be used by States, health plans, and providers for more consistent identification of and delivery of services to CSHCN. It is included in the National Survey of Children with Special Health Care Needs, the National Survey of Children's Health, the Medical Expenditure Panel Survey, and the Consumer Assessment of Healthcare Providers Children with Chronic Conditions survey. (To learn more visit: *http://cahmi.org/ViewDocument.aspx?DocumentID=199*. Also see: *www.ahrq.gov/chtoolbx/bethellscreener.pdf*)

Healthy People Goals for CSHCN

- CSHCN receive coordinated ongoing comprehensive care within a medical home.
- Families of CSHCN have adequate health coverage for the services they need.
- Children are screened early and continuously for special health care needs.
- Community-based services for CSHCN are organized so families can use them easily.
- Families of CSHCN partner in decision-making at all levels and are satisfied with the services they receive.
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Discussion questions

Defining and identifying CSHCN

- Is the State's definition of CSHCN consistent with the national definition?
- Does your State have a common, shared definition of CSHCN across Title V, Medicaid, special education and other programs? Is such a definition used in Medicaid managed care arrangements (e.g., contracts)?
- Is your State using the CSHCN screening tool to help identify those who require services beyond that required for children generally?

Administrative structures and financing to support families and providers

- Does the CSHCN program operate as part of a family health, MCH, Medicaid, or other independent agency?
- How is the CSHCN program linked to other programs in the larger children's services systems and health care system (e.g., mental health, special education, developmental disabilities, or disease management programs)?
- How many/what proportion of the estimated population of CSHCN in your State receive direct service financing from the Title V program? From Medicaid? From Part C?
- Has your State conducted strategic planning to set goals, objectives, and activities that will assist in reaching the national objectives?
- What are the contractual responsibilities of Medicaid managed care organizations in terms of identifying and serving CSHCN?
- Do Medicaid managed care contracts permit families to choose an appropriate medical home provider, including a specialist?

Family support and leadership

- Are families engaged in the leadership of your State CSHCN program? Are they engaged at the community level as well?
- Has your State implemented a Family-to-Family Health Care Information and Education Center for Families of CSHCN?
- Has your State made a commitment to assure a medical home with appropriate care coordination for all CSHCN? How is progress being measured? What has been achieved?

Eligibility policies

- Which CSHCN are eligible for Title V financing of health care services or for financing of family support?
- Are CSHCN enrolled in Medicaid managed care arrangements in your State?
- Has your State adopted the Family Opportunity Act Medicaid buy-in option (enacted as part of the Deficit Reduction Act of 2005), which permits States to extend coverage to children with severe disabilities (at the SSI disability level) and family incomes up to 300 percent of the Federal poverty level?

Children with Special Health Care Needs (CSHCN) are defined as: "Children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." (McPhearson, 1998) Each State defines the categories of children who will be eligible for the CSHCN programs services financed with Federal and State funds. Typically, these categories include children with chronic illnesses, genetic conditions, and physical disabilities, but often not those with mental health or developmental conditions. Moreover, the definition of CSHCN may be unique to the Title V program and not used by Medicaid, IDEA, mental health or other programs. Opportunities for improvement of services to CSHCN exist in every State.

10 Effective Medicaid managed care arrangements depend on contracts appropriate to child health needs and systems.

Medicaid Managed Care and Child Health

A large number of children receive health coverage and services through Medicaid or CHIP managed care arrangements. Half of the States enroll more than three-quarters of Medicaid beneficiaries under age 21 in managed care. Overall, more than half of all Medicaid beneficiaries who are children are enrolled in some form of managed care.

Children are the group in Medicaid most likely to be required to enroll in managed care. They are more likely than other beneficiary groups such as the elderly, pregnant women, and adults with disabilities to be placed in mandatory managed care enrollment arrangements under Medicaid.

Certain children, such as CSHCN, those whose eligibility is based on SSI disability, or those in foster care, may be exempt from managed care enrollment requirements and receive all of their coverage on a fee-for-service basis.

Managed Care Arrangements and Contracts

To a great extent, State Medicaid agencies define the structures of how managed care services are provided and financed. They must, however, define structures that can attract plans and providers.

Contracts define the relationship between the purchaser and the managed care organization (MCO), as well as between the MCO and its network providers. The contract between the MCO and the purchaser – in this case the State Medicaid or CHIP agency – sets boundaries on what services will be delivered, when, and how. Such contracts have become an increasingly important part of the legal and regulatory framework under which children and families receive health care.

In some States, managed care plans are responsible for the provision of all EPSDT services, and States structure contractual arrangements with plans. In other States, the Medicaid agency may be responsible for coverage of services beyond those listed in the managed care agreement (e.g., case management, dental services, specialty care). Typically, those services that fall outside of managed care contracts are financed on a fee-for-service basis.

Primary Care Case Management

Primary care case management (PCCM) is a form of managed care that can be used to create and sustain a medical home model. Participating families choose a provider who is responsible for managing their child's care and, often, acting as a gate keeper to specialty services. Typically, PCCM providers are required to provide routine preventive and primary care, 24-hour access to information, emergency contact, and appropriate referrals. In some States, these activities are fulfilled under Medicaid contracts with managed care organizations, in others through an agreement with provider practices or clinics.

- Does or might your State use a primary care case management (PCCM) approach?
- Do the qualifications for existing PCCM providers fit with the concept of a medical home?

Discussion questions

The questions below from the George Washington University (GWU), School of Public Health and Health Services, Department of Health Policy can help to guide your discussions about how well your State's Medicaid managed care contract provides for and protects child health.

These review questions are drawn from the GWU larger set of publications that analyze State's Medicaid managed care contracts, provide sample purchasing specifications, and study the impact of managed care on vulnerable populations. ***http://gwumc.gwu.edu/sphhs/departments/healthpolicy/CHPR/managedcare_publications***

Questions for Review of Contracts Purchasing Child Health Services in Medicaid Managed Care

Does your State's Medicaid managed care contract:

1. Specify EPSDT/pediatric services covered, including items necessary to prevent, correct, or ameliorate a condition, disability, illness, or injury or to promote growth and developmental, or to maintain functioning.
2. Specify coverage of recommended childhood immunizations without prior authorization.
3. Specify coverage of items and services for an enrolled child under an Individualized Family Services Plan (IFSP) or an Individualized Education Program (IEP) developed by an agency under the Individuals with Disabilities Education Act (IDEA)
4. Specify how dental services are to be covered and financed (i.e., inside or outside of contract).
5. Reference "*Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*" and/or other applicable medical and dental association guidelines.
6. Prohibit prior authorization with respect to comprehensive well-child (EPSDT) screens based on a State's periodic visit schedule, as well as inter periodic visits not on the schedule.
7. Prohibit denial of coverage for newborns due to a "pre-existing condition" according to the Newborns' and Mothers' Health Protection Act of 1996.
8. Require that plans offer the family or caregiver of a child with special health care needs the option of designating as the child's primary care provider a pediatric specialist participating in the provider network as described in enrollee information materials.
9. Require that safety net providers (e.g., federally qualified health centers, local health departments) be included in provider networks.
10. Require timely access to pediatric services, including an initial assessment of an enrolled child conducted by a primary care provider using the standards of Bright Futures.
11. Specify elements for Memorandum of Understanding (MOU) defining relationships between the contractor and public health departments, Title V agency, CHIP agency, child welfare agency, State and local education agencies, developmental disabilities agency, and mental health and substance abuse agency.
12. Specify use of quality measures or studies appropriate for children (e.g., HEDIS and others).
13. Specify that the contractor shall collect and report to the purchaser on under utilization of services by enrolled children.
14. Require that contractor ensure that each provider furnishing covered immunizations participate in the Vaccines for Children Program.
15. Specify remedies for noncompliance or nonperformance, such as withholding payments, suspension of enrollment, or money penalties.

Source: *George Washington University Center for Health Services Research and Policy. Pediatric Purchasing Specifications Module © 2001. Used with permission.*

11 Public-private and interagency collaboration are a foundation of child health quality efforts.

Improving Child Health Quality

The Federal Centers for Medicare & Medicaid Services (CMS) defines quality in health care as: The right care for every person every time. First and foremost, providers should perform the right service in the correct fashion at the right time to avoid medical errors, and quality health care also must be tailored to the patient's needs.

There is considerable evidence, however, that the quality of child health services is not as good as it should be. A study by Mangione-Smith and her colleagues found that insured children received only 53 percent of recommended care for chronic conditions and 41 percent of recommended preventive care. Gaps are greater for minority children.

Efforts to improve health care quality have been guided by reports of the Institute of Medicine such as "Crossing the Quality Chasm," by Federal agencies (e.g. Agency for Healthcare Research and Quality), and by universities and organizations. Quality improvement initiatives such as those guided by the Institute for Healthcare Improvement (IHI) model are underway across the country, but mainly related to chronic diseases or hospital care.

Children have received relatively little attention in any such quality improvement efforts, to date, but that may be changing. Congressional action through the CHIPRA and health reform legislation call for greater attention to measuring child health quality. More State and local efforts also are being launched.

Improvement Partnerships

Child health "improvement partnerships" are underway in more than a dozen States across the country. The Vermont Child Health Improvement Program (VCHIP) has guided the initiative. With staff support, research knowledge, and relationships to ground their efforts, Improvement Partnerships have led to more preventive services (e.g., immunization), more early intervention (e.g., developmental screening and services), and more effective treatment (e.g., asthma management). They have demonstrated that clinical practices can achieve change better and faster through the partnership. Improvement Partnerships are a means to increase the knowledge and assure the competency of providers. This collaborative work focuses beyond quality measurement to directly support changes in provider knowledge, attitudes, and practices.

Monitoring Child Health Quality

Child Health System Performance

A scorecard approach developed by the Commonwealth Fund reports on variations among States' child health care systems. The review focuses on 13 performance indicators of access, quality, costs, equity, and the potential to lead healthy lives. The rankings indicate areas for improvement in each state. (To learn more, visit: *http://www.commonwealthfund.org/Maps-and-Data/Childrens-Scorecard.aspx*.)

Every StateTitle V agency has responsibility for reporting annually on a core set of 18 performance measures, as well as on outcome and system capacity measures. Each performance measure describes a need that, when successfully addressed, can lead to a better health outcome. (To learn more, visit: *https://perfdata.hrsa.gov/MCHB/TVISReports/default.aspx*.)

Child Health Quality Measures

CHIPRA provides for a new national initiative to devise child health quality measures. Health reform legislation — the Patient Protection and Affordable Care Act (PPACA) and the Health Care and Education Affordability Reconciliation Act — also emphasize child health quality measurement. This new work should yield new and more precise measurement strategies over the next few years.

Currently, the most common measures used to assess the quality of child health services come from the Health plan Employer Data and Information Set (HEDIS). This includes measures of: the effectiveness of care (e.g., immunization rates, use of appropriate medications for asthma); access to care (e.g., annual dental visit); satisfaction with care; and use of services (e.g., well-child visit rates, mental health utilization). Plan performance benchmarks are available. All States with Medicaid managed care use HEDIS as part of their management strategy.

Quality Surveys

Quality also can be measured by level of satisfaction with care received and provider-family relationships. From one national survey, we learned that less than half of parents of young children reported that their pediatric provider offered thorough guidance related to their child's health and development, and minority parents more often reported that providers never or only sometimes understood their child-rearing preferences. Similar surveys can be done at the State and practice levels.

EQROs

Federal regulations that encourage State Medicaid agencies to use "external quality review organizations" (EQROs) to help implement strategies for assessing the quality of services provided in managed care plans. States are required to use an EQRO if their Medicaid program contracts with comprehensive health plans, which most States do.

Discussion questions

The following questions can help guide your State's discussion of child health quality:

- Does your State monitor the quality of data reporting using practice record reviews?
- Is your State using both required EPSDT 416 data and HEDIS measures related to child health to monitor the quantity and quality of child health services?
- Does your State have a child health improvement partnership? Are Medicaid and public health agencies involved and supportive?
- If your State uses Medicaid managed care extensively, are you using the EQRO to focus on child-health related topics?
- If your State uses Medicaid managed care extensively, does the State define common quality and performance measures across MCOs?
- Do or might providers in your State use surveys such as the Promoting Healthy Development Survey (PHDS) or Young Adult Healthy Care Survey (YAHCS) (both endorsed by the National Quality Forum)?
- Has your State reviewed its child health system performance ratings, as published by the Commonwealth Fund?
- How are Title V performance monitoring data being used to drive policy and program decisions?
- Are incentives and rewards linked to performance and quality measurement at the State, community, plan, and practice levels?
- In what areas is further work needed to define quality and performance measures?
- Are measures and measurement strategies aligned across systems?
- Do the quality efforts underway aim to improve access, increase value, and improve outcomes?
- Do these efforts serve families, as well as government and health plans and providers?

12 Scenarios to review and map child health systems in early childhood and adolescence.

Using scenarios to better understand the child health system

The American Academy of Pediatrics defines children as those ages 0 (birth) to 21 years. Many States have special initiatives designed to improve the health and development of the youngest and oldest children. At both ends of childhood, rapid changes in development are normal and health decisions and habits may affect an individual across the life span.

The following pages offer scenarios for guided discussion. One set focuses on early childhood health and development issues and a second set on adolescent health. They can be a framework for discussing how the child health system services and supports work under different circumstances, for children with different conditions.

For some State leader groups, working through these scenarios can fill one or two whole days of discussion. The discussion questions are drawn from across the other topic sections, including medical home, referrals, treatment, and related systems issues.

Focus on early childhood

Please refer to the diagram on opposite page as you discuss scenarios focused on a toddler. You may want to make notes or draw your own version of the child health system map diagram during the discussion.

SCENARIO ONE: A TODDLER

An 18-month-old toddler is receiving his/her comprehensive well-child (EPSDT) visit according to the State's periodicity schedule. Following the standard protocol for such a visit, the pediatric primary care provider (PCP) identifies an area of concern that requires further action.

If you have limited time, you may want to discuss only one or two conditions.

1. Concern about speech-language development
2. Problem with social-emotional development or mental health
3. "Baby-bottle" tooth decay or similar oral health problem
4. Maternal depression
5. Sickle-cell disease or another condition identified through newborn screening.

Discussion questions

Managing conditions in the medical home

Please discuss what would happen if the PCP wants to see the child in their practice for a follow up visit in 6 weeks.

- Does Medicaid reimburse for a repeated comprehensive well-child (EPSDT screening) visit that is indicated but not on the EPSDT visit schedule?
- Does Medicaid reimburse for a developmental or mental health screen (ideally with objective measurement tools), separate from an EPDST visit? (Note: This is sometimes referred to as unbundled services.)
- Does the Medicaid provider manual clearly explain how to bill for such visits? Are billing codes specified?

Making effective referrals for treatment

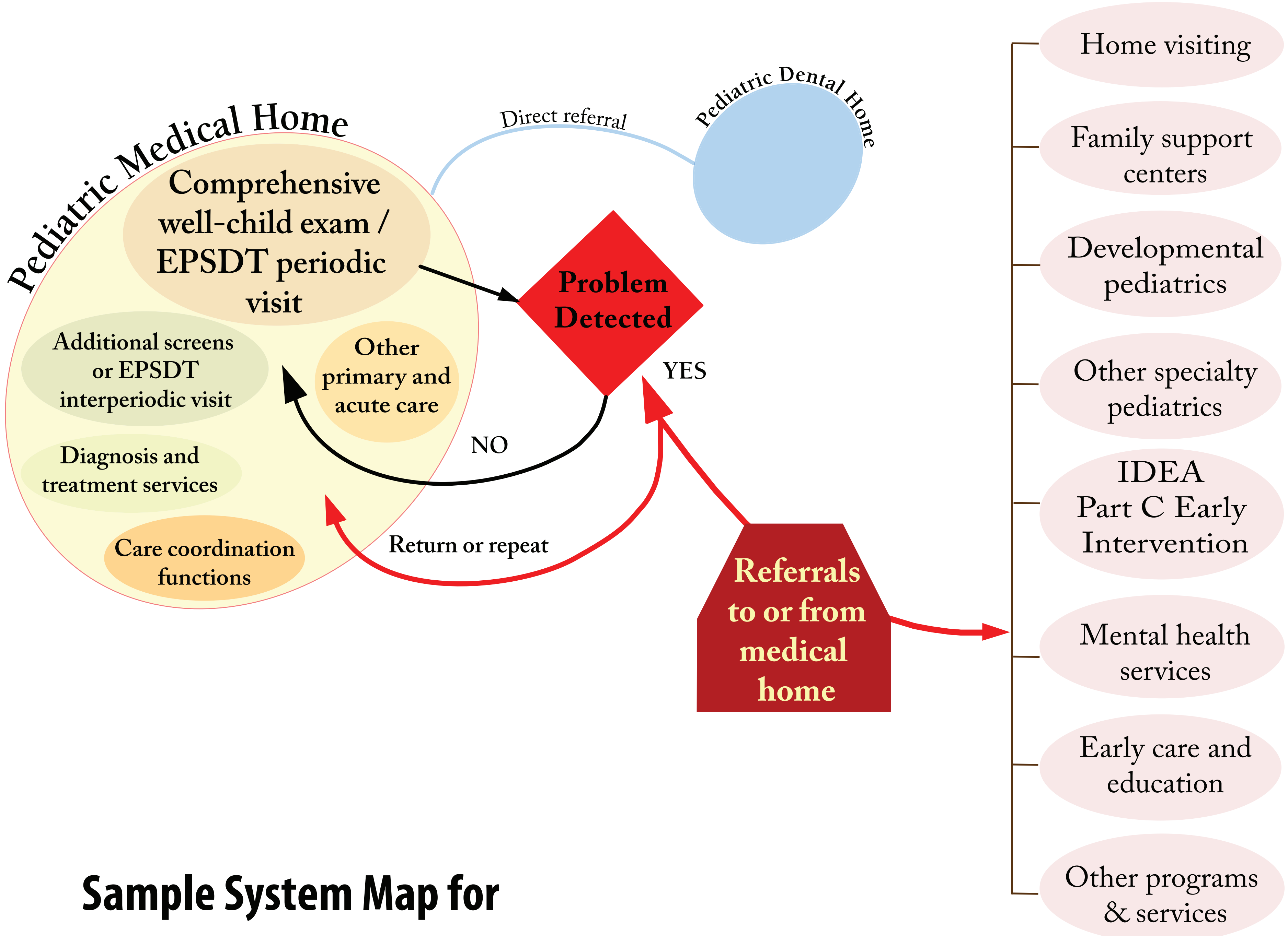
Assuming the provider needs to make a referral for further diagnosis and treatment services, please discuss and describe what would happen in your State.

- How does the child health system support effective referrals and linkages? (See Section 7 for additional questions)
- Are case managers available to assist families that face barriers?

Reducing Systemic Barriers

Next, focus your discussion on system challenges. The following questions may stimulate your discussion. They reflect typical concerns discussed in State Leadership Workshops on EPSDT and Title V Collaboration.

- What providers are available to accept the referral and complete the necessary follow-up diagnosis and treatment?
- Is there an overall lack of capacity or a shortage of Medicaid providers?
- Are there particular shortages in provider capacity that would affect the ability of the PCP to make an effective referral (e.g., dental, mental health, subspecialty medicine)?
- What is the role and capacity of the Part C Early Intervention program? Of Special Education?
- What if the child is enrolled in the State's CSHCN program?
- If the child does not receive a specific diagnosis (e.g., for mental health) or have a measurable delay (e.g., in speech-language development), what services might be available?
- Can mother and toddler can be served under child's Medicaid number (i.e., for maternal depression or infant mental health services)?
- Would some of the needed services likely fall outside the scope of the State's Medicaid managed care contract (if applicable)? What services would likely be financed on a fee-for-service basis?



Pediatric Medical Home

Comprehensive well-child exam / EPSDT periodic visit

Additional screens or EPSDT interperiodic visit

Other primary and acute care

Diagnosis and treatment services

Care coordination functions

Direct referral

Pediatric Dental Home

Problem Detected

YES

NO

Return or repeat

Referrals to or from medical home

Home visiting

Family support centers

Developmental pediatrics

Other specialty pediatrics

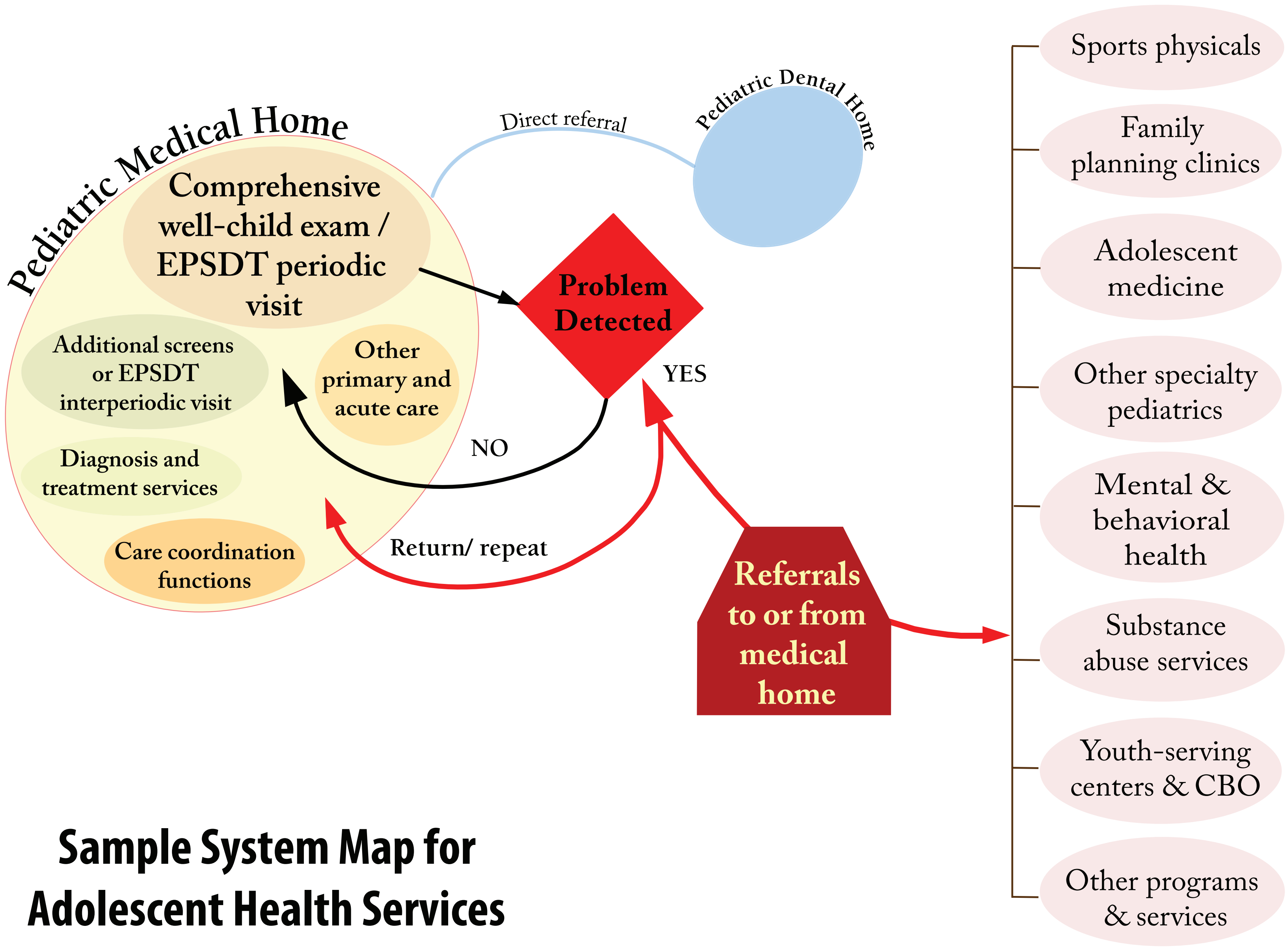
IDEA Part C Early Intervention

Mental health services

Early care and education

Other programs & services

Sample System Map for Early Childhood Health Services



Sample System Map for Adolescent Health Services

Focus on Adolescent Health

The following brief examples offer a framework for discussing how the child health system services and supports work under different circumstances, in this case for teens.

Please refer to the diagram as you discuss the following scenario focused on an adolescent You may want to make notes on a blank copy of the diagram during the discussion. (See pages 28-29.) The group may want to draw their own shared vision of what the map would look like for adolescent health.

SCENARIO TWO: AN ADOLESCENT

A 12-year-old adolescent is receiving his/her comprehensive well-child (EPSDT screening) visit. Following the standard protocol for such a visit, the pediatric primary care provider (PCP) identifies an area of concern that requires further action.

Discuss and describe what would happen in your State if the following conditions were identified. If you have limited time, you may want to discuss only one or two conditions.

1. A chronic disease such as asthma
2. A problem with mental health / social-emotional development (e.g., depression, aggressive behavior)
3. Risks for early initiation of sexual activity
4. Severe obesity
5. A need for orthodontia services

Discussion questions

Managing Conditions in the Medical Home

Please discuss what would happen if the PCP wants to see the child in their practice in six months.

- Does Medicaid reimburse for a repeated comprehensive well-child (EPSDT screening) visit that is indicated but not on the EPSDT visit schedule?
- Does Medicaid reimburse for a developmental or mental health screen (ideally with objective measurement tools), separate from an EPDST visit? (Note: This is sometimes referred to as unbundled services.)
- Does the Medicaid provider manual clearly explain how to bill for such visits? Are billing codes specified?

Making Effective Referrals for Treatment

Assuming the provider needs to make a referral for further diagnosis and treatment services, please discuss and describe what would happen in your State to support the referral.

- How does the child health system support effective referrals and linkages? (See Section 7 for additional questions)
- Are case managers available to assist families that face barriers?
- Are case management supports available directly to teens, particularly in the case of confidential services?

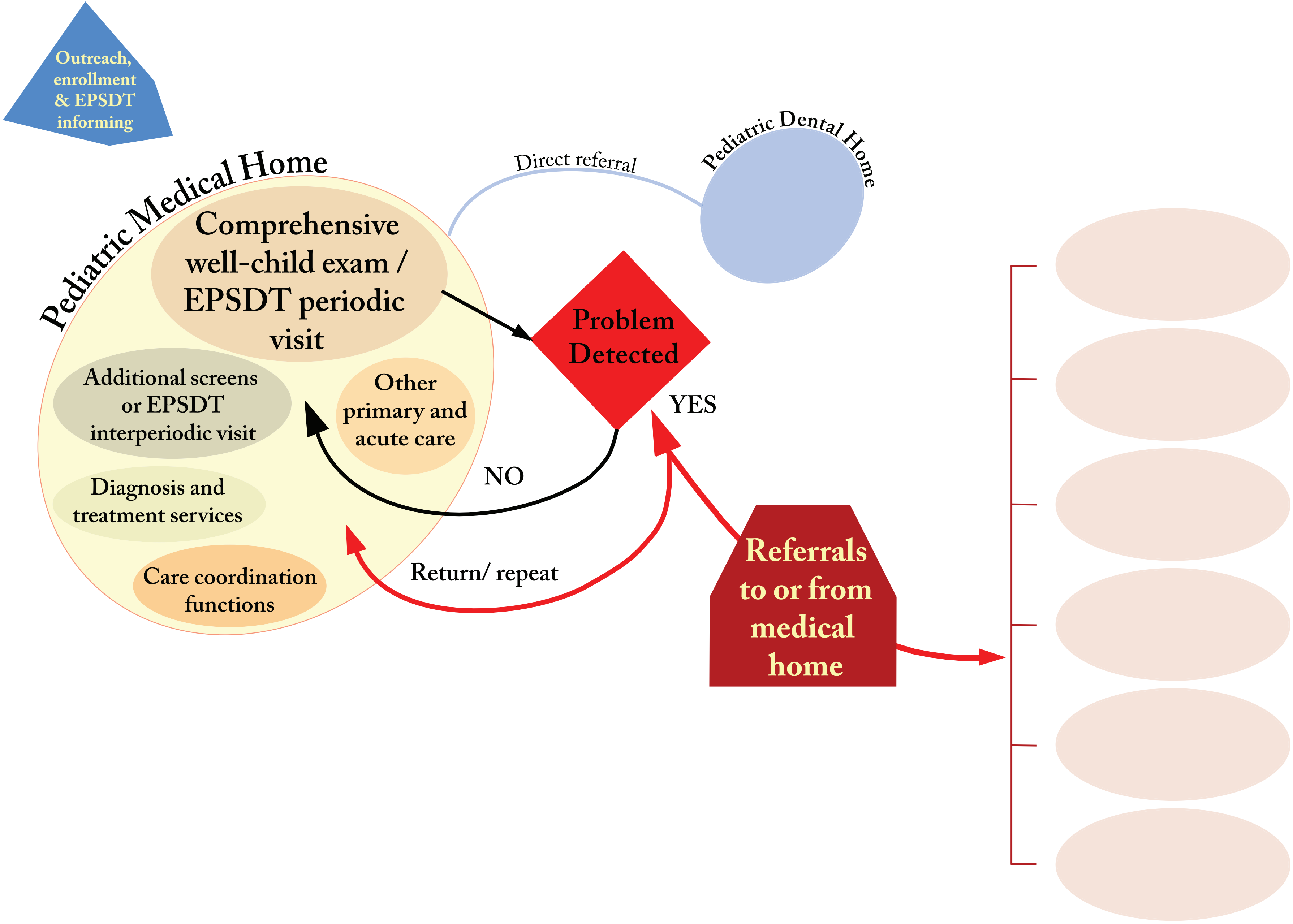
Reducing Systemic Barriers

Next, focus your discussion on system challenges. The following questions may stimulate your discussion. They reflect typical concerns discussed in State Leadership Workshops on EPSDT and Title V Collaboration.

- What providers are available to accept the referral and complete the necessary follow-up diagnosis and treatment?
- Are there particular shortages in provider capacity that would affect the ability of the PCP to make an effective referral (e.g., dental, mental health, subspecialty providers)?
- What is the role and capacity of school health programs or school-based health clinics?
- Do special adolescent health clinics exist?
- What if the adolescent is enrolled in the State's CSHCN program?
- Does Medicaid have contracts for disease management services that would be available to or used for an adolescent with asthma or another chronic disease?
- Would some of the needed services likely fall outside the scope of the State's Medicaid managed care contract (if applicable)? What would likely be financed on a fee-for-service basis?

Use this space to draw your State's child health system as you see it and compare to the master diagram and to what others see

Use this diagram as a worksheet and add elements of State's child health system as you see it



Outreach, enrollment & EPSDT informing

Pediatric Medical Home

Comprehensive well-child exam / EPSDT periodic visit

Additional screens or EPSDT interperiodic visit

Other primary and acute care

Diagnosis and treatment services

Care coordination functions

Direct referral

Pediatric Dental Home

Problem Detected

YES

NO

Return/ repeat

Referrals to or from medical home

Appendix A.

Tips on Designing and Facilitating a State Leadership Workshop

What was Learned in the State Leadership Workshops

This toolkit offers an approach for advancing child health through the use of a discussion questions and system mapping. It can help participants in a workshop develop an understanding of existing systems of care and the potential for improved coordination, integration, and management of services among providers, delivery mechanisms, and financing streams.

As reflected in the participant evaluations and State follow-up actions, the success of the 14 State Leadership Workshops previously conducted depended heavily upon four main factors. First, it is important to convene a public-private, interagency group of senior-level leaders who could discuss and envision the whole child health system, not just their program. Second, using a small planning group to develop the agenda keeps the Workshops focused on existing priorities and grounded in current context. Third, the process was more effective when an outside facilitator with content knowledge was available to add information and offer technical assistance through the whole Workshop as the discussion advanced. Last but not least, it was essential to success that State leaders had an opportunity to focus on their priorities and action steps.

Note that the report on these Workshops provides more details on each of these factors. It is available on through www.mchb.hrsa.gov.

Convening Child Health Leaders

Convening an appropriate group of State-level child health leaders is a critical element of success. Participants need to have a perspective on larger child health and health systems issues. The prior Workshops involved senior leaders from government, providers who are leaders among their peers, and parents who can speak for themselves and advocate for the concerns of other families. Experience suggests that having too many participants who only know the realities of their own, smaller projects or practices did not lead to a productive discussion or to subsequent State action.

The model for the Workshops called for having cross-agency and cross-sector participation. The group also need to involve both public and private sector leaders. (Government-only groups seemed to generate fewer new ideas). There is inherent value and importance of "setting the table" and convening a group of people that includes multiple perspectives.

Guidelines for effective meetings indicate that this type of discussion should be limited to no more than 30 people arranged in a "hollow-square" room set up. Our experience supported this rule. Workshops with more than 30 participants were less effective.

The essential, core participants for the prior EPSDT Workshops were senior leadership from State Medicaid and Title V Maternal and Child Health/Children with Special Health Care Needs Programs. In half of the previously held Workshops, commissioners of health, Medicaid directors, or umbrella health and human service agency commissioners attended. Depending on each State's priorities, participants also included representatives from other State agencies (e.g., Children's Health Insurance Programs—CHIP, Part C Early Intervention, Child Welfare, Mental Health, Public Health Nursing, Developmental Disabilities, Oral Health, Adolescent Health, or Education), as well as from local city/county public health programs. Representatives from State legislatures, Governor's offices, and so-called "children's cabinets" were included, as appropriate.

In addition to governmental officials, Workshop planners invited private sector partners, such as health care providers, academic experts, health plans, and families and their advocates. Provider organizations typically included the State Chapter of the American Academy of Pediatrics and/or American Academy of Family Physicians, as well as school nursing, local public health clinics, and primary care associations representing community health centers and federally qualified health centers.

Another approach used by States is to use an existing work group or collaborative entity. This might include, for example, groups regularly convened to support initiatives for Early Childhood Comprehensive Systems, children's mental health, medical home, or children with special health care needs. Again, experience suggests that additional participants (as described above) should be added to these existing groups in order to stimulate new ideas and strategies.

Using a Planning Group to Design the Agenda

A planning group of 5-7 people was convened to design each State Leadership Workshop. In addition, a lead person from the State with sufficient position and authority is needed to be a convener and coordinate workshop planning. This might be a leader from public health, Title V, or Medicaid.

In the planning process, Title V and Medicaid staff members concerned with child health developed the overall topic and the discussion questions for the agenda. As discussed below, the agenda topics should fit with current challenges, initiatives, and priorities.

The primary learning objectives for the previously held Workshops were: a) to improve interagency efforts that can strengthen EPSDT; and b) to increase knowledge of available strategies that can improve child health services and systems. This toolkit reflects the many facets of this work, focusing on structures and mechanisms that support outreach and informing, medical home, care coordination and linkages, and quality improvement.

A sample agenda is included in this section. For more State Leadership Workshop agendas, users of this toolkit are referred to the report on the workshop project.

Each Workshop had a mixture of short didactic presentations, group discussions led by an expert facilitator, and group problem solving. The main activity was full-group, 90-minute discussions, supported by seating in a hollow square arrangement. These discussions were open ended and not intended to be structured "brainstorming" (i.e., not listing all thoughts through a structured process). Their effect, however, was to generate new ideas and strategies to overcome ongoing challenges and breakdown interagency barriers.

Special Facilitation Style

While generally a facilitator should be someone who doesn't have a strong opinion to express on the meeting's topics, in this case, effective facilitation also requires background knowledge of child health issues and good questioning skills. Guiding groups through the questions and maps in this toolkit cannot be done well unless the facilitator has background knowledge of the topics.

This Workshop approach builds on similar projects using a combined facilitator/technical assistance role. The Workshop design calls for having a facilitator with broad knowledge of child health and Medicaid issues. In this approach, the facilitator not only manages the discussion but also shared knowledge about topics and generally provided technical assistance through the discussion. The background knowledge of the facilitator also enables him/her to reduce barriers among participants who may not know the jargon of another agency. Without knowledge of the broad issues in child health, the facilitator would not be able to advance the discussion of the group effectively.

Other general rules for good facilitation do apply here. For example:

- Facilitating any meeting involves thinking through and managing the anticipated process and results. Effective meeting facilitation starts with a review of the agenda and the anticipated outcomes. The facilitator helps participants stay on track and on time, as well as ensuring the accomplishment of expected results from the meeting.
- Facilitators should involve each attendee in the accomplishment of the meeting goals. More will be accomplished with the whole team pulling than with one dominant person trying to push everyone else up the hill. Don't be afraid to call upon someone who has not spoken or ask an overly eager participant to "hold their thought" until others have had a chance to contribute.
- Facilitators should encourage the expression of various viewpoints. The more important the decision, the more important it is to have all pertinent information (facts, feelings and opinions) on the table. Encourage people to think of fresh solutions as well as to look for possible compromises. Try to help the group move beyond "whining" about how bad things are and toward opportunities for improvement.

- Good facilitation can enable participants to do their best thinking and make shared decisions with commitment and enthusiasm. When you test for consensus, state in question form what you feel participants agree upon. Be specific: "Do we agree that…?" Be suspicious of agreements reached too easily. Test to make sure that people really do agree on essential points.

Build on State's Current Work and Priorities

The success of a Workshop equally depends on how well the discussions are grounded by current challenges and opportunities in child health for a particular State. This process is not aimed at creating new initiatives, but rather at better using existing resources to improve child health systems.

From the start of agenda development in the planning phase to participant group discussions to selection of priorities at the end, State leaders in the prior Workshops made decisions about what would be discussed and what actions would be taken. Setting their own priorities throughout the process enabled State leaders in most Workshops to advance collaboration and integration that could improve the child health system and outcomes.

By the end of each Workshop, a set of 3-5 interagency, consensus priorities were generated that called for action in the coming 6, 12, or 18 months. Experience indicates that State leaders do not have the time and resources to follow up on more than 3-5 priorities.

While the prioritization process is not explained in detail here, the general approach is to use the following steps.

1. Following all of the discussion periods, the facilitator works with the State planning group to generate a list of the key issues/opportunities raised in through the series of Workshop discussions. This may be a list of large and small items (e.g., create a quality improvement partnership, develop an integrated child health database, inform providers about a new billing code for developmental screening, or amend Title V-Medicaid interagency agreement).
2. Workshop participants are given time to review, clarify, and amend the list of issues on screen and/or on paper. Remind the group not to worry if the list seems like "apples and oranges." Clarify but do not remove items at this time.
3. Next participants rank statements based on potential impact on child health (importance) and feasibility. Each individual decides what impact and feasibility mean to them. (Tip: For a list of 15 items ask participants to rank their top 3 on impact and top three on feasibility and for a list of 20 items ask for top 5 rankings.)
4. These rankings by impact and feasibility are then plotted (using Excel) to show those with the highest expected impact and feasibility. Projecting the resulting scatter plot helped participants see the priorities of the group overall.
5. For most workshops, two or three rounds of voting/ranking with discussion and clarification in between are sufficient to reach consensus on 3 to 5 priority areas for action.
6. For each of the 3 to 5 priorities, volunteers are identified who would accept responsibility for follow up after the Workshop. There names are recorded. The process can result in just another "wish list" without defining who will take the next required action step (e.g., calling a meeting, preparing an analysis of data, or reviewing current policies and procedures).

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www.hrsa.gov/epsdt

www.hrsa.gov/mchb

http://www.cms.hhs.gov/medicaidearlyperiodicscrn/02_benefits.asp

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