

Partnerships: Families and Title V

Getting to Know Title V



FAMILY VOICES®

Getting to Know Title V



For more information contact:


3701 San Mateo Blvd. NE, Suite 103, Albuquerque, NM 87110


(505) 872-4774 ♥ Fax (505) 872-4780

www.familyvoices.org

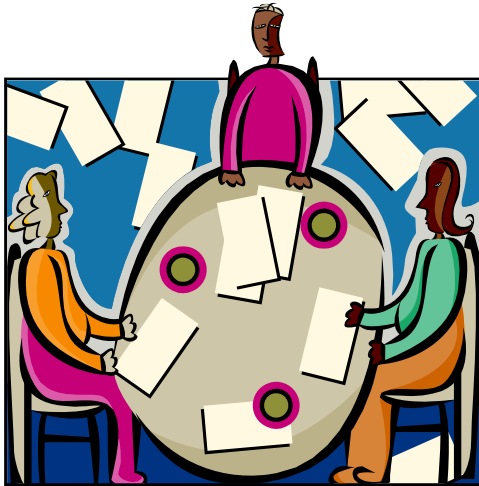
This project is funded by the US Department of Health and Human Services - Health Resources and Services Administration - Maternal and Child Health Bureau, Division of Child, Adolescent and Family Health (UC4MC21535).



-  **A national grassroots advocacy network** of families and friends founded in 1992

-  **Advocating** on behalf of CYSHCN for:
 - Family-centered, community-based, comprehensive, coordinated, culturally competent care
 - Families as decision makers
 - Essential partnerships between families and professionals

Family Voices thanks the former Title V Advisory Committee for their help with this publication:



- ❖ Susan Colburn (AL)
- ❖ Rodney Farley (AR)
- ❖ Lyn Thoreson-Land (OK)
- ❖ Phyllis Landry-Ratcliff (LA)
- ❖ Ruth Walden (NY)

Title V

The Nation's oldest Federal-State partnership to *improve the health of all mothers, children, and youth including children and youth with special health care needs and their families.*



Title V Administration



Federal:

- ↳ U.S Department of Health and Human Services
 - ↳ Health Resources and Services Administration (HRSA)
 - ↳ **Maternal and Child Health Bureau (MCHB)**
 - ↳ ***Division of State and Community Health***
 - *administers the provisions of Title V*

State:

- ↳ **Maternal and Child Health (MCH)**
- ↳ **Children with Special Health Care Needs (CSHCN)**
 - *programs most often in state health departments*

Background..... 2

1912 Children's Bureau established – forerunner of the Maternal and Child Health Bureau

1921 Sheppard-Towner Act – first public health grants to states (opposed by many – American Medical Assoc., Catholic Church)

1930 White House Conference on Children → Children's Charter: *detailed needs in health, education, welfare, and protection.*

Formation of the American Academy of Pediatrics



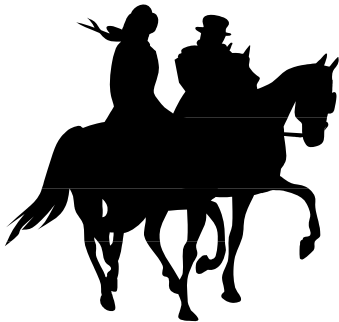
Background..... 2

1934



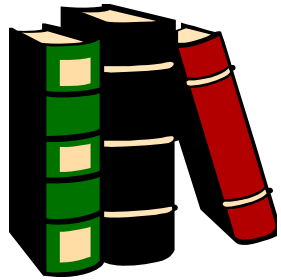
“Sometimes when I get home at night in Washington I feel as though I had been in a great traffic jam... In that traffic jam there are all kinds of vehicles moving up toward the Capitol... conveyances of the Army ... limousines in which the Department of Commerce rides... it becomes more congested and more difficult, and then because the responsibility is mine and I must, I take a very firm hold on the handles of the baby carriage and I wheel it into traffic.”

Grace Abbott, Chief, Children’s Bureau



“I am mighty glad so many people in America are taking up the children’s work. Being a ranchman and a farmer, and also a child owner, I have often wished that when one of my children get sick, I could wire or call some government expert and have him look after them, like I can do if one of my cows or pigs get some disease.”

Will Rogers, social commentator, humorist



Title V History.....1

1935 Authorized as Title V of the Social Security Act

1969 Title V administration transferred to the Public Health Service

1981 OBRA 81* - converted Title V to a Block Grant**
(combining 7 programs: MCH/CSHCN, SSI, lead screening, hemophilia treatment centers, Sudden Infant Death Syndrome counseling programs, genetic diseases, adolescent programs)

* Omnibus Budget Reconciliation Act

** Block Grants – Set amount of federal money given to states to carry out programs

Title V History2

1989 OBRA introduced major changes. States' applications for Title V funding require:

- 1) needs assessment and priorities
- 2) measurable objectives
- 3) budget accountability
- 4) documentation of matching funds
- 5) maintenance of efforts
- 6) public input



Learn More at:

MCH Timeline: History, Legacy and resources for Education and Practice - <http://mchb.hrsa.gov/timeline/>

Title V: Federal – State Partnership

- States receive federal \$\$ based on a formula
- States provide a financial match



Title V authorizes appropriations (\$\$) to States to:



1. Assure access to quality care, especially for those with low-incomes or limited availability of care;
2. Reduce infant mortality;
3. Provide and ensure access to comprehensive prenatal and postnatal care to women (especially low-income and at risk pregnant women);

Appropriations2



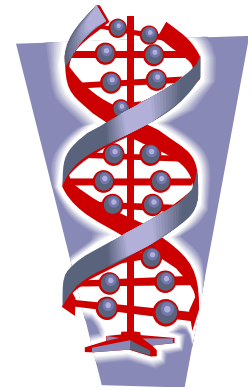
4. Increase the number of children receiving health assessments and follow-up diagnostic and treatment services;
5. Provide and ensure access to preventive and child care services as well as rehabilitative services for certain children;



Appropriations.....3

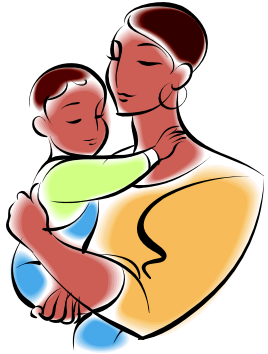
6. Implement family-centered, community based, systems of coordinated care for children with special health care needs; and
7. Provide toll-free hotline and assistance in applying for services to pregnant women with infants and children who are eligible for Title XIX (Medicaid).

In addition, Title V authorizes grant appropriations (\$\$) to:



- Provide for **SPRANS***, **research**, and training for MCH and CSHCN, for genetic disease testing, counseling, and information, for grants relating to hemophilia, and for the screening of newborns for sickle cell anemia, and other genetic disorders and follow-up services.

* Special Projects of Regional and National Significance



Title V requires States to:

- Establish a fair method for allocating funds among such individuals, areas, and localities who need MCH services.
- Apply guidelines for the content of health care assessments and services and for assuring their quality.
- Assure [that] charges, if imposed, will be public, are met for low income mothers and children, and will be adjusted to reflect income, resources, and family size.



Title V requires States to:

- Provide for a toll-free hotline for the use of parents to access information about providers for Title V and Medicaid and about other relevant health care providers.
- Coordinate activities with EPSDT* including periodicity and control standards and ensure no duplication.
- Arrange and carry out coordination agreements for care and services with Medicaid.

* Early and Periodic Screening, Diagnosis and Treatment

Title V requires States to:

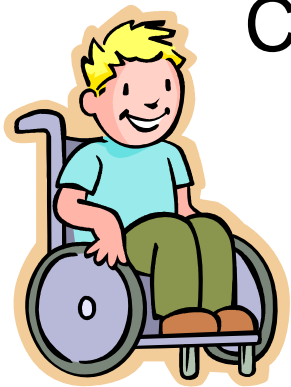


- Provide for services to identify pregnant women and infants eligible for Medicaid and assist them in applying for assistance.
- Make the [Title V Block Grant] application public within the State to facilitate comment from any person during its development and after its development.

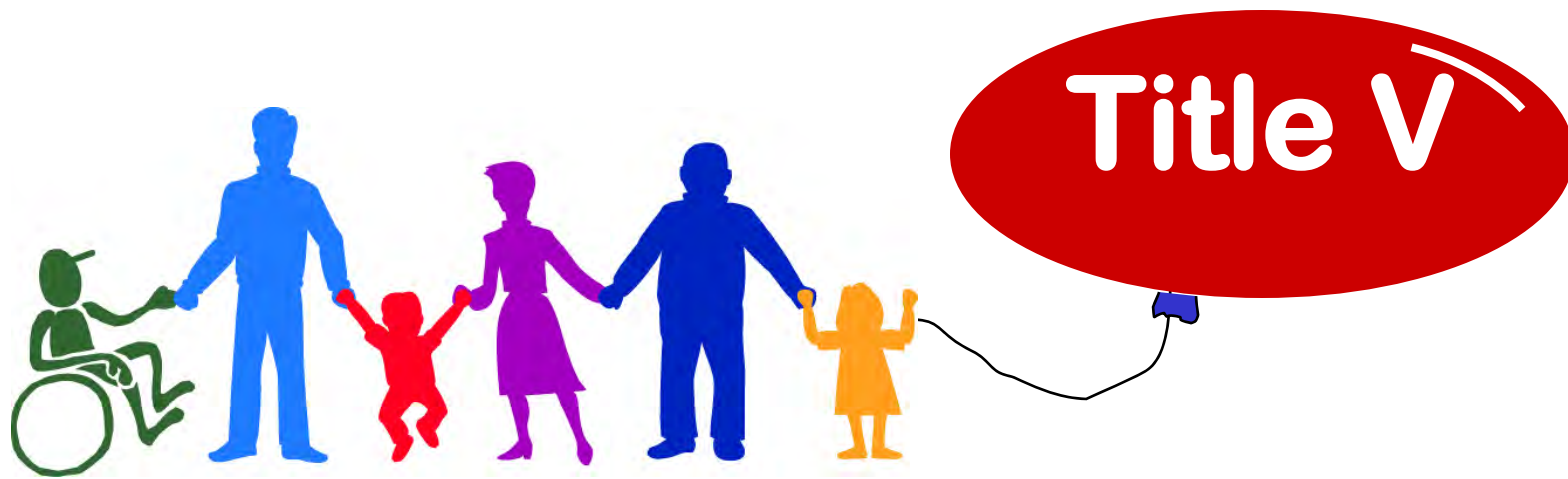
MCH Populations



- Mothers, Pregnant Women, Infants to Age 1
- Children and Adolescents
- Children and Youth with Special Health Care Needs



Family-Centered Care and Family Involvement with



1992/94: Family Participation* Survey and Conference

Family members:

- participate on advisory councils
- receive financial support for parent activities
- become involved with the Block Grant process
- are involved with in-service trainings
- are paid as staff/consultants
- are from diverse cultures

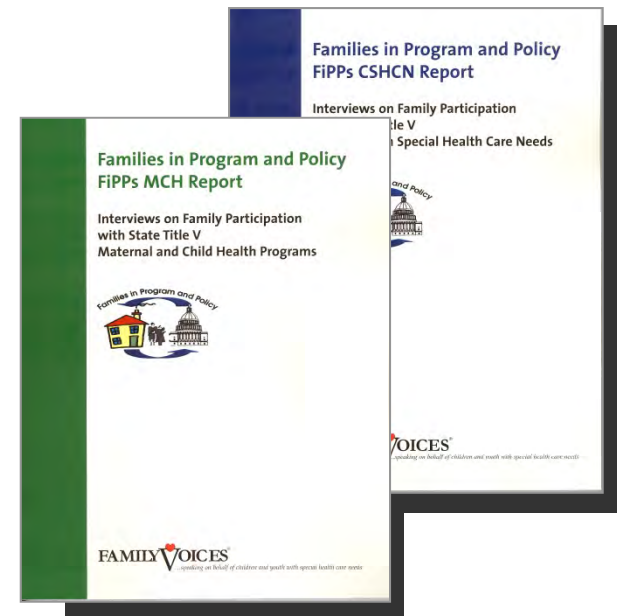
* (now Form 13 of the Block Grant)



2002: Families in Program and Policy (FIPPS)

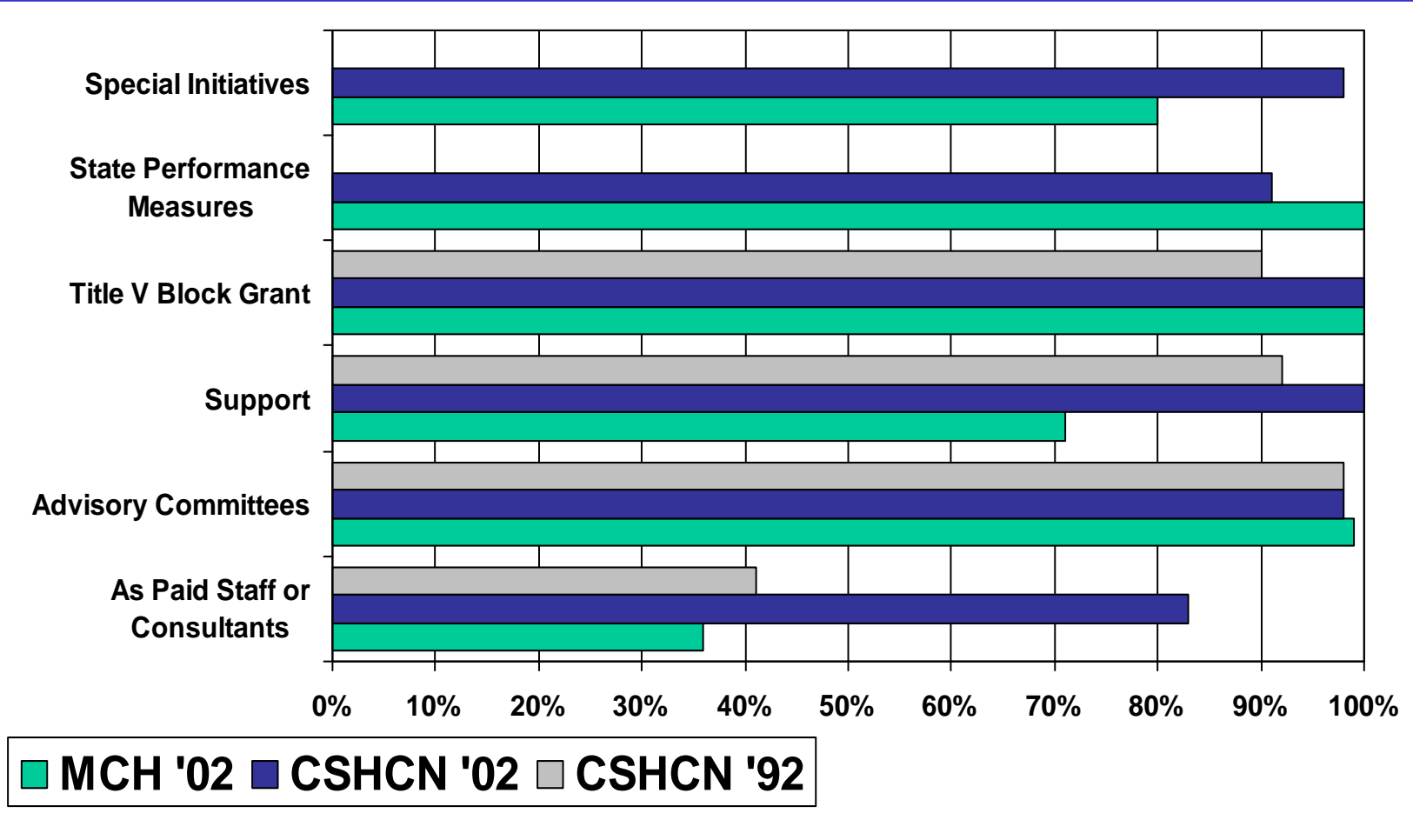
Interviews were conducted with State Title V programs to:

1. **Learn about progress in family participation with:**
 - State MCH Programs**
 - State CSHCN Programs**
2. **Gather materials that support family participation**



www.familyvoices.org/work/title_v?id=0012

FiPPs Study: *Progress of Family Involvement in Title V Activities*



Learning More About: **Partnerships - Families and Title V**



Family Voices Title V materials:

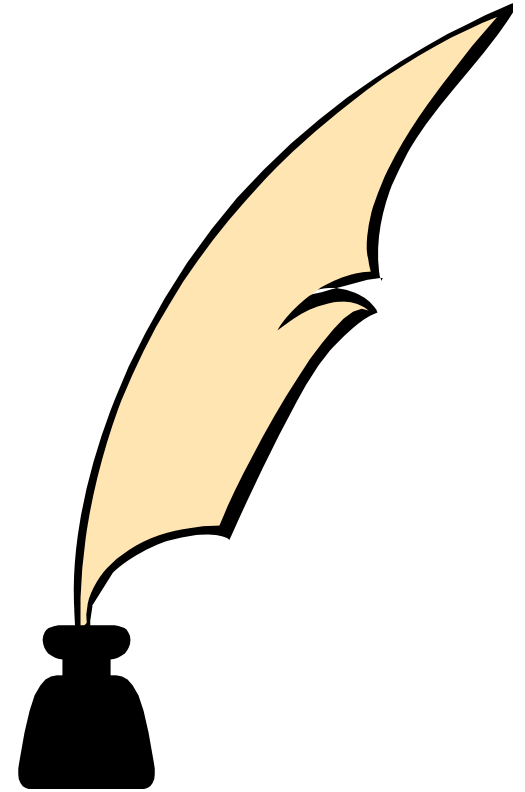
<http://www.familyvoices.org/projects?id=0001>

Sample

Identify highlights for your state

State Public Health History

- When was your public health program first established? Why?
- Who have been some of the interesting and important people associated with it?
- What have been some of the landmark events?
- What are some recent important accomplishments?



Sample
Identify highlights for your state

State History with Families



- When did families first become part of the public health history in your state?
- What were families' interests?
- What activities were families first involved with?
- How are families involved now?

Goals and Challenges...

- Healthy People 2020 – Health Objectives for the Nation
- Incremental Health Care Reform/Affordable Care Act (ACA)
- Medical Home
- Life Course Model
- Health Disparities
- Health Care Quality
- Workforce
- Government Performance and Results Act (GPRA)

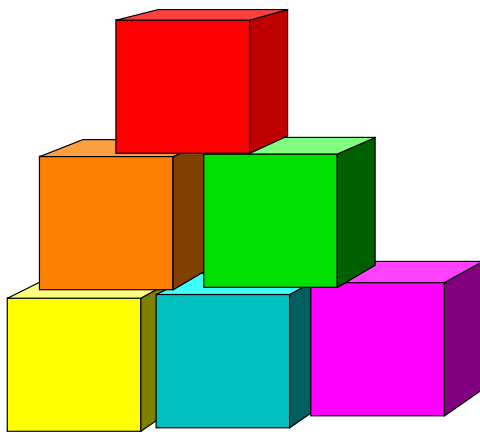


Title V

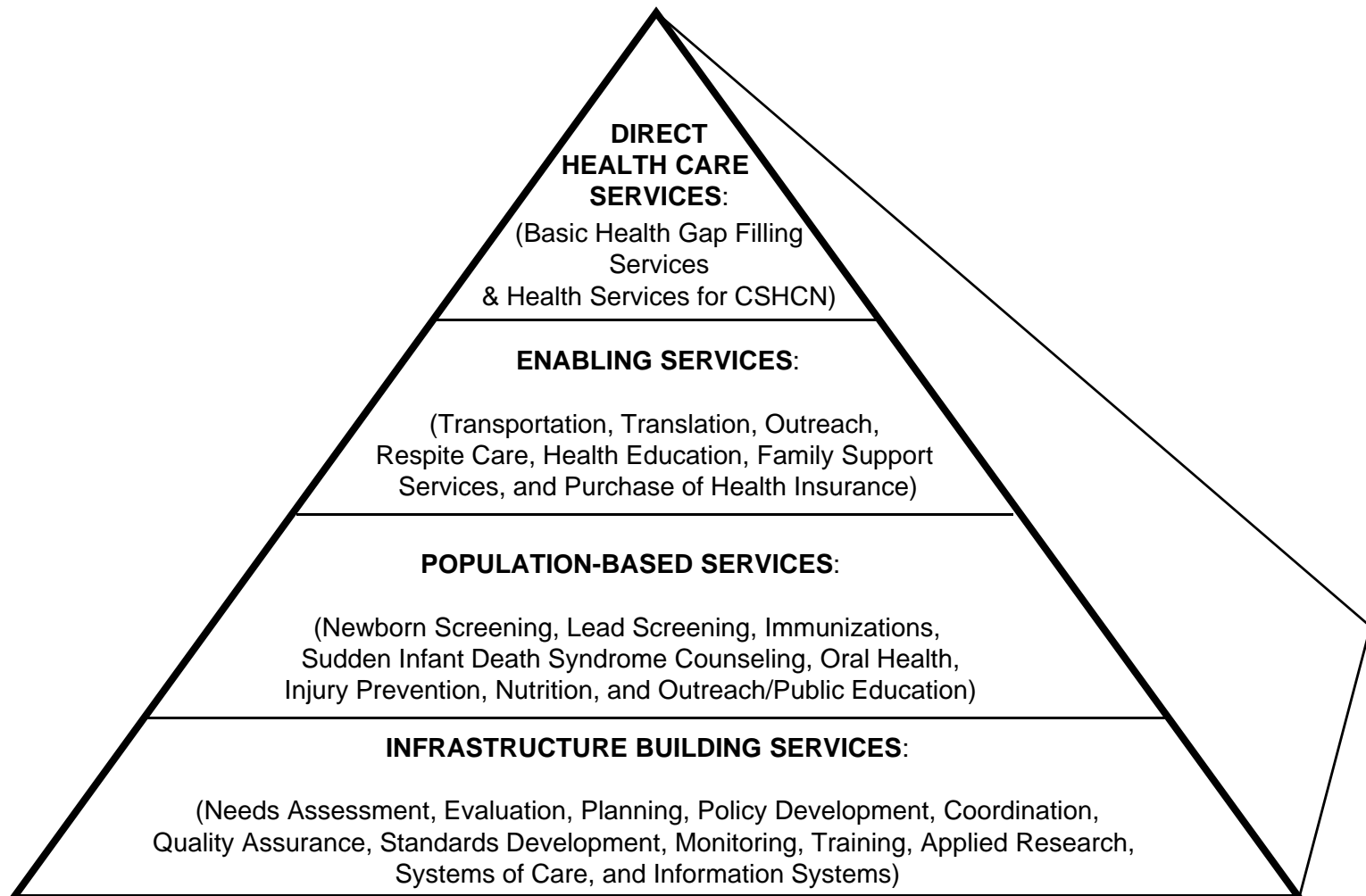
Block Grant &

Performance

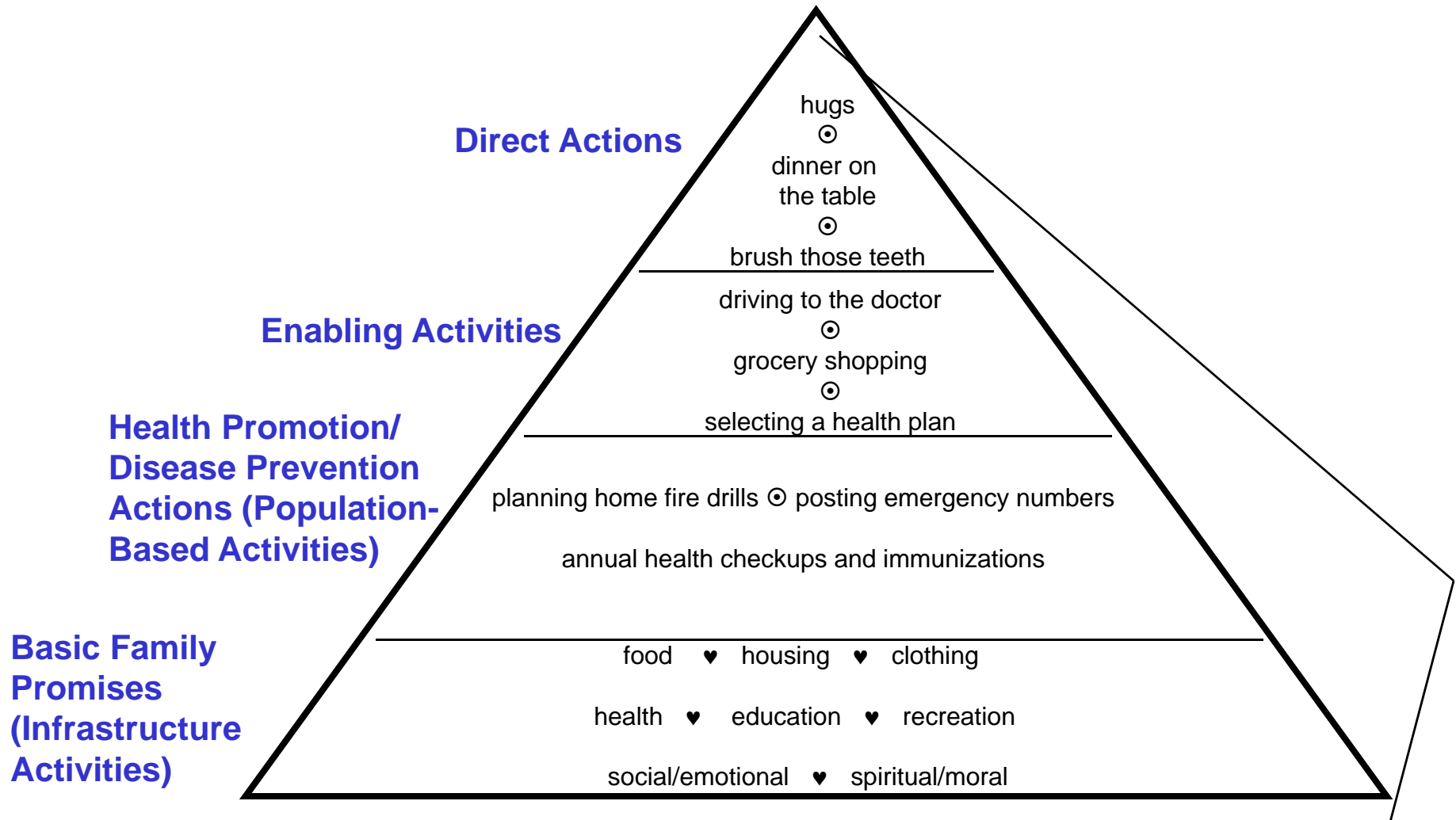
Measures



MCH Pyramid



Family Pyramid

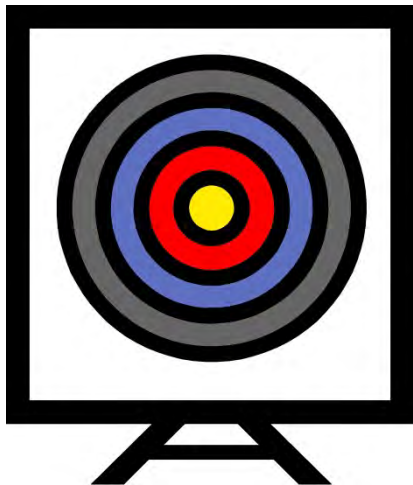


Title V Needs Assessments



- Submitted every 5 years (2010, 2015, 2020)
- Overview of health status by MCH population
- Description by the four levels of the pyramid
- List of 10 priority needs

MCHB Performance Measures

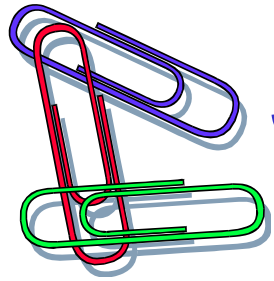


- All State Title V programs collect data on 18 National Performance Measures
- MCHB discretionary grants collect data on additional Performance Measures

Title V Block Grants: Accountability



- State reviews occur with Federal and State staff and outside experts, including families
- Extensive narrative description of state Title V services with special attention to each performance and outcome measure
- Completion of required reports and financial data tables



State Title V Block Grant

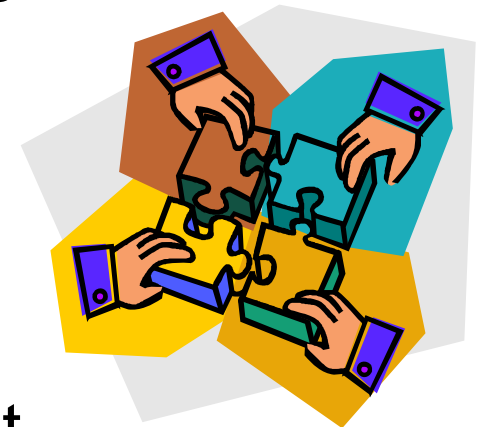
Annual Report 1

- What the State has accomplished
- States' performance and assurance of proper expenditure of funds
- Description of program activities
- Documentation of progress toward meeting performance measures
- Consistency between Report and Application

Annual Report..... 2

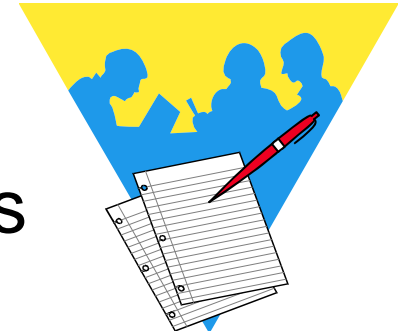
States must show that:

- 30% of funds are spent on preventive and primary care for children
- 30% of funds are spent on CYSHCN
- No more than 10% of funds are spent on program administration



Annual Report..... 3

Title V Performance & Outcome Measures

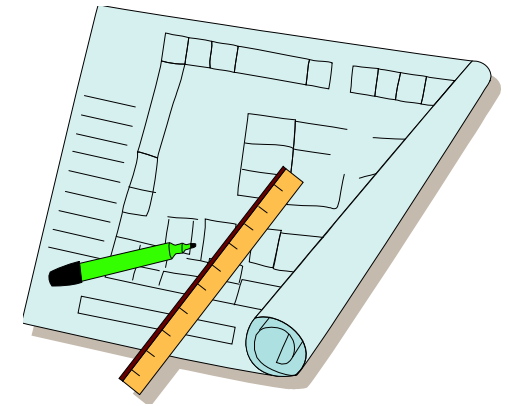


18 national performance measures

7-10 state performance measures
(at least one for CYSHCN)

6 health outcome measures
(may also develop 1 additional state measure)

State Title V Block Grant Annual Application



- State's plan for the coming year
- Relationship of priority needs, performance measures, and capacity and resources of the state program
- Described by four levels of the pyramid



Families and Title V Block Grants

- Since 1997 family members have served as reviewers:
 - All States and Territories have been reviewed by family members
- Some States bring family members to reviews as part of their state teams

This is a great learning process - we learn as much as we give!

- Parent Reviewer

www.familyvoices.org/work/title_v?id=0007

What Family Reviewers say about the Block Grant Process:

"I recommend it for anyone wanting to really understand the Title V system."



"Each state is different and has unique challenges, but recognizing how resources are being utilized - and to what outcomes - has been enlightening."

"The review was an exceptional experience - I was truly welcomed as a team member."

"We're ahead of the curve as far as parent involvement is concerned."

"Very eye-opening to see what other states are doing and where we could vastly improve."

Want to learn more?
Contact Your state MCH /CSHCN Director or Family Voices

What is Title V Information System (TVIS)?



The Title V Information System is a great way to learn about Maternal Child Health resources and data for all families and children, including children with special health care needs. It includes snapshots of each state.



Access at:

<https://perfddata.hrsa.gov/mchb/TVISReports/Default.aspx>



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