

# State Policy and Finance Framework for Newborn Screening Programs: Case Studies of Select States

*Presentation by:*  
**Kay Johnson, MPH, EdM**

**President, Johnson Group Consulting**

**Research Assistant Professor,  
Department of Pediatrics, Dartmouth  
Hitchcock Medical Center**

# Acknowledgements

- *Project officers:*
  - Michele Puryear, Chief, Genetics Services Branch, DCSHCN/MCHB/HRSA
  - Lauren Raskin, Director for Maternal and Child Health, Association of State and Territorial Health Officials
- *State leaders cooperating in this study:*
  - CA - Gil Chavez, Kathy Lottes, and George Cunningham
  - MS - Daniel Bender, Daniel Miller, and Gerald McClure
  - MN - Dianne Mandernach, Penny Hatcher, and Mark McCann
  - MD - Arlene Stephenson and Susan Panny
  - NY - Dennis Whalen and Ken Pass
  - OK - Suzanna Dooley and Pam King
  - OR - Grant Higginson, Mike Skeels, and Donald Dodson

# Policy History of Newborn Screening

- US newborn screening did not start as a legislated or public health activity.
  - During the 1970s, when physicians were slow to adopt screening, parents and organizations advocated for policy change.
  - As a result of this advocacy, legislatures mandated screening in most states.
- Similar advocacy and policy development is going on today.

# States' Authority & Challenge

*“Only public health agencies – with their authority... – could implement systems that would mandate screening for all infants, ensure the quality and availability of testing, and provide follow-up on a population basis.”* N.A. Holtzman

- State public health agencies face the challenge of financing newborn screening systems, with:
  - additional tests and equipment,
  - staff skilled in new technology, and
  - more effective follow-up with families.

# State Public Health Policy for NBS

## *State Policy Framework from National Task Force*

- Focus on system, not just a test.
- Set policies for adequate funding.
- Involve professionals and consumers.
- Adopt mandates & privacy protections.
- Establish new criteria for adding tests.
- Set program guidelines (quality, etc.).

# Framework for Financing



# What needs to be financed?

## *Goals from National Task Force:*

### Adequate financing for:

1. **Screening, short-term follow up, and diagnosis;**
2. **Comprehensive care and treatment** for all individuals with conditions identified by newborn screening; and
3. **Quality assurance** and evaluation.

# Financing Newborn Screening

## *Principles from National Task Force:*

- Core funding for NBS programs:
  - Fees sufficient to finance testing, short-term follow-up, and diagnosis
  - Use other public health dollars as necessary
- Coordinate and blend funds for treatment



# Financing for Treatment

## *Opportunities noted by National Task Force:*

- States can coordinate public resources.
  - Medicaid, and SCHIP
  - Title V Maternal and Child Health Block Grant (MCHBG).
- In Medicaid/SCHIP managed care contracts:
  - require coverage of services related to NBS, and
  - require that MCOs ensure access to specialty providers, as necessary.
- For the health insurance plans they regulate, states can mandate coverage of services.

# Federal/State Policies related to Financing for NBS

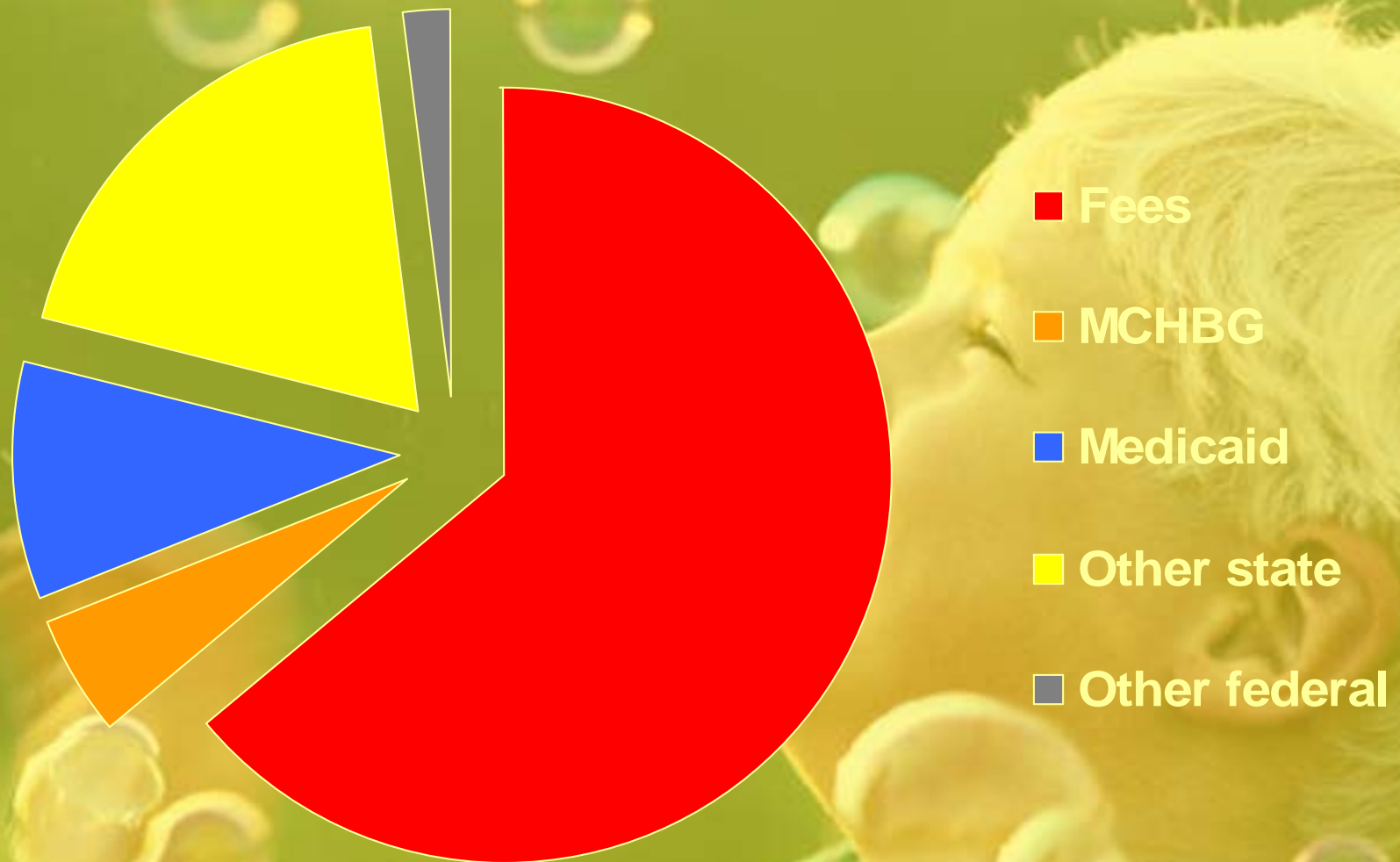
## Federal policies

- HIPAA on genetics
- HIPAA on newborn coverage
- ADA rights
- IDEA entitlements
- Medicaid/EPSDT child health coverage

## State policies

- NBS mandates & program structure
- NBS financing
- Insurance benefit mandates
- SCHIP benefits
- Children with special health needs program

# Distribution of Funds, by Source, 2001



Source: GAO-03-449. State Newborn Screening Programs.

# Financing Newborn Screening

## *Finance myth 1*

NBS programs fully funded by fees.

## *In reality*

- 5 states and DC not collecting fees.
- Fees typically cover only test/lab costs.
- Fees may not support expansion of new technology and equipment.
- Economic pressures may limit fee increases.

# Financing Newborn Screening

## *Finance myth 2*

Tax dollars fund newborn screening.

## *In reality*

- 45 states use fees, not public dollars, as core funding for tests.
- For residual funding, mainly Title V – MCH and Medicaid to finance follow-up and treatment.

# Financing Newborn Screening

## *Finance myth 3*

NBS paid for by third-party reimbursement.

## *In reality*

- Fees not always covered by insurance or Medicaid.
- Even when they pay the fees, Medicaid reimbursements are typically below cost.

What did we learn in  
this study?



# Study questions:

- How did states address recent challenges?
    - State budget shortfalls
    - Consumer demand for more tests
    - Rapid technology change
    - Pressure to privatize
  - What policies and finance strategies were used to expand and sustain NBS?
- 
- A young child with light-colored hair is shown in profile, blowing bubbles. The background is a soft, greenish-yellow color with many bubbles floating around. The child is wearing a blue top and a red collar. The overall mood is bright and cheerful.



# State Selection Criteria - MIX

- Geographic distribution
- Variation in number/type of tests
- Recent expansion or innovation
- Public vs. private labs
- Fee vs. blended funding
- Various approaches to follow-up
- One regional lab model

## Study States: Primary Focus of Case Study

- California - Pilot MS/MS program
- Maryland - Integrated programming
- Minnesota – Public-private partnership
- Mississippi – Rapid expansion to 40 tests
- New York – Adding CF and others
- Oklahoma – Expansion with blended funds
- Oregon – Regional support

# Overview of Screening Panel

State	PKU	CH	GAL	MSUD	HCY	BIO	SCD	CAH	MCAD	CF	MS/MS	Hearing
CA	☑	☑	☑				☑					66%
MD	☑	☑	☑	☑	☑	☑	☑	☑	☑		☑	85%
MN	☑	☑	☑	☑	☑	★	☑	☑	☑		☑	92%
MS	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	98%
NY	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	☑	97%
OK	☑	☑	☑				☑	★	★	★	★	94%
OR	☑	☑	☑	☑	☑	☑	☑	☑	☑		☑	94%

☑ test for condition required by the state

★ test mandated/authorized but not yet implemented

Source: NNSGRC, NCHRAM, March of Dimes

# Overview of Screening: MS/MS

State	MS/MS	Fatty acids	Organic acids	Amino/ urea
CA	pilot completed			
MD	☑	9	11	4
MN	☑	10	12	5
MS	☑	10	12	8
NY	☑	1		
OK	★			
OR	☑	9	13	3

★ test mandated/authorized but not yet implemented

Source: NNSGRC, NCHRAM, March of Dimes

# Change in Fees, 1997-2004

State	Fees 1997	Fees 2004	% increase
CA	\$ 42.00	\$ 60.00	43%
MD	\$ 15.00	\$ 42.00	180%
MN	\$ 13.00	\$ 61.00	369%
MS	\$ 20.00	\$ 70.00	250%
NY	\$ -	No fee	
OK	\$ 10.50	\$ 75.59*	620%
OR	\$ 28.00	\$ 54.00	93%

\* Fee increase approved, scheduled to take effect on January 1, 2005.

Source: NNSGRC, NCHRAM, March of Dimes

# Sources of core funding for: Screening, Short-term follow up and Diagnosis

State	Fees 2004-2005	Fee	State	MCHBG	Medicaid
CA	\$ 60.00	<input checked="" type="checkbox"/>		Not routinely	
MD	\$ 42.00	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
MN	\$ 61.00	<input checked="" type="checkbox"/>		Not routinely	
MS	\$ 70.00	<input checked="" type="checkbox"/>		Not routinely	<input checked="" type="checkbox"/>
NY			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
OK	\$ 75.59	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
OR	\$ 54.00	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	

# Medicaid Financing for Births

State	Number of Births (2002)	% Births financed by Medicaid	Income eligibility limit as % Poverty (FPL)
CA	529,357	42%	300% FPL
MD	73,323	29%	250% FPL
MN	68,025	31%	275% FPL
MS	41,518	54%	185% FPL
NY	251,415	41%	200% FPL
OK	50,387	46%	185% FPL
OR	45,192	32%	170% FPL
U.S.	<i>Study states = 26% of total US births</i>	36%	

Source for Medicaid data: Kaiser Family Foundation, Commission on Medicaid and the Uninsured. [www.kff.org](http://www.kff.org) Data for 2002.



# California

- Finance approach
  - Fees pay for program up to diagnosis
  - \$1 per test form + \$59 per baby screened
  - Hospitals may charge (keep) \$6 for collecting blood
- Challenges in adding tests
  - Huge undertaking for 500,000 births
  - Success with pilot project on MS/MS
  - Unable to increase test panel or add MS/MS due to state budget pressures
- Public health management + private lab capacity





# Maryland

- Finance approach
  - Fees cover lab costs
    - Increase to finance upgrade of lab equipment
  - MCHBG for short and long-term follow up
- Challenges as tests added
  - Pediatrix in competition with state lab
  - Effective parent informing/consent
  - Two screens (repeats)
  - Follow-up for many more families
  - State budget pressures



# Minnesota

## *“hit the restart button”*

- Financed a new approach with fee increase
- Focused on family as customer
- Expanded number of tests
- Created new public-private partnership
  - State lab (initial screening)
  - Mayo Clinic (MS/MS screen and specialist care)
  - University of Minnesota (coordination & specialist care)
- Structured linkages to medical home/primary care pediatricians



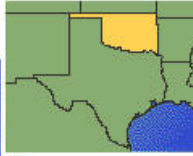
# Mississippi

- Expansion to “comprehensive screening” (~40 tests)
- Finance approach
  - Did fiscal analysis, doubled fee \$35 up to \$70
  - Hospital charges vary, insurance & Medicaid pay through global payment for birth
- Political pressure to change
  - Parents and others through legislature
  - Recommendation of Genetics Advisory Committee
- Lab services
  - No state lab capacity (formerly used Tenn.)
  - Found desired services & price with Pediatrix
- More PH follow up staff in each health district



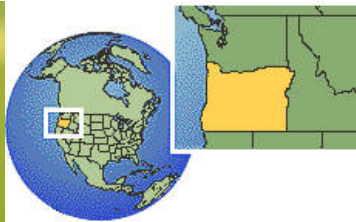
# New York

- Finance approach
  - Not fee-based program
  - Public health dollars directly finance NBS
- Change and challenges
  - Advocacy by parents and other organizations (MOD, AAP) stimulated interest of Governor & legislature
  - State budget pressures ongoing
  - 3-year push to add cystic fibrosis testing in 2003
  - Large scale effort -250,000 births, 3,800 positive screens
  - Innovations to link primary and specialty physicians



# Oklahoma

- Finance approach
  - Fee increase to do more tests
  - Medicaid and private insurance billing
  - Legislative commitment to financing
  - Small HRSA grants to plan for innovation
- Political pressures & opportunities
  - Genetics Advisory Committee strong role
  - Parents and others advocate to legislature
  - Medicaid agency and hospitals involved
- Authority to expand tests, implement 2005
- More public health staff for follow-up



# Oregon

- Finance approach
  - Fee-based budget
    - Fees are collected at the time prepaid kits are ordered.
    - Reconsidering allocation for lab vs. follow up
- Change process
  - In 2001, legislature approved adding 20 disorders
  - **No to cystic fibrosis:** Considered seeking legislative approval to increase fees and add CF test. Instead, created a task force to guide decision.
- Regional lab is a vendor
  - Regional lab for 5 states (AK, HI, ID, OR, and NV)
  - Testing for 100,000 newborns

What factors are enabling states to expand and sustain newborn screening programs?



# Creating a Climate for Change

## Federal system support through:

- Genetics planning grants
- Program integration grants
- National Newborn Screening & Genetics Resource Center (NNSGRC)
- Demonstration projects
- Regional collaboratives
- National Advisory Committee
- Laboratory quality control

## Action & advocacy by:

- Parents
- March of Dimes
- State Genetics Advisory Committees
- Health professionals (AAP, AAFP, etc.)
- Condition-focused support groups
- Pediatrix



# NBS – What is driving change?

- State perspective
  - National Task Force recommendations
  - Advocacy by parents and professionals
  - Arguments for equity across states
  - HRSA efforts to increase state capacity
  - Advances in science and technology



# What did these states do?


- Focused on a system, not just testing
- Expanded the number of conditions/tests
- Invested in state-of-the-art testing
- Financed more follow up
- Engaged parents/advisory committees
- Negotiated quality and privacy issues

# Three Factors affecting Future

- Adding MS/MS capacity in the lab is simple, compared to the fiscal, ethical, and system of care (follow-up) decisions.
- NBS follows in the wake of genetic science
- Introducing profit into newborn screening programs has changed everything.
  - What does it mean when private lab takes funding but not the public health role?
    - Like Medicaid managed care, requires oversight

# Political Pressures & Finance

- The political pressure is against increasing health care costs.
- Legislators may say:
  - Nice idea but we cannot afford it.
  - Good idea, do it (with no new resources)
- Health insurance plans and Medicaid may come forward to say this will drive up costs.
- Fiscal constraints often drive policy instead of policy driving fiscal decisions.



Without a broad, inclusive panel of tests established by states:

*“Parents may go from doctor to doctor seeking a diagnosis (for their child) and generating costs, without being prepared for the outcome.*

*If you miss a child and miss the opportunity for intervention, the costs are much higher.*

*Program managers have to look at all of the costs and make judgments that balance the interest of individual child and the public.*

*We are not (just) spending taxpayers money.”*

# Goals for NBS Today?

- Every baby, regardless of where born, has access to newborn screening (NBS).
- Every child receives screening, diagnosis, and needed treatment.
- New consensus on criteria for adding tests to NBS programs achieved.
- NBS programs meet quality standards.