

Minnesota Medical Foods Initiative: Building a Long-term Strategy for Assisting Families in Obtaining Medical Foods and Dietary Supplements for IBEM Management

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Goal of Newborn Screening

- Improve health outcomes in the screening population of newborns
- Six parts
 - Testing
 - Follow-Up
 - Diagnosis
 - Intervention and/or management
 - Evaluation
 - Education

Maximum
benefit to the
child

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The Need for Equitable Therapeutic Access

Children identified with inborn errors of metabolism through newborn screening may be unable to gain the full benefits associated with early detection due to:

Lack of universal, guaranteed *access* to and *coverage* of medically recommended foods, formulas and dietary supplements



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This is Not a New Issue :-)

- Surveys have been done
- Meetings held
- Papers published
- Medical Foods Equity Act attempted
- Position statements

And yet... we're still talking about this topic!

MN Medical Foods Initiative: Purpose

Develop a long term strategy to assist families to obtain medical foods, formulas and dietary supplements as recommended or prescribed by their medical specialty providers for the management of rare inborn errors of metabolism.

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Initial Steps

October 2014: Work Group formed to examine:

- Commonalities and differences in programs, services, coverage within and between states
- Evidentiary basis

Goal

Develop a feasible and sustainable solution that enables patients with IBEMs of all ages to receive appropriate medical foods, formulas, vitamins, and supplements

Initiative Strategies

- Identify current barriers to therapeutic access
- Utilize best/evidence-based practice guidelines for lifelong management
- Collaborate with public health colleagues to improve understanding of program/service/coverage successes and challenges
- Collaborate with other agencies involved in the coverage of medical interventions (DHS, Commerce, etc.)
- Explore and propose solutions to achieve equitable therapeutic access

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2015 Medical Foods Survey

Purpose:

- Improve understanding of current programs, services and requirements related to medical foods/formula and dietary supplement access and coverage, and
- Incorporate knowledge to explore sustainable options to assist MN families living with IBEM in obtaining the recommended/prescribed medical foods/formulas and dietary supplements to optimize long term health outcomes

2015 Medical Foods Survey

Key survey content:

- State provided or guaranteed medical foods and/or formula coverage (by each condition on the RUSP)
- Statute information relating to coverage (including vitamins/supplements)
- Program eligibility, types, advice, obstacles

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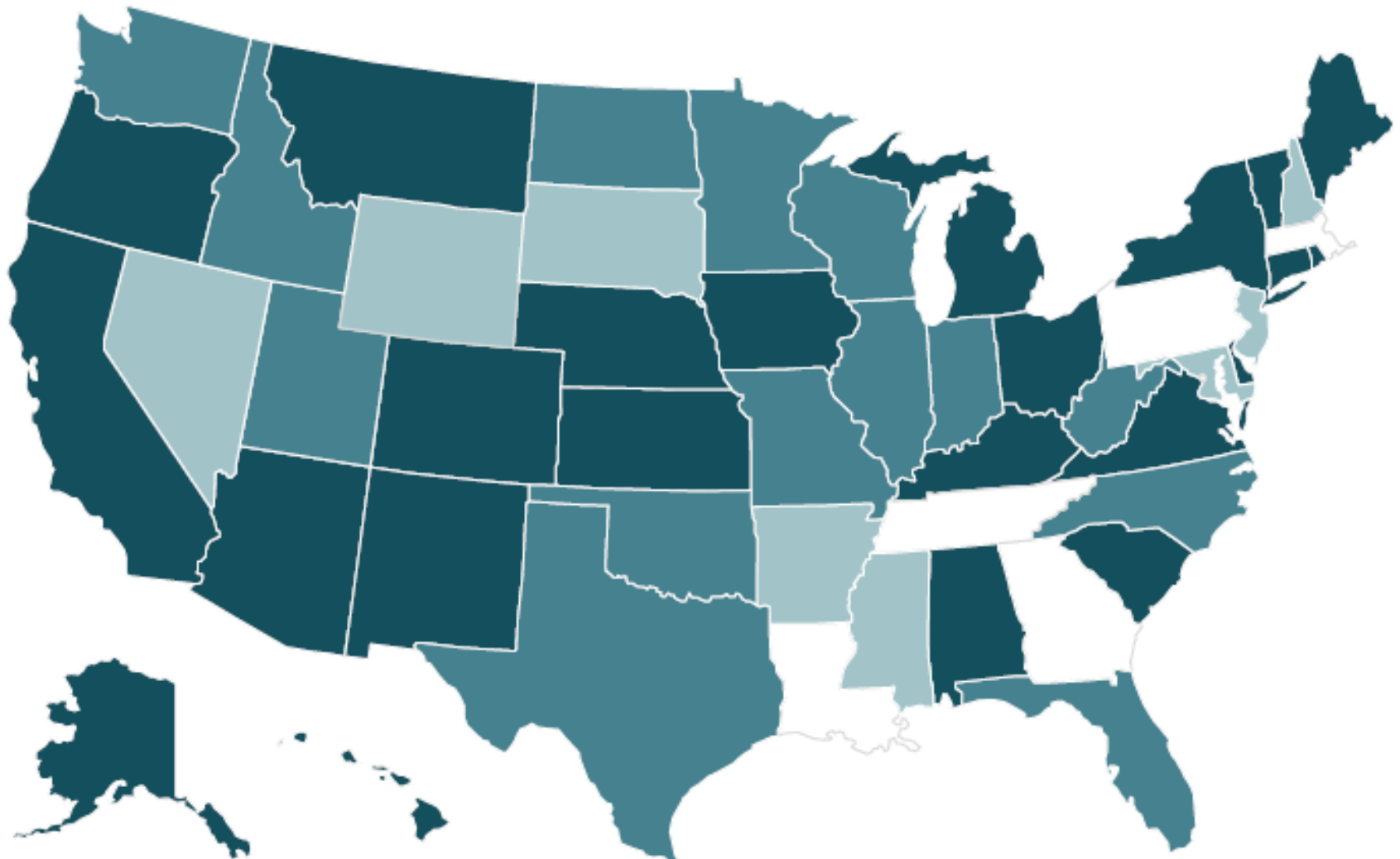
2015 Medical Foods Survey

Survey process:

- Sent to all states
 - Used known Newborn Screening Program contacts and/or Baby's First Test contacts
 - Some states forwarded on to WIC, CYSHN, etc.
- 45 of 51 respondents completed the survey /responded: (response rate = 88%)

United States Data Map

Medical Formula: State-Provided or Guaranteed

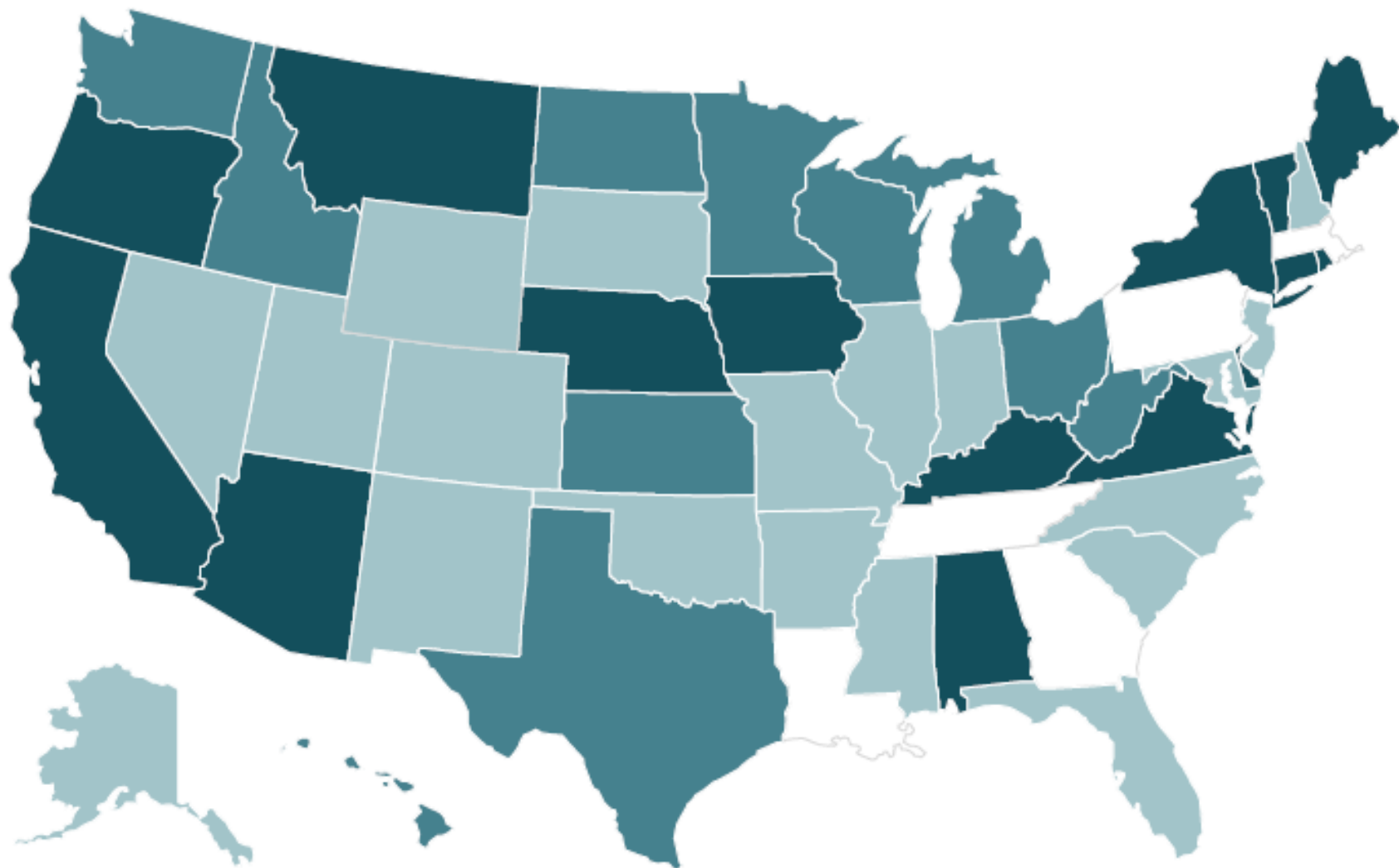


Coverage for conditions on the Recommended Uniform Screening Panel:

	No Response		NONE		SOME		ALL
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United States Data Map

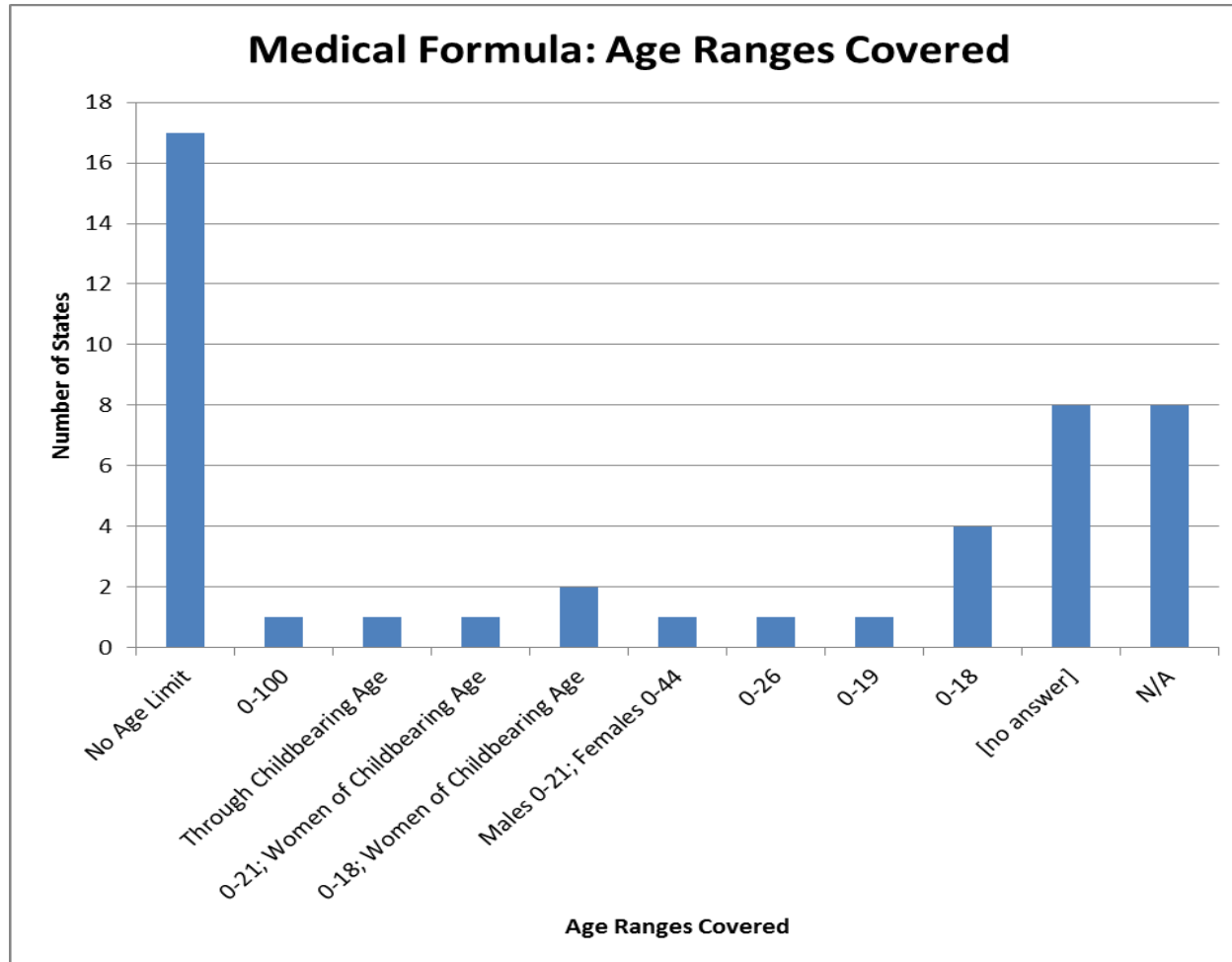
Medical Food: State-Provided, or Guaranteed



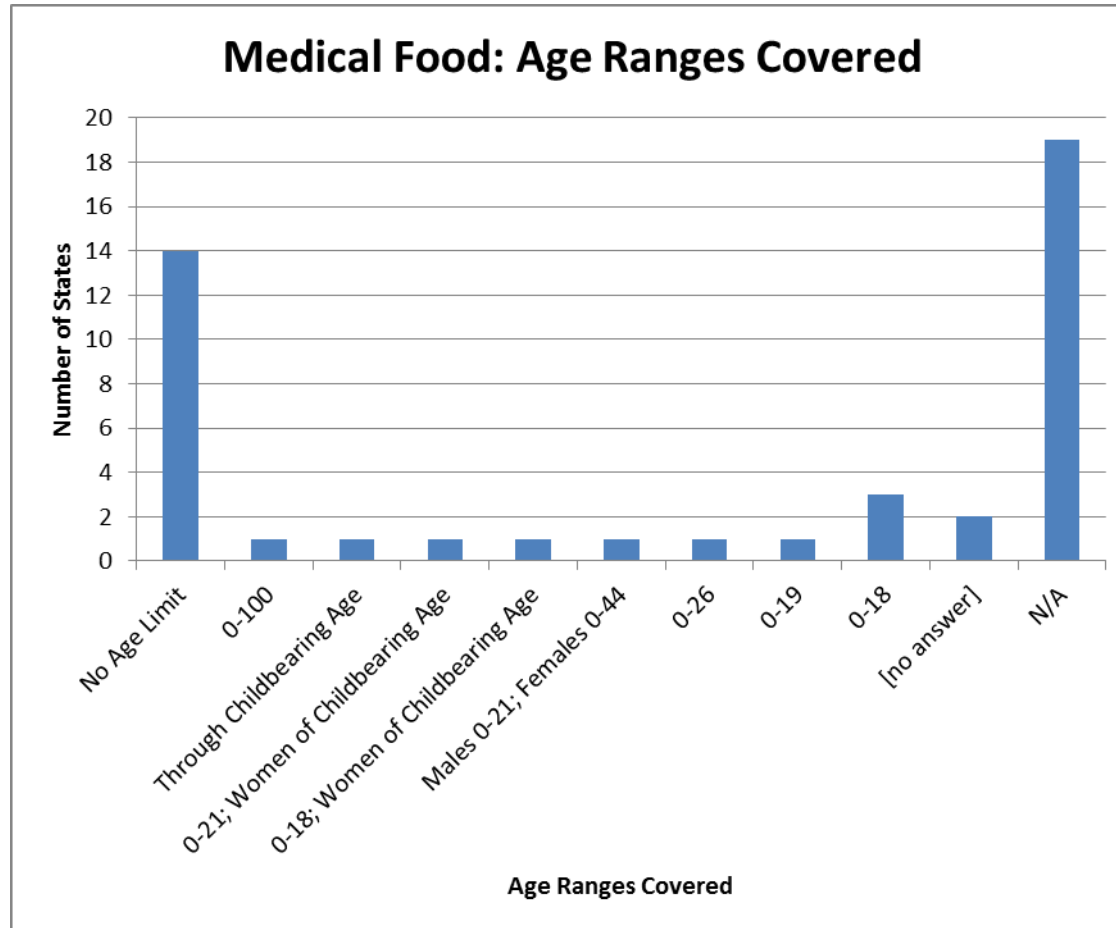
Coverage for conditions on the Recommended Uniform Screening Panel:

No Response NONE SOME ALL

Timespan of Coverage

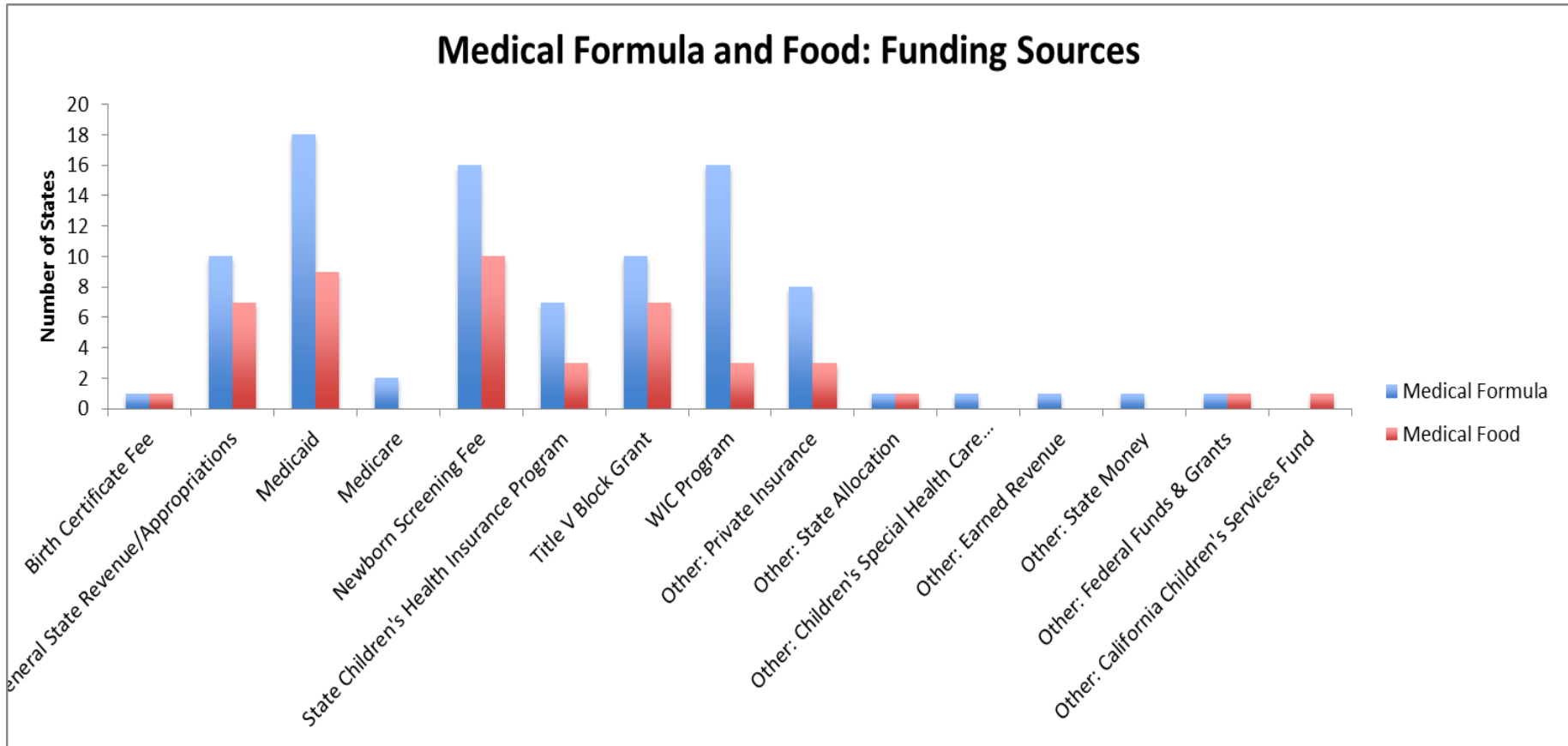


Timespan of Coverage



Funding Sources

Medical Formula and Food: Funding Sources



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Funding Allocated

(Cover Med Foods/Formula for ALL Disorders)

STATE	AMOUNT	APPROX BIRTHS PER YEAR
A	\$2000 to \$3000 per clinic	36,000
B	\$15,000	11,000
C	65,000 in NBS (Title V funds vary)	102,000
D	\$160,000 + insurance/family pmts	39,000
E	\$200,000	56,000
F	300,000	21,000
G	\$550,000 formula/\$68-75000 foods	26,000

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Funding Allocated

(Cover Med Formula for ALL Disorders and
Med Foods for SOME Disorders)

STATE	AMOUNT	APPROX BIRTHS PER YEAR
H	\$100,000	39,000
I	\$900,000	139,000
J	\$1,000,000	113,500

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Funding Allocated

(Cover Med Formula for ALL Disorders and
Med Foods for NO Disorders)

STATE	AMOUNT	APPROX BIRTHS PER YEAR
K	\$20,000	26,300

Funding Allocated

(Cover Med Formula for SOME Disorders and
Med Foods for SOME Disorders)

STATE	AMOUNT	APPROX BIRTHS PER YEAR
L	\$65,804	10,600
M	\$135,000	22,400
N	\$167,200	86,600
O	\$800,000	387,000
P	\$1,750,000	67,000

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Funding Allocated

(Cover Med Formula for SOME Disorders and
Med Foods for NO Disorders)

STATE	AMOUNT	APPROX BIRTHS PER YEAR
Q	\$60,000	51,000
R	\$66,000	53,000
S	\$150,000 to \$200,000	75,000
T	\$841,000	215,500
U	\$2,000,000	157,000

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Obstacles identified by respondents

- No formal application process/eligibility criteria
- Limited funds/Staffing/Budget/Procurement Process
- No insurance mandate
- Program runs in a deficit/Escalating costs
- Pharmacy Ordering Process
- Coverage of Medical Food by Medicaid/care in adults
- Contracts with food vendors
- List of needed medical foods/Lack of understanding of complex reimbursement structure

IBEMC Study

Proposal: *Nutritional and pharmacotherapy coverage, program participation and adherence for children with select IBEM enrolled in the IBEMC*

- Proposal designed and submitted, review pending

Goals: Utilize IBEMC data to determine

- Whether self-pay/lack of insurance correlates with higher rate of therapeutic non-adherence
- Whether those receiving WIC or Patient Assistance have a higher rate of therapeutic adherence

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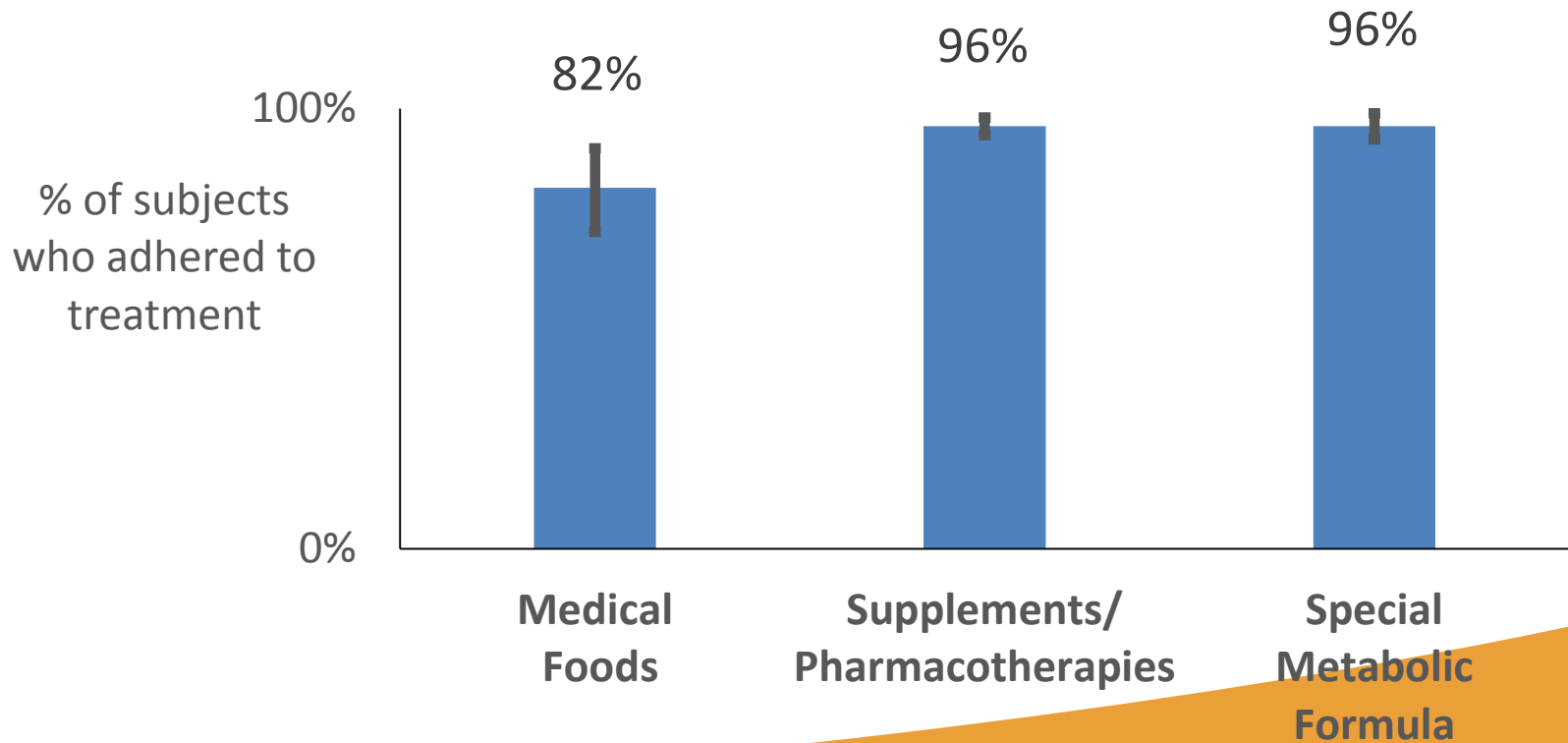


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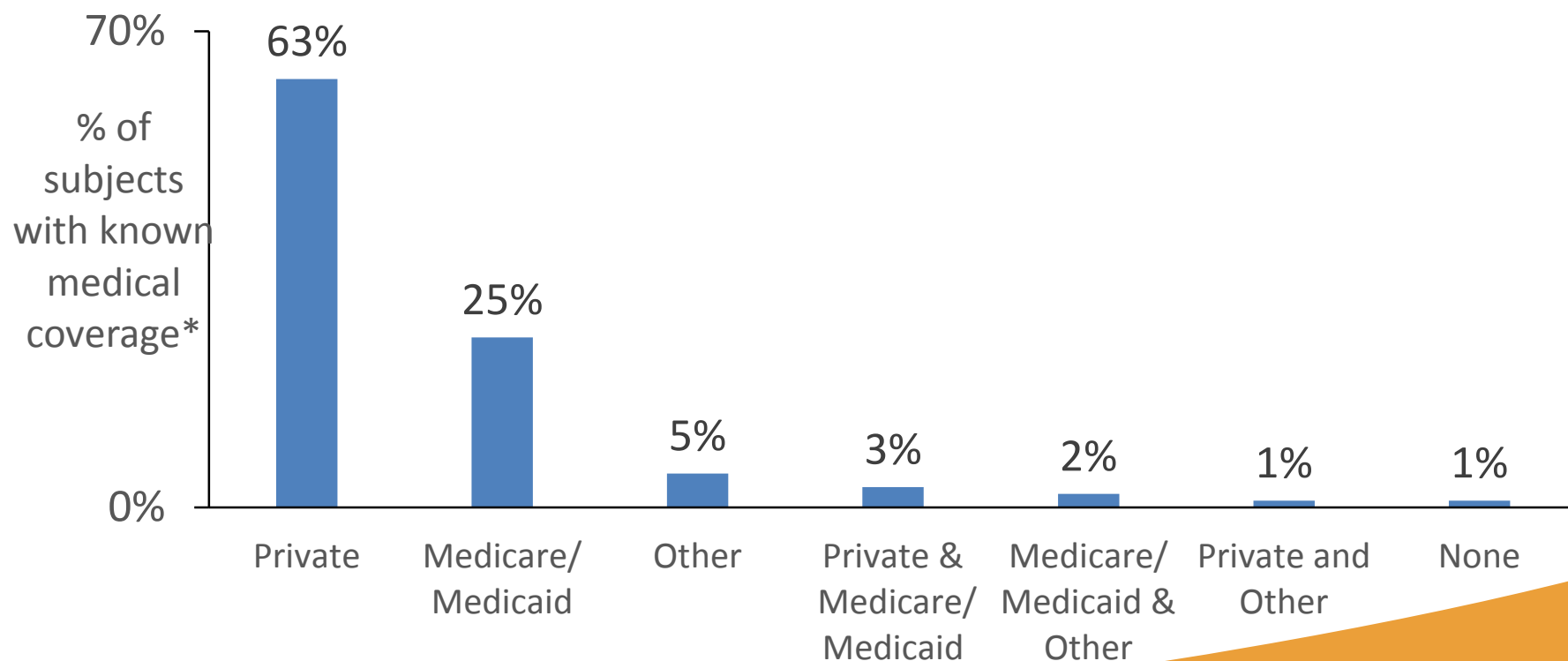


Adherence to treatments:





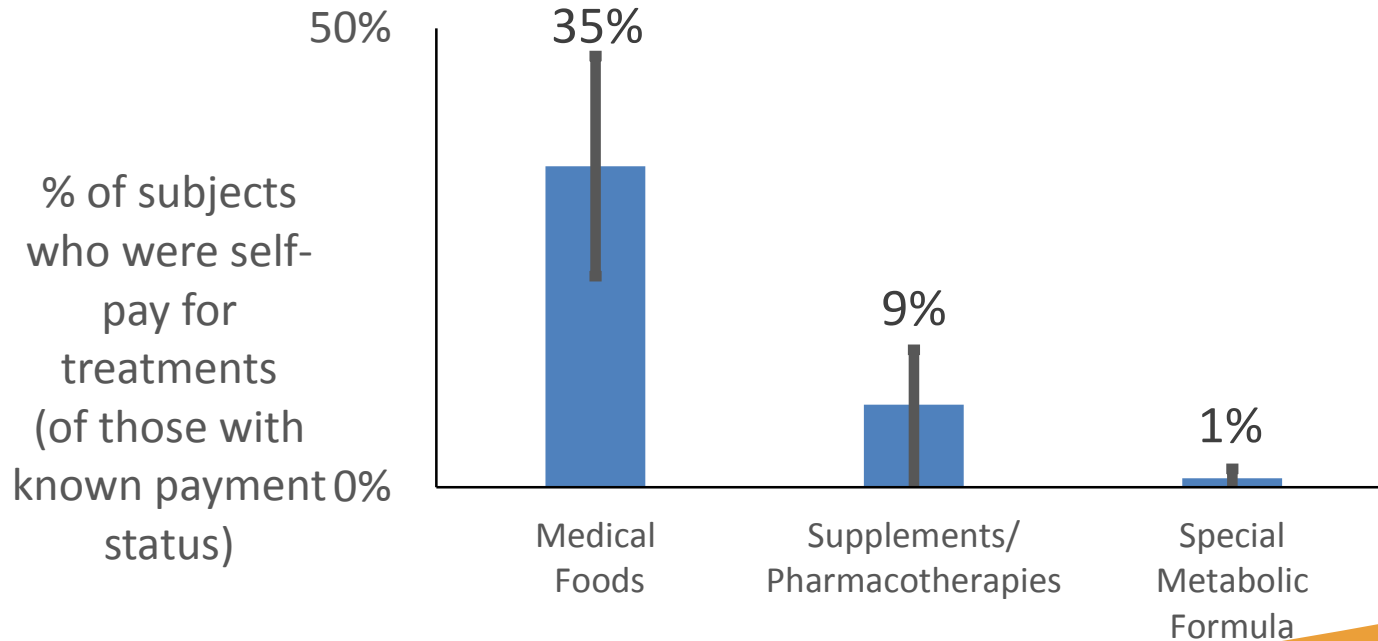
Medical Coverage at IBEMC Intake:



* Medical coverage was unknown for 91 subjects.



Method of payment:



Advice

- Strong state law is important
- Work with insurance carriers to maximize coverage
 - Understand if insurance mandate would cover self employed, etc.
- Secure as much funding as you can
- Work with dieticians on best products/keep formulary broad
- Collaborate with Medicaid/WIC/CSHCN Program
- Have clear eligibility guidelines

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