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FAMILY
CAREGIVER
COALITION

Developing a Policy Agenda for Respite Care

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Mississippi Family Caregiver Coalition

Respite Care

Respite is defined as “planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult” (ARCH Respite, n.d.). Mississippi lacks a recognized policy agenda regarding respite care that would support caregivers. A policy agenda is the means by which policy makers and other interested parties align to address the issues with the most political pressure, evidence-based solutions, and political determination. This presentation identifies policy strategies enacted by other states and uses a Delphi method to reach consensus of priorities of advocates and policy leaders in Mississippi.

Background & Significance

- The Strickland Family
- Up to 80% of care is provided by family caregivers
- 53 million people in the U.S. have been declared to have a disability – 30 million are between 5 and 64 years of age, 23 million are over 65
- Providing care for family members often competes with other responsibilities that require energy
- Respite is the concept that provides for a planned break for caregivers to be rejuvenated for the continued task of caregiving
- Of the nearly 3 million Mississippi residents, 800,000 are caregivers
- There is no formal respite plan for Mississippi



Current Situation

- Mississippi currently has no policy agenda for Respite Care
- Other issues have received recognition for statutory inclusion through a policy agenda, such as Diabetes Self-Management Reimbursement and Texting-While-Driving penalties

Challenges

- Lack of awareness among policymakers (extent and policy solution)
- Lack of awareness among public (extent and policy solution)
- Consensus on policy approaches for Mississippi
- Lack of united advocacy message
- Lack of a champion for the cause
- Lack of foundational policies (aging in general)
- A relatively short legislative session to consider the other worthy causes
- No staff in legislature working to forward the idea of respite
- A general lack of provider engagement
- Current respite through government entities is fragmented
- Medicare, Medicaid, nor private insurance policies provide respite as a service for all recipients
- There is no central repository of information regarding respite in Mississippi

Opportunities

- Mississippi can learn from the other 30 states that have embarked on similar efforts to define a policy agenda for respite
- Four Main Outcomes
 - Raise Awareness
 - Engagement of Policy Makers
 - Concerted effort to engage Mississippi Caregivers Task Force, Mississippi Family Caregiver Coalition, and Mississippi Legislature in determining three policy agenda issues for Mississippi
 - Policy makers can follow the example to Representative Gregg Harper in his sponsoring of HR 3099, the RAISE Act
- Use the momentum of the creation of the Mississippi Caregivers Task Force in 2014 with its subsequent Blueprint
- Use the momentum of the newly formed Mississippi Family Caregiver Coalition

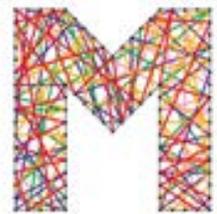
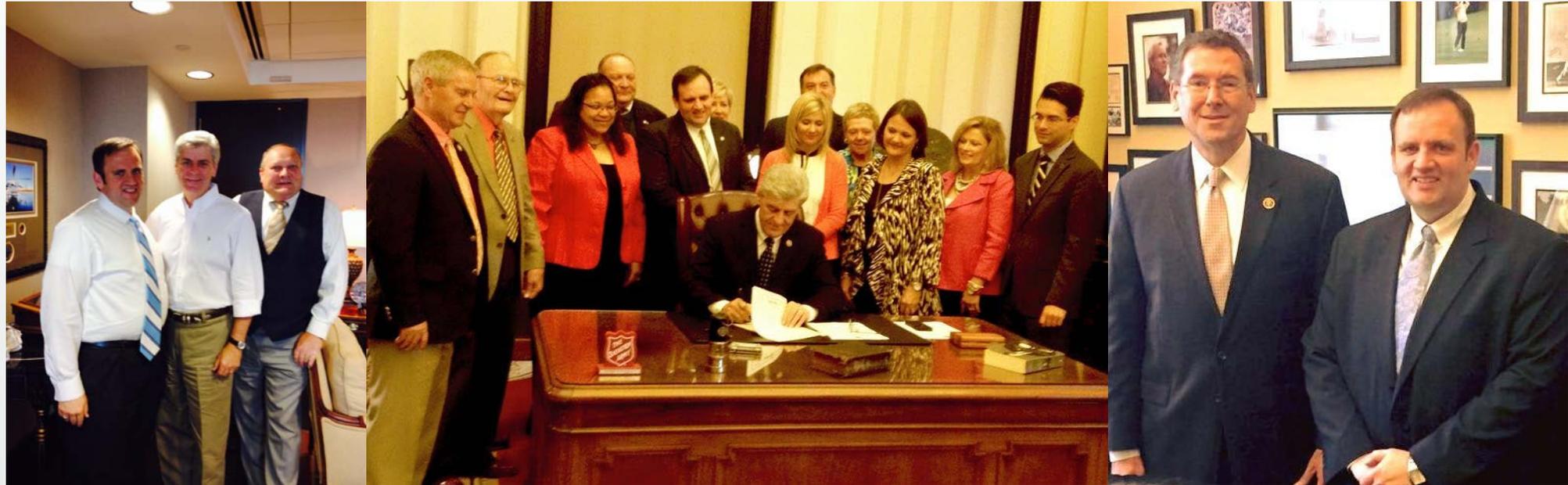
Interest of the Author

<http://www.newsms.fm/caregivers-lives-lifted-legislation-lives-passage-video-included/>



Caregivers Task Force

Making Care Possible for All Mississippians



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Clinical specialist pushes for caregiver assistance in D.C.

By Demetrius Thompson
dthompson@newtoncountyappeal.com

Local social worker Spencer Blalock's longtime work on the behalf of home caregivers earned him a trip to Washington, D.C., this past week.

Blalock was invited to DC by The National Alliance for Caregiving's for its 20th annual conference on March 21. The conference's theme was "The Next 20 Years in Caregiving."

Blalock, who is the clinical specialist for the Rush Health System's Senior Care Intensive Outpatient Program in Union, was appointed in 2014 by Gov. Phil Bryant to be the chair of the Mississippi Caregivers Task Force, which was initiated by state Sen. Terry C. Burton in 2013.

"The main goal of the task force was to provide a report to the governor or the legislature regarding the needs of caregivers in Mississippi," Blalock said. He said that home care-

givers are the some of the most unsung heroes of our society, and he wanted to be a part of the effort to give them the help and recognition they needed.

"They're an unseen population because most of the time they're at home taking care of someone and they can't really get out and advocate for themselves," Blalock said.

The task force's first recommendation was the creation of U.S. house bill HR 3099 or the RAISE (Recognize, Assist, Include, Support and Engage) Family Caregivers Act, which was sponsored by District 3 U.S. Rep. Gregg Harper.

This bill directs the Department of Health and Human Services to develop, maintain, and periodically update a National Family Care giving Strategy.

"It helps come up with ways on a national level to support caregivers," Blalock said. "I feel like it's a great thing for Mississippi that we have a Missis-



U.S. Rep. Gregg Harper, District 3 and his deputy policy director, Jordan Downs, right, visited with social worker Spencer Blalock, center, of Decatur, who chairs the Mississippi Caregivers Task Force during his recent visit to Washington D.C.

U.S. House of Representatives Photo

sippian who is trying to do something nationally for caregivers."

The task force also distributes cards that give caregivers information

about The Caregiver Act to hospitals and clinics around the state.

"Many times, the patient is discharged from the hospital and the caregiver may not know what their care responsibilities are," Blalock said. "The card allows them to be educated by the hospital regarding the needs of that patient so this is a step forward."

The task force also created the Mississippi Family Caregiver Coalition and Blalock serves on the coalition's steering committee.

Blalock said that although much progress has been made, he would continue to strive for aid for caregivers; which can include children, grandchildren, parents, siblings, neighbors, friends, spouses, partners, church members, across the state and the nation.

"Although we turned in that report, if we don't keep the voice active then other priorities will take precedent," he said. "So we want to make sure that the voices of caregivers are heard and that we are the advocates for that."

Definitions

- Respite care is defined as “planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult” (ARCH Respite, n.d.)
- Policy agenda is defined as “the list of subjects or problems to which policymaker and people outside of government closely associated with those officials, are focused on at any given time. Policy agenda setting is the process of adopting a social issue or problem as a policy problem and working towards making the issue an issue requiring government intervention” (Kingdon, 2011)

Extent of Respite Policy in Mississippi

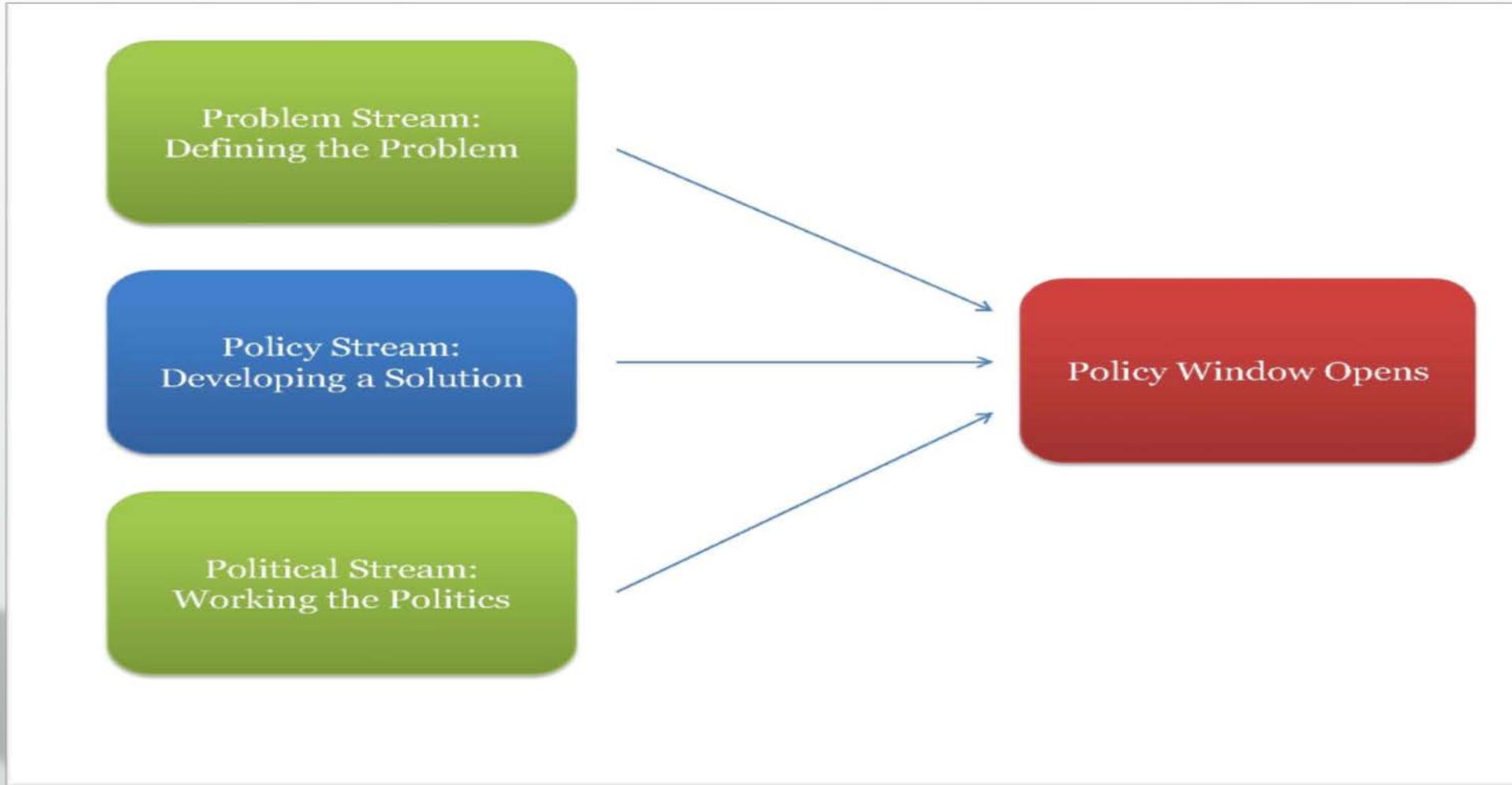
Program	Receiving Services	Waiting List	Respite Available	Responsible Agency
Bridge to Independence (Demonstration Grant)	235	None	No	Mississippi Division of Medicaid
Independent Living Waiver	2,424	1,225	No	Mississippi Department of Rehabilitation Services
Traumatic Brain Injury/ Spinal Cord Injury Waiver	858	None	Yes	Mississippi Department of Rehabilitation Services
Elderly and Disabled Waiver	15,064	4,797	Yes	Mississippi Department of Human Services
Assisted Living Waiver	605	200	No	Mississippi Division of Medicaid
ID/DD Waiver	2,132	1,781	Yes	Mississippi Department of Mental Health

Table 1: Mississippi Medicaid Waiver Programs including Respite for 2015 *Source: (T. Creel, personal communication, October 23, 2015)*

Evidence about Policy for Respite Care

- 30 States have developed policy through statute
- Alabama started a coalition in 2000 to develop services to support caregivers and in 2012 the legislature enacted law to support respite
- Texas recently developed policy on a legislative level for Senate Bill 271 and House Bill 802 that created a respite network
- In addition the following states have recognized policy agendas for Respite: Arizona, California, Colorado, Connecticut, Delaware, District of Columbia, Hawaii, Illinois, Kansas, Louisiana, Massachusetts, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Tennessee, Virginia, Washington, and Wisconsin

Kingdon – Policy Streams (2011)



Senator Terry C. Burton – President Pro Tempore of the Mississippi Senate

“I have seen people across the state who have major struggles juggling the responsibilities to care for others, maintain employment, take care of home responsibilities, and sustain their own health and sanity. Seeing the real-life struggles of Mississippians gives me energy to make these major supports a reality. Let me say, Mississippi’s caregivers deserve respite that is supported through a state plan that addresses the needs of all caregivers. I have served in the legislature for 24 years and I have always pushed for improving access to supports for caregivers. You have my commitment to do all in my power to help bring this to pass. We’re on the right track but we need each of you passionate people willing to put forth energy to

sustain these efforts.” [The Daily News](#), 1/11/2017

...people. Each caregiver helps make it possible for older adults and people with disabilities to live independently in their homes and communities. Respite is one of the most frequently requested support services among family caregivers; however, the vast majority of family caregivers still go without it. With access to respite services, family caregivers are given the opportunity to recharge as they continue to face the physical, emotional, and financial challenges of caregiving. Access to respite services has been shown to ease that burden, improving caregiver health and promoting family stability.”

Representative Gregg Harper (R-MS) of U.S. House
(J. See, personal communication, March 30, 2016)



Policy Can Be Useful for Changing Population Health

Health policies in the United States are driven by issues that impact public welfare and safety. They generally do not rise to the level of becoming public policies without first having been evidenced as impacting public wellbeing and safety. A history of policy development related to current laws for seat belts in motor vehicles and tobacco use will be useful as a demonstration of how an issue evolves to the point of becoming law.

Seat Belt Safety

Patented in 1885, it took until 1984 for the State of New York to legislate seat belt usage. 48 states have made similar laws. Due to a strong policy agenda for seat belt safety, hundreds of thousands of lives have been saved.

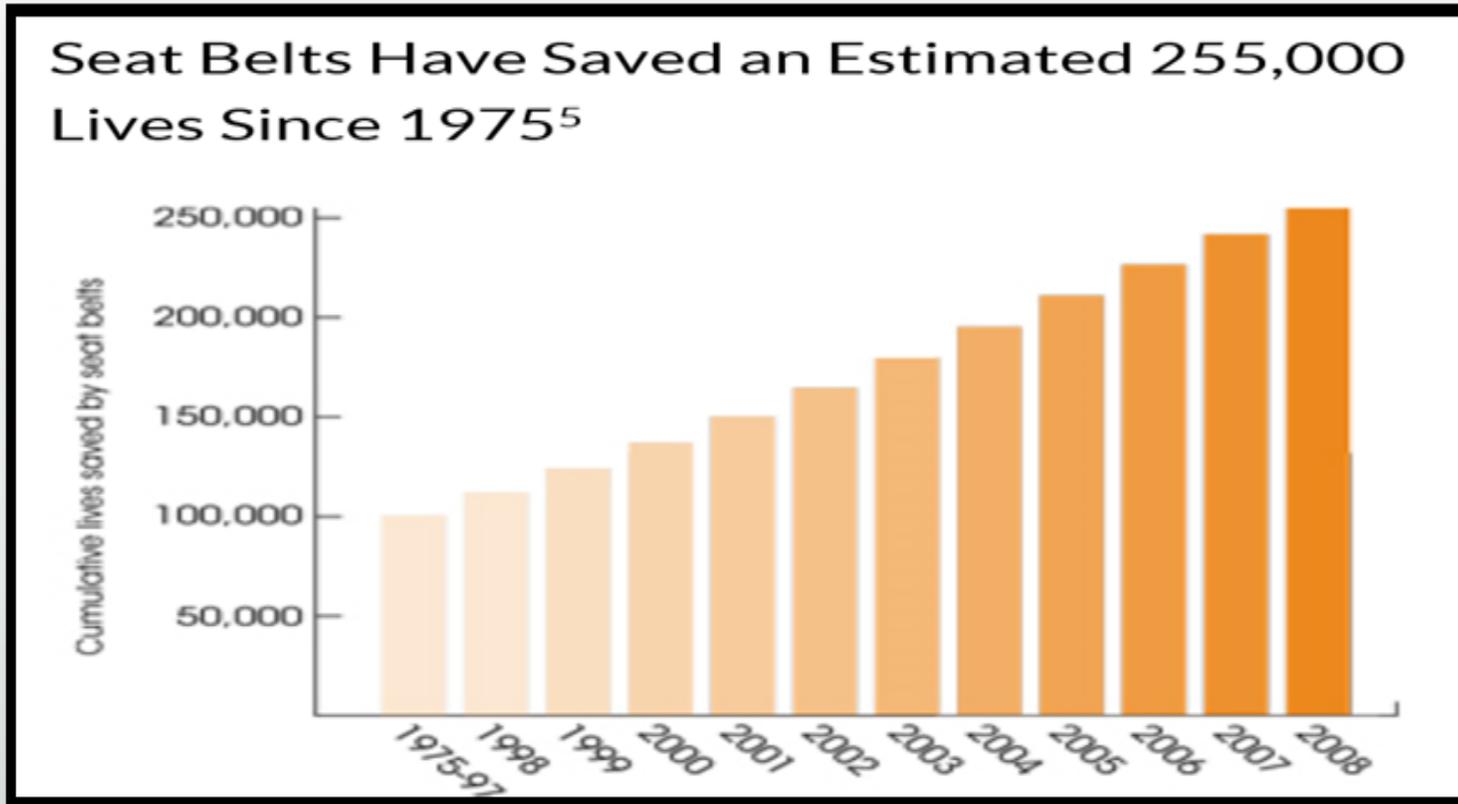
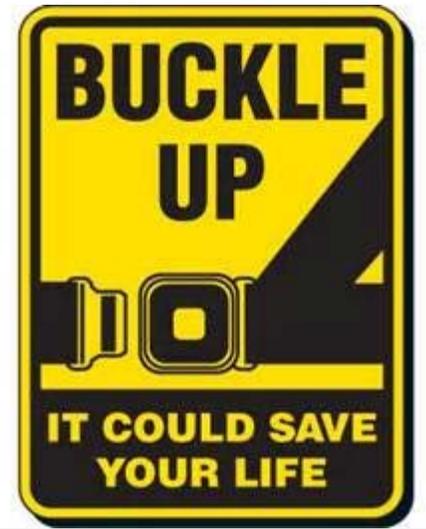


Figure 2: Lives Saved by Using Seat Belts Since 1975 (Source: Centers for Disease Control and Prevention, 2014)

Tobacco Control

With the discovery of the Western Hemisphere in the 1400's came the introduction of tobacco into the lives men, women, and children worldwide. It was not until 1946 that two prominent physicians asserted that tobacco was a culprit in cancers of the respiratory system. In 1957, the U.S. Surgeon General reported that tobacco was a serious health threat. In 1964, a separate U.S. Surgeon General made an emphatic report that tobacco was dangerous to health. In 1965, the U.S. Surgeon General required labeling on all tobacco, "Caution: Cigarette Smoking May Be Hazardous To Your Health". It took 19 years from negative report to policy change, but a policy agenda made the difference.

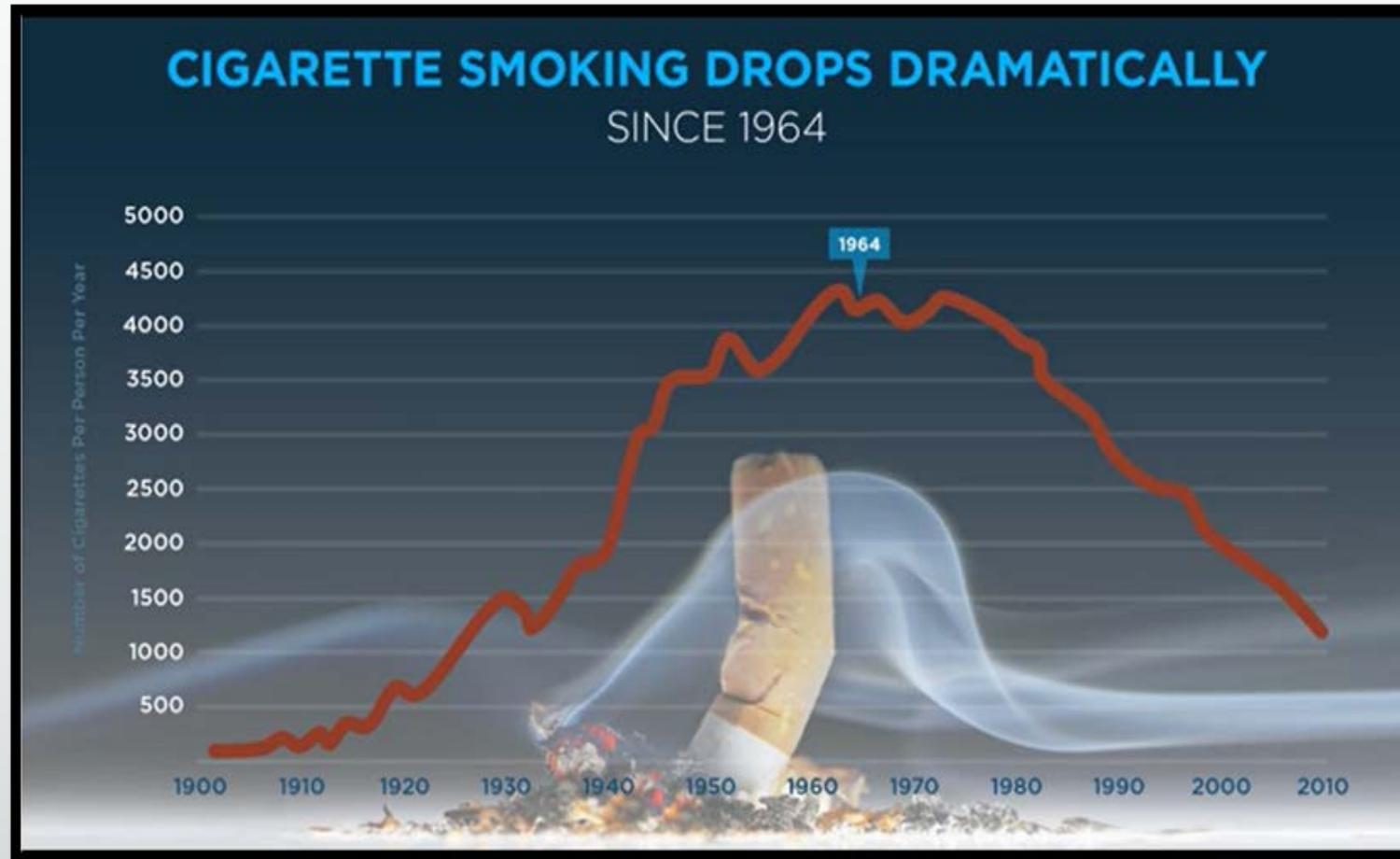


Figure 3: Change in Tobacco Usage Since Surgeon General Policy Agenda (Source: Robert Wood Johnson Foundation, n.d.)

Lives Saved Since Tobacco Control Policy Agenda Initiated

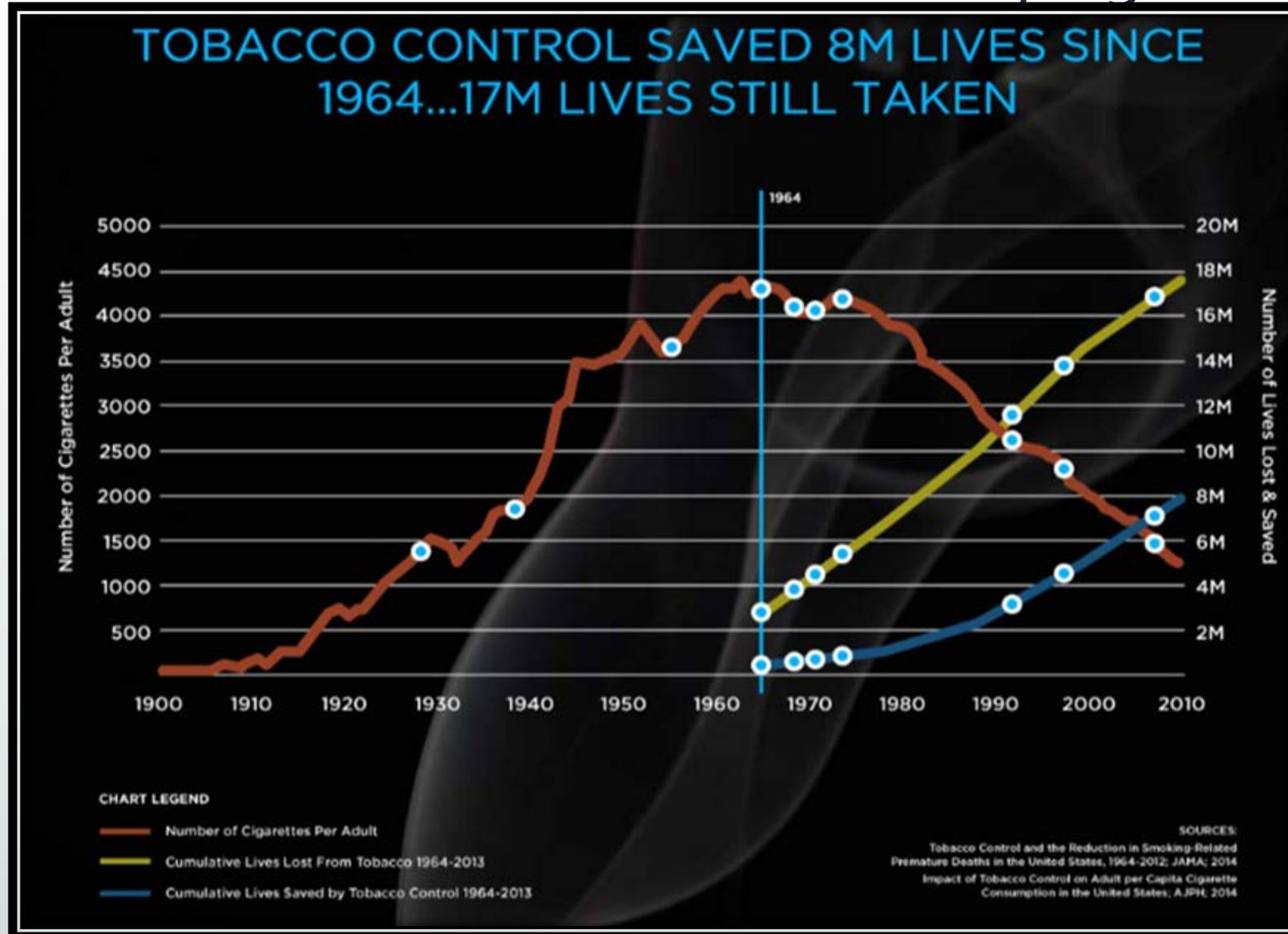
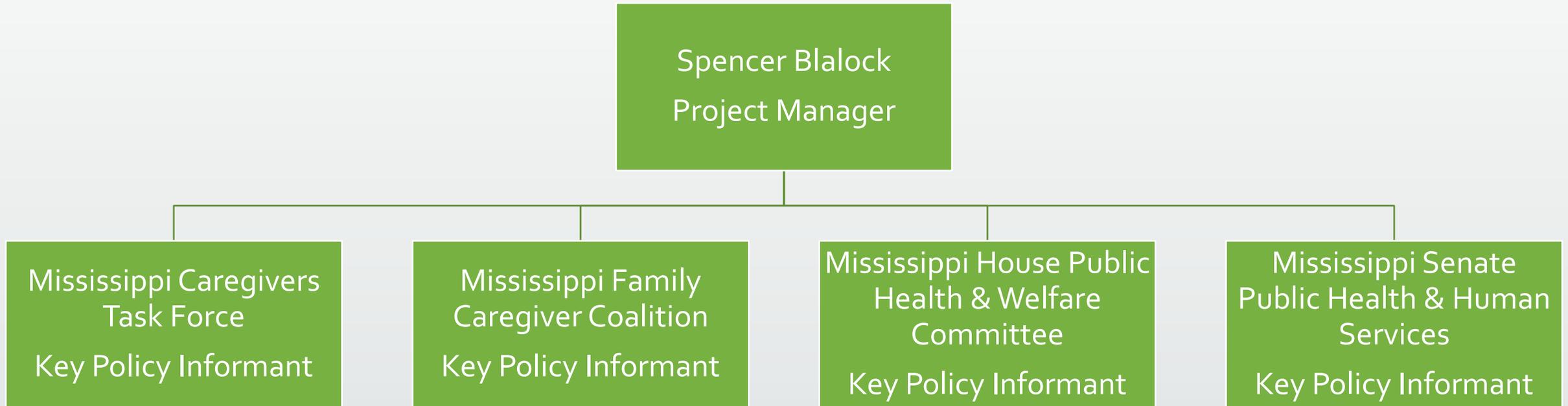


Figure 4: Lives Saved Through a Policy Agenda for Tobacco Control (Source: Robert Wood Johnson Foundation, n.d.)

Key Policy Informants



Delphi

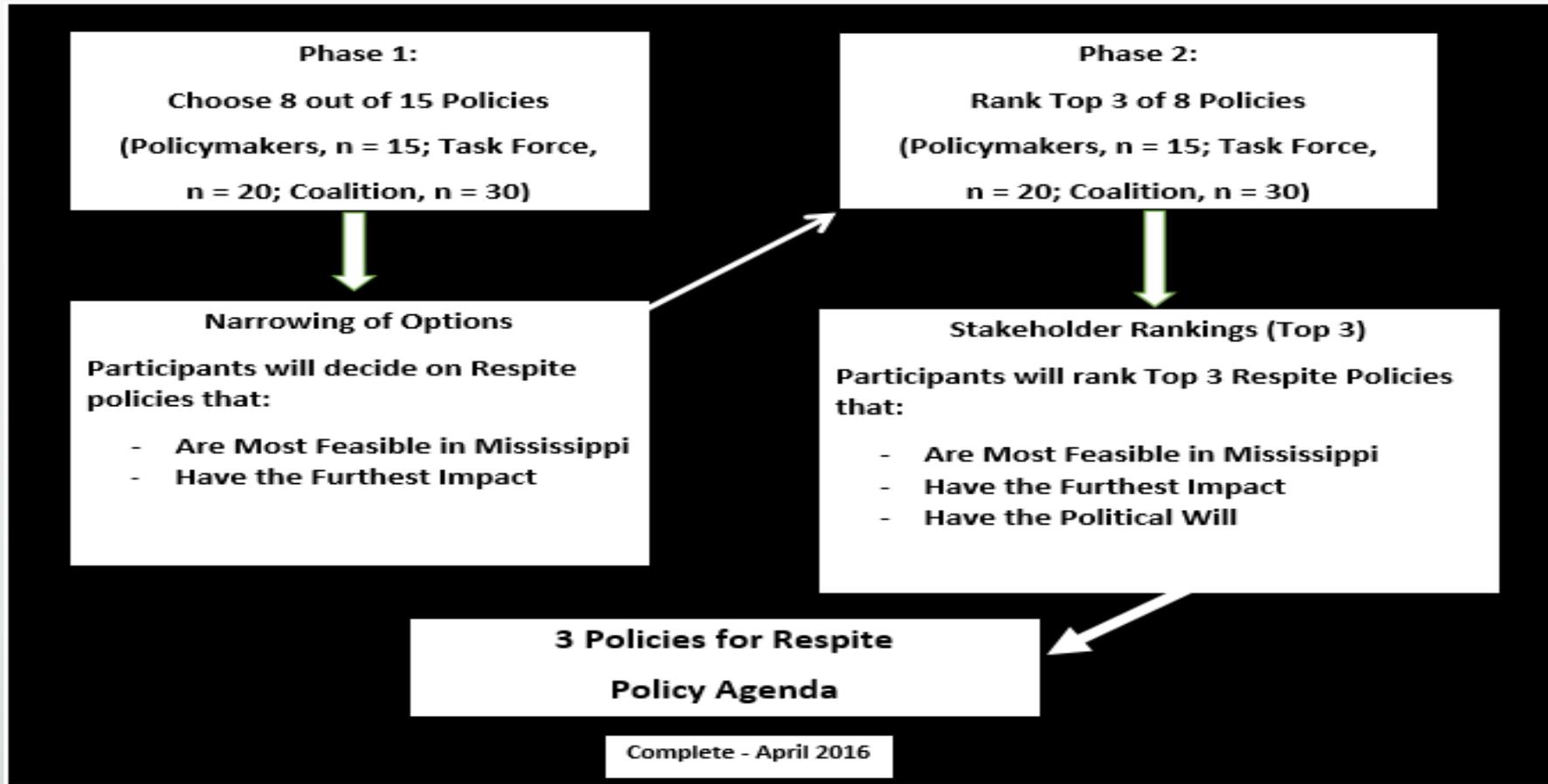
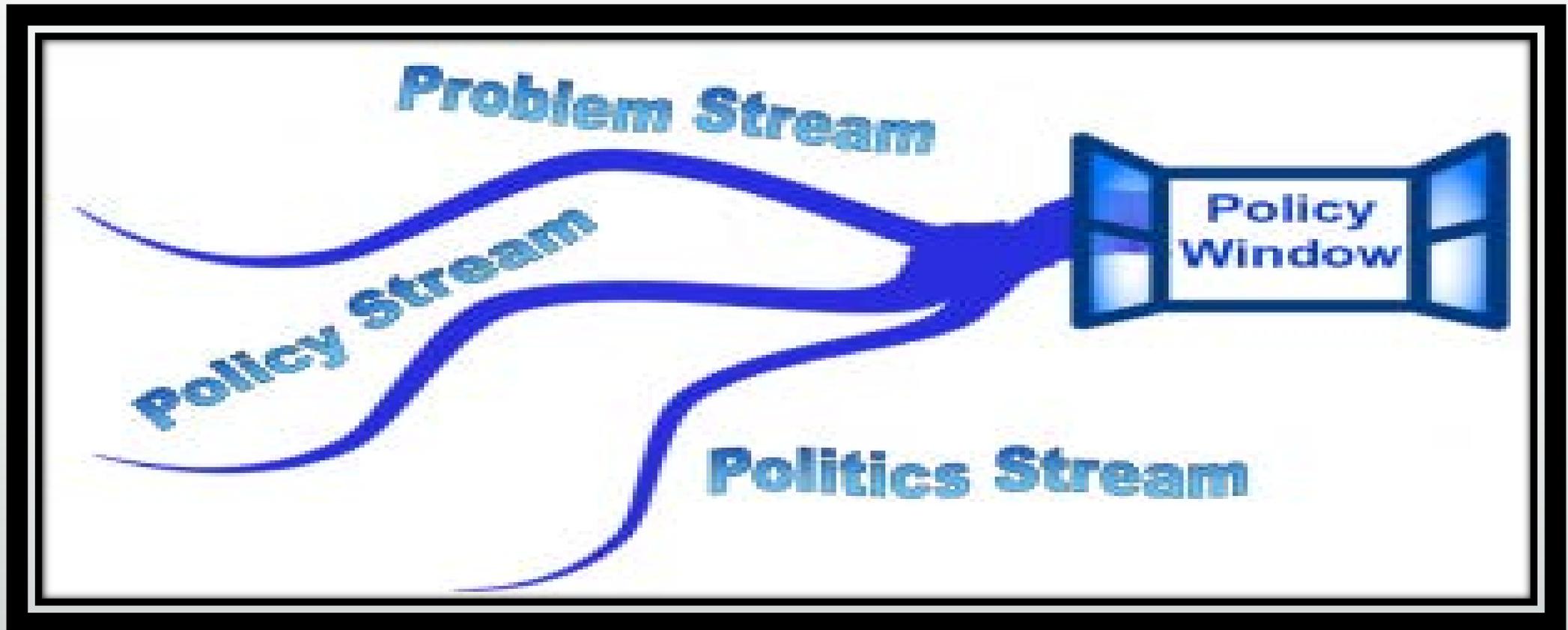


Figure 1: Delphi Method Used for Consensus

Evidence of the Power of Policy

Policy does not happen by chance;

Kingdon's Three Streams must converge



Extent of Respite Policy in Mississippi

2011 - 2016, the Mississippi Legislature has mentioned respite 98 times in bills. None of the bills have been related to creating respite policy.

Year	Department of Mental Health	Mental Health Reform Act	Children's Mental Health	Day Camps	Special Education Reform	Medicaid & Human Services	State Property	Criminal Cases & Pardons & Background	Child Care Facilities	Long-Term Ins.	Care-givers
2016	2	-	-	-	1	3	1	1	-	-	-
2015	-	-	-	-	3	-	-	1	-	-	-
2014	3	-	-	1	-	-	3	1	1	6	2
2013	18	-	1	-	-	1	4	1	-	-	-
2012	8	3	1	-	-	-	-	7	3	-	-
2011	2	10	2	-	-	1	-	3	-	-	-
Total	33	13	4	1	4	5	8	14	4	6	2

State Level Respite Policy

“When you are looking for solutions to problems in Mississippi, you may see laws and policies in other areas of the country that look impressive and admirable. These may be, in actuality, good solutions. However, I would encourage you to look at our close neighbor states for solutions. The legislature and governor are leery of solutions from far away where circumstances, such as demographics, socio-economic status, worldview, and the like, are likely much different than that of Mississippi. Our neighbors have circumstances much like our own and have probably fought some of the same fights we will have to face” (T. Burton, personal communication, May 20, 2014).

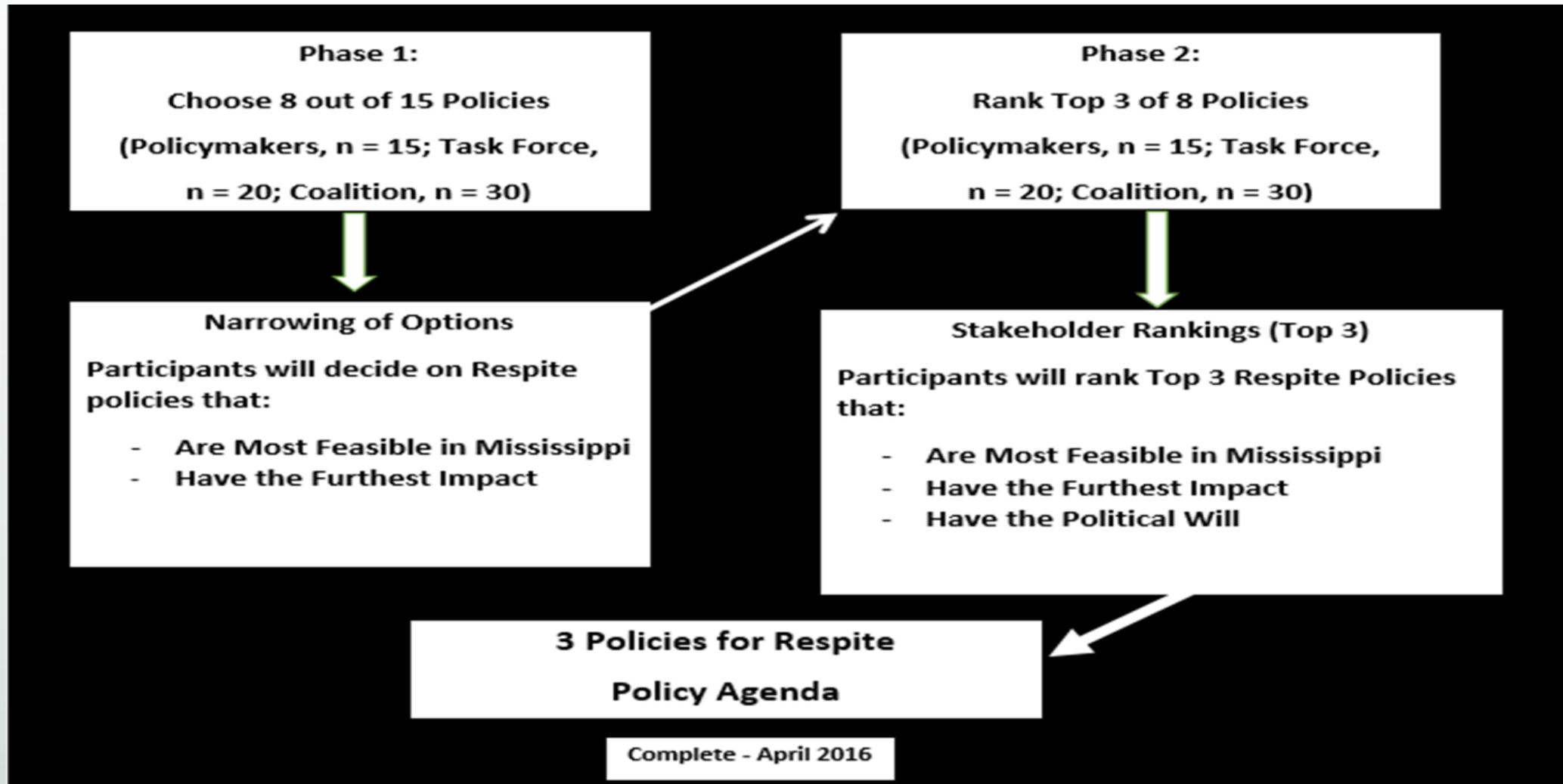
Fifteen Policy Examples through Legislative Action

- Alabama - Legislature created the Alabama Lifespan Respite Network Act (2012) to: Coordinate respite resources, provide training to respite providers, serve as a point of contact for respite issues, provide vouchers as funds are available for primary caregivers, and keep state educated on respite needs through the Alabama Respite Coalition
- Arizona - Legislature created the Arizona Lifespan Respite Network Act (2005 and 2016) to: establish respite for those not currently receiving through another service, coordinate other respite services already provided in other settings, identify training resources, perform a statewide needs assessment, create a respite care quality assurance survey
- California - Legislature created the Lanterman Act of 1969 to support individuals with developmental disorders, including respite for primary caregivers
- Colorado - Legislature created a Respite Care Task Force (2015)
- Colorado – Legislature passed a bill to support respite through a surcharge on crimes against at-risk seniors and juveniles (2012)
- Colorado – Legislature appropriated funds to support respite in the amount of \$150,000 for SFY14; \$250,000 for SFY15; and \$350,000 for SFY16
- Nebraska - Legislature created Nebraska Respite Network (1999) to: with Respite Coordinators who are responsible for Information and Referral for families needing access to respite, recruitment of respite providers, marketing activities to increase the public's awareness of respite, coordinating training opportunities for providers and consumers, and quality assurance and program evaluation
- Nebraska - Legislature appropriated funds for respite care vouchers through the Department of Health and Human Services for individuals with special needs across the Lifespan based on need and income of the caregiver for planned need or emergencies
- New Hampshire - Legislature set wording for Respite Care for Individuals with Alzheimer's Disease (1991) at "appropriate fees" versus a fixed \$900 per year for family caregivers
- New Hampshire - Legislature passed a concurrent resolution for facilitate short-term admissions the skilled nursing facilities for the purpose of respite care by cutting down the admissions process (2008)
- New York – Legislature appropriated \$931,500 to the New York State Office for the Aging to support respite care for individuals over 60 years of age in SFY 2014
- North Carolina - Legislature created a commission to study Respite Care in order to improve service delivery and utilization (2007)
- South Carolina - Lt. Governor's Office funded Respite Vouchers in the amount of \$3 million
- Texas - Legislature created Lifespan Respite Program (2009) and appropriated \$1 million to support informal caregivers through Respite Care
- Wisconsin - Legislature (1999, 2009) created respite care options for parents with disabled children as well as foster parents, elderly and disabled; appropriations of \$225,000 General Purpose Revenue annually to support respite

Six Common Policies for Delphi Surveys

- Create a Lifespan Respite Network through a state agency to coordinate respite resources, provide training to respite providers and serve as a point of contact for respite issues facilitated through a single state agency.
- Provide vouchers with state funds for primary caregivers in a home setting.
- Set up a state funded Respite program to document and support respite services already provided in non-home settings, identify training resources, perform a statewide needs assessment, create a respite care quality assurance survey.
- Employ a respite coordinator within a state agency who will be responsible for information and referral for families needing access to respite, recruitment of respite providers, marketing activities to increase the public's awareness of respite and coordinating training opportunities for providers and consumers.
- Facilitate short-term admissions to skilled nursing facilities for the purpose of Respite Care by cutting down the admissions process.
- Provide respite care training to providers coordinated through a single state agency.

Delphi Survey – Phase 1 and Phase 2

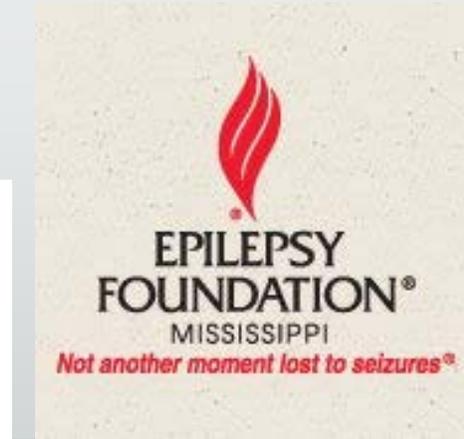
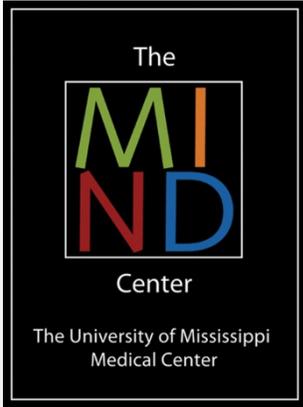




MISSISSIPPI
STATE DEPARTMENT
OF HEALTH



MHCA
Mississippi Health Care Association



Mississippi Family Caregiver Coalition



Legislators



Delphi Survey – Phase 1

- Anonymous online survey sent to 65 individuals from April 22 – May 6, 2016:
 - Mississippi Caregivers Task Force
 - Mississippi Family Caregiver Coalition
 - Mississippi House Public Health and Welfare Committee
 - Mississippi Senate Public Health and Human Services Committee
 - The Question: “Out of the six policy examples, choose the top three options by the following criteria: Furthest Reach in Mississippi (impacting the most people across the lifespan) and Most Feasible for our state. The examples are listed in no particular order or rank. Merely choose three.”
- Twenty-eight (28) Responses Received = 43% response rate

Three Priorities Selected from Delphi - Phase 1

- Create a Lifespan Respite Network through a state agency to coordinate respite resources, provide training to respite providers and serve as a point of contact for respite issues facilitated through a single state agency.
- Employ a respite coordinator within a state agency who will be responsible for information and referral for families needing access to respite, recruitment of respite providers, marketing activities to increase the public's awareness of respite and coordinating training opportunities for providers and consumers.
- Provide vouchers with state funds for primary caregivers in a home setting.

Delphi - Phase 2

- Anonymous online survey sent to 65 individuals from May 10-18, 2016:
 - Mississippi Caregivers Task Force
 - Mississippi Family Caregiver Coalition
 - Mississippi House Public Health and Welfare Committee
 - Mississippi Senate Public Health and Human Services Committee
 - The Question: “Out of three policy examples selected during the first Delphi Survey, please determine the rank of the top three by the following criteria: Furthest Reach in Mississippi (impacting the most people across the lifespan), Most Feasible for our state, and for which there is the most Political Will (commitment to take policy action): The examples are listed in no particular order or rank. Merely select the rank of 1st, 2nd, & 3rd in the order you feel fits the above criteria.”
- Twenty-nine (29) responses received = 45% response rate

Top Choice from Delphi – Phase 2 for Policy Agenda

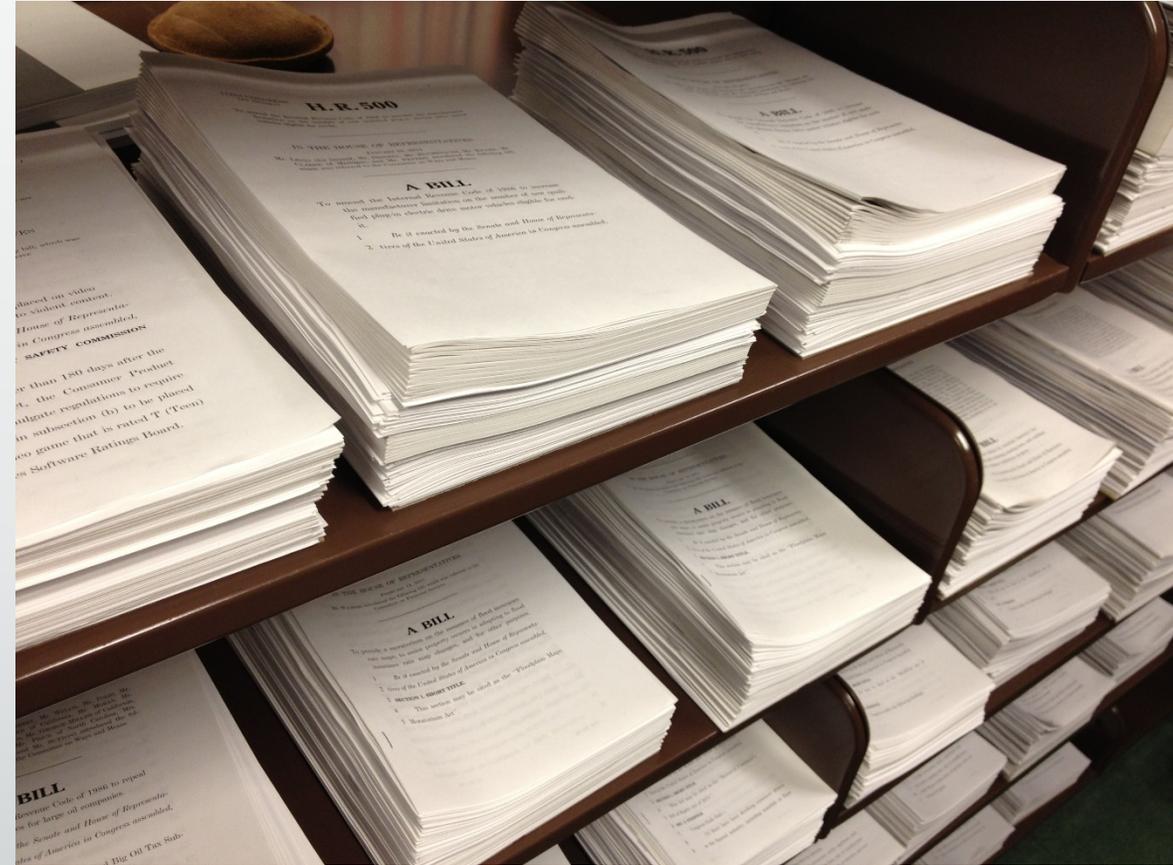
- 1st - Employ a respite coordinator within a state agency who will be responsible for information and referral for families needing access to respite, recruitment of respite providers, marketing activities to increase the public's awareness of respite and coordinating training opportunities for providers and consumers.

Question to be Answered

"Can the Mississippi Caregivers Task Force, Mississippi Family Caregiver Coalition, and State Legislators agree on a common set of policies to address respite care in Mississippi?"

Answer: 'Yes'

The Next Challenge



Limitations

- 2,000+ Bills per 90-day session
- Extremely tight budget
- Caregivers have little voice as they are often overwhelmed with caregiving = Difficulty self-advocating
- Political climate: of the few that were contacted, who truly understands and is willing to take a stand and champion the issue?

Chartered Course

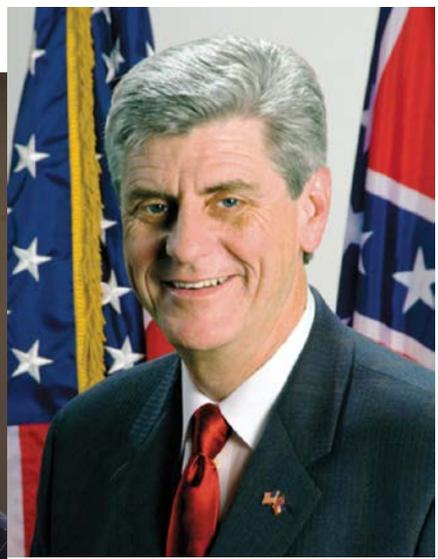
- Policy examples have been selected by a diverse group of policy informants
- Financial benefits of supporting Respite Care (eg, cost savings for uncompensated caregiving, prolonged care at home vs. institutional care) will need finessing

"Employ a respite coordinator within a state agency who will be responsible for information and referral for families needing access to respite, recruitment of respite providers, marketing activities to increase the public's awareness of respite and coordinating training opportunities for providers and consumers."

Dissemination Plan

Group	Activity	Completion Date	Follow-up Date
Mississippi Caregivers Task Force	Send email with results of Delphi surveys and Policy Recommendations	July 22, 2016	July 26, 2016
Mississippi Family Caregiver Coalition	Send email with results of Delphi surveys and Policy Recommendations	July 22, 2016	July 26, 2016
House Public Health and Human Services Committee	Send email with results of Delphi surveys and Policy Recommendations	July 22, 2016	July 26, 2016
Senate Public Health and Welfare Committee	Send email with results of Delphi surveys and Policy Recommendations	July 22, 2016	July 26, 2016
President Pro Tempore of the Mississippi Senate	Send letter with results of Delphi surveys and Policy Recommendations	July 22, 2016	July 26, 2016
Speaker of the Mississippi House	Send letter with results of Delphi surveys and Policy Recommendations	July 22, 2016	July 26, 2016
Lt. Governor	Send letter with results of Delphi surveys and Policy Recommendations	July 22, 2016	July 26, 2016
Governor	Send letter with results of Delphi surveys and Policy Recommendations	July 22, 2016	July 26, 2016
House Public Health and Human Services Committee	Meet with Committee Chair and Co-chair	August 31, 2016	September 5, 2016
Senate Public Health and Welfare Committee	Meet with Committee Chair and Co-chair	August 31, 2016	September 5, 2016
President Pro Tempore of the Mississippi Senate	Meet with	August 31, 2016	September 5, 2016
Speaker of the Mississippi House	Meet with	August 31, 2016	September 5, 2016
Lt. Governor	Meet with	August 31, 2016	September 5, 2016
Governor	Meet with	August 31, 2016	September 5, 2016

Mississippi Legislature and Executives



Steps after Dissemination

- ❖ Identify a policy champion in the House and Senate who has the political energy and motivation to influence his or her peers
- ❖ Draft a bill to support one of the policy options chosen in the Delphi surveys before September 2016
- ❖ Secure one legislator in the Senate and one legislator in the House to sponsor the bill in January, 2017; Seek commitments for multiple co-sponsors from each chamber to support the passage of a bill supporting Respite Care in Mississippi

New Considerations to Impact Political Will

- Political Will may be defined simply as “commitment to policy action”

Pacheco and Boushey (2014) assert the following factors strongly impact political will:

- Governor mentions particular health issue in the State of the State address
- Neighboring state is paying more attention to the issue and making policies related to it
- The state may be the recipient of federal funds through grants for particular health issues
- Highly professional legislative body (eg, educated, seasoned in variety of fields)
- Democrats are more likely to author health-related bills

Browson, Dodson, Kerner, and Moreland-Russell (2015) also found the following:

- The source of the information regarding health issue was important (relevance, delivered by someone respected, supports one’s own position)
- Telling a story from constituents regarding health issue
- Timeliness matters – is it a high current state priority and feasible when information is received?
- Results suggest the importance of short narrative forms of communication relevant to the policymakers’ constituents in a brief, concise format

What's Happened Since Then?

- We received the grant to support the creation of a Lifespan Network
- We started training Respite Trainers (R.E.S.T.)
- We had a Respite bill but it died earlier this year
- We continue to meet to push this agenda forward and create stronger networks to enforce this major issue

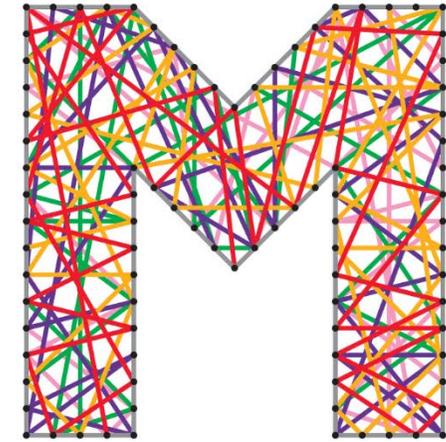


Conclusion

Reaching consensus among the Mississippi Caregivers Task Force, The Mississippi Family Caregiver Coalition, and members of the House Public Health and Human Services Committee and Senate Public Health and Welfare Committee will be a first step in a successful strategic approach to respite policy in Mississippi. Leaders in these groups are poised to propose policy solutions. This process will raise awareness and set the stage for a policy agenda for the state. This policy agenda may improve resources for caregivers and has the potential to impact delivery of care.

Spencer Blalock

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