

# Advocacy for Children

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Paul A. Harper Lecture

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# Dr. Paul A. Harper



- Worked to eradicate Malaria in WWII
- Authored Preventive Pediatrics, Child Health, and Development (1962)
- Chaired Maternal and Child Health and later Population Dynamics
- Established a Baltimore pediatric clinic and a family planning program in Bangladesh

# Themes

- Pediatrics is prevention
- Focus on outcomes
- Be practical

# Why Advocate for Children?

- Poverty
- Birth outcomes
- Health outcomes
- Life outcomes
- Disparities



# More than Economics

- Poverty is a risk factor for many adverse health outcomes
- But many non-poor children suffer from significant health and life challenges, including mental illness, substance abuse, and school failure
- Poor health—poverty link is bidirectional

- *Advocacy: The act of pleading or arguing in favor of something, such as a cause, idea, or policy.*

Source: American Heritage Dictionary

# Some Assumptions on Advocacy for Children

- Purpose is to improve children's health
- Success = children are healthier
- Must consider unintended consequences (can be positive or negative)
- Compromise can be fine ... if it leads to real progress and sets the stage for more

# What I Am Not Going to Cover

- What specifically to advocate for...that's up to you.
  - Have complete information
  - Consider alternatives
- My goal is to focus on the critical step between policy development and action – how do we get it done?

# Should Academics Advocate?

- (or should the person who knows the most about a problem not engage in the solution?)



# Strategies for Effective Advocacy

1. Pivot from treatment to prevention
2. Focus on outcomes
3. Be practical



# Strategies for Advocacy

1. Pivot from treatment to prevention
2. Focus on outcomes
3. Be practical

# Rationale

- Illness in childhood is a powerful force for change
- Makes prevention concrete
- Provides answer for why public policy intervention is required

# A Child

- 14-month-old girl with a 2-week history of a diaper rash that then generalized, associated with body swelling, light hair, and pallid skin.



# More History

- Breastfed until 8 months
- Did not tolerate formula
- Switched to rice-based “milk”

# Diagnosis: Kwashiorkor

- Body requires 1-2 g/kg/day of protein
- Rice-based beverages <1 g per 8 oz
- At least 12 cases of kwashiorkor in literature from rice-based beverages, including deaths

## Marketing of Rice-Based Beverages (2005)

- Rice Dream: “Complete nutrition – Rice dream is enriched with the same amount of Calcium, Vitamins, A, D & B12 found in milk.”
  - Website: Nutritional profile is “similar to milk.”
- WestSoy Rice Beverage:

Exploring alternatives to milk? Don't skip our delicious WestSoy Rice Beverage or you'll miss out on a refreshing, nutritious drink you're sure to love! It tastes so good, and it's enriched with calcium and vitamins A and D, making it a perfect choice for people who don't drink dairy milk.<sup>21</sup>

# Stepping up the Pressure

- Research Paper: Katz, K et al. Rice Nightmare, Journal of the American Academy of Dermatology, May 2005.
- Press: *Philadelphia Inquirer*
- Government: Congressman Henry A. Waxman letter to FDA

# Results

- Most packages and websites now advise against use by kids under 5 unless advised by physician

# A Child

- 9 month-old boy referred for evaluation of crying and fever.
- Febrile but clinically stable in the emergency department; laboratory values normal.
- Sent home after antibiotic shot and asked to return in the morning.

- 12 hours later, infant returned in full cardiopulmonary arrest
- Pronounced dead after 20 min of cardiopulmonary resuscitation.

# Diagnosis: Drug Intoxication

- Postmortem blood and hepatic tissue analyses revealed markedly elevated levels of pseudoephedrine, phenylpropanolamine and dextromethorphan.

# The Baltimore Statement (2006)

- “The evidence shows that these products have no benefit, and the side effects may indeed cause harm”
- “Recommend that families be aware of these risks and not use over-the-counter cough and cold medications for children ages five and under.”

# Further Research

- OTC cough and cold meds approved through FDA monograph
- Never evaluated in pediatric population
- Not safe, not effective, not generally recognized as such

# FDA Petition

- Provide a statement to the public
- Take action against misleading marketing.
- Amend monograph labeling requirements.



# The New York Times

March 2, 2007

U.S. Reviewing Safety of Children's Cough Drugs

By GARDINER HARRIS

WASHINGTON, March 1 — Federal drug regulators have started a broad review of the safety of popular cough and cold remedies meant for children, a top official said Thursday.

The official, Dr. Charles J. Ganley, director of the office of nonprescription drug products at the Food and Drug Administration, said in an interview that the agency was “revisiting the risks and benefits of the use of these drugs in children” and that “we’re particularly concerned about the use of these drugs in children less than 2 years of age.”

# Results

- Companies pulled all cough-and-cold products for children under 2
  - Then, companies pulled products for under 4
- 2 studies show major declines in poison control calls and ED visits attributable to OTC cough and cold medications in young children

# Another child

- 12 year old boy
- Prince George's County
- Untreated dental abscess
- Meningoencephalitis and a subdural empyema

# Oral Health Statistics

- 42% of all Maryland children had untreated dental decay in 2001.
- Rates of decay highest on the Eastern Shore and in Baltimore City
- Significant gaps in access to care

# Key Advocates

- Governor O'Malley/Lt. Gov Brown
- Congressman Cummings
- Senator Mikulski
- Senator Cardin
- Congressman Sarbanes
- Dental Action Committee
- State and local officials and others

# Steps Taken

- Raise Medicaid reimbursement rates
- Improve oversight and payment
- Institute fluoride varnish

# Results

Before	After
743 dentists participating in Medicaid	1,057 dentists (41% increase)
46% of Maryland children served (2006)	59% served (2009, 28% increase)
No trained nondental varnish providers	400 trained pediatricians, family physicians, nurse practitioners

# Approach

- Pivot from treatment to prevention
- **Focus on outcomes**
- Be practical

# Rationale

- Good outcome measures are simple, understandable, engaging, and achievable.
- Also: Sustainable and flexible

# Infant Mortality



# What Does Not Work as Well

- Dozens of measures
- Overpromising specific programs
- Assuming only certain types of solutions are possible



# Examples of Governor's Delivery Unit Measures

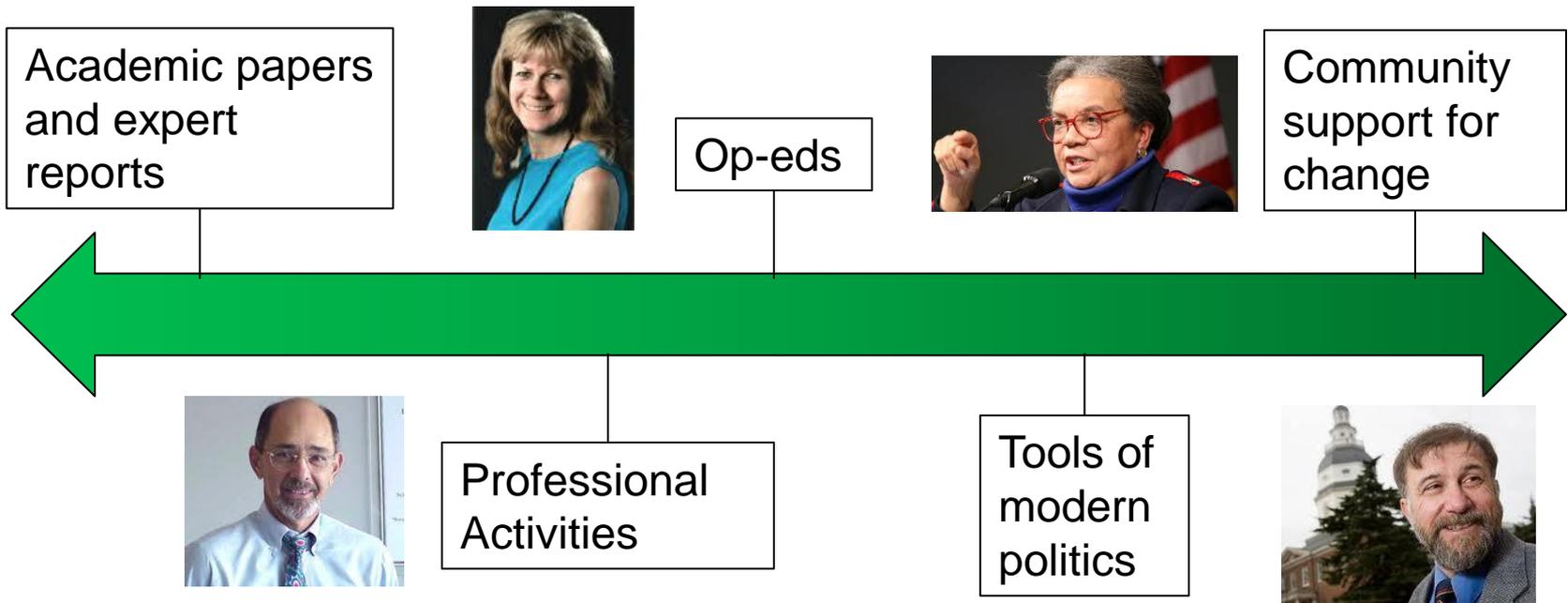
- Reduce violent crime by 20% by end of 2012
- Reduce domestic violence by 25% by end of 2012
- End childhood hunger in Maryland by 2015

<http://www.gov.state.md.us/statestat/gdu.asp>

# Approach

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# Spectrum of Advocacy



# Tools of Politics

(not a complete list)

- Polling
- Advertising
- Engaging the media
- Social media
- Phone calls and letter-writing
- Lobbying
- Alliances
- Compromise (when appropriate)

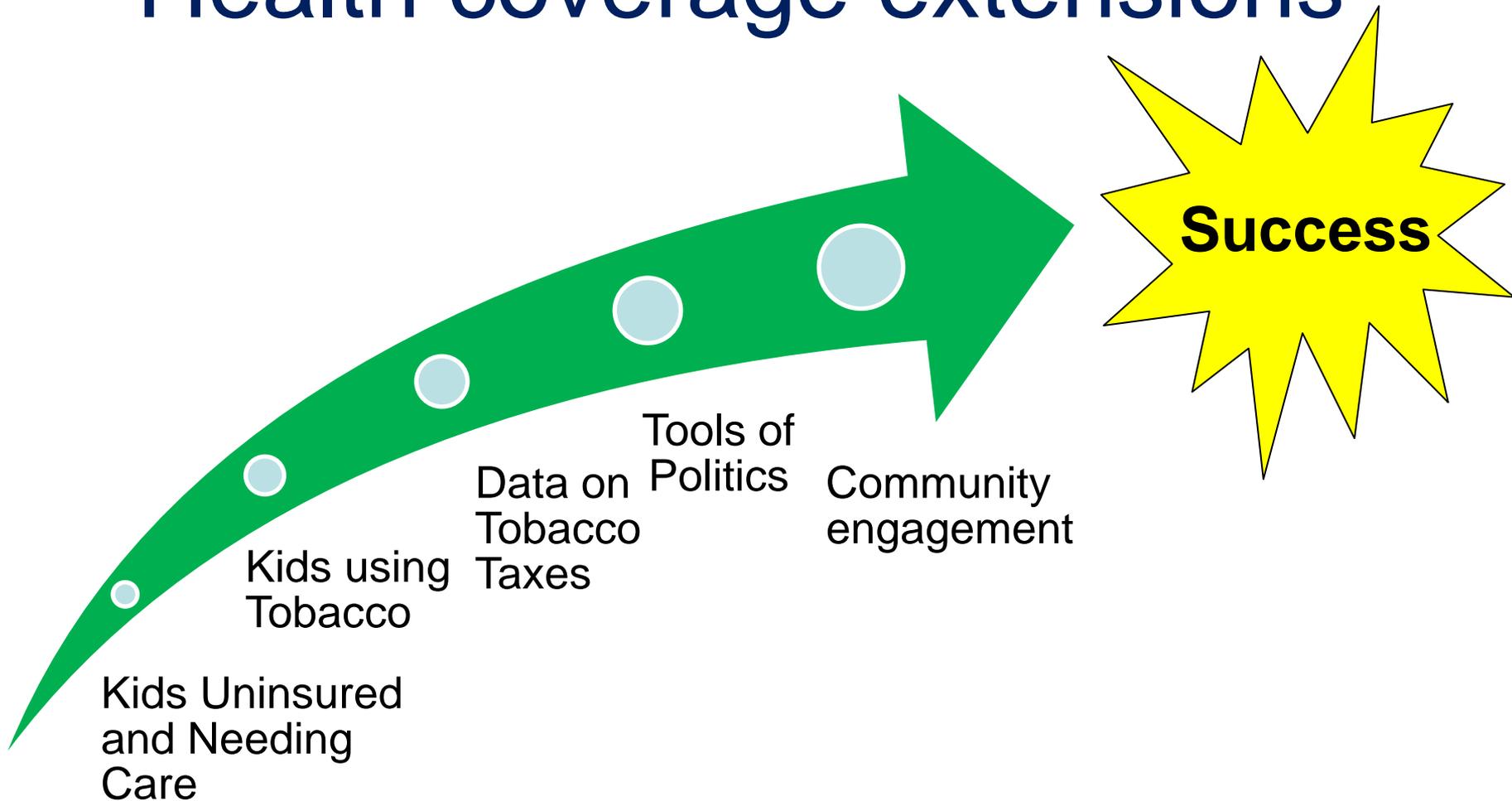
# When Is a Community Engaged?

- Priority for large number of people in a community
- Internal efforts to address problem
- External component needed to complement
- Key institutions speak out
- Leaders speak out

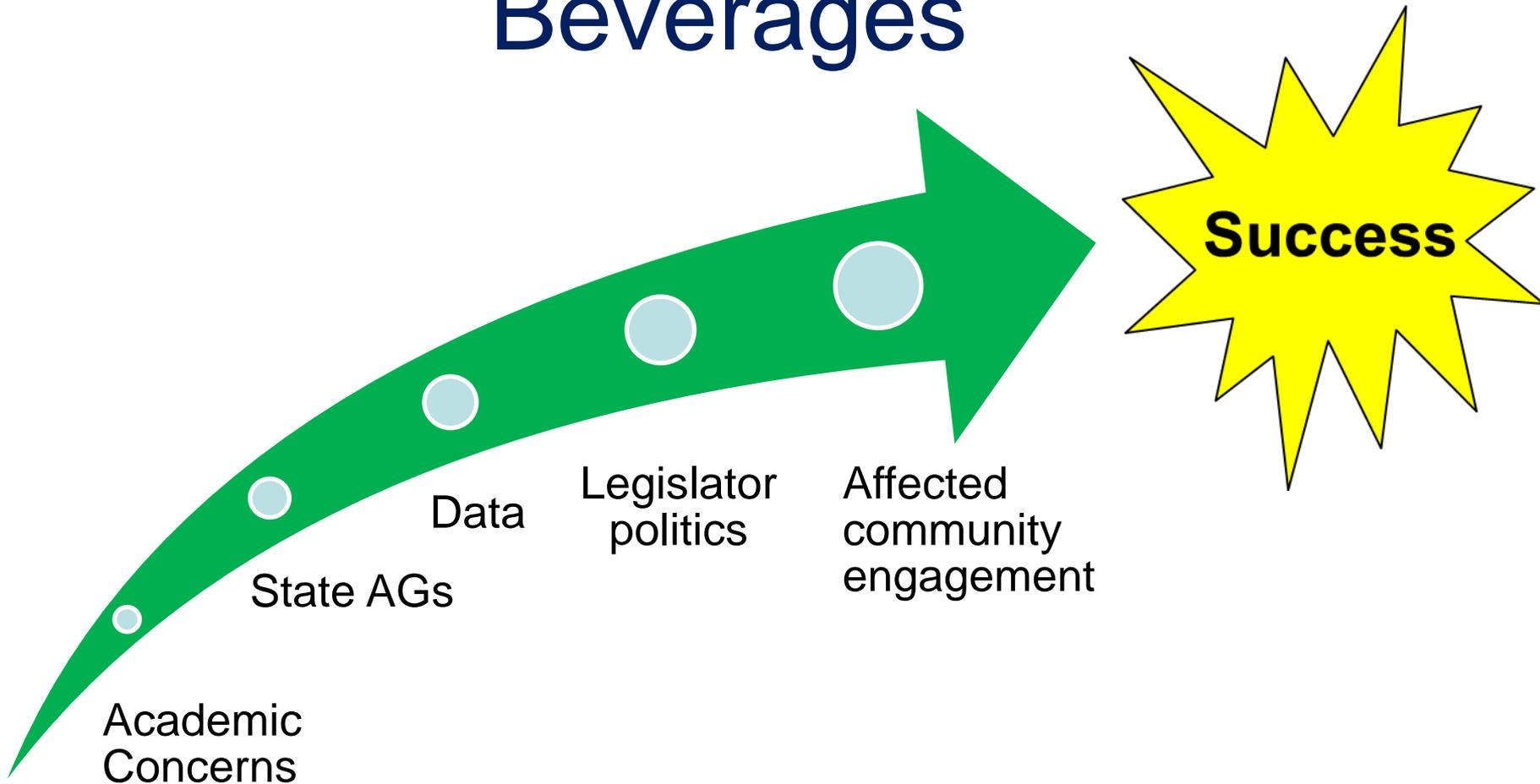
# In general

- The greater the opposition, the greater the number and range of advocacy approaches needed.
- The more persuasive the evidence and the more effective the advocacy for a solution, the easier it is for legislators and agencies to take action.

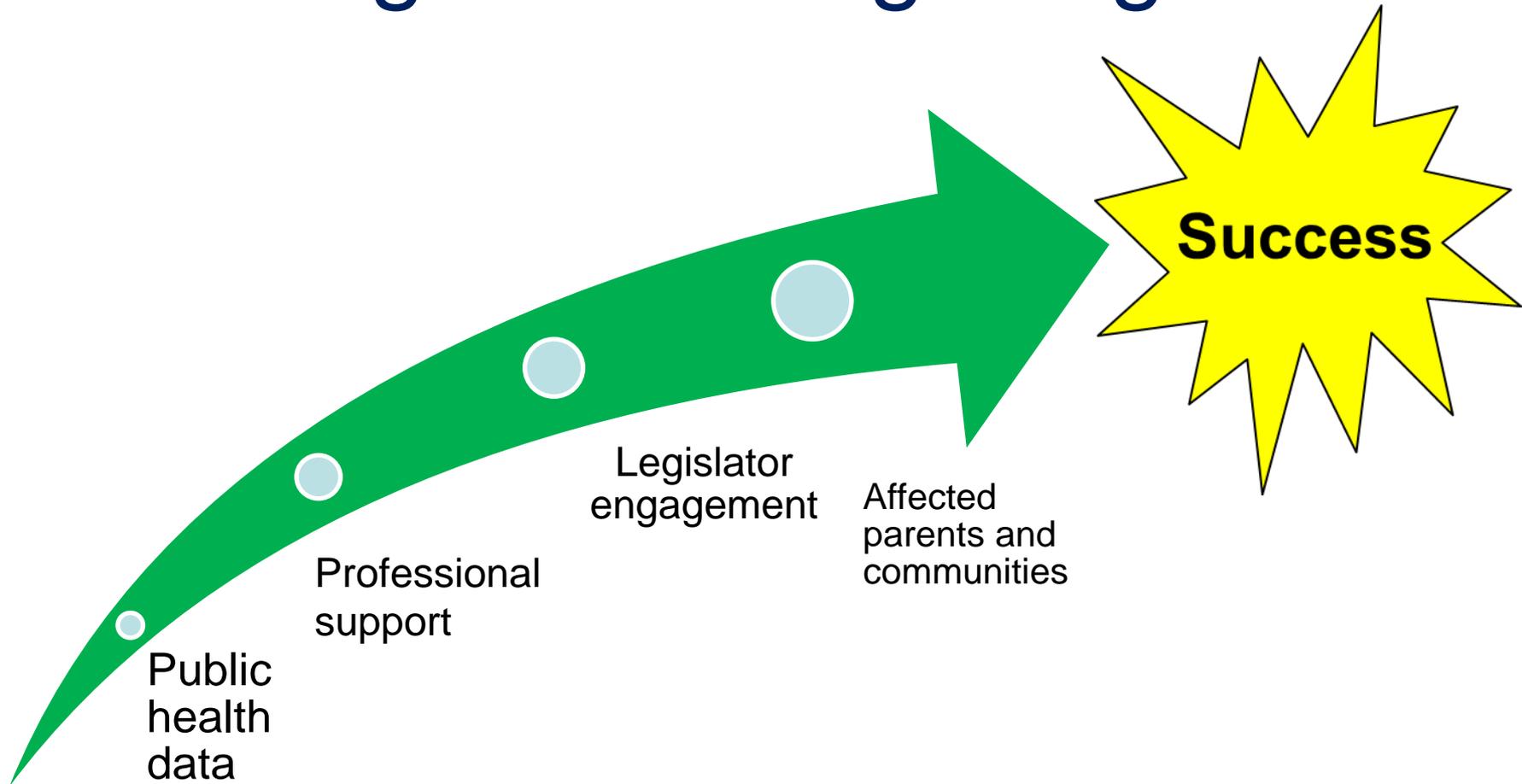
# Health coverage extensions



# Caffeinated Alcoholic Beverages



# Rx Drug Monitoring Program



# #Failure

- It happens
- Not a badge of honor ...
- ... but can be a learning experience
- Burning bridges is a bad idea
- Many failed efforts lay the groundwork  
future success

# Looking Ahead

- Filling the academic gaps (2 kinds)
- Cost a growing and cross-cutting consideration
- Social impact bonds and other creative solutions
- Moment of health care reform special challenge and opportunity ...