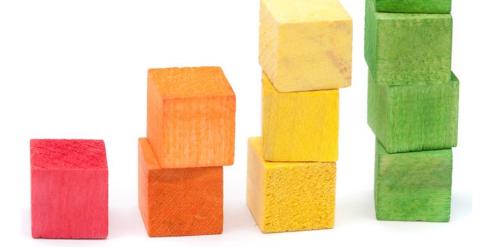


## Building Blocks for a Child Health Coalition



 $\ensuremath{\mathbb{C}}$  2021 National Association of Pediatric Nurse Practitioners

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APNAP's Health Policy Committee is pleased to offer you this new resource as you lead grassroots efforts to improve the health of children in your state. Don't think you need to go it alone – consider a coalition of

like-minded stakeholders to effect change. Henry Ford said, "Coming together is a beginning; keeping together is progress; working together is success."

Please reach out to <u>healthpolicy@napnap.org</u> as you consider and/or establish a child health coalition in your state.



# Background on the Importance of Coalition Building



#### What is a coalition?

A coalition is an alliance of organizations that come together for combined action. Coalitions form for the purpose of gaining more influence and power than the individual organizations can achieve on their own.<sup>1</sup>

#### Why is a coalition important in addressing child health issues?

Addressing a variety of child health issues requires comprehensive solutions. Coalition building can be a challenging but powerful tool for mobilizing individuals into action, bringing community actions to prominence, and developing policies.<sup>2</sup> They also serve as a way to integrate health services with other human services so that resources are not wasted or efforts duplicated.<sup>2</sup> Coalitions may form based on an assessment of data, may stem from an existing programmatic emphasis, or may be set by a funding mandate.<sup>3</sup>

#### What are the advantages and disadvantages of a coalition?<sup>4</sup>

Advantages of Coalition	Disadvantages of Coalition
Complex issues often require large numbers of people and many resources to win.	It takes time and resources to participate in a coa- lition. In the worst case, your work and the coali- tion's work may both suffer.
The best coalitions make your own work more effective, expand the understanding and experi- ence of your members, and provide opportuni- ties for your leaders to develop their skills.	To keep a coalition together, it is often necessary to compromise and sometimes play to the least common denominator, especially when it comes to taking action.
If the coalition's issue is central to your organi- zation, you may directly benefit from additional support and funding, and share resources to overcome deficiencies. The sum is often greater than the parts.	If all activities are done in the name of the coali- tion, groups that contribute a lot often feel they do not get enough credit.
A coalition may provide the opportunity for your group to work on state or national issues, thus expanding the scope and impact of your work.	The dynamics of experience, resources and power can create internal challenges.
By participating in a coalition you can learn from others and acquire new skills.	By joining a coalition, you are likely to lose some control over the message and tactical decisions.
A successful coalition can forge new partner- ships and understanding among organizations and constituencies with a history of stressful interactions.	By associating with other members of a coalition, your group may also be associated with the nega- tive aspects of those members.

<sup>1</sup> Western Organization of Research Councils: How to Work in Coalitions

<sup>2</sup> Prevention Institute. Eight steps to Effective Coalition Building.



<sup>&</sup>lt;sup>3</sup> Prevention Institute. Developing effective Coalitions. An eight step Guide, p.6.

<sup>&</sup>lt;sup>4</sup> Western Organization of Research Councils: How to Work in Coalitions

### **Before Diving into a Coalition**



#### **Research the facts**

Any child health issue worthy of advocacy and coalition building needs to be supported by evidence of the problem occurring in the state. Examples of important data points include<sup>5</sup>:

- the number of vaccine-preventable disease which occurred in the state that year
- the number of ED visits for traumatic brain injury
- the number of students who stay home from school or report physical symptoms from fear of being bullied
- the cost of screening for children with critical congenital heart disease
- the number of children injured in crashes involving a distracted driver
- the number of child poisonings due to liquid nicotine products
- the number of ER visits for asthma exacerbations related to environment
- the number of rifle and pistol magazines that have been used in mass shootings in certain states or the number of states banning assault weapons

#### Survey other states which have passed laws in particular child or family health areas.

- <u>National Council of State Legislatures</u>
- Kaiser Family Foundation (KFF)
- Georgetown Center for Children and Families
- Data Resource Center for Child and Adolescent Health
- The Network for Public Health Law
- <u>State Network</u> by Robert Wood Johnson Foundation

#### Before starting/joining a coalition, consider the following questions:

#### <u>Step 1</u>

Can the particular child health issue be addressed by the state?

- Typically, state child advocacy laws are directed toward certain vulnerable populations. Examples: services directed toward foster care children, child injury prevention, improved prenatal care, improving newborn screening, advocacy for early intervention services for Medicaid recipients, increasing home visitation services.
- The Federal government is usually involved with broader child health advocacy issues that will ultimately apply to all states. Examples: federal budgeting for Children's Health Insurance Program (CHIP) programs and Centers for Medicare & Medicaid Services (CMS) funding for child health coverage.

#### <u>Step 2</u>

At what level of government does the issue need to be addressed?

- A **statutory** change would require action by the state legislature to pass a new law or amend an existing law.
  - Example: setting the legal age to get a driver's license or seat belt laws
- **Regulations** are developed by agencies or boards within state government to carry out the statutes/laws passed by the legislature





- Administrative rules focus on government agencies' operations and procedures.
  - Examples: process for applying for CHIP or Medicaid at public health departments or public health agencies process to test children for lead poisoning
- Local or institutional rules are "in-house" policies that govern a specific entity.
  - Example: Board of Education policies, local hospital policies

If you do not know what level of government pertains to your issue, contact healthpolicy@napnap.org for assistance.

#### <u>Step 3</u>

Once you identify the issue and level of government with the authority to enact the change you are striving for, ask yourself (or colleagues) these questions.

- Is a coalition the best way to address the issue? If not sure, see Appendix C for other ways to organize around a topic.
- What is the desired end result?
- What are the pros and cons associated with the proposed coalition?
- What are our objectives and what types of activities seem logical?
- Is organizing and managing a coalition worth the time and resources required?
- How can your chapter leaders and membership participate?
- Will participating in the coalition align with your chapter's strategic goals/mission?
- How will participating in the coalition build your organization?
- What have other potential members of your coalition publicly said about the topics?



### **Getting Started**



A coalition is an alliance of organizations that come together for combined action. Coalitions form for the purpose of gaining more influence and power than the individual organizations can achieve on their own.<sup>1</sup>

#### Who will be the key stakeholders for this particular child health issue?

• Identify other children's or health and safety related advocacy groups, which have already started to work on the issue or have been involved with similar issues in the past.

Child Health Issue	Potential Stakeholders Beyond NAPNAP <sup>5</sup>
Childhood Immunization	Centers for Disease Control and Prevention (CDC), Advisory Committee on Im- munization Practices (ACIP), American Academy of Pediatrics (AAP), American Congress of Obstetricians and Gynecologists (ACOG), American Academy of Fam- ily Physicians (AAFP),
Bullying Prevention	US Department of Education, School Psychologists
E Cigarettes	Campaign for Tobacco Free Kids, The Public Health Law Center
Corporal Punishment	Prevent Child Abuse America, National Children's Advocacy Center (NCAC) Child Abuse Library Online (CALiO)
Teen Driving	National Safety Council, Insurance Institute for Highway Safety, National Highway Transportation Safety Admin., Governor's Highway Association, Safe Kids USA
Gun Violence	Giffords, Children's Defense Fund, affected family, affected school districts
LGBTQIA	Advocates for Youth, CenterLink, Gay, Lesbian, and Straight Education Network (GLSEN)
Child Sex Trafficking	HEAL Trafficking, Shared Hope International, National Center for Missing and Exploited Children

- Are there individuals who have been active or outspoken about your issue?
  - Consider that a key stakeholder may be an individual or family that were significantly affected by the issue in question. Such people can often provide advice and outreach from a different, and perhaps more personal, perspective. For example, individuals who had been injured may be the best spokespeople for legislative hearings and meetings with the press.<sup>2</sup>

#### How large does your coalition need to be?

- The more groups you can recruit to participate, the more traction and more influence you may have with legislators. Legislators are more likely to champion issues they see as important to their constituents.
- That being said, the size of the group matters. It may take larger groups more time to define and agree on objectives. However, larger groups may have access to greater resources to accomplish certain tasks.<sup>2</sup>

#### Now, convene your first meeting!

- Invite potential members.
- Present your data.
- Discuss the potential for forming a coalition.
- Anticipate that not all invited members will want to join your coalition.



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<sup>10</sup> Health Policy Application for Nurses and Other Healthcare Professionals, pp. 204-205.

<sup>11</sup> http://foundationcenter.org/getstarted/tutorials/establish/statements.html.



<sup>&</sup>lt;sup>12</sup> Prevention Institute. Eight steps to Effective Coalition Building, p.14.

<sup>&</sup>lt;sup>13</sup> Prevention Institute. Eight steps to Effective Coalition Building, p.15.

### The Nuts & Bolts



Once you have your coalition partners, the following steps will guide your collected efforts.

#### Setting up the coalition<sup>6</sup>

Start with strategic considerations.

- Define needs, objectives, scope of interest and type of influence needed from coalition members
- Analyze the breadth of the influence of the coalition members
- Develop vision and mission statements. Your vision statement expresses your coalition's reason for existence, while the mission statement provides an overview of the coalition's plans to realize that vision by identifying the values and goals of the coalition.<sup>7</sup>
  - Example vision: NAPNAP is recognized as the global leader, trusted authority, and indispensable resource on comprehensive pediatric advanced practice nursing.
  - Example mission: NAPNAP is recognized as the global leader, trusted authority, and indispensable resource on comprehensive pediatric advanced practice nursing.
- Determine what model (Appendix C) you plan to use. Establish separate legal non-profit entity if necessary or clearly determine which coalition partners are going to manage the financial or lobbying aspects.

Once you have your strategy set, you can operationalize you plans.

- Establish the coalition's identity (name, bylaws if formal incorporation, logo, letterhead, etc.)
- Utilize feedback from coalition members to refine objectives; invite more members; develop strategic plans and action items
- Develop coalition materials (fact sheets, position papers, policy briefs, etc.)
- Engage in advocacy and other defined activities of the coalition.

#### Funding

Determine if outside fundraising is necessary or will coalition members able to donate services (meeting space, conference call capability, document production, staff/volunteers with lobbying experience, event space/catering). In addition to hiring external lobbyists, other out of pocket expenses include media buys and event expense.

- A lead agency will likely devote staff time. To assure meeting attendance and success, extensive work must be done prior to the meetings, including agenda preparation and written and phone contact with the representatives. A coalition succeeds when staffing is adequate to handle the detail work.
- Periodic discussions about resources, support and time limitations of the members can minimize potential problems.<sup>2</sup>
- Staff time may be needed for clerical, meetings, membership, research and fact gathering, public relations, coordination of activities and fundraising.
- Possible sources for supplementing coalition resources, whether in the form of cash or donated services include the media, foundations, local service clubs, students and trainees and volun-teers.<sup>2</sup>

<sup>6</sup> Health Policy Application for Nurses and Other Healthcare Professionals, pp. 204-205.

<sup>7</sup> http://foundationcenter.org/getstarted/tutorials/establish/statements.html.



<sup>&</sup>lt;sup>2</sup> Prevention Institute. Eight steps to Effective Coalition Building, p.14.



#### Targeted individuals depending on level of government

- Statutory issue: target members of the committee hearing the bill
- Good policy objectives should garner bipartisan support, so be sure to solicit support of members of all political parties
- Regulatory issue: determine preferred method of communication for the specific agency. The agency may elicit comment letters, or old public hearings
- Administrative issue: target key administrative leadership or committee members within the administrative agency who work on the rules and regulations in a specific area
- Anticipate the oppositions message and address it first

#### **Controlling the message**

- Provide consistent external messages to educate lawmakers, parents, families, child advocates and secure agreement coalition members to stick to this message
- Agree to a lead spokesperson who will best maintain consistency of coalition's message and not be biased toward individual members' priorities
- Create clear internal communication: email blasts, one-page fact sheets (Appendix A example), bulleted meeting points to be used during meetings with legislators, follow up on any legislator questions
- Refine or revise message when warranted

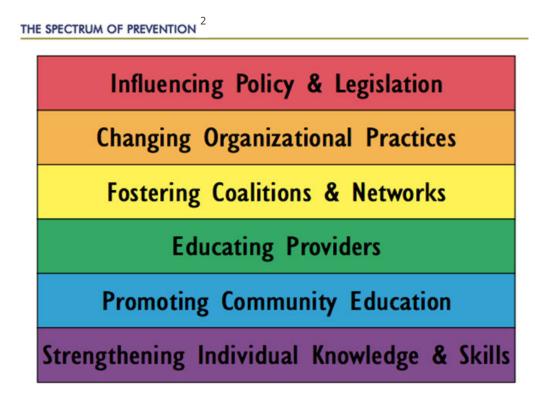
#### Maintaining viability of the coalition<sup>2</sup>

- The coalition's original objectives must be kept in the forefront of all planning at the same time that a balance is struck between those objectives and the concerns and interests of each member group.
- Methods for noting and addressing problems
- Sharing leadership
- Recruiting new members
- Celebrate successes! Identify some activities that will result in short-term successes, such as a press release announcing the organization's formation and purpose, or a report outlining the group's initial findings. These incremental achievements increase members' motivation and pride while enhancing coalition visibility and credibility.
- Evaluation process. How do you define success and measure progress toward it?



### Final Thoughts Before You Dive In

Coalitions provide an important vehicle by which to advocate for child health concerns. Coalitions can help demonstrate the broad appeal of the objective to policymakers and put into play a wider range of advocacy skills and materials than any one organization can provide.<sup>8</sup> Once a coalition is built, and successes are won in passing legislation (or creating/changing regulations), the journey is still not over. Once legislation is in place, it is equally important for coalition members to translate those policies into educating colleagues and promoting community and individual knowledge and awareness. Only then will the hard work of the coalition be appreciated. Coalition members should continue to provide a unified message to the community suggesting to policymakers the importance of the child health issue.



<sup>8</sup> Annie E Casey Foundation. (2006). http://www.aecf.org/resources/child-advocacy-primer <sup>2</sup> Prevention Institute. Developing Coalitions: An Eight Step Guide



### **Child Health Coalition Success Stories**



#### **Utah vaccine education**

Vaccinations are required for children to attend school. However, parents may seek vaccination exemptions for medical, religious or personal reasons. In Utah, 95% of exemptions related to for personal reasons, including fear of side effects and distrust of the pharmaceutical industry. As vaccine exemptions increased in Utah, rates of vaccine-preventable diseases increased. A coalition that included pediatric-focused APRNs worked to pass legislation that required parents to complete an educational module on vaccines, vaccine-preventable diseases and recommendations to prevent unvaccinated children from contracting vaccine-preventable diseases prior to seeking exemptions for personal reasons. Parents who completed the modules report increased knowledge of vaccine-preventable diseases. Data on the impact of the legislation on vaccination rate is being collected now. (reference: https://law.utah.edu/a-greatcompromise-utahs-bill-to-require-education-for-exemption-from-vaccination/)



#### California statue on gun violence prevention

California has some of the countries toughest gun laws. In response to mass shootings in 2017 and 2018, California passed new gun laws to limit access to guns. Pediatric advocates worked with the state legislature and governor and were able to pass legislation that limited gun sales to people 21 year of age or older and prevented anyone who had a misdemeanor conviction for domestic violence from ever purchasing a gun. (reference https://calmatters.org/ explainers/california-gun-laws-policy-explained/)



#### Maryland Safe Harbor Child Trafficking Pilot

Maryland is among the states with the highest number of National Human Trafficking Hotline reports. As national attention to the problems of trafficking led to the passage of SOAR to Health and Wellness Act, state are also working trafficking. In Maryland, pediatric advocates worked to make it one of a minority of states to provide specialized services for high-risk or trafficked youth. This legislation increased coordination and prevention efforts, and ensures that victims and survivors of human trafficking receive the services they need to heal and rebuild their lives and futures. (reference: https://sph.umd.edu/ news-item/maryland-strengthens-efforts-fight-human-trafficking-and-support -survivors; https://www.eshttf.org/wp-content/uploads/2017/06/Human-Trafficking-Report-5-10-17.pdf)



### Case Study Appendix A Example of Successful Coalition Effort:

Identify Problem: Increasing number of children who are suffering from window falls in the state

#### Background data:

- Look at reasons for why children experience these falls and targeted areas where/when this is occurring
- Look at ED admissions, trauma database to collect state in state
- Review extent of injury experienced in this patient population
- Review cost of admissions

Review other state/city legislation around this topic: New York and Minnesota and states such as New York and Boston legislation targeted toward the prevention of window falls.

Identify this is a state wide issue which requires statutory law change which mandates the placement of window guards/provide window safety education. Also opportunity to have more informal window fall safety education program.

Identify key stakeholders: tenant rights organizations, landlords, trauma centers, local EMS, insurance companies, parents of children affected by this injury

Informal coalition development with lead agency; conference calls and draft report created.

#### Action items once report drafted:

- Continue to take in feedback from unintentional injury prevention stakeholders
- Create printed versions of the document in various layout formats to be most accessible to different audiences
- Create more targeted pieces and fact sheets
- Rally stakeholders around several pieces of legislation and or statewide administration actions
- Plan and carryout media event(s) to release the report publically
- Set up small content expert teams to meet with key policymakers (e.g. legislators, agency leadership, foundation leadership, etc.) to review unintentional injury generally and a summary of the findings in the report.



### Case Study Appendix B Example of Successful Coalition Effort: Georgia Concussion Coalition



#### Our Mission<sup>9</sup>

To minimize risk for sports-related concussion in children and youth participating in organized athletic events in the state of Georgia.

#### **Our History**

In November of 2011 Dr. Julie Haarbauer-Krupa founded an action group as part of the Children and Youth Committee of the Brain and Spinal Injury Trust Fund Commission to discuss the growing concern about concussions, particularly in youth sports. In 2011, the group expanded in scope and formed the Georgia Concussion Coalition (GCC), an independent entity focused on concussion prevention, education and management. The GCC expanded quickly to over 80 members, representing districts all across the state of Georgia.

The Georgia Concussion Coalition became very involved in championing the need for Return to Play legislation in Georgia and was instrumental in getting HB284 signed into law in April of 2013. In 2014 the Coalition strategically joined forces with the Brain Injury Association of Georgia to further expand the organization's capacity and reach. Today the Georgia Concussion Coalition functions as a program of the Brain Injury Association of Georgia that focuses specifically on concussion awareness and prevention and helping stakeholders throughout Georgia put into practice what Georgia's Return to Play Law now requires.

We are here to help athletic organizations across the state formulate sound policies, best practices and prevention programs. As more concussions are being recognized, diagnosed and treated because of greater awareness, we are here to connect parents and athletes to the resources they need to get the best care and treatment available. As schools strive to help students get back to the classroom after a concussion, we are here to help educators formulate sound Return to Learn programs too. GCC also works with healthcare professionals across the state to keep clinicians current on the latest concussion management practices and protocols.

GCC is comprised of diverse group stakeholders, including physicians, athletic trainers, researchers, educators, nurses, parents, caregivers, coaches, and athletic and non-athletic organizations. The NAPNAP Georgia chapter was also active participant in this coalition. We invite you to share your thoughts and ideas with us as to how we can be of greater service in your community and help us identify needs and gaps you see across the state that will help us to evolve and expand our work in concussion awareness and prevention.

#### Our Leadership

The Advisory Board of the Coalition helps to oversee and guide the focus and big picture for the organiza-



tion. Members of our Advisory Board include:

- Jeff Hopp, ATC, LAT Head Athletic Trainer, Marietta High School Chairman
- David W. Wright, MD, FACEP Associate Professor & Director of Emergency Neurosciences Emory University School of Medicine
- Michelle LaPlaca, PhD Associate Professor Coulter Dept. of Biomedical Engineering Georgia Tech & Emory University
- Kaveh Khajavi, MD Director of Neurosurgery Shepherd Center
- Marat L. Reyzelman, MD Neurologist Marietta Surgical Center
- Kenneth Mautner, MD, PM&R The Emory Clinic
- Stephanie Lotti Director, Member & Practice Services Georgia Dental Association
- Adam W. Shunk, PhD, HSSP, NCSP Neuropsychologist The Concussion Institute at Gwinnett Medical Center-Duluth
- Jeremy Hertza, PhD Neuropsychologist & Executive Director NeuroBehavioral Associates, LLC

The day-to-day work of the Coalition is managed by Paige Havens, Director of Programming & Development for the <u>Brain Injury Association of Georgia</u>.



### Appendix C Other Models of Cooperative Efforts<sup>10</sup>

Network:	formed to share information and learning on topics of common interest
Association of Organizations:	a formal umbrella nonprofit that brings together or- ganizations and/or individuals with common needs
Coordinated Project:	frequently used by two or more distinct organizations to coordinate work and share resources on a specific issue or program they have in common
Campaign Coalition:	brings together organizations committed to pursuing a single common issue in a jointly staffed campaign
Ongoing Partnership/Strategic Alliance:	a long term, formal relationship among multi-issue or- ganizations that provides mutual advantage
Multi-Stakeholder Process:	brings together organizations with diverse and some- times conflicting perspectives on an issue, with the goal of discovering common ground and in some instances working together



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