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Executive Summary

Children make up 22.6 percent of the American population, yet there are few disaster preparedness and response funding streams designated for children, and those that exist are insufficiently funded and difficult to locate. A disaster response system is inadequate without accounting for the well-being of children and their unique needs. Pediatric disaster preparedness can serve as an indicator of overall system capability and highlight crosscutting issues that also stand to improve care for adults.

It is unclear how much funding is available for pediatric disaster preparedness, and it is difficult to locate the funding opportunity announcements (FOAs). The FOAs are scattered throughout multiple agencies and databases with little standardized language. Once individuals and organizations procure funding for research or programming, there are no standardized metrics to assess the efficacy, cost-effectiveness, or return on investment (ROI) of particular studies or programs for children. With many health-related and non-health-related priorities competing for funding, it is essential to evaluate the most cost-effective and valuable pediatric disaster preparedness activities.

The National Advisory Committee on Children and Disasters (NACCD) identified several best practices and recommendations to improve the funding environment for pediatric disaster preparedness. First, organizations and government entities should economically incentivize pediatric disaster preparedness, which can be accomplished via regulatory mandates, economic self-interest, insurance models, or public accountability. The U.S. Department of Health and Human Services (HHS) should continue to prioritize medical countermeasure (MCM) projects that have dual-use functions and focus on pediatric formulations. In terms of fulfilling research needs, a dedicated and pre-established fund reserved for pediatric disaster preparedness research should be formed to enable rapid emergency research. This will avoid delays in public health emergency response, such as those that occurred during the Zika outbreak in 2016.

The Office of the Assistant Secretary for Preparedness and Response (ASPR) and HHS should evaluate how much funding has been devoted toward pediatric goals in the past decade and gauge the value of these various activities. It is challenging to replicate and scale effective strategies without having a baseline of how much has been spent and what the ROI on various programs has been. Public Health Emergency Preparedness (PHEP) and Hospital Preparedness Program (HPP) grantees should be required to report progress on pediatric-specific metrics annually, with grant terms extended to longer than one year, to increase awareness of pediatric needs, create accountability, and enable activities that are most effective. Measures of cost-effectiveness that promote rational investment in children, such as quality-adjusted life years
(QALYs), lifetime costs, and lifetime productivity, should be considered when evaluating funding projects. Lastly, the federal government should create a clearinghouse for pediatric disaster-related funding opportunities across agencies and departments to streamline the granting process. The NACCD also would like to see Congress fully fund the HHS Public Health Emergency Fund and increase funding for existing public health programs to strengthen everyday preparedness.

These recommendations seek to make funding streams more pediatric focused, efficient, better funded, and cost effective to support an improved disaster preparedness and response system for all Americans.

**Introduction**

The National Advisory Committee on Children and Disasters (NACCD) was established in 2014 by the Pandemic and All-Hazards Preparedness Reauthorization Act of 2013 (PAHPRA) to provide expert advice and consultation to the Secretary of the U.S. Department of Health and Human Services (HHS) and the Assistant Secretary for Preparedness and Response (ASPR) on the medical and public health needs of children related to all-hazards emergencies and to provide input on preparedness activities such as disaster drills and exercises, as well as input on medical and public health grants and cooperative agreements.

The 15-member NACCD (see Appendix) comprises public health and medical experts from federal, state, and local health agencies and child experts experienced in disaster preparedness and response. NACCD members understand that children have unique needs and should not be treated as little adults when it comes to public health emergencies and disasters.

This report summarizes the findings of the Funding Strategies Work Group and its exploration of pediatric disaster funding streams. This report describes the current limitations of and gaps in pediatric disaster funding priorities, recommends changes to improve these priorities, and calls attention to best practices and effective mitigation strategies.

**Task and Methods**

The NACCD recognized a need to analyze funding streams, including sources and amounts. The purpose of this analysis was to understand and prioritize limited resources and specific activities that would be most beneficial for children. Planners, funders, and economists want to
receive a higher return on investment (ROI), which can be difficult to determine when attempting to compare spending on disparate measures, such as medical countermeasures and community resiliency. Adding to the challenge, it is difficult to develop an assessment of ROI in relation to disaster planning in general.

The NACCD formed the Funding Strategies Work Group (see Appendix) under its auspices to explore these issues in depth. The work group invited diverse subject matter experts (SMEs) (see Appendix) to provide their expertise and perspectives on disasters and funding priorities based on their extensive real-world experiences. ASPR Staff and NACCD members assessed the literature to gather additional information. The work group approached disaster preparedness from an economic standpoint and considered pediatric disaster preparedness from a cost-benefit perspective. As the members deliberated on these topics, they also kept the following question at the forefront: What could the ASPR and the HHS Secretary do and/or influence to strengthen pediatric disaster readiness funding and funding effectiveness?

Subject matter experts shared various ways to analyze ROI and the economic effectiveness of various interventions that might benefit children in disaster with the following questions:

- What initiatives serve the most people?
- What delivers the greatest benefit?
- What are the greatest risks (or “soft spots”) that need to be most urgently addressed?
- What activities best address existing gaps?
- How do we stretch our dollars further, as we can through public-private partnerships and dual-use projects? How do we determine ROI on projects that deliver less quantifiable gains, such as community resiliency and social capital?

Economic analysis has confirmed that investing in preparedness ahead of a disaster is more cost effective than paying for response and treatment later. For instance, an inability to handle surge results in a premium on obtaining equipment, increased staffing and overtime costs, more nosocomial infections, physical and mental complications, and generally greater lifetime costs. The World Bank has reported that investment in vulnerable populations ahead of a disaster leads to greater resiliency and self-support and less need for government expenditure after a disaster (Hallegatte et al, 2017). A dollar invested in preparation can save as much as five dollars in recovery.
Key Findings

Finding 1: There is an economic benefit to investing in children before, during, and after disasters.

Children are one of the populations most vulnerable to the adverse effects of disasters. While children are only a quarter of the population, disasters have unique effects on them, and the suffering and disruption in their lives has a ripple effect with enormous implications for their families and communities. For example, when children suffer, adults become distressed, and communities cannot fully function when their children are not safe. Adult caregivers cannot resume regular and/or full-time work until the children return to a familiar routine, such as school or child care. Families who evacuate a disaster-affected area will not want to return until children’s services, including children’s health services, are restored and available. SMEs, including economists from the World Bank and the Center for Disaster Philanthropy, agreed that there is an important economic argument for pediatric preparedness funding. We pay dearly as a society when we do not weave children’s needs into the very fabric of disaster preparedness. Therefore, focusing on the needs of children is an investment in the community as a whole. Investing in children is also an investment in the future. Children have more years of future productivity and quality-adjusted life years (QALYs) ahead of them than adults. Any intervention that improves well-being (whether before, during, or after disaster) will therefore have a greater lifetime economic benefit for children than adults. Education, physical health, mental health, and resiliency all interact to promote long-term wellness, higher earning potential, and longer lifespan. The converse is also true: studies on adverse childhood experiences (ACEs) show that early life trauma is a risk factor for chronic physical illness in adulthood, such as diabetes or cardiovascular disease; lack of education is associated with worse physical and mental health; and physical or mental impairment negatively affects educational achievement (Monnat, 2018). In addition, some disasters have direct long-term physical sequelae of particular concern to children. Radiologic and nuclear events, for example, present greater lifetime risk of cancer for children due to their more rapidly dividing cells as well as their longer future lifespan.

Methods to improve the care of children in disasters translate directly to improved care for adults. Examples of issues that affect both children and adults with chronic and functional needs include communication challenges, difficulties administering medication to patients unable to swallow tablets and capsules, tracking and reunification of unaccompanied children with their families, limited literacy, and emotional issues. A robust ability to care for children can thus serve as a bellwether for overall system capability. A system that can address
children’s needs every day will be better positioned to care for larger numbers of both children and adults during public health crises.

Past events such as the 1995 Oklahoma City bombing and the 2004 school hostage crisis in Beslan, Russia, demonstrate that children also can be a “soft spot” or “soft target” for terrorists. Prioritizing children for protection is a prudent investment that serves to deter violence against children as well as the society-wide trauma and fear such events generate.

**Finding 2: Pediatric disaster preparedness can be incentivized in several ways. Approaches include direct funding, regulatory mandate, economic self-interest, the “insurance” model (shared risk, deferred payoff), and public accountability (metrics).**

Each has benefits and drawbacks that will be discussed below. Other incentives exist, such as tax credits; however, the five areas discussed are the most common as well as the simplest to enact and quantify.

**A. Direct funding: grants** (for example, the Hospital Preparedness Program, Biomedical Advanced Research and Development Authority (BARDA))

Direct funding is a powerful and effective way to achieve results. It enables activities that would otherwise be difficult to undertake due to resource limitations. Direct funding also directs resources to what the free market will not support—which can yield both public and private benefits. One example is BARDA, which was created to spur development of medical countermeasures (MCMs) for which the federal government would likely be the primary or sole purchaser. This enterprise has successfully brought MCMs to market and into the Strategic National Stockpile (SNS) and has also spurred a focus on dual-use countermeasures (for use in both disasters and everyday care). BARDA will be discussed in more detail below.

Minimal funding has been explicitly and directly allocated for pediatric needs in disaster (see Finding 3, below). Pediatric-specific funding would be the most direct way to increase pediatric preparedness. Any proposed expenditure, however, faces competing priorities, both within the scope of disaster funding (for example, adults vs. children) and outside of it (e.g., disaster preparedness vs. military spending vs. any number of other government budgetary concerns). Deciding what gets funded is often reactive, subject to politics, and driven by a desire for quick and tangible progress as opposed to what is the most prudent and best investment. As a result, specific threat-based activities often receive funding over broader health system resiliency. While this approach can improve preparedness (often in a
narrow way), we believe it is more economically sound to focus on strategies or resources that are common to all disasters—in other words, funding of systems. During the past decade we have seen the opposite, unfortunately, with declining funding in public health and the Hospital Preparedness Program (HPP). Of note, the HPP does have the ability to fund Demonstration Grants, and a novel pediatric-focused coalition would be an intriguing pilot project; however, the HPP does not have any funding appropriated for such Demonstration Grants and thus cannot bring such an experiment to fruition under current budget conditions.

In addition, while Congress has historically recognized the need for additional appropriations to respond rapidly to unexpected major public health events—such as Hurricanes Katrina and Sandy, H1N1 influenza, and Ebola virus—the 2016 funding debate over Zika illustrates that such mechanisms cannot be assured or taken for granted. The funding delay hampered health departments’ ability to respond and researchers’ ability to proceed on developing a vaccine and required pulling funds from other projects, such as Ebola response, or from other public health budgets. The budget fight illustrates the need for a designated fund, separate from political considerations, for HHS to respond to emerging health crises when needed. The Federal Emergency Management Agency (FEMA) has a capacity of this nature, and it works well for its response to disasters.

A similar fund for HHS, the Public Health Emergency Fund, was established by Congress in 1983, with appropriation authorization to maintain $30 million in reserve at the start of each fiscal year (H.R. 98-49, 1983). Nevertheless, appropriations were made only in 1987 and 1993, and the fund has been reduced to $57,000 as of June 2016 (Kodjak, 2016). Former Centers for Disease Control and Prevention (CDC) director Tom Frieden, the Association of State and Territorial Health Officials (ASTHO), the National Association of County and City Health Officials (NACCHO), and others have supported the reestablishment of the Public Health Emergency Fund (ASTHO, 2016). In 2017, Senate Bill 196 was introduced with bipartisan support to accomplish this objective, with target funding based on prior annual average expenditures for public health emergency declarations (Public Health Emergency Response and Accountability Act, 2017).

Outside of the government, there are no foundations that see disaster philanthropy as a primary focus. Non-profits generally view disasters as an “add-on” to their primary areas of concern. For instance, most funders of children’s needs do not focus on those needs in the context of disaster, which implies a relative lack of experience and expertise in this area. These organizations may be very knowledgeable about children’s needs but lack awareness as to how those needs can be impacted by disasters. Many separate the issues of disasters
and children when it is actually necessary to connect the two issues. In other words, disasters need to be considered an important influence on the well-being of children.

Grants facilitate activities and programs that might not otherwise be accomplished, but they are not a complete solution to preparedness. According to one SME, grants are an essential policy lever but cannot be the sole creator of a prepared health care system. Organizations and communities need to also invest in their own preparedness to achieve sustainability.

**B. Regulatory mandate: unfunded directive** (e.g., Centers for Medicare and Medicaid Services, Joint Commission)

Mandates are a way to advance pediatric preparedness without investment by government; this means they place the implementation burden on the end-user, which can be unwelcome and require redirection of time and capital. For preparedness in particular, complying with a mandate means lost revenue with little likelihood of immediate pay-off. If an institution is compelled to comply without buy-in, it probably will do the minimum needed in order to “check the boxes” and satisfy requirements.

Mandates are generally issued from a state or national level and are intended to reach a broad audience. They are not designed to take into account unique local strengths or challenges. Therefore, mandates are not always the best implementation path or foci for affected institutions, which may end up spending resources complying with regulations, as opposed to concentrating on other activities that may be more valuable for the individual institution or locality. Mandates work best if institutions are convinced of their importance and are given some degree of flexibility in meeting them. Even in this case, however, different agencies may mandate different and possibly conflicting requirements, creating further challenges in compliance and/or prioritization for subject organizations.

The most effective mandates would be developed by appropriate subject matter experts, sensitive to implementation concerns, and produce tangible progress for minimal investment. Within disaster preparedness, for example, existing all-hazard, all-population directives might include one or two select pediatric-specific requirements. The 2016 CMS Emergency Preparedness Rule neglected an opportunity to include even a single pediatric-specific requirement for community hospitals (which, per the American Academy of Pediatrics, Emergency Medical Services for Children, and other organizations, should be ready to—and do—treat children on an everyday basis) (the Centers for Medicare and Medicaid Services, 2016). Some potential pediatric metrics might include explicit attention
to family separation and reunification, or inclusion of pediatric patients in all drills and exercises. Such an addition would have required minimal effort in comparison to the rest of the rule requirements but likely would have yielded significant improvements.

C. Economic self-interest: the business case for preparedness (e.g., BARDA)

Preparedness can be considered an investment in the future, and ultimately, a risk-management strategy; institutions can either “pay now or pay later.” Just as societal funding of preparedness is of greater value and savings compared to payment for response and recovery, individual institutional expenditure is of benefit in advance of an event. **Planning, mitigation, and prevention can minimize disaster-related loss of capital and other physical resources. A rapid return to operations means the resumption of revenue as well as the ability to serve the community in a time of need.** Preparedness for large-scale events might seem an unwise investment if the feared event never materializes. There can be a payoff, however, in a better ability to withstand more frequent and likely smaller-scale events. That is, by investing in enhanced capacity and coordination within the medical home, robust communication strategies, and infrastructure, and planning for infection control and surge capacity, institutions are better able to handle and mitigate smaller-scale events, such as power outages, supply shortages, facility damage, and infectious outbreaks and pandemic influenza. Similarly, community emergency departments that increase their ability to handle children in disasters should also be more comfortable in addressing everyday pediatric issues, which might translate to more efficient use of resources during episodes of care and greater market share compared to competitors less skilled in this area. **Providers of property and overhead insurance also benefit from institutional disaster planning and should consider incentivizing insured businesses to invest in preparedness through lower insurance premiums for robust preparedness efforts.**

A significant limitation of individual institutions is that they generally have limited resources that can be set aside for preparedness purposes. Emergency items that have dual-use capacity, that are used relatively frequently, or that would enable institutions to offset losses otherwise incurred might be considered a worthwhile investment. An example of such an item would be a generator that would protect against loss of vaccines, which in themselves represent a significant investment of capital. Other investments, though potentially valuable in the event of a disaster, might represent a significant dedication of capital with lower likelihood of payoff. An example might be a large stockpile of N95 masks. As with all potential disaster interventions, institutions must evaluate and prioritize how to invest limited resources and determine which investments make the most economic sense.
to pursue—in other words, institutions must compare the opportunity cost of different options.

Recent movement of the health care system away from fee-for-service toward value-based payment and payment for outcomes (e.g., Accountable Care Organizations, or ACOs) also creates an economic argument to invest in disaster preparedness. Under this new model, anything that adversely impacts a patient’s well-being can have negative financial consequences for the health care provider. Promoting health and resilience of patients and communities becomes a legitimate financial strategy, and preserving access and service during times of crisis reduces overall costs of care with concordant savings. While most ACOs are currently operating under the Medicare program, and thus do not involve significant numbers of children, this health care delivery model is likely to expand to include Medicaid (and therefore children) in the near future. Even if children and other patients are not directly covered by an ACO plan, any organizational changes made to adapt to ACO payments are likely to provide benefits.

With respect to medical countermeasures and federal promotion of their development, BARDA represents a blend of directed funding with an appeal to industry self-interest. BARDA creates a market for medical countermeasure development—the federal government—that might not otherwise exist. Therefore, private industry has a profit motive to participate in research, development, and manufacturing. While this has already proven an effective way to bring pediatric-specific medical countermeasures to market, BARDA has taken the additional step of promoting development of products that have dual-use capability, with both MCM and daily applications. For these products, product development that manufacturers might not see as economically worthwhile on its own becomes significantly more lucrative with some seed money, analogous in some ways to venture capital. Pharmaceutical platforms that can yield stable, orally dissolvable products with acceptable palatability and shelf life represent a particular investment that would greatly advance children’s preparedness and MCM stockpiles but also have applicability to adult populations (see earlier in this report) and mass-market pharmaceuticals. The success of over-the-counter “meltaways” and dissolvable strips for children illustrate the appeal of this approach.

D. Insurance model: group investment, group benefit (e.g., Community Coalitions)

As an alternative or supplement to external support, groups may decide to self-finance their own preparedness activities. Per above (“Economic self-interest”), individual investment may be limited by perceived value and/or later pay-off (utility); therefore, the pooling of
resources by a larger group can enable greater initiatives, and the group members can reap the shared benefit if their coalition is put to the test. As an example, a community coalition might decide to self-fund local preparedness initiatives, with each member contributing a certain amount. Members would seek participation because they would be promoting greater resiliency for the community, which would yield fewer expenses after disaster and generate cost savings. A better community recovery would have the additional benefit of a stronger local economy, which translates to increased profitability of individual member institutions compared to the absence of the coalition and a more sluggish or anemic recovery. Coalition membership would also be expected to produce everyday benefits of improved coordination, increased awareness of community resources, and sharing of ideas and best practices.

Self-funded coalitions have the advantage of sustainability, as long as members see value concordant with their contributions. Extensive activities requiring large member investment, or activities that do not appear relevant to individual members, would likely lead to declines in participation, which would decrease the pooled resources and the scope of activities. Large, ambitious projects, such as purchasing expensive equipment, would likely be outside the scope of coalitions on their own and would require additional outside funding. Pediatric initiatives, in particular, would require members to agree on the importance of preparedness for children and the value in investing in it.

One variation on the insurance model consists of specific local taxes, which enable the entire community to become the coalition and share the benefit of directed investment. As discussed earlier under “Direct Funding,” creation of such a special tax would be dependent on political will but can effectively provide the impetus and resources for particular initiatives, such as preparedness for children.

Coalitions and self-funded models enable some degree of economic investment in preparedness but have a greater dividend in less quantifiable, operational benefits such as collaboration. As one SME conveyed, disaster response requires physical tools, but equipment does not automatically guarantee preparedness.

One unique type of insurance model worth mentioning is “catastrophe bonds,” or, more recently, “pandemic bonds.” These bonds involve the purchase of bond instruments against specific catastrophic events by private investors. If a disaster does not occur within a certain time frame, the investor is paid interest on the principal (Lewis, 2007). If the disaster does occur, however, the investor loses the principal, which is redirected to cover the losses and expenses incurred by the issuer in managing the event. In 2017, in response to prior events
such as Ebola, the World Bank introduced the Pandemic Emergency Financing Facility (Hansen, 2017). This first pandemic bond was created to facilitate a rapid mobilization of funding to aid response to an infectious pandemic in low-income countries, with the ultimate goal of containing the outbreak before it spread further. While catastrophe and pandemic bonds are not truly self-funded and are currently used for response (as opposed to preparedness), they are a creative way for groups to find capital to effectively respond to a crisis (Pandemic Emergency Financing Facility, 2017). Perhaps future economists will explore how to use or modify such instruments to address children’s issues or for pre-disaster preparedness and mitigation activities.

E. Public accountability: metrics (e.g., National Pediatric Readiness Project)

Metrics are an essential way to measure progress toward preparedness and to prove the value of investment. Metrics tied to reimbursement or revenue get attention, but even without, have proven value in inducing change and improvement in health care. When metrics are released and disseminated publicly, accountability and psychological factors, such as competitiveness, can drive achievement. Institutions will want to avoid being perceived as lacking and instead seek to promote excellence compared to their peers. Superlative performance compared to peers can also be a marketing tool, increasing perceived value and reputation.

One outstanding illustration of the power of metrics has been the National Pediatric Readiness Project (NPRP). A collaboration between Emergency Medical Services for Children, the American Academy of Pediatrics, the American College of Emergency Physicians, and the Emergency Nurses Association, the NPRP was established to measure and improve the readiness of community emergency departments to care for children. Studies have shown that while community emergency departments provide services to the majority of children needing emergency care, many of these facilities have very limited pediatric capabilities (Gausche-Hill et al, 2007). The NPRP utilized existing multi-society guidelines as a standard and surveyed all emergency departments in the United States as to their compliance. Participation was voluntary and uncompensated, and the results were consolidated and published online. An astonishing 82% of emergency departments completed the survey, and participants were eager to improve their pediatric readiness scores and retake the survey to assess progress. Results show that overall hospital Pediatric Readiness scores significantly improved between 2003 and 2013, from 55 percent to 69 percent (Pediatric Readiness: Key Assessment Findings, 2015). The increased quality of pediatric care not only has clear everyday benefits, but it is also the foundation for being able to handle a surge of pediatric patients in disaster. It is important to note that the NPRP
was not tied to any financial incentives or penalties; presumably, emergency departments participated out of a recognition of responsibility and accountability to the community and the desire to improve quality of care, particularly in regard to peers.

Metrics are not a panacea and may be more effective in certain situations than others. The NPRP likely succeeded because participants felt the project’s goals to be worthwhile and of value, the standards were clear, evidence based, and from a consortium of respected organizations, and the investments required for improvement were modest and reasonable. Larger, more ambitious projects, particularly those that require substantially more capital investment and initiatives that are not perceived as having significant value or aligning with the institution’s priorities, will be much less likely to work.

**Finding 3: It is unclear how much funding is devoted to pediatric disaster preparedness and response, and it is difficult to locate pediatric-specific funding opportunity announcements (FOAs).**

While we cannot create a prepared health care system through grants alone, we also cannot achieve a prepared health care system without some funding to develop and sustain activities. Pediatric preparedness, response, and recovery are significantly less likely to occur in the absence of dedicated funding.

The NACCD experienced great difficulty in locating funding opportunity announcements (FOAs) from either governmental or private sources devoted to pediatric-specific disaster readiness. The FOAs we did locate were nonspecific about funding of pediatric activities. Potential funding sources are disparate, strewn across a number of different federal databases, and under different departments or agencies. When pediatric opportunities are identified, they may use inconsistent search terms, taxonomies, or metadata, further complicating any searches.

This current situation creates formidable barriers for organizations or individuals wishing to identify and apply for funding for pediatric disaster-related projects. As a result, what few opportunities exist may not reach the widest possible audience and may serve to reward those in the know, as opposed to those with the best expertise, resources, drive, partnerships, or other favorable characteristics. This is a distinct disadvantage for those new to the field.

There also appears to be few or no just-in-time/rapid funding sources for emergency research. The sole instance we found was in the case of the Zika virus, for which the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) had one open R21 grant mechanism entitled “Rapid Assessment of Zika Virus Complications” with rolling grant
submissions and expedited external peer review and award, which permitted rapid start-up of research (PAR-16-106, n.d.).

In summary, there does not appear to be significant funding targeted for pediatric emergency disaster research or readiness. The NACCD spoke with several groups of experts and was unable to determine how much funding exists specifically to support pediatric disaster activities. While research and readiness funding often target and reach different audiences (with research funding targeting academia and readiness funding targeting those involved in public health), these two foci inform each other and are equally important for effective overall readiness and response. This Committee was unable to locate any clearinghouse or similar mechanism for finding funding devoted to pediatric disaster preparedness, despite considerable effort. There are several funding streams, from federal, state, city, county, tribal, and nongovernmental sources, but again, it was difficult to determine to whom the funds went and the amount of funding available.

The need for dedicated pediatric funding streams is discussed later in this report. In order to improve the effectiveness of any existing and future pediatric funding, the NACCD strongly recommends efforts be made that improve the ability of potential grantees and contractors to find pediatric disaster funding opportunity announcements, for both research and implementation activities. HHS should require that FOAs/RFPs have uniform pediatric-specific language and search terms to make them easy to locate. ASPR’s Technical Resources, Assistance Center, and Information Exchange (TRACIE) can be used as a reasonable, easy-to-use platform for sharing pediatric funding opportunity announcements. TRACIE has the advantage of being usable by people within government as well as outside of it, and the posted content on TRACIE requires little curation and maintenance from ASPR staff. HHS should also explore the feasibility of constructing a more formal database of funded grants/contracts and results, similar to the NIH RePORTER system.

**Best Practices**

The NACCD Funding Strategies Work Group identified three Best Practices that deserve to be highlighted and replicated as existing strategies that have been working well to address children’s disaster needs in an economically sound way.

**Best practice 1: Continue to develop and leverage partnerships between government and nongovernmental organizations.**
HHS, the ASPR, the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), the Food and Drug Administration (FDA), the Administration for Children and Families (ACF), FEMA, and other federal agencies have created valuable working partnerships with nongovernmental organizations (for example, Save the Children, the American Red Cross, the American Academy of Pediatrics) to address children’s needs. These relationships have helped improve public health preparedness and response. These partnerships have also enabled pediatric studies, increased situational awareness of pediatric issues, and fostered the development of recommendations and best practices for state and local governments and nongovernmental organizations. Such partnerships maximally leverage federal funding streams by utilizing outside expertise to help inform decisions. Through these partnerships, the partners can disseminate joint messages and programming, combine resources, and diffuse work across more people and organizations. The cooperative agreement between the CDC and the American Academy of Pediatrics is an illustrative example of the benefits of such a partnership. The American Academy of Pediatrics and the CDC worked together on disaster response during the 2009 H1N1 influenza pandemic, following the creation of the Children’s Health Desk within the CDC Emergency Operations Center (Krug et al, 2012). The two organizations partnered to develop clinical guidance, a triage algorithm, and an after-action meeting with state pediatricians and public health officers (which led to the Pediatric Preparedness Resource Kit discussed earlier). The partnership continues thanks to a five-year cooperative agreement and a grant, which has resulted in joint guidelines on anthrax, smallpox, Ebola, and Zika; joint webinars; articles in numerous professional and lay media (including the “Ready Wrigley” series of disaster-themed activity books for children); research activities; joint presentations at national conferences such as the National Preparedness Summit and the American Academy of Pediatrics National Conference and Exhibition (where the CDC’s lead for Children’s Preparedness, Dr. Eric Dziuban, was a highlighted plenary session speaker in 2016); and the joint performance of a multi-state pediatric-public health tabletop exercise in 2016 (Chung et al, 2018), followed by a “virtual tabletop” in early 2017 (Chung et al, 2017). These activities have resulted in better, more refined guidelines, increased state-level collaboration between pediatricians and public health officers, higher disaster preparedness among early childhood providers, including Head Start, greater awareness of disaster issues among pediatricians and pediatric specialists, and heightened awareness of pediatric issues among disaster and public health professionals.

Both the CDC and the American Academy of Pediatrics derive numerous benefits from the cooperative agreement. The American Academy of Pediatrics receives grant funding to drive preparedness and outreach activities that otherwise would likely not occur, access to national
experts within the CDC, and input into guidelines that directly impact both the well-being of children and the practice of pediatrics. For its part, the CDC derives access to nationwide pediatric subject matter experts in a wide variety of subspecialties; print, electronic, and in-person communications with over 60,000 pediatric physicians on the front lines of health care delivery; the ability to leverage limited in-house funding and pediatric experts to maximum effect; and a trusted responsible partner to help it carry out its mission through all areas of the country. As with any good partnership, this collaboration enables both organizations to share resources and expertise, yielding activities that neither entity would be able to implement independently.

**Best practice 2: Continue to prioritize MCM projects that have dual-use or are otherwise economically lucrative to pharmaceutical companies in developing SNS MCMs (with a focus on pediatric formulations).**

The prioritization of broad-use development corresponds to Objective 1.3 of the PHEMCE. Development of MCMs for at-risk populations, including children, corresponds to Objectives 4.1 through 4.3 of the PHEMCE (PHEMCE Strategy and Implementation Plan, 2017). Recent years have seen the pursuit of several medical countermeasures specific to children, including the following:

- ciprofloxacin for pediatric treatment of plague;
- filgrastim and pegfilgrastim for pediatric treatment of radiologic;
- intramuscular midazolam for treatment of pediatric seizures (e.g., by nerve agents) (Silbergliet et al, 2011);
- meropenem-vaborbactam for treatment of serious bacterial infection in children;
- solithromycin for treatment of pneumonia in children; and
- recombinant quadrivalent influenza vaccine in children.

Other products have been approved or are in process for children, such as the H5N1 vaccine and the anti-anthrax monoclonal antibodies obiltoxaximab and raxibacumab. The products listed above, however, are highlighted because they have either direct everyday (i.e., non-MCM) uses (as is the case with recombinant influenza vaccine, solithromycin, and meropenem-vaborbactam); or their use for CBRNE threats may translate to treatment for other conditions, creating multiple markets (which could prove to be the case with ciprofloxacin, filgrastim, pegfilgrastim, and midazolam); or their approval under the Animal Rule (MCM Regulatory Science, 2018) demonstrates the utility of this new method for approving pediatric indications for adult pharmaceuticals (which is the case with ciprofloxacin, filgrastim, pegfilgrastim, and obiltoxaximab) (2014-2015 CHILD Report, 2017).
These product developments highlight success in examining dual-use MCMs, demonstrating that this prioritization is in fact yielding results. Separately, the NACCD learned from Pfizer of their work to develop a pediatric multi-particulate platform. Such a platform would enable scalable, consistent, orally dissolvable, “taste-neutral” pharmaceuticals that would be available to other manufacturers. Pfizer emphasized that such a platform offers benefits beyond pediatric administration, such as flexible dosing and extended shelf life—qualities that are attractive (and cost-effective) for the SNS as well as the prescription and over-the-counter consumer market.

Gaps remain in covering children against CBRNE and Emerging Infectious Disease threats, which is why development and investment needs to continue. The Johns Hopkins Center for Health Security recently convened a stakeholder meeting on biodefense, which concluded that “without BARDA support for advanced development, basic science investments will not continue into product development for biodefense” (Summary of Key Recommendations, 2017). This situation, and the importance of BARDA’s contribution, is even more heightened for pediatric biodefense. The NACCD believes the current MCM enterprise of PHEMCE, BARDA, government-industry cooperation, and especially the PHEMCE Peds-OB Integrated Product Team, has proven to be one of the best ways to bring pediatric MCMs to fruition.

**Best practice 3: Ensure a dedicated funding stream for pediatrics needs.**

Emergency Medical Services for Children (EMSC) is a prime example of successful and impactful funding specifically directed to children’s needs. EMSC was created more than 30 years ago due to lack of progress on children’s needs and unacceptable morbidity and mortality within general, adult-focused emergency medical systems. Despite never having annual appropriations greater than $20 million, EMSC has disseminated grants across all states and territories to improve pediatric emergency response nationwide; enabled significant advances in research and research infrastructure; and established a national Data Analysis Research Center. The EMSC’s National Pediatric Readiness Project and other data sources have documented improved quality of care, coordination, training, equipment, resources, staffing, and outcomes for children in the pre-hospital and emergency settings in communities across the United States. It is doubtful that any of these pediatric-specific activities or accomplishments would have been undertaken without the creation and funding of EMSC—and certainly not on a national level. EMSC has been “The Little Program That Could” and serves as a model of what can be accomplished with a dedicated pediatric funding stream, creative thinking to enable federal dollars to have maximum impact, and partnerships with state agencies, professional societies, academia, and practitioners. (Pellegrini et al, 2017).
For all of its success, EMSC’s scope is limited to pediatric emergency care. While such care is a significant component of disaster preparedness and response, many other important areas for pediatric disaster preparedness (such as pediatric needs in disaster recovery or disaster research) lack a similar dedicated funding stream. The NACCD believes funding targeted to pediatric needs is a powerful, cost-effective, and necessary mechanism to improve children’s health in disaster.

Future research needs

In its research and discussions with SMEs, the NACCD Funding Strategies Work Group recognized two pressing goals for future research:

Create a dedicated and pre-established fund and infrastructure reserved for pediatric research in disasters. Procuring grants for research generally follows a six- to nine-month process of writing and submitting an application, awaiting review, receiving an award decision, and receiving the distribution of funds. In an emergency, when new research concerns can arise quickly, funding must be available almost immediately (Faherty et al, 2016). In addition, research infrastructure (for example, protocols, forms, IRB approval) must be pre-positioned and ready to deploy to rapidly carry out research in the midst of disaster (AAP Disaster Preparedness Advisory Council, 2016). Most of our knowledge base about preparedness, response, and recovery around disasters comes from past experiences and expert opinion. While such opinions are valuable and helpful, they do not replace actual research in disaster settings, particularly research that compares multiple possible interventions or that is descriptive early on during an event (descriptive research involves observing and characterizing responses or the effects of a disaster). Research with children in a disaster is even more difficult. Not only are adults the default subjects in most general-population research, but children require additional ethical protections that complicate planning. These difficulties do not mitigate the need for, or justify not conducting, pediatric disaster research; instead, researchers and HHS must work to overcome these challenges so that disaster studies involving children can take place (Challenges in the Use of AVA, 2011) (Safeguarding Children, 2013).

While the ASPR and other agencies have been exploring disaster research infrastructure concerns, funding sources for disaster research need to be more extensively investigated. Faherty, Rasmussen, and Lurie have referred to the National Science Foundation rapid research grants and NIH funding as a possible means of funding this research. The ASPR should explore and identify additional funding possibilities for pediatric disaster research, not only within HHS,
but from other Departments (e.g., Homeland Security, Education) as well as nonprofit philanthropic organizations. Established grant programs should examine the feasibility of rolling grant submission and review, rather than the set submission, review, and award dates, to permit flexibility in emergencies. In addition, any existing and in-process disaster research infrastructure should be reviewed to ensure it possesses the ethical and medical capability to address pediatric research applications.

**Conduct research on the effectiveness, cost-effectiveness, and return on investment on various pediatric disaster preparedness measures to maximize preparedness value, given limited funding resources.** A major challenge in prioritizing preparedness activities relates to measuring effectiveness. With limited funding and resources, what are the activities that will have the greatest impact, or “bang for the buck”? There are many measures of effectiveness: lives saved, QALYs, direct and indirect costs, outcomes, and performance measures, to name a few. For children, additional measurements might involve school and child care attendance, learning measures and academic performance, juvenile justice and social service involvement, Early Intervention referrals, or Adverse Childhood Event scores, among others.

The range of possible preparedness activities for children is similarly daunting and includes the following: public health investment, strong emergency medical services, engaged children’s hospitals, increased community hospital and ED capability, primary care engagement and resiliency, active community coalitions, biosurveillance, targeted MCMs, enhanced workforce training, youth resiliency, school and child care preparedness, and equipment for greater pediatric surge capacity. Furthermore, for optimal preparedness, all of the above activities should be undertaken. Nevertheless, no single agency or organization has the funds or resources to embark on all of these activities simultaneously.

To better prioritize from such a wide range of activities, with many possible measures of effectiveness, there should be a common method of comparison. Cost-effectiveness, and return on investment, is one way to evaluate different options. Cost-effectiveness should not be the only basis for comparison, but it is a useful factor to help in the decision-making process.

Part of the challenge in determining ROI is the lack of a clear baseline for evaluating interventions against the status quo—in other words, what are the costs of not preparing for a disaster scenario? Adding to the difficulty, large uncommon disasters are particularly difficult to quantify in comparison to smaller, more frequent events. Still, even an estimate of baseline costs serves as a point of comparison for evaluating the costs and benefits of investment opportunities, not only for grant-making, but also for policy decisions and individual institutions. By way of example, a private pediatric practice could better decide whether to
invest in a generator to preserve vaccines if it knew the annualized risk of loss from disaster as well as other opportunity costs.

The ASPR should engage experts from a variety of organizations and disciplines to begin developing reasonable estimates for this sort of data. Economists, business experts, research analysts, FEMA, the Agency for Healthcare Research and Quality (AHRQ), FDA, and the SBA might be just a few potential participants. Such a rational, research-based analysis will help decision-makers to better determine how to allocate resources for pediatric preparedness.

**Recommendations**

Based on its findings, the NACCD recommends that HHS and the ASPR prioritize implementation of the following:

**A. Evaluate how much funding from the ASPR and HHS has been used toward pediatric goals and objectives in the past 5-10 years.**

Currently we have no baseline on how much federal funding is allocated to pediatric disaster concerns, let alone to what types of preparedness activities, either in absolute dollars or as a percentage of overall disaster funding. This is concerning since children make up nearly 25% of the population, are a designated at-risk group, and have special needs that are often not addressed in general preparedness planning and response. Many positive activities are occurring despite the small relative investment. A baseline level of spending, correlated to measures of pediatric preparedness, is necessary to better quantify the ROI. Such an analysis would reveal funding and activity gaps and help us and others predict the greater impact a concordant increase in spending (and/or designated children-specific spending) would create. The 21st Century Cures Act of 2016 (21st Century Cures Act, 2016) requires the NIH to quantitate pediatric inclusion in research activities; the ASPR can lead a similar effort for programmatic activities.

The NACCD recommends that HHS identify how much funding has been designated over the past 5–10 years to pediatric-specific disaster activities, and to which ones, and to prepare such a report within the next year in order to better inform future efforts at pediatric-specific preparedness. The methodology used in developing this report would also be useful in application to other populations and future accountability.
B. Require Public Health Emergency Preparedness (PHEP) cooperative agreement and Hospital Preparedness Program (HPP) grantees to report progress on specific pediatric preparedness metrics annually.

Funding with specific expectations and metrics focused on children is one of the most effective ways to implement such activities. Awardees and coalitions will focus their activities when they know they will be asked to report on them and held accountable.

Discussions with HPP staff revealed the challenges in mandating certain tasks or requirements as a condition to receiving HPP funding. Program activities are largely left to the discretion of state and local recipients. Nevertheless, it is reasonable to hold grantees accountable for their funded activities and to demonstrate progress. The Emergency Medical Services for Children’s National Pediatric Readiness Project offers a successful and tested model for improving children’s needs through reporting of performance on non-binding pediatric measures. There are no statutory or funding consequences for failure to report or failure to achieve a certain level of performance. Nevertheless, the program appears to work because organizations know they are being watched and measured, because they want to do well in comparison to their peers, and because the ultimate test—a real-life incident—carries numerous significant consequences if they are not prepared. Similarly, PHEP and HPP grantees should be required to report on a limited number of non-binding metrics because “it’s the right thing to do.” Simply having metrics also raises awareness of pediatric issues and their importance.

The 2017-2022 HPP Performance Measures Implementation Guidance does contain one pediatric-specific metric: Performance Measure 22, percent of hospitals with an emergency department (ED) recognized through a statewide, territorial, or regional standardized system that are able to stabilize and/or manage pediatric medical emergencies. This data is already collected by EMSC but represents an appropriate target for HPP grantees. The inclusion of this measure represents a promising start; however, additional pediatric measures should be created, and more importantly, results need to be disseminated and publicized to stakeholders, other grantee coalitions, Congress, and the general public.

The NACCD recommends that the ASPR develop a limited number of additional performance metrics specific to children’s preparedness for HPP grantees to report annually. The NACCD recommends that children’s stakeholder groups, such as the
Emergency Medical Services for Children and the American Academy of Pediatrics, be engaged to help partner in this activity and offer their experience and expertise. Possible examples of relevant metrics might include the following: presence of pediatric SMEs in an HPP coalition; inclusion of pediatric patients in drills and exercises; percentage of coalition health professionals trained in Pediatric Advanced Life Support (PALS) and/or Advanced Pediatric Life Support (APLS); availability of pediatric specialists, whether in the community or by telemedicine; or pediatric capacity for medical surge. The NACCD also recommends that the ASPR release the results of such Pediatric Performance Measures data collection when available.

C. Change HPP grant terms to longer than one year.

The HPP functions on a five-year project period. Funding appropriations, however, are made one year at a time, making it challenging to invest in larger, more comprehensive, and more sustainable projects. As a result, recipient coalitions tailor their grant expenditures and primary activities to programs that can be completed within one year, which are not necessarily the projects that have the greatest impact or represent the best investment. Change across healthcare delivery systems is particularly challenging and takes time and engagement with bureaucracies; pediatric-focused activities require time, careful planning, and identification of resources and needs. The National Preparedness and Response Science Board and the Government Accountability Office (GAO) made similar observations and recommendations in the past concerning BARDA funding, realizing that pharmaceutical and medical countermeasures research and development require multi-year funding, reflecting the prolonged timeline and commitment that these projects require. Such a change was successfully implemented and has led to the development of a number of novel medical countermeasures.

The EMSC also funds projects on five-year terms.

The NACCD recommends that the ASPR provide feedback to the NACCD on our proposal to change HPP grant terms to longer than one year. Specifically, the NACCD would like to hear of challenges in implementing this proposal and how such challenges might be overcome.

D. Develop analyses of cost-effectiveness that include long-term quality-adjusted life years (QALY), lifetime productivity, and other alternative criteria that promote investment in children when evaluating funding projects and priorities.
Disaster-related investments are often measured by their impact on preserving infrastructure or mitigating loss of assets. Because such assets are usually owned by the rich, poor people and communities receive fewer disaster-related investments and are believed to have less to lose. The World Bank’s recent report “Unbreakable” challenges this view by incorporating the ideas of socioeconomic resilience and well-being losses into disaster mitigation analysis (Hallegatte, 2017). The poor are at higher risk for post-disaster suffering and governmental assistance precisely because they have fewer assets from the start. Once well-being losses are considered, many disaster mitigation programs yield a significantly higher dividend and greater long-term savings when oriented toward helping and protecting the poor—sometimes resulting in savings of as much as four dollars for every dollar invested.

Current measures for assessing the impact, costs, and return on health care preparedness and disaster spending often focus on the adult population because the majority of health system costs address adults’ needs, and adults make up 75% of the population. Reducing health care costs after a disaster and protecting the largest number of people are important and valid goals, but they cannot be the only measures to prioritize efforts. From an economic standpoint, these outcomes marginalize the benefits of investment in children, which often carries larger long-term payoffs. Many long-term measures are already standard in the research literature when analyzing economic effectiveness of certain interventions; these include quality-adjusted life years (QALYs), lifetime costs, and lifetime productivity and earnings. These measures may even underestimate the tremendous value of investing in children given that adverse childhood events can lead to numerous secondary long-term effects that can be difficult to quantify, yet carry staggering economic implications, including increased incidence of chronic disease, decreased education and subsequent lower earning potential, family stress and parental loss of income, and even intergenerational adverse effects. Still, these metrics are a good starting point to evaluate the economic impact of directing funding to children’s needs. Other applicable measures relevant to evaluating recovery for children might include educational achievement, days out of school or child care, or physical growth parameters.

The NACCD recommends that HHS develop cost-effectiveness measures that recognize the impacts of interventions (or lack thereof) on children. The NACCD also recommends that HHS pilot test the use of such measures through a retrospective analysis of existing programs and/or as a prospective non-binding metric in evaluating new programs.
In addition, the Funding Strategies Work Group has two recommendations for funding priorities. While the Work Group is aware that appropriations are the work of Congress, not the ASPR or HHS, we hope that Congress will consider enacting these recommendations and that the ASPR will endorse these recommendations and bring them forward to legislators in any discussion of HHS’s funding needs:

A. **Fund the HHS Public Health Emergency Fund to allow rapid response to new threats, and particularly pediatric-focused response, without depending on Congressional appropriation for every new event or threat.**

Emerging public health crises require rapid scientific research and development of medical and other countermeasures. These activities cannot happen without funding for research scientists, epidemiologists, academicians, industry, and others. Delays mean greater opportunity for these emerging infectious diseases to spread, and engender the risk that responders will use ineffectual (or even counter-productive) mitigation and treatment measures. Therefore, funding must already be available and be used in the early stages of these threats to achieve an effective response. Existing funding streams are usually allocated to pre-existing programs and cannot be diverted elsewhere without disruption of current specialized research or efforts, or without impairing the effectiveness of everyday preparedness and response. Until 2016, Congress had generally authorized special funding for most rapidly emerging large-scale health crises, at the recommendation of HHS, the ASPR, the CDC, and other public health experts. For example, Congress provided special funding to address the emerging threats of H1N1 and Ebola. However, Zika funding was not authorized for much of 2016 as Congress debated political considerations, allowing the virus to establish local transmission in Miami and Puerto Rico and delaying the development of a vaccine. It is unclear how many infants were—or will be—born with Zika-related symptoms in the U.S. and territories as a result of this delay, but it is indisputable that infants have been affected at this point (Delaney et al, 2016). The current emergency appropriation process is no longer tenable or responsive enough to effectively address rapidly emerging public health threats. Instead, there should be a robust “reserve” fund that would be appropriately funded (and re-funded) during or after crises. This fund would be usable at the discretion of HHS in accordance with scientific assessments and subject to certain controls and audits. Early investment in research and countermeasures would have the potential to avoid more expensive long-term costs.

The NACCD supports appropriate investment in the Public Health Emergency Fund so that HHS may lead a rapid and effective response to emerging threats and lessen future
morbidity and costs. This Fund should not diminish or displace existing funding streams for everyday preparedness given that these programs form the basis for community and nationwide resiliency regardless of threat. Rather, the Public Health Emergency Fund would be reserved for unanticipated, threat-specific activities not covered under other existing programs.

B. **Increase funding for existing preparedness programs to strengthen everyday preparedness and resiliency and reverse funding cuts from the past decade.**

Preparedness funding streams should be strengthened and continue to be funded, and funded well, as opposed to being diverted to fund other activities. Everyday readiness and capacity are essential to prepare for unknown threats of tomorrow, particularly for public health-related threats such as emerging infectious diseases. The decline in public health spending at the state and local levels over the past decade has translated into decreased staffing, stretched response capabilities, and suboptimal investment in community resiliency (Impact of the Redirection, 2016). While every public health threat may be unique, they all share certain characteristics and needs in terms of community impact. Having strong and robust public health systems, health care delivery, preparedness coalitions, schools, and child care facilities enables rapid detection and response, containment and prevention of adverse consequences, and increased capacity for local management. Therefore, strong funding for everyday systems is also an investment in preparedness.

The NACCD Funding Strategies Working Group reiterates the ideal of dedicated pediatric readiness funding but recognizes the legislative challenges in creating such funding streams de novo. The next most effective way to achieve preparedness for the nation’s children is to strengthen existing preparedness, public health, and health care delivery programs so that they can adequately address the needs of children and all members of the population.

**Recommendations Summary:**

**Implementation Recommendations**

1. Evaluate how much funding from the ASPR and HHS has been used toward pediatric goals and objectives in the past 5–10 years.
2. Require Public Health Emergency Preparedness (PHEP) cooperative agreement and Hospital Preparedness Program (HPP) grantees to report progress on specific pediatric preparedness metrics annually.
3. Change HPP grant terms to longer than one year.
4. Develop metrics and analyses of cost-effectiveness that include long-term quality-adjusted life years (QALY), lifetime productivity, and other alternative criteria that promote investment in children. Once these analyses and metrics are developed, use these analyses and metrics for evaluating funding projects and priorities.

**Funding Recommendations**
1. Fund the HHS Public Health Emergency Fund to allow rapid response to new threats, and particularly pediatric-focused response, without depending on Congressional appropriation for every new event or threat.
2. Increase funding for existing preparedness programs to strengthen everyday preparedness and resiliency and reverse funding cuts from the past decade.

**Research Recommendations**
1. Create a dedicated and pre-established fund and infrastructure reserved for pediatric research in disasters.
2. Conduct research on the effectiveness, cost-effectiveness, and return on investment on various pediatric disaster preparedness measures in order to maximize preparedness value, given limited funding resources.

**Other Recommendations**
1. Improve the ability of potential grantees and contractors to locate pediatric disaster funding opportunity announcements by standardizing language in these FOAs.
Works Cited


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The following references were also used in developing some of the ideas in this report


Appendix A: NACCD Voting Member Roster

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