

Testimony of the American Academy of Pediatrics
Concerning the U.S. Government Response: Fighting Ebola and Protecting America
Submitted for the Record to the Senate Appropriations Committee

November 7, 2014

Submitted by: James M. Perrin, MD, FAAP, President, American Academy of Pediatrics

The American Academy of Pediatrics (AAP), a non-profit professional organization of 62,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, appreciates the opportunity to submit this statement for the record regarding the U.S.'s response to the Ebola outbreak. When evaluating the federal government response to the Ebola outbreak, the AAP urges Congress to consider the special health needs of children, especially those in West Africa, as well as the importance of funding for public health preparedness and response programs abroad and in the United States.

Children are not just small adults. Their needs differ in terms of identification, treatment, isolation, and recovery from infectious diseases, especially one as deadly as Ebola. The toll Ebola has taken on children in West Africa is not yet known but countless children have died, been orphaned, or face stigma and isolation as a result of this disease outbreak. Though no children in the U.S. have contracted Ebola, it is imperative that Federal, state and local governments and health systems are adequately prepared, trained, and equipped to handle actual or suspected pediatric cases. It is essential that the Federal government support USAID's Emerging Pandemic Threats (EPT) program and the USAID and CDC global health programs, which help countries strengthen their health systems and increase their surveillance and diagnostic capabilities.

As Congress considers additional funding for the U.S. government response to Ebola, the AAP urges members to treat this situation as the emergency that it is. Any additional funds to combat Ebola should not come at the expense of cuts to other non-defense discretionary accounts. Many of the agencies and state and local public health departments that are on the front lines on Ebola have faced cuts to their operating budgets for many years, weakening their ability to respond to all public health threats. Any new funding under consideration should not be limited only to the Ebola response since the public health system and medical countermeasures enterprise are responsible for protecting Americans from many ongoing infectious disease threats such as Enterovirus D68 and seasonal influenza.

The AAP has created a number of resources to assist pediatricians which are accessible through aap.org/disasters and for parents at healthychildren.org/Ebola. The AAP applauds the Centers for Disease Control and Prevention (CDC) and its Emergency Operations Center (EOC) for activating its Children's Task Force. The EOC At-Risk Desk established the Children's Task Force to allow for a faster, more coordinated response that ensures the needs of children are reflected in CDC response efforts. The guidance released by the CDC and other Health and Human Services (HHS) agencies is critical to ensure that schools, Head Start and child care facilities, ambulatory care settings, inpatient facilities, and others are prepared to meet the needs of actual and suspected pediatric Ebola cases.

As the U.S. government continues to respond to the Ebola outbreak, the AAP hopes that HHS will utilize the expertise of the National Advisory Committee on Children and Disasters, authorized by the *Pandemic and All-Hazards Preparedness Reauthorization Act*, which is comprised of key federal and non-federal leaders in pediatric disaster preparedness.

The AAP urges Congress to take the following aspects into account while evaluating the federal government response to Ebola:

African children from the outbreak epicenter need our help.

It is important that we remember the needs of the West African children who are at the epicenter of the outbreak. The West African nations at the heart of the outbreak have very fragile health infrastructure with gaps exacerbated by poverty and inequity, and the facilities that are in place are overwhelmed. Children already bear a disproportionate burden of vaccine preventable infectious diseases, and may suffer the consequences of these diseases due to the health care disruptions caused by Ebola. It is crucial that the U.S. commit to enhancing the health care infrastructure in the area, not only to ease the effects of the disease, but also to ensure that children are receiving appropriate care and treatment.

In addition to concerns about fragile health infrastructure, there are concerns about the orphaned children who have lost their parents to Ebola. UNICEF has estimated that nearly 4,000 children have been orphaned as a result of the current outbreak. Some orphans as young as two years old are living in the streets without access to proper health care, nutrition, or supervision. The countries in the affected area lack the resources to appropriately care for and place these children in foster or adoptive homes.

Diseases do not stop at borders, and a strong U.S. investment abroad is needed to quell the outbreak abroad in order to protect our own citizens.

Though the epicenter of the Ebola outbreak is indeed far away, the few cases that the U.S. has seen have proved that we are not immune to Ebola's spread. It is imperative that the U.S. commit the appropriate resources to stop the spread of Ebola abroad in order to protect our own citizens. This is best done through a strong commitment to programs abroad.

U.S. investment in helping doctors and health workers strengthen their systems in countries like Nigeria and Uganda has helped to contain Ebola outbreaks. Specifically, in Nigeria, healthcare workers were able to build upon the existing infrastructure for polio eradication in order to contain the outbreaks of Ebola, with guidance from the World Health Organization and a rapid, effective response from their own government. Uganda has managed to contain Ebola after all four of its outbreaks since 2000, relying on an experienced health system that has increasingly partnered with the United States to address other health threats including HIV/AIDS, malaria, nutrition, and preventable maternal and child deaths. It is crucial that any U.S. funding for the Ebola response be additive, and not take away from any current health care funding commitments through the U.S. Agency for International Development, the CDC, the President's Emergency Plan for AIDS Relief (PEPFAR), and the President's Malaria Initiative (PMI).

It is harder to screen children for Ebola.

Recognizing the symptoms of Ebola in children can be difficult to recognize because of the non-specific nature of the signs and symptoms of the disease, particularly in its early stages. Some symptoms, such as febrile illnesses with nausea, vomiting and diarrhea are quite common in children and are present year-round. Therefore, it is of critical importance that travel history or epidemiological connection to individuals with Ebola are obtained from symptomatic children or their parents or guardians.

In addition to these concerns, Ebola outbreaks have typically occurred in low-resource settings, and therefore, there is limited data on pediatric cases of Ebola. Without appropriate data, it is difficult to extrapolate findings from afflicted areas and learn from them to better treat children who may have the disease.

There are limited data about the treatment of children with Ebola.

Though treatment protocols are evolving with the development of new therapies, there are several scenarios for infants in which there is limited data and no guidance. For example: what evaluation or treatment should be offered for infants who may have been exposed to Ebola in utero or at the time of delivery? There are also questions about whether a woman who is recovering from Ebola can breastfeed a child. Ebola has been found in the breast milk of women in the convalescent phase of the disease, but we

do not know if mother-to-infant transmission is possible in this way. Further study of these scenarios is needed so that pediatricians and other health care providers may effectively counsel their patients.

Children have unique requirements for isolation.

Typically, when children are isolated or quarantined, they are isolated with a family member so that the child can continue to be nurtured while ill. The nature of Ebola and its transmission complicate this situation. Pediatric providers urgently need public health guidance that addresses whether and when to isolate a child, and who can remain with the child.

In addition to determining who can remain with a child who may have Ebola, a child's isolation will likely be prolonged because of the need to transport testing samples to a public health laboratory. This testing is already placing a burden on hospitals and public health laboratories, and it has the potential to impact normal clinical operations as well as the potential to lead to closures of clinics. This means that not only are children awaiting test results while quarantined, but unaffected children also may be losing access to care. Another challenge that arises is the need to decontaminate ambulatory sites following a positive Ebola test.

While CDC has prepared clinical guidelines on personal protective equipment to be used by healthcare workers treating patients with Ebola, we would also welcome guidance for family members and caregivers for a child with suspected or confirmed Ebola. It is important for these individuals who are interacting with the children to have appropriate direction as to what equipment must be worn, and when it must be worn in order to reduce instances of transmission of the virus.

Children who have been infected, or who have had a family member who was infected have special mental health needs.

Many children in the Ebola-stricken countries have special mental health care needs that have arisen from the outbreak due to the loss of family members, being quarantined, or because they are being shunned by people who are afraid of them because they or their family members have been infected. Many of these children are outright abandoned by their families, and are experiencing Post Traumatic Stress Disorder (PTSD) as a result of their situation. It is important that the U.S. provide assistance to support care facilities that meet the mental health needs of these children, as well as programs that can appropriately place children in foster or adoptive homes.

In order to be properly prepared if there were to be an Ebola outbreak in the U.S., we must develop an infrastructure for handling the mental health care needs of the children who are either infected, or who have a family member who has been infected. These are protocols that must be developed with the best interest of children in mind.

There is no established timeline for children recovering from Ebola to return to school or child care.

At some point following treatment, children recovering from Ebola will need to return to school or child care. There are numerous concerns around the implications of having a child at school or child care facility who is suspected of having Ebola. It is likely that schools and child care facilities will close in the event of a child with Ebola. We are appreciative for the Administration of Children and Families guidelines for Head Start Programs and Child Care Providers that provide good guidance on proper washing, cleaning, and handling of soiled bedding, equipment and toys. We also appreciate the fact that the CDC is working with the U.S. Department of Education on more detailed guidelines to help address Ebola-related issues at schools and child care facilities.

The AAP urges Congress to support research efforts on the timeline of children returning to school or child care after surviving Ebola. In particular, more data must be collected on the period of infectivity.

These data can be used to create evidence-based recommendations for schools and child care facilities to follow.

Children are not included in clinical trials for Ebola treatments and vaccines.

Though supportive care is recommended for all Ebola patients, there are several experimental therapies and vaccines in clinical trials. Children are often not included in clinical trials, and in order for them to benefit from these treatments of vaccines, an ethical framework for including children in trials for Ebola treatments must be developed.

Crucial public health preparedness programs are underfunded.

A strong public health and healthcare infrastructure is essential to the U.S.'s biosecurity and public health preparedness. Programs like the ASPR Hospital Preparedness Program (HPP) have been cut by nearly a third since Fiscal Year 2010, resulting in the loss of personnel, expertise, and coordination within healthcare coalitions charged with protecting the healthcare system during a disaster. The CDC Public Health Emergency Preparedness (PHEP) grant program builds the first line of public health defense against disasters and disease outbreaks, including surveillance, emergency operations, response, and recovery. The PHEP helps all community sectors work together – local and state health departments, health care providers, emergency management, first responders, business, education, faith-based and service groups – so that when disaster strikes, everyone is prepared.

To prevent, control and treat a disease outbreak like Ebola, it is essential that first responders and health care providers have the right medical countermeasures (MCMs) for the right population at the right time. This poses a challenge for children since many MCMs approved for use by adults do not yet have pediatric indications, formulations, or dosing information. As a result, the nation's stockpiles are lacking in the MCMs that would be required by children in the event of a disaster. More funding and leadership by the U.S. government are necessary to ensure the Public Health Emergency Medical Countermeasure Enterprise and the Strategic National Stockpile have adequate MCMs for children. The Academy stands by to help by identifying appropriate pediatric subject matter experts who can help with this.

In addition, there needs to be sustained federal investments in scientific research. Since the doubling of the National Institutes of Health (NIH) budget last decade, federal funding for scientific research, as well as the purchasing power of the NIH budget, has declined steadily. The lack of federal research funding that keeps pace with the economy prevents scientists from accessing cutting edge resources that are needed to create new treatments for adverse conditions in children both at home and abroad, including infectious diseases not adequately studied by private industry. The Budget Control Act continues to threaten even larger cuts to much-needed federal research funding. While the nation faces fiscal challenges, consistent and increasing federal funding for research programs are needed to develop new treatments, drugs, and protocols for children to counter deadly threats such as Ebola.

The U.S. is in a unique position to lead a global response to the Ebola outbreak. As a country with numerous programs designed to prepare for, address, and recover from public health crises, it is now more important than ever for the U.S. to embrace this role both abroad and within our own borders. The AAP urges Congress to consider the unique health care needs of children both here and abroad.

The American Academy of Pediatrics looks forward to working with Members of Congress to prioritize the health of our nation's children in the federal response to Ebola. If we may be of further assistance please contact Pat Johnson at the AAP Department of Federal Affairs at 202-347-8600 (phone), 202-393-6137 (Fax) or pjohnson@aap.org. Thank you for your consideration.