

January 10, 2019

The Honorable Frank Pallone  
Chairman  
Committee on Energy & Commerce  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Greg Walden  
Ranking Member  
Committee on Energy & Commerce  
U.S. House of Representatives  
Washington, DC 20515

Dear Chairman Pallone and Ranking Member Walden:

As organizations dedicated to improving the health of children and their families, we read with interest that two of the first hearings the committee intends to hold will focus on the future of the Affordable Care Act and the health and safety of children separated from their families at the border. As you prepare for these hearings, we encourage you to ensure that the considerations of children and youth with special health care needs (CYSHCN), including those with disabilities, are specifically addressed.

As you know, the Affordable Care Act has provided critical protections for CYSHCN such as coverage for preexisting conditions, prohibition on annual caps and lifetime limits, and the provision of essential health benefits. Changes that limit these protections would have an especially harmful effect on CYSHCN and their families, who rely heavily on access to comprehensive health services and whose health care expenses are very high.

With regard to the health and safety of children separated from their families at the border, we similarly urge paying special attention to the unique and complex needs of CYSHCN. These children require extra supports and services ranging from vigilant monitoring, regular medications, and specific medical interventions when they experience a crisis (such as a seizure or asthma attack) to the calming, supportive presence of their parent when suffering from pain or an episode of anxiety. It is critical that the U.S. Department of Health and Human Services' Office of Refugee Resettlement be equipped to meet the distinctive needs of CYSHCN.

Our organizations are available to provide you and your staff with background information, to suggest witnesses, and to serve as a general resource as you examine these critical issues. We encourage you to contact any of us with questions or requests for further information related to the unique health care needs of CYSHCN.

Sincerely,

Association of Maternal & Child Health Programs (*contact: Amy Haddad ahaddad@amchp.org*)  
Association of University Centers on Disabilities (*contact: Rylin Rodgers rrodgers@aucd.org*)  
Family Voices (*contact: Janis Guerney jguerney@familyvoices.org*)