



Published in final edited form as:

Disaster Med Public Health Prep. 2012 June ; 6(2): 91–93. doi:10.1001/dmp.2012.26.

Children With Special Health Care Needs and Preparedness: Experiences From Seasonal Influenza and the 2009 H1N1 Influenza Pandemic

Georgina Peacock, MD, MPH, Cynthia Moore, MD, PhD, and Timothy Uyeki, MD, MPH, MPP
National Center on Birth Defects and Developmental Disabilities (Drs Peacock and Moore);
National Center for Infectious and Respiratory Diseases (Dr Uyeki), Centers for Disease Control
and Prevention, Atlanta, Georgia.

Children (< 18 years of age) make up about 25% of the population in the United States¹ and, therefore, represent a large demographic population who require more planning for different medical needs during public health emergencies than adult populations. Within the pediatric population, approximately 14% has special health care needs,² and one in six children has a developmental disability.³ The Maternal Child Health Bureau describes children and youth with special health care needs (CYSHCN) “as those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions who require health and related services of a type or amount beyond that required by children and youth generally.”⁴ As defined, such CYSHCN might need particular attention during some public health emergencies. A child’s developmental level, underlying medical condition(s), and mobility status may affect his or her need for support, as well as the effectiveness of any medical countermeasures such as vaccines or other medications (eg, antimicrobials). Planning and targeting of interventions including countermeasures, and nonpharmaceutical interventions during an emergency might be necessary to address the increased needs of these specific groups of children.

The experience with the 2009 H1N1 pandemic can help plan for the needs of CYSHCN during future public health emergencies. Before the pandemic, children with neurologic and neurodevelopmental conditions, including those with cerebral palsy, intellectual disability, and certain genetic conditions, were found to be at higher risk for severe complications associated with seasonal influenza, including complications that resulted in intensive care unit admission and death.^{5–8} Similarly, CYSHCN with influenza A (H1N1) pandemic 2009 (H1N1) virus infection were at increased risk for hospitalization, intensive care unit admission, and death.^{9–12} In a case series of the first 36 pediatric deaths associated with 2009 H1N1 reported to the Centers for Disease Control and Prevention (CDC), the majority (61%) had an underlying neurologic condition and, of those, 41% had a chronic pulmonary condition.¹³ Experiences with seasonal influenza and the 2009 H1N1 pandemic highlight the importance of using standard measures such as vaccination and, when appropriate, antiviral

Correspondence: Georgina Peacock, MD, MPH, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 1600 Clifton Rd, MS E 86, Atlanta, GA 30333 (gpeacock@cdc.gov).

Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

treatment for CYSHCN; for considering additional measures such as school and child care center closure; and for planning a future influenza pandemic and other public health emergencies and disasters.

ISSUES FOR PREVENTION

2009 H1N1 Vaccination

Because the monovalent 2009 H1N1 vaccine was not going to be available in the United States until the fall of 2009, in July 2009 the Advisory Committee on Immunization Practices issued a priority list of high-risk populations to be targeted once the 2009 H1N1 vaccine became available. This list included all children aged six months or older and those recognized to be at higher risk for severe complications, such as CYSHCN.¹⁴ To ensure that these recommendations could be implemented, CDC and the American Academy of Pediatrics (AAP) jointly sent letters to immunization coordinators at state health departments to highlight these populations with increased vulnerability and need for priority vaccination. The CDC worked with AAP and other partners to disseminate information, focusing on the special needs of CYSHCN through COCA (Clinician Outreach and Communication Activity) calls and webinars for parents and child care providers who care for CYSHCN.

Public acceptance of vaccines in general has diminished in the past few years.¹⁵ In the United States, annual influenza vaccination of all children six months of age or older is recommended.¹⁶ Many parents are concerned about influenza vaccination and associations with adverse outcomes.^{17–19} Parents of children with neurologic conditions in particular may be ambivalent about influenza vaccination of their children, relying instead on good hand-washing practices, avoidance of places where a child might be exposed to influenza, and optimal nutrition to prevent influenza. Targeting messages to parents of children with these conditions is essential in addressing barriers to influenza vaccination. This approach is particularly important with vaccines that are new or, as was the case with the 2009 H1N1 vaccine, are perceived as new. In addition, vaccinating other household members and caregivers can help reduce transmission of influenza viruses to CYSHCN.

The AAP recommends that all children with chronic medical conditions have a *medical home*, which means that they receive “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care from a team including a primary care physician.”²⁰ Primary care providers are strong allies of public health, as they work on the front lines to increase influenza vaccine coverage. While they must underscore the importance of vaccination for all children, they also should understand and address concerns of parents of children at higher risk for serious complications from influenza, such as those with neurologic conditions and other CYSHCN. Many of these children are cared for by a variety of subspecialty providers in addition to their primary care providers. Typically, subspecialists do not administer vaccinations; however, they are in an ideal position to emphasize the importance of vaccination by primary care providers and encourage influenza vaccination so that opportunities for vaccination are not missed.²¹ In a public health emergency situation, pediatric health care providers must be made aware of the

needs of vulnerable children and work with their families to ensure the success of any public health response that involves mass vaccination.

Influenza vaccine effectiveness varies from year to year, depending in part on the match between circulating influenza viruses and vaccine strains²²; effectiveness also can vary among specific populations. Hara and colleagues found decreased immunogenicity to the 2009 H1N1 vaccine among individuals with severe motor and intellectual disability.²³ Consecutive doses in the same season did not improve immunogenicity among these individuals. While vaccination is still strongly recommended, providers and parents of such children needed to be informed about these findings and the need for additional strategies to prevent influenza among these vulnerable children.

Antiviral Treatment

Antiviral treatment of influenza is most effective when started early (within two days of illness onset), and has continued clinical benefit when antiviral agents are initiated through four days after illness onset.^{23,24} Because CYSHCN are at high risk for severe complications from seasonal influenza and pandemic influenza, and influenza vaccination is not 100% effective, providers must educate parents about the importance of bringing ill children with possible influenza for medical evaluation as soon as possible so that antiviral treatment can be initiated promptly if influenza is suspected or proven.²⁵ For CYSHCN who live in long-term care facilities, prompt recognition of an influenza outbreak, even among vaccinated children, and prompt implementation of control measures, including antiviral treatment of ill children and antiviral chemoprophylaxis when appropriate, is critical.²⁶ During the pandemic, CDC worked with other federal partners and national professional groups to host COCA calls presenting cases of children who were critically ill to assist in sharing information about treatment of influenza.

ISSUES FOR NONPHARMACEUTICAL INTERVENTIONS

Young children with complex medical conditions may be cared for during the day, either in specialized (“medical”) or traditional child care settings. Children in medical child care settings receive skilled nursing services and other therapies that are not offered in traditional child care settings. Both settings require consideration of the child’s special needs to protect him or her from influenza. In addition, the possible effects on the child and family when these services are not available must be considered.²⁷ During the 2009 H1N1 pandemic, CDC held webinars for child care providers working at Easter Seals facilities, child care centers at Young Men’s Christian Associations (YMCAs), and other child care organizations, as well as coordinated weekly telephone calls with leaders in child care including those in leadership roles in national child care associations and directors of large child care organizations, to discuss potential problems and solutions to issues they were dealing with during the pandemic. Planning to minimize transmission of influenza through nonpharmaceutical interventions, such as social distancing and encouraging good hand washing, as well as through vaccination of staff and children who are in these settings, can decrease the number of children who become ill. Similarly, in school settings, whether the CYSHCN are in a classroom with typical peers or in specialized classrooms or schools, planning for influenza outbreaks or other emergencies should occur.

In addition to influenza vaccination of all child care staff, practicing good hand and respiratory hygiene and cough etiquette can help prevent influenza virus transmission to or from CYSHCN. Caregivers need to be educated that such children are at high risk for severe influenza complications and to notify parents about possible exposures to other children or staff with acute respiratory illness. In specialized child care settings that include children with neurologic or medically complex conditions with healthy peers or for child care centers that provide care only to CYSHCN, discussion of planning for proactive closure to prevent the spread of illness should be considered. School nurses or child care health consultants can assist child care facilities, schools, and parents in planning what to do during an outbreak or emergency event. During the 2009 H1N1 pandemic, some camps serving children with special medical conditions such as muscular dystrophy were closed proactively to prevent transmission of pandemic influenza. Planning for influenza outbreaks among CYSHCN at child care centers and special camps also can be informative for preparing for other types of emergencies and disasters.

CONCLUSIONS

CYSHCN potentially have greater needs during public health emergencies, and many of these can be anticipated ahead of time. Different public health emergency situations might confer higher risk for poor outcomes among different subsets of CYSHCN, depending on their particular areas of vulnerability. The 2009 H1N1 pandemic had a major effect on CYSHCN and, together with data from seasonal influenza, has highlighted the increased vulnerability of children with chronic neurologic, developmental, and pulmonary conditions for severe and fatal influenza outcomes. Parents and providers of CYSHCN should be educated about prevention and control of seasonal and pandemic influenza, including the need for influenza vaccination, early antiviral treatment, nonpharmaceutical interventions, and advance planning.

A better, more complete understanding by providers of the needs of families and CYSHCN, as well as awareness by those families about the needs of their children, during a public health emergency is needed. To formulate targeted interventions, research is needed to identify which children with specific conditions are at heightened risk during different emergency situations. Specific guidelines and health education messages targeting these special populations should be developed for families of CYSHCN and health care providers to optimize care during future public health emergencies.

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