

NASDDDS

National Association of State Directors of Developmental Disabilities Services

113 Oronoco Street, Alexandria, VA 22314
Tel: 703-683-4202; Fax: 703-684-1395
Web: www.nasddds.org

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Vince Campbell Ph.D.
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
Division of Human Development and Disability
1600 Clifton Road Mailstop E-88
Atlanta, Ga. 30033

Dear Dr. Campbell,

I am writing in follow-up to our telephone conversation on Monday July 6, 2009 regarding the provision of advice and technical assistance to state agencies serving individuals with intellectual and developmental disabilities. One of the areas of importance that we discussed was the need to ensure that the 2009 Novel H1N1 Influenza Vaccination Program include among the targeted priority groups, (a) individuals with intellectual and developmental disabilities (ID/DD) and related conditions and (b) staff supporting these individuals.

By way of background, data reported by the University of Minnesota Research and Training Center on Community Living reveal that as of June 2007 approximately 1,000,000 individuals with intellectual and developmental disabilities, including autism, cerebral palsy and related conditions received publicly financed residential supports through Medicaid and other state/federally funded programs. The majority of these individuals, approximately 56% live with their families, receiving the supports that they need at home, at work and in a variety of in day programs in the community. Of the approximately 440,000 remaining individuals, about 72% live in local group homes or other neighborhood settings of less than 6 persons. Only about 28% reside in large state and privately operated institutions. Estimates reported by the Institute on Community Inclusion (UCEDD) University of Massachusetts Boston suggest that an additional 566,895 individuals with ID/DD received day or employment supports from state developmental disabilities during that same year.

Because of the intensity of personal healthcare needs among individuals with ID/DD, limitations in their ability to take the recommended precautions to avoid spreading or coming in contact with the virus, and frequent reliance on congregate residential and day service settings, people with ID/DD have increased vulnerability to diseases spread through human contact.

The majority of individuals with ID/DD receiving services rely on direct support and physical assistance to accomplish basic activities of daily living. The number of staff furnishing day and residential supports to individuals with ID/DD varies depending on recipients' needs and service or program type. Traditionally, the highest staff to client ratios exist in intermediate care facilities for persons with mental retardation and related conditions (ICF/MR) and Medicaid waiver funded community programs serving high needs individuals. Comparatively lower staffing rates exist in day and family support programs. A report to Congress on the supply of direct support professionals serving individuals with intellectual disabilities and other developmental disabilities submitted by the DHHS Office of the Assistant Secretary for Planning and Evaluation in 2006 identifies approximately 875,000 direct support staff providing a range of services and supports to persons with ID/DD. Additional services are furnished by a wide range of health, educational, training and treatment professionals and paraprofessionals. We estimate that the number of staff has grown to just under a 1,000,000 today. Because of the close working relationships between individuals receiving support and staff each of these staff are at high risk for contracting and spreading influenza and similar diseases.

As you know, the CDC, the National Foundation for Infectious Diseases (NFID), the Infectious Disease Society of America, the Joint Commission on Accreditation of Health Care Organizations (JCAHCO) and many other groups recommend annual influenza vaccinations for health care personnel (HCP) because of their increased risk of contracting and transmitting influenza. I understand that the CDC's Advisory Committee on Immunization Practices has provided specific vaccination recommendations, including target populations and priorities for periods of limited or phased vaccine supply. We believe that it is essential that individuals with ID/DD be included among the targeted groups. And, that the staff providing direct and ancillary supports to persons with ID/DD be identified as critical health care personnel (HCP) because of their increased risk of contracting and transmitting H1N1 and other influenzas.

Thank you for your interest in assisting state developmental disabilities agencies in their efforts to assure the health and welfare of individuals with intellectual and developmental disabilities through adequate preparation for and response to the current influenza pandemic. I look forward to our continuing collaboration. Please let me know if you have any questions or need additional information.

Sincerely,

Charles Moseley Ed.D.
Associate Executive Director
National Association of State Directors of Developmental Disabilities Services

C: Nancy Thaler
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