

# **Pandemic Influenza Preparedness and Response for People with Disabilities**

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The findings and conclusions in this report have not been formally disseminated by the Centers for Disease Control and Prevention and should not be construed to represent any agency determination or policy.

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# Disability

“An umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).”

- World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva: WHO; p. 213.

i.e., Not disease specific

# Impairment, Activity and Participation Domains Associated with Disability

- Learning and understanding
- Seeing *MISSING -> MENTAL ILLNESS*
- Hearing
- Communicating
- Mobility
- Self-care
- Domestic life (Instrumental activities of daily living)
- Interpersonal interactions and relationships
- Major life areas (education, work and economic life)

# Estimating Size of the Population

- Number varies depending on the survey used, the sampling frame, the survey mode, the questions asked, even skip patterns employed
- Usually limited to noninstitutionalized civilian population
- Estimates vary but generally 15% -20% of the population and 40 - 50 million people
- Estimates vary by location, race, sex, age
- Disparities exist between people with and without disabilities on health status, income, education

# Estimated Population and Percentages with Self-Care Disability, by Age Group and Residential Status

Age (yrs)	Living Alone		2 People Living Together – 1 or both w Dis (1 may be a child)	
	N	%	N	%
5-17	0	-	27,069	1.0%
18-44	126,435	1.0%	281,898	1.2%
45-64	341,382	4.8%	1,075,680	3.5%
>=65	291,433	9.1%	1,483,033	7.9%
>=5	759,250	3.4%	2,867,680	3.8%

Source: American Community Survey, 2006, Public Use Microdata Samples, US Census Bureau

# Community-Based Services – Care Recipients and Workforce, 2003

## ■ Service Recipients:

– MR/DD	396,909
– Aged	117,462
– Aged/Disabled	383,636
– Disabled/Physically Disabled	50,101
– Children	9,868
– HIV/AIDS	14,203
– Mental Health	2,193
– TBI/SCI	7,757
– Total	982,129

## ■ Workforce, Estimated number of PAS workers and workers with people with self-care difficulty 1,001,464

Kitchener, M., Ng, T., & Harrington, C. (October 2006). Medicaid Home and Community-Based Services Data, 2003.

# Issues That Make People with Disabilities More Vulnerable

- lack of data on experience of people with disabilities in emergency events and pandemic flu
- accessibility to information and health services
- people with disabilities reside in a variety of community and institutional settings
- number of people with disabilities who require on-going support and the potential impact of disruptions to needed services and supports
- inconsistency in emergency preparedness plans at governmental levels in previous emergencies



# What about People with a Disability and Pandemic Influenza?

- No data on how people with disabilities have been affected by previous outbreaks of pandemic influenza
- We know that people with disabilities are slightly more likely to receive annual seasonal influenza immunizations

- CDC. Disability and Health State Chartbook, 2006

# Pandemic and All-Hazards Preparedness Act (PAHPA), 2007

Establishes a new Section 2814 of the PHS Act to address the needs of *at-risk individuals*, defined as children, pregnant women, senior citizens and other individuals who have special needs in the event of a public health emergency, as determined by the Secretary. Requires the Secretary to take the needs of at-risk individuals into account in managing several preparedness programs, including the SNS and preparedness grants to states.

# Response Issues and Concerns

- Data collection systems that document disability status still need to be developed
- If assessments of disaster preparedness are valid indicators, state, territorial, tribal and local planning and readiness may be lacking.
- While accessible messages have been developed for people with hearing loss who have technology access, messaging for people with cognitive limitations is less developed

# Response Issues and Concerns

- People with disabilities have had difficulty getting involved in planning.
- Social isolation may put homebound people with disabilities and those who rely on paid caregivers at risk for disrupted care and support
- There is concern about people with disabilities being given appropriate priority for and access to vaccines and antiviral medications

# Recommendations

- Inclusion of disability questions routinely in all data collection related to pandemic influenza
- Involving people with disabilities, advocates and caregivers in all aspects of planning and response
- Specific guidance to states, localities, territories and tribes to promote:
  - continuity of services to homebound people with disabilities
  - alternative/accessible communications to people with disabilities and other hard-to-reach populations

# Recommendations

- Discussions between state and local authorities regarding vaccination plans and distribution of anti-viral medications
- Specific contingencies for continued staffing for in-home, personal assistance and congregate care supervision
- Continuing evaluation and feedback to state, territorial, local pandemic influenza planners on performance with regard to their preparations for all at-risk populations.