



Implications of Pandemic Influenza for People with Disabilities

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Outline

- What are disabilities?
- How many people with disabilities?
- Characteristics of populations with disability
- Why may people with disabilities at greater vulnerability during an influenza pandemic?
- Legislative and administrative foundations for including provisions for people with disabilities in all hazards preparedness, including planning for pandemic influenza
- Status
- Major issues, concerns, and current recommendations for preparedness
- General recommendations for preparedness for pandemic influenza with regard to people with disabilities



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



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Focus

- Functional issues that may put people with disabilities at additional risk in the event of pandemic influenza
- Not on potential drug interactions or contraindications related to conditions underlying the functional limitations of people with disabilities



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Activities and Participation

- Learning and understanding
- Seeing
- Hearing
- Communicating
- Mobility
 - moving
 - moving around
 - moving things
- Self-care
 - Domestic life (Instrumental activities of daily living)
 - Interpersonal interactions and relationships
 - Major life areas (education, work and economic life)

MISSING -> MENTAL ILLNESS



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Disability and Emergency Preparedness and Pandemic Influenza Planning and Response

- Focus is on functioning and environment
- Can we identify and anticipate features of people with disabilities (impairments and activity limitations) and environmental factors that can yield desired outcomes of emergency preparedness activities (including pandemic influenza)
 - Mitigation
 - Response
 - Recovery



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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 geographic location, race, sex, age
- Disparities exist between people with and without disabilities on health status, income, education, etc.



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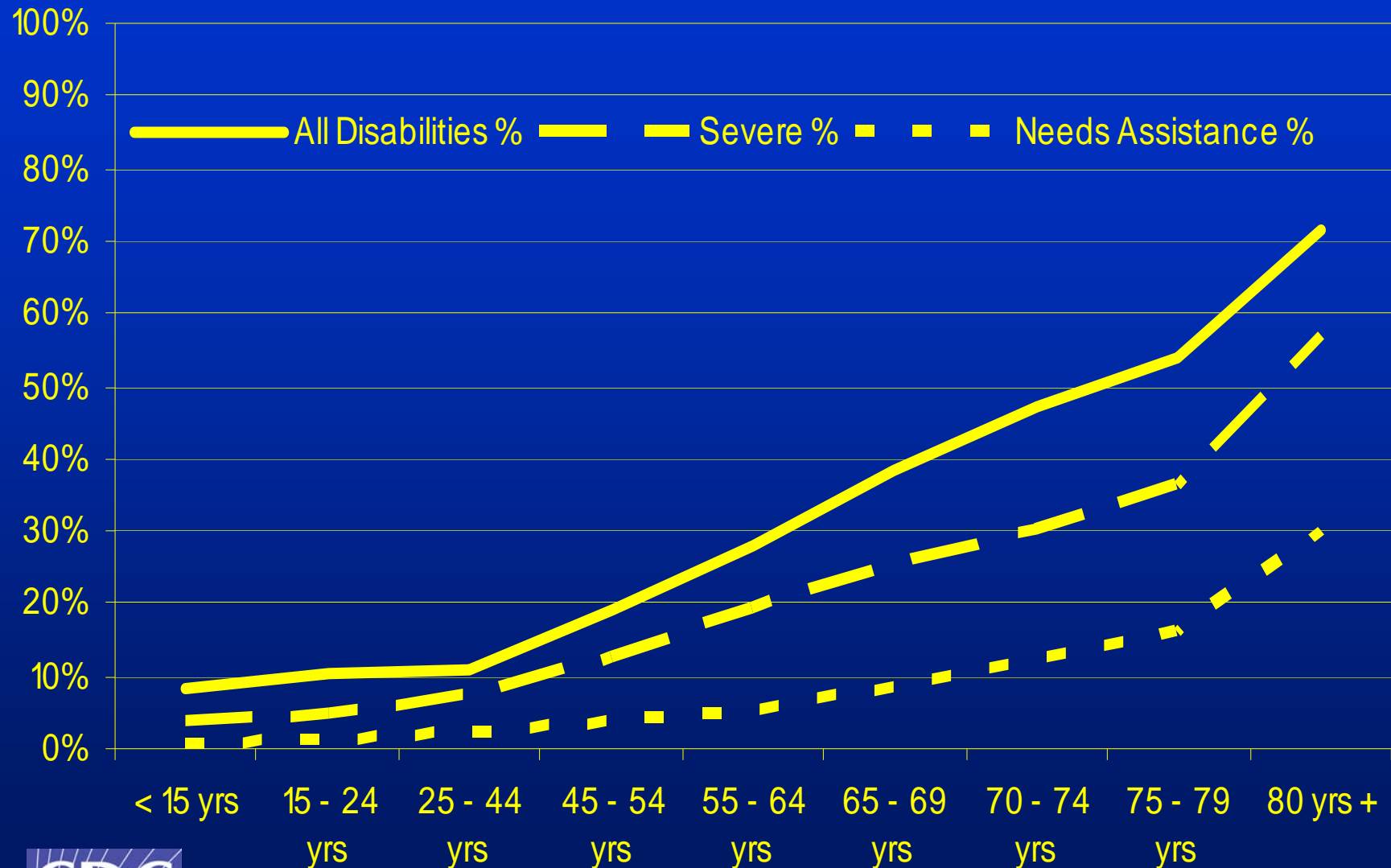
Number (000) and Percentage of USA Population 15 years and older, SIPP, 2002

	All Disabilities		Severe		Needs Assistance	
	N	%	N	%	N	%
All ages	51,235	18.1%	32,532	11.5%	10,746	3.8%
< 15 yrs	5,111	8.4%	2,044	3.4%	179	0.3%
15 - 24 yrs	4,128	10.5%	1,911	4.8%	479	1.2%
25 - 44 yrs	9,230	11.1%	6,023	7.3%	1,659	2.0%
45 - 54 yrs	7,705	19.4%	5,021	12.6%	1,506	3.8%
55 - 64 yrs	7,415	28.1%	5,090	19.3%	1,421	5.4%
65 - 69 yrs	3,633	38.4%	2,400	25.4%	780	8.2%
70 - 74 yrs	3,984	46.9%	2,554	30.1%	999	11.8%
75 - 79 yrs	3,895	53.9%	2,609	36.1%	1,160	16.0%
80 yrs +	6,134	71.7%	4,880	57.0%	2,563	30.0%



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Percentage of the Population with Disability by Severity and Need for Assistance, by Age, SIPP, 2002



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Noninstitutional Population with Disability, Age >= 15 Years, by Race/Ethnicity, Severity and Need for Personal Assistance

	All Disabilities		Severe		Needs Assistance	
	N(000)	%	N (000)	%	N (000)	%
White (Non-Hispanic)	37,437	19.0	23,227	11.8	7,679	3.9
Black	7,155	19.8	5,054	14.0	1,708	4.7
Asian/Pacific Islander	1,303	11.5	817	7.2	286	2.5
Hispanic (of any race)	5,209	13.8	3,335	8.8	1,095	2.9
Total (includes Native Americans, Multiple Race/Eth. And Unknown)	51,235	18.1	32,532	11.5	10,746	3.8

Source: Survey of Income and Program Participation, 2002; US Census Bureau;
<http://www.census.gov/hhes/www/disability/sipp/disab02/ds02t1.html>



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Percentage of Noninstitutional Population Living Below Poverty Level, by Age Group and Disability Status

	N (000)	%	N (000)	%
5 – 15 years	781	28.5	6,951	16.9
16 – 20 years	378	26.8	3,431	18.8
21 – 64 years	5,673	25.4	13,799	9.2
>= 65 years	2,001	13.7	1,516	7.2
5 years and older (Total):	41,051	21.5	229,737	11.2

Source: American Community Survey, 2006; Table B18030. Disability Status by Sex by Age by Poverty Status for the Civilian Noninstitutionalized Population Age >= 5 Years



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Estimated Population and Percentages with Self-Care Disability, by Age Group – United States

	N (Noninstitutional)	%	Pop. N Includes institutional
5 – 15 years	388,277	0.9	393,835
16 – 20 years	155,434	0.7	161,256
21 – 64 years	4,032,058	2.3	4,285,421
65 – 74 years	1,132,102	6.1	1,309,994
>=75 years	2,587,142	15.3	3,709,034
5 years and older	8,295,013	3.0	9,859,540

Source: American Community Survey, 2006, Public Use Microdata Samples,



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

Age (yrs)	Living Alone (Pop)		2 People Living Together (Pop) – 1 or both w SC 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



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Estimated Population and Percentages with Going-Outside- Alone Disability, by Age Group and Residential Status

2 People* Living Together, 1 with G-O-A Disability (1 could be a child or other person)			2 Adults Living Together, At Least 1 Has G-A-O or SC Disability		
Age (yrs)	N	%	Age (yrs)	N	%
5-17			5-17		
18-44	196,890	1.6	18-44	548,581	2.4
45-64	438,614	6.1	45-64	1,760,331	5.7
>=65	444,824	14.0	>=65	2,695,619	14.3
>=5	1,080,328	4.8	>=5	5,004,531	6.9

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



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Community-Based Services

Medicaid provides two programs:

- Personal Care Services benefit
 - 683,000 recipients

- Home and Community-Based Service waiver
(person requires institutional level of care but receives in home or other community setting)
 - 352,000 recipients

- Kitchener, Ng, and Harrington, 2006



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Group Quarters for People with Disabilities

From 2000 Census enumeration of the population

– Institutionalized:

◆ Nursing homes	1,720,500
◆ Hospitals, residential schools for people w/ disabilities	234,241
◆ Residential centers for emotionally disturbed children	12,725

– Noninstitutionalized:

◆ Group homes	454,055
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What about People with a Disability and Pandemic Influenza?

- We have no data on how people with disabilities have been affected by previous outbreaks of pandemic influenza (any more than we know how they were affected by specific natural events like earthquakes or hurricanes) – we can speculate
 - In general, we have no surveillance that captures data on functional limitations and emergencies – after Katrina, 38% of residents in Houston shelter reported that they did not evacuate New Orleans during Katrina because they or someone they were caring for were physically unable to leave
- Survey conducted by Kaiser Foundation, Harvard & Washington Post, 2005



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Federal Legislation on Disability

- Rehabilitation Act of 1973, as amended
- Americans with Disabilities Act of 1990
- Fair Housing Act of 1968, as amended
- Architectural Barriers Act of 1968
- Communications Act of 1934, as amended
- Individuals with Disabilities Education Act (IDEA) of 1975, as amended



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Exec. Order 13347 - Individuals with Disabilities in Emergency Preparedness, July 22, 2004

Focuses on disasters, including earthquakes, tornadoes, fires, floods, hurricanes, and acts of terrorism.

- Mandates consideration in emergency planning of the needs of federal employees; employees of state, local, territorial and tribal governments; their service recipients; and the general public
- Establishes an interagency coordinating committee, chaired by DHS to integrate planning for people with disabilities in emergency preparedness.
- Annual report to the president on best practices, etc.



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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.



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HHS and CDC PI Planning



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CDC Resources to Grantees

- 50 States
- 3 Municipalities
- 1 Commonwealth
- 7 territories
- No tribes
- \$400 million total distribution (Phase I (1/2006), Phase II (6/2006), 2007 allocations, FY 2007 (8/2007))

- <http://www.pandemicflu.gov/news/allocation.html>



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CDC Guidance to Grantees

- Address the needs of vulnerable/special populations (references Public Health Workbook to Define, Locate and Reach Special, Vulnerable and At-Risk Populations in an Emergency at www.bt.cdc.gov/workbook)
- Assess and map local community; identify and build social networks; and develop community outreach information networks, pre-event, to a) define, locate and reach special, at-risk and vulnerable populations and b) maximize capacity to effectively disseminate public information during a pandemic.
 - www.bt.cdc.gov/planning/coopagreement/pdf/phase2-panflu-guidance.pdf



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PH Activities and Relationship to People with Disabilities

Key Pandemic Response Activities:

- Surveillance, investigation, and protective health measures
- Vaccines and antiviral drugs
- Health care and emergency response
- Communications and outreach

- <http://www.cdc.gov/flu/pandemic/cdcplan.htm>



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Key Pandemic Response Elements and Disability Considerations (HHS Plan)

Surveillance, investigation, and protective health measures

Implement public health measures to limit the spread of infection (e.g., canceling public gatherings) as well as individual measures to decrease the risk of acquiring or spreading infection (e.g., personal hygiene, isolation of ill persons); closure of schools; non-essential personnel stay home

CONSIDERATION FOR PWD - CONTINUITY OF SERVICES



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Vaccines and antivirals

- (1) Consider administration of pre-pandemic stockpiled vaccine, to pre-defined groups, critical to the pandemic response
- (3) Allocate and administer pandemic vaccine to pre-defined groups

CONSIDERATIONS FOR PWD – TRIAGE,
CONTINUITY OF SERVICES



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Communications and outreach

Public education and information campaign to

- 1) communicate measures the public can implement to minimize risk and decrease the spread of infection;
- 2) provide honest, accurate understandable and timely information; and
- 3) counter confusion and panic.

CONSIDERATION FOR PWD – ACCESSIBLE
COMMUNICATION



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CDC Pandemic OPLAN – Antivirals

July 11, 2007

- Annex F, Appendix 1 – Use of Antiviral Drugs
- C.1. ‘Depending on antiviral supplies prioritization of antiviral agent use may be necessary, i.e., treat those at highest risk of severe illness and death and to preserve the delivery of healthcare other essential critical services through early treatment of targeted persons.
- C.2. “After a vaccine becomes available, antiviral drugs may be used to protect persons who have an inadequate vaccine response (e.g., the elderly and those with underlying immunosuppressive disease) . . .



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CDC Pandemic OPLAN - Vaccines

4.b.4. Guidance for Special Needs Populations:

- Ensure information is available in local languages
- Accommodate personnel without transportation and those requiring specialized transportation
- Accommodate the needs of people with physical disabilities.
- Plan for vaccinating homebound persons
- Ensure communication with special needs populations.



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HHS Pandemic Influenza Plan – Priority Groups

November 2005

1. Healthcare workers w/ direct pt. contact (includes nursing homes, SNFs . . . home care . . .)
2. People 2-64 years with medical condition for whom vaccination is recommended and people 6-23 months and 65 and older regardless of medical status (excluding NH residents and severely immunocompromised people who are not expected to respond well)
3. Critical infrastructure staff
4. Public health emergency response workers
5. People in SNFs – assumption is that the risk is lower
6. Severely immunocompromised people
7. Children under 6 months of age

Appendix D: Recommendations for prioritization of ... vaccine and ... antiviral drug use



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Accessibility of Messages

NCHM has developed messages for people with hearing loss during emergencies -

http://emergency.cdc.gov/disasters/hurricanes/psa/video/psa-preparing-for-hurricane_asl.wmv

- Exists as on web site; URL has been disseminated informally to HL organizations (e.g., Nat. Assn. of the Deaf), related blogs and listservs.
- Not to local TV stations, etc.
- PI messaging to be developed



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So . . . Where Do We Stand?

- With regard to PI preparedness . . . ?
- Nationwide Plan Review Phase 2 Report, 6/16/2006: “The CRCL Review revealed major fragmentation, inconsistencies, and critical gaps throughout the plans. Few plans demonstrate in-depth planning and proactive thinking in preparing to meet the needs of people with disabilities before, during, and after emergencies. Most plans delegate critical responsibilities to third parties or other governmental entities without adequate coordination, oversight, or assurance of resources. Most plans contain no indication that a delegated function will be executed in a timely and effective manner” (p. 45).



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Response Issues and Concerns Regarding PI Planning for People with Disabilities

- National planning has included people with disabilities and their representatives
- If assessments of disaster preparedness are valid indicators - State, territorial, tribal and local planning and readiness are inadequate.
- Accessible messages have been developed for people with hearing loss with access to a computer and internet but no evidence of messaging for people with cognitive limitations
- Social distancing measures may put homebound people with disabilities and those who rely on paid caregivers at risk for disrupted care and support.
- There is concern among advocates for people with disability that they will be devalued (it's happened in the past) and given low priority for vaccines and antiviral medications.



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Concerns/Issues

- Lack of adequate surveillance systems
- Lack of consistent guidance to grantees
- Lack of involvement of people with disabilities in the planning and preparations for pandemic influenza at the local level
- Lack of tested messaging and communications



Recommendations

- Disability questions routinely included in all data collection related to pandemic influenza (and preparedness) activities
- Involvement of people with disabilities, advocates and caregivers to assess the adequacy of planning and response
- Specific guidance to states, localities, territories and tribes concerning:
 - involvement of people with disabilities and their representatives in pandemic influenza planning
 - continuity of services to homebound people with disabilities.
 - Alternative/accessible communications to people with disabilities and other hard-to-reach populations



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Recommendations

- Involvement of people with disabilities and their representatives, and inclusion of disability-related scenarios in PI exercises.
- Continuing evaluation and feedback to state, territorial, local, and tribal PI planners on performance with regard to their preparations for ALL risk populations.



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Thank you

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Other Considerations for People with Disabilities

- Residence in 'Group Quarters'
 - Nursing homes
 - Group homes
 - Institutions for subpopulations
- Receiving care from others
- Many assistive devices that are required to perform activities and that increase independence require maintenance and workers in this area may not come to work in the event of PI

