Leonard Davis Institute of Health Economics

Volume 13, Number 4 • February 2008

Jason Karlawish, MD

LDI Senior Fellow, Associate Professor of Medicine and Medical Ethics University of Pennsylvania

Voting by Older Adults with Cognitive Impairments

Editor's Note: This presidential election year reminds us of the importance of each vote and of the integrity of the electoral process. Recent elections have been decided by very narrow margins. In this context, the voting rights and capacity of persons with dementia warrant attention. About 4.5 million Americans currently live with dementia. Whether these citizens should vote raises a host of ethical, legal, and practical issues. At what point does someone lose the capacity to vote, and who decides? What kinds of assistance should these voters get, and who should provide it? And how can the voting rights of residents in long-term care facilities be protected?

Little practical guidance exists on whether persons with dementia can vote Dementia is characterized by progressive and irreversible cognitive and functional impairments. Because it is progressive, many individuals with dementia will cross a threshold from being capable to being incapable of reflecting their own wishes in an election.

- Caregivers may incorrectly assume that individuals with dementia have lost the capacity to vote.
- "Proxy voting" on behalf of another person is illegal. However, helping someone to vote is not. In fact, people have a right to receive assistance.
- As dementia progresses, individuals who retain capacity may need help registering, getting to a polling place and completing the ballot. Caregivers need guidance in deciding whether and how to assist impaired individuals in voting.
- By moderate stages of dementia, many individuals must move to assisted living
 facilities or nursing homes. It is estimated that nearly two-thirds of residents in
 long-term care facilities have some form of dementia. But 28 states have no
 guidelines that address voting accommodations in long-term care facilities; the
 remainder of states have guidelines that differ substantially in their content and
 utility.
- In 2001, a federal district court decision in Maine, Doe v. Rowe, laid out legal criteria for assessing whether a person is competent to vote. Although the case involved the automatic exclusion of people under guardianship because of mental illness, the criteria apply to all individuals whose competence to vote may be in

Continued on next page.

question. The court struck down the automatic exclusion and adopted an individualized test of competence: people are judged to be incompetent "if they lack the capacity to understand the nature and effect of voting such that they cannot make an individual choice."

Investigators develop and test an instrument to measure capacity to vote

Karlawish and colleagues developed an instrument that applied the federal court standard in a small group of community-dwelling persons with very mild to severe Alzheimer's disease. Dementia severity was defined by using standard cut points on the Mini-Mental State Examination (MMSE). The patients were recruited from the Penn Memory Center at the University of Pennsylvania.

• The instrument asked three questions corresponding to the nature, effect, and choice criteria of the federal court. These commonsense criteria assess whether the person understands that people vote to pick elected officials and that the winner of the election is the one with the most votes. See box.

QUESTIONS TO ASSESS VOTING CAPACITY

Imagine that two candidates are running for Governor and that today is Election Day.

Nature of voting: What will the people do today to pick the next governor?

Effect of voting: When the election for governor is over, how will it be decided who the winner is?

Choice: [After handing the person a card describing Candidate A and Candidate B] *Based on what I just told you, which candidate do you think you are more likely to vote for: A or B?* [Which candidate is chosen is irrelevant.]

The investigators also asked questions that went far beyond the standard, and
measured the ability to reason about and appreciate the significance of voting.
These questions assessed the person's ability to compare the candidates and
explain why they would or would not want to vote in the next election.

Voting capacity can be measured simply and reliably

The results indicate that a structured interview can be used to identify persons whose voting capacity is in question, such as in a guardianship hearing. In actual voting practice, capacity issues work themselves out when the voter who receives assistance cannot make a choice.

- Thirty-three subjects completed the interview, which took, on average, 3.6 minutes for the three standard questions and 6.6 minutes for the entire interview.
- Dementia severity was strongly correlated with the capacity to vote as measured by the three standard questions. Results suggest that most people with mild dementia retain adequate ability to vote, and most people with severe dementia do not. People with moderate dementia have variable scores on the standard questions.
- The results suggest that questions about comparative reasoning and appreciation of voting would likely disenfranchise some people who retain the capacity to vote by judicial standards.

Study assesses voting processes in nursing homes and assisted living settings after the 2003 Philadelphia mayoral election To understand the need for guidelines for voting in long-term settings, Karlawish and colleagues surveyed Philadelphia nursing homes and assisted care facilities immediately following the 2003 mayoral election, a sharply contested race. The city has no guidelines about voting in these settings.

- The investigators identified 45 nursing homes and 39 assisted living settings in Philadelphia. Thirty-one of 45 nursing homes (69%) and 20 of 39 assisted living settings (51%) completed the telephone survey one month after the election.
- Just over half of the facilities had a written policy for voter registration, which usually specified a procedure for change of address on admission. Twenty facilities reported that they served as polling sites on Election Day.
- The survey included questions about three aspects of voting: 1) whether residents voted and the reasons they did not; 2) procedures for voter registration, voting, and voting assistance; and 3) how, if at all, staff decided whether a resident could not vote.

Current procedures in many long-term care facilities fail to protect voting rights

The results indicate that residents' access to the polls was mostly determined by the policies, practices, and attitudes of staff.

- Across all sites, the estimated proportion of residents voting was 29%, but there
 was substantial site to site variability in the proportion of residents who voted.
 Two sites reported that all residents voted, and two sites reported that none voted.
 At nearly one-third of the sites, residents who wanted to vote were unable to do
 so. Voting rates were no greater at facilities that were polling places than those
 that were not.
- The main explanations for why residents did not vote were perceived lack of ability to vote due to cognitive impairment (88%), perceived lack of resident voting interest (57%), and site-based logistical problems, such as procedural mixups or missed registration deadlines.
- More than 80% of sites reported that some residents voted at a polling place, while 63% reported that some residents voted by absentee ballot. Voting at a polling place was more common in assisted living facilities; absentee ballot use was more common in nursing homes.
- Most sites reported someone provided assistance to voters, most frequently facility staff. The reasons for providing assistance fell into two categories: ballot-related and voter-related issues. Ballot related issues included the ballots' small font size, length, and complexity. Voter-related issues included voters finding the ballot too confusing, and problems related to illness and cognitive impairment.
- Nearly two-thirds of the sites reported that someone, typically staff, assessed
 whether a resident was capable of voting. The most common method included an
 assessment of resident cognition often combined with an informal assessment
 using election-related questions (for example, knowledge about current political
 figures). This approach reflects inappropriate assumptions about what constitutes
 competence to vote.
- Respondents voiced concern about whether their assessment techniques were appropriate and the degree of discretion and power they had over residents' voting rights.

Continued on back.

POLICY IMPLICATIONS

The present electoral system does not sufficiently protect the basic right to vote for persons with dementia. Federal, state and local election officials should consider immediate changes in policy and practice.

- As the nation ages, voting policies that affect cognitively impaired Americans become increasingly important. This importance increases given close and contested elections.
- Informal assessments of voting capacity may disenfranchise individuals who are able
 to vote. Given that the capacity to vote may be reasonably well preserved until the
 severe stage of dementia, caregivers should focus on assuring access, limiting fraud,
 and assisting individuals who want to vote.
- The data suggest that voting rights of long-term care residents might be better promoted and protected if election officials took charge of registration, delivering ballots, and assisting with ballot completion. Long-term care staff want and need training on voters' rights and reasonable accommodations.
- The possibility of "mobile polling" should be explored. Australia and Canada have successfully implemented this model, in which election officials visit facilities prior to registration, and return to assist voters and gather the ballots. States would need to create and fund elections commissions that were adequately staffed for this purpose. As a start, the U.S. Election Assistance Commission could partner with states to develop a set of best practices and test their feasibility.
- Recently, the U.S. Senate Special Committee on Aging held a hearing on opportunities
 and challenges for older voters. It identified voting in long-term care facilities as a
 particular challenge and asked the U.S. Election Assistance Commission to conduct
 further research and devise voluntary guidelines to help states facilitate such voting.

This Issue Brief is based on the following articles: J.H.T. Karlawish, R.J. Bonnie, P.S. Applebaum, et al. Identifying the barriers and challenges to voting by residents in nursing home and assisted living settings. Journal of Aging & Social Policy, 2008, vol. 20, pp. 65-78; P.S. Applebaum, R.J. Bonnie, J.H. Karlawish. The capacity to vote of persons with Alzheimer's disease. American Journal of Psychiatry, November 2005, vol. 162, pp. 2094-2100; see also Symposium: Facilitating Voting as People Age: Implications of Cognitive Impairment. McGeorge Law Review, 2007, vol.38, pp. 843-1137.

Published by the Leonard Davis Institute of Health Economics, University of Pennsylvania, 3641 Locust Walk, Philadelphia, PA 19104. Janet Weiner, MPH, Associate Director for Health Policy, Editor

David A. Asch, MD, MBA, Executive Director

Visit us on the web at www.upenn.edu/ldi

Issue Briefs synthesize the results of research by LDI's Senior Fellows, a consortium of Penn scholars studying medical, economic, and social and ethical issues that influence how health care is organized, financed, managed, and delivered in the United States and internationally. The LDI is a cooperative venture among Penn schools including Dental Medicine, Medicine, Nursing and Wharton, and the Children's Hospital of Philadelphia. For additional information on this or other Issue Briefs, contact Janet Weiner (e-mail: weinerja@mail.med.upenn.edu; 215-573-9374).

© 2008 Leonard Davis Institute

ody yd bodeildu Sentitienl eiwn Dennood eimonood dilaoH Yo innolyenno Yo yierovinU





Permit No. 2563 Philadelphia, PA 19104

d I A 9

noitazinagrO titorqnoN U.S. Postage **VDDKESS COKKECLION KEGNESLED**