



Advance Care Planning in New Jersey

Florida Case Highlights Need for Advance Directives

The recent case of Terri Schiavo highlights the importance of having an advance directive. Ms. Schiavo, a Florida resident, has been in a vegetative state since 1990 when she was 26 years old. She has been kept alive using life support and did not have an advance directive to determine whether or not to withhold medical treatment in this situation. As a consequence, her husband and her parents have been involved in a legal controversy for six years over whether her feeding tube should be removed. Her husband feels that she would not want to be kept alive, while her parents believe she would.

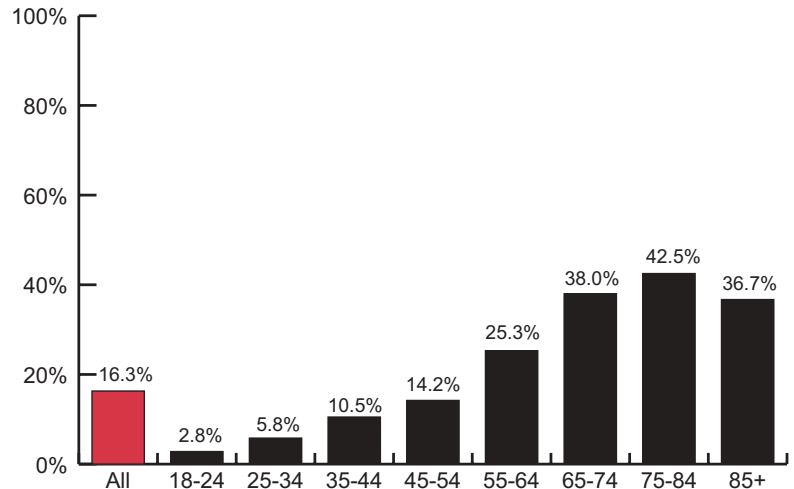
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In 1991, the New Jersey Legislature passed the "New Jersey Advance Directives for Health Care Act" (P.L. 1991, c. 201). This law states that adults have the right to decide whether or not medical or surgical treatment should be

used or withheld in the event that they are incapable of making such a decision at that time.

Figure 1: Few Adults in New Jersey Report Having an Advance Directive

Older residents are most likely to have a directive



Source: Rutgers Center for State Health Policy, New Jersey Family Health Survey, 2001

These "advance directives" are legal documents, and include both living wills, which specify the person's wishes about life-sustaining treatment, and durable powers of attorney for health care, which appoint another individual to make these decisions concerning the person's health care. This legislation followed the passage of the federal "Patient Self-Determination Act of 1990" (42 U.S.C., s.1395), which permits people to have advance directives. All states have enacted laws allowing durable powers of attorney for health care and almost all permit the use of living wills.

In 2001, Rutgers Center for State Health Policy (CSHP) conducted the New Jersey Family

CSHP's Facts & Findings

This is the first in a series of *Facts & Findings* from Rutgers Center for State Health Policy. These briefs highlight findings from major research initiatives at the Center, including the New Jersey Family Health Survey and the New Jersey State Physician Census.

Health Survey. This survey examined many issues related to health and health care, including the use of advance directives. Our findings reveal that about one in six (16.3%) of New Jersey adult residents have some form of advance directive. This figure is low compared to a 1997 national survey sponsored by the Nathan Cummings Foundation and the Fetzer Institute¹, signaling the need for further education and outreach in New Jersey. That earlier study showed that nationwide, 28% of adults age 18 or older reported having an advance directive.

Young Adults Report Fewest Advance Directives

The New Jersey survey results indicate that young adults are considerably less likely to have an advance directive (see Figure 1): 2.8% of adults ages 18-24, 5.8% of adults ages 25-34,

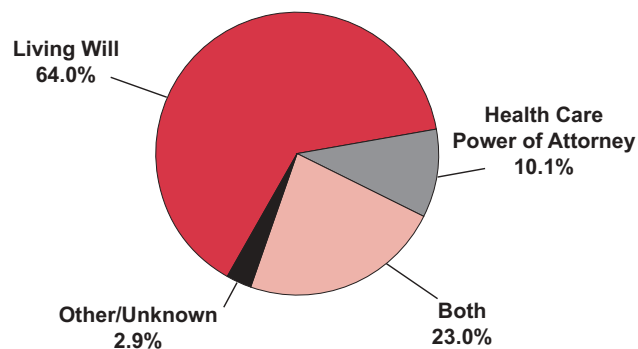
Approximately one in six New Jersey adult residents have some form of advance directive... signaling the need for further education and outreach...

and 10.5% of adults ages 35-44 report having one. Older New Jersey residents report much higher levels of having advance directives: 25.3% of adults ages 55-64, 38% of adults ages 65-74, 42.5% of adults ages 75-84, and 36.7% of adults 85 and older reported having either a living will or a durable power of attorney for health care.

Living Wills Most Common

Among the New Jersey residents who do have an advance directive, 87% of them have a living will, while an estimated 33% have a durable power of attorney for health care. These statistics include 23% of respondents who have both types of advance directives (see Figure 2).

Figure 2: Living Wills are the Most Common Form of Advance Directive in New Jersey



Source: Rutgers Center for State Health Policy, New Jersey Family Health Survey, 2001

Large Disparities by Race, Ethnicity, and Immigration

Table 1 shows large variations in the demographics of who has an advance directive. Non-Hispanic white respondents were more than six times as likely to have advance directives as either Hispanics or Asians, and nearly three times as likely as African Americans. Similarly, New Jersey residents born in the United States were more than three times as likely as those not born in the United States to have advance directives. These differences are even greater for people who do not speak English at home: those who speak English in their homes are over ten times as likely to have advance directives as those in non-English-speaking homes.

Other Predictors of Having an Advance Directive

Table 1 also highlights other differences in the likelihood that New Jersey adult residents report having an advance directive.

- New Jersey residents with a college degree were about 1.5 times more likely to have advance directives than those with less education.

Table 1: Who has Advance Directives?

Characteristics of New Jersey Adults (age 18 and older) Reporting Advance Directives		
Population Characteristics	% of All New Jersey Adults	% Reporting Advance Directive
All New Jersey Adults	100.0	16.3
Gender		
Men	46.8	13.2
Women	53.2	19.2
Race/Ethnicity^a		
White	68.9	20.9
Black/African American	12.0	7.8
Hispanic	12.5	3.3
Asian	2.9	3.6
Other and not reported	3.7	12.7
Nativity		
US Born	84.4	18.3
Not US Born	15.6	6.0
Language Spoken at Home		
English	87.9	18.4
Other Language	12.1	1.7
Education		
College Graduate or Higher	29.1	21.7
Some College or Technical School	26.2	13.9
High School Graduate or Less	44.8	14.6
Marital Status^b		
Never Married	24.9	11.8
Married	51.3	19.9
Separated/Divorced	13.7	21.5
Widowed	10.2	42.6
Religion^b		
Protestant	25.2	21.6
Roman Catholic	47.7	20.2
Jewish	4.6	33.2
Other	8.9	14.8
None	13.6	18.3

Source: Rutgers Center for State Health Policy, New Jersey Family Health Survey, 2001

Notes:

^aWhite, Black/African American, Asian, and other are non-Hispanic only; Hispanics may be of any race.

^bAsked only of one respondent per household. The percentage with an advance directive among these respondents is higher (20.4%) than the percentage among all adults (16.3%).

- Those who have experienced the death of a spouse are about twice as likely as married, separated, or divorced respondents to have advance directives. Never married respondents are most at risk of not having advance directives.
- Jewish respondents were about 1.5 times more likely to have advance directives than Protestants or Roman Catholics. Those reporting other religions or no religion were even less likely to have advance directives.

Conclusion and Opportunities

Although the Cummings–Fetzer survey reported higher levels of advance directives nationally than did the New Jersey survey (28% vs. 16%), similar demographic patterns emerged. For example, in the national study, older adults were more likely to have advance directives (40%), as were widows (50%) and college graduates (36%).

The results from the New Jersey Family Health Survey define opportunities for education and outreach. Such programs should focus on

ethnic populations, particularly those who do not speak English, and outreach to religious institutions could present another opportunity to inform the debate.

¹The Nathan Cummings Foundation and Fetzer Institute. *Spiritual Beliefs and The Dying Process; A Report on a National Survey*. Princeton, NJ: The George H. Gallup International Institute, October 1997.

The New Jersey Family Health Survey

In late 2001 and early 2002, Rutgers Center for State Health Policy conducted the New Jersey Family Health Survey, a telephone survey of a statistically representative sample of 2,265 New Jersey families, including 6,466 individuals of all ages who do not reside in an institution (e.g., nursing home). This *Facts & Findings* is based on information for 4,574 state residents age 18 or older. The New Jersey Family Health Survey was funded by The Robert Wood Johnson Foundation. More information about the survey can be found at www.cshp.rutgers.edu/NJFHS_Methods.



Rutgers Center for State Health Policy

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Rutgers Center for State Health Policy informs, supports, and stimulates sound and creative state health policy in New Jersey and around the nation.