HEALTH ACCESS

HEALTH ACCESS FOR WOMEN WITH DISABILITIES
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Controlling Your Choices

by Marianne Valls

Laws and the Independent Living Movement have enabled many people with disabilities to live on their own and make their own way in the world. Many of us cherish our independence.

But, like everyone else, we will grow old and may be forced by illness to become dependent again. Just as planning is a key element to a successful life, it plays a major role in determining and maintaining control over a decline into dependency.

Unpleasant though it be, the time to start investigating your options is now. Choose a loved one or close friend to help you in your planning. Choose wisely, because the person may become your voice when you can no longer speak for yourself.

Give the person you choose the legal authority to carry out your wishes and act as your health agent. You do this by creating an "advance directive." An advance directive is a legal document describing the type of medical care you wish to receive in the event you become incapacitated. An advance directive is not a necessity but will ensure that your

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for Women with Disabilities

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Additional Resources for Planning Healthcare Decisions

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, is a national initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.

Call their toll-free HelpLine, 800-658-8898 for help in understanding a state's advance directive or for assistance in dealing with a difficult end-of-life situation. Caring Connections web site is www.caringinfo.org

Information about and copies of the New Jersey Instruction Directive, also called a Living Will, and the New Jersey Appointment of a Health Care Representative, also called a Proxy Directive, to fill out for yourself are available at www.njhealthdecisions.org/Advance

wishes will be carried out.

According to www.WebMd.com, there are four important steps in preparing an advance directive:

1. Get the appropriate living will and medical power of attorney forms for your state.
2. Choose someone to be your health care agent.
3. Complete the forms and have them notarized or witnessed, as your state requires.
4. Ensure that your doctor, your family, and your health care agent have copies.

The internet is an important resource for information about the legal aspects of medical care. You can access the internet at your public library if you can't do so at home.

Another thing to consider when planning for your future is placement in a nursing home if that becomes necessary. Preparing ahead of time will allow you, family and /or friends to evaluate a facility in advance rather than having to make a hasty decision when serious illness strikes.

"The New Jersey Report Card for Nursing Homes" can be found at http://www.state.nj.us/health/ltc/hcfa/index.shtml. The Report Card was created by the New Jersey Department of Health and Senior Services to ensure "that facilities accepting Medicare and Medicaid payment for services provided to program beneficiaries meet federal regulations and certification rules."

The report is meant to help consumers make intelligent, informed choices when considering long-term health care facilities. However, the site points out that no single document should be relied on to make an adequate determination. Visits to nursing facilities, with family and/or friends, should be given priority in making your decision. Talking to staff members and nursing homes residents may aid you in your choice.

The Report Card contains a rating system which shows the efficiency and quality of care for each nursing home. The nursing home is evaluated on "nursing care, resident rights, food service, environment, and administration."

In addition, you should consider the location of the facility. Will friends and family be able to visit you easily? Unfortunately, the quality of many nursing homes appears to be less than satisfactory. You and/or your advocate must be extremely vocal and vigilant about your needs.

These are only two of the important options that should be considered when planning for your future. Plan now! Waiting could cost you your life.

State Senate Committee Passes Social Security Resolution

by Anita Clavering

New Jersey Senate Resolution 94, introduced by Senator Barbara Buono (D-18) on March 21, 2005, memorializes Congress to reject Social Security privatization proposals of the President's Social Security Commission that would create private accounts, require deep cuts in guaranteed Social Security benefits and lead to excessive federal borrowing.

Representatives from New Jersey Citizen Action (NJCA), the Monday Morning Hudson County Network and the New Jersey Tenants Organization (NJTO) testified before the Senate Budget and Finance Appropriations Committee in support of SR-94. It passed nine to six.

"Social Security is not welfare; it is a family insurance program that has worked successfully for more than 70 years keeping senior citizens, people with disabilities and families without a breadwinner out of poverty," said NJCA Executive Director Phyllis Salowe-Kaye.

"The Administration's claim about a solvency of Social Security is the domestic equivalent of weapons of mass destruction."

NJCDD Women with Disabilities Health Care Task Force member and Monday Morning Hudson County Network co-facilitator Paulette Eberle, who also co-chairs NJCA's Board of Directors, testified, "This plan for people with disabilities is absolutely devastating. I've yet to hear anybody from Mr. Bush's administration address the issue of people with disabilities, other than to say that 'Oh, that will be a different plan,' but nobody is saying what that plan will be."

NJTO President Matthew Shapiro stated that many tenants rely on Social Security as their primary source of income. "If Social Security benefits are reduced, these senior citizens and disabled citizens will likely lose their homes as they will no longer be able to pay their rent," said Shapiro.

SR-94 was passed by a vote of 23 to 15 in the full Senate on June 23, 2005.

Legislative Update

Acting Governor Richard Codey signed Assembly Bill 779 (A-779) into law on March 2, 2005, prohibiting automatic liens against individuals for cost of care received at state or county psychiatric facilities. Before A-779 was signed, New Jersey was the only state that still placed automatic liens on former psychiatric consumers without sufficient insurance or income to pay hospitalization.

Senate Bill 2455, passed on June 20, 2005, requires the Department of Human Services, in conjunction with the Division of Developmental Disabilities (DDD), to apply for federal Medicaid waivers that bring matching federal funds. Waivers would include an expansion of the State's current Community Care Waiver and other waivers to fund family support services and services to young children who are medically fragile.

Assembly Bill 1988 passed both houses and was signed on June 15, 2005 as Public Law 2005, Chapter 98. It requires the Commissioner of Health and Senior Services to establish a public awareness campaign to inform the general public about post-polio sequelae. The commissioner is to provide for the development of educational materials, in consultation with health care facilities and providers that have expertise and interest in this subject. The

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New Jersey Women with Disabilities Health Care Task Force:

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materials will be available to local boards of health, physicians, hospitals and clinics for distribution to consumers.

A-336 passed the Assembly on March 11, 2004. It would require health maintenance organizations (HMOs) and/or other managed care plans to provide in-network level insurance benefits to people with disabilities from out of network providers when in-network care is inaccessible to people with disabilities. A336 has been sent to the Senate, which has not acted on it.

On August 3, 2005, Acting Governor Richard J. Codey signed landmark legislation establishing a $200 million Special Needs Housing Trust Fund that will help create 10,000 new affordable housing opportunities for people with mental illness and other special needs across New Jersey.

Codey said, “This landmark legislation will enable people with mental illness to focus on their recovery instead of worrying about where they are going to live.”

The money will be used to develop permanent supportive housing, community residences and other supportive housing arrangements for people with special needs, including mental illness and physical or developmental disabilities.

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