

Joint Commission on Health Care

Staff Report Alternatives to Long Term Care

HJR 69 Patron: Delegate Kenneth Plum

and

Support for Family Caregivers

SJR 102 Patron: Walter Stosch

HJR 238 Patron: Stephen Shannon

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September 4, 2008



Presentation Outline

- ❖ The traditional long term care model
- ❖ Alternatives in long term care
 - ❖ Culture Change in LTC Facilities
 - ❖ Cultural, Organizational, & Physical Changes in Traditional Facilities
 - ❖ Cluster Homes (e.g. The Green House® Project)
 - ❖ Primary Focus on Aging at Home
 - ❖ Increased Availability of Services
 - ❖ Person-Centered / Consumer-Directed
 - ❖ Innovative Approaches
 - ❖ Cash & Counseling Service Model
 - ❖ Intentional Communities
- ❖ Support for Family Caregivers
- ❖ Policy options

The Traditional Long Term Care Model

- ❖ Not designed to help elders age at home
- ❖ Large institutional facilities
 - ❖ Based on medical model
 - ❖ Focus on efficiency
 - ❖ Hierarchical management structure
 - ❖ Based on 3 R's: Rules, Routines, & Requirements



Alternatives in Long Term Care

- ❖ Culture Change in LTC Facilities
 - ❖ Cultural, Organizational, & Physical Changes in Traditional Facilities
 - ❖ Cluster Homes
- ❖ Primary Focus on Aging at Home
 - ❖ Increased Availability of Services
 - ❖ Person-Centered / Consumer-Directed
 - ❖ Innovative Approaches
 - ❖ Cash & Counseling Service Model
 - ❖ Intentional Communities



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Culture Change in LTC Facilities

❖ What is Culture Change?

“Culture change in long-term care is an ongoing transformation in the physical, organizational and psycho-social-spiritual environments that is based on person-centered values. Culture change restores control to elders **and** those who work closest with them.”

Pioneer Network

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Culture Change in LTC Facilities

- ❖ A national movement
 - ❖ Many organizations, nationally and in Virginia, have already made culture changes or are in the planning stage.
 - ❖ CMS is encouraging culture change
 - ❖ Training
 - ❖ Addressing regulatory concerns
- ❖ Applicable to all levels of care including assisted living facilities and nursing homes

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Core Constructs of Culture Change

- ❖ Resident-Directed Care and Activities
- ❖ Home Environment
- ❖ Relationships with Staff, Family, Resident, & Community
- ❖ Staff Empowerment
- ❖ Collaborative Management or Shared Leadership
- ❖ Measurement-Based Quality Improvement Processes

Source: Adapted from "Measuring Culture Change," Englewood, Colo.: Colorado Foundation for Medical Care.
Publication No.: PM-411-144 CO 2006

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Culture Change in LTC Facilities

- ❖ Culture change increases:
 - ❖ Quality of life for residents
 - ❖ Quality of work environment for staff
 - ❖ Lower turnover rates
 - ❖ In many cases, without substantially increasing operating costs
- ❖ All long term care organizations can implement some level of culture change

Source: Grant, Leslie A. and Edward McMahon. 2008. "The Cultural Evolution, Part Three: Strategic Investments in Person-Centered Care," *Provider*. March.

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The Green House® Project

“Green House® homes are residences for 6 to 10 elders who require skilled nursing care and want to live a rich life. They are a radical departure from traditional skilled nursing homes and assisted living facilities, altering size, design, and organization to create a warm community. Their innovative architecture and services offer privacy, autonomy, support, enjoyment and a place to call home. Green House® homes are developed and operated by long-term care organizations in partnership with The Green House Project and NCB Capital Impact.”

Source: www.ncbcapitalimpact.org

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The Green House® Project

“With grant funding from [The Robert Wood Johnson Foundation \(RWJF\)](#), NCB Capital Impact is pursuing the rapid replication of The Green House model on a national level, offering technical assistance and [pre-development loans \(PDLs\)](#) to organizations that want to establish a partnership with The Green House Project. Over the next five years, under the leadership of Robert Jenkins, NCB Capital Impact plans to develop Green House homes with 50 or more organizations throughout the country.”

Source: www.ncbcapitalimpact.org

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Exterior

(Asbury Park, Newton, KS)



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Exterior

(Presbyterian Villages of Michigan, Redford, MI)



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Living Area / Hearth

(Presbyterian Villages of Michigan, Redford, MI)



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Dining Area & Kitchen

(Tabitha Health Care Services, Lincoln, NE)



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Dining Area

(Mississippi Methodist Senior Services, Inc., Tupelo, MS)



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Patio

(Tabitha Health Care Services, Lincoln, NE)



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Outside Dining

(Calvary Baptist, Columbus, GA)



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Shahbazim

(Calvary Baptist, Columbus, GA)



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Campus Approach

(Chelsea Jewish Nursing Home, Chelsea MA)



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A Home Environment

(Pinecrest Medical Care Facility, Powers, MI)



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Staff – Elder Relationship

(Resthaven, Holland, MI)



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Family-Like Culture

(Mississippi Methodist Senior Services, Inc., Tupelo, MS)



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Communal Activities

(Pinecrest Medical Care Facility, Powers, MI)



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Elder Participation

(Mississippi Methodist Senior Services, Inc., Tupelo, MS)



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Good Friends

(Mississippi Methodist Senior Services, Inc., Tupelo, MS)



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The Green House® Challenges

- ❖ Capital Costs
- ❖ Low Medicaid Rates
- ❖ Moving Green House® homes off of campuses and into communities “where people live and homes belong”
 - ❖ Multiple homes will need to be licensed together to share costs
 - ❖ Federal nursing home rules may not support this umbrella approach

Source: Robert Jenkins, The Green House® Project Director. Testimony before the Senate Special Committee on Aging. July 23, 2008.

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Recommendations by The Green House® Project Director

- ❖ Need to create programs to offset development costs for low-income projects.
 - ❖ Tax credit equity programs, targeted grants, interest rate reductions
- ❖ Work with states to enhance Medicaid reimbursement rates for person-centered models of care.
 - ❖ Support fast-track review process for state plan amendments that relate to payment rate changes for Green House® providers

Source: Robert Jenkins, The Green House® Project Director. Testimony before the Senate Special Committee on Aging. July 23, 2008.

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Support for Culture Change & The Green House® Project

- ❖ The Promoting Alternatives to Nursing Homes Act will be introduced in 2008 (Patron: Senator Robert Casey)
 - ❖ "...fosters significant culture change in long term care for older citizens by providing favorable loan funding and loan guarantees for entities that provide person-centered care within a 'small house' nursing facility framework."

Source: <http://casey.senate.gov>

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Virginia Green House® Project: The Virginia Mennonite Retirement Community

- ❖ Harrisonburg, VA
- ❖ Hope to be first Green House® in Virginia
- ❖ Currently in planning and fund-raising stage
- ❖ 10 houses serving 10 elders each
 - ❖ 6 houses in first phase
 - ❖ 4 houses in second phase
- ❖ Financially feasible without increasing cost to elders
 - ❖ VMRC current private room rate is \$228 per day for private payers
 - ❖ No change in cost for Medicaid recipients
 - ❖ No change in number of Medicaid recipients served (40%)

Source: Melissa Fortner, VMRC Vice President of Supportive Living

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Adaptation of The Green House® Model: Riverside Cluster Homes

- ❖ Riverside Health System (RHS)
- ❖ Williamsburg, Va
 - ❖ Located on 350-acre development which will also include a hospital, medical office building, and diagnostic services.
- ❖ Estimated date of opening: May 2010
 - ❖ Has acquired Certificate of Public Need (COPN) for 120 beds
- ❖ Skilled nursing facility
- ❖ Household setting
- ❖ Empowered & dedicated staff
- ❖ Resident control of daily activities

Source: George Phillips, Director of Strategic Support Services, Riverside Health System

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Adaptation of The Green House® Model: Riverside Cluster Homes

- ❖ 3 households in first phase. 3 more households in second phase (approx. 2 years after opening)
- ❖ Approximately 20 elders in each house
 - ❖ Determined original Green House® model of 10-12 elders was not financially feasible due to Virginia's low Medicaid/Medicare reimbursement rates
- ❖ Cost to residents should be equal to or slightly higher than traditional nursing home
- ❖ Requires higher ratio of private pay patients (approx. 50%)

Source: George Phillips, Director of Strategic Support Services, Riverside Health System

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Aging at Home

- ❖ Most individuals prefer to stay in their homes if possible
- ❖ Person-Centered & Consumer-Directed LTC system
- ❖ Requires the ability to obtain needed services at home
 - ❖ CNA, companion & chore services, support for caregivers, technology, etc.
- ❖ Virginia is moving in the right direction:
 - ❖ No Wrong Door & Virginia Easy Access
 - ❖ Program of All inclusive Care for the Elderly (PACE)
 - ❖ Money Follows the Person

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Aging at Home

However...

- ❖ Limited reimbursement for in-home care
- ❖ Fragmented services and funding sources
- ❖ Personal in-home care under Elderly or Disabled with Consumer Direction (EDCD) Medicaid waiver is restricted to individuals who meet nursing home criteria (assistance with 4 of 5 activities of daily living)

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Innovative Approaches for Aging at Home

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Cash & Counseling Program

- ❖ A consumer-directed model that empowers individuals to control their community support services
- ❖ Gives elderly and disabled Medicaid consumers who receive personal assistance services the option of directing their own care through a flexible budget they control
- ❖ Can use budget to hire personal care aides, purchase items or services (including home modifications), and/or pay a family caregiver
- ❖ Counseling: Assistance in planning budgets, handling employee wages and tax paperwork, and accounting for expenditures

Source: www.cashandcounseling.org

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Cash & Counseling Program

- ❖ National Program sponsored by the Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation in U.S. Department of Health and Human Services, and the Administration on Aging
- ❖ 3 state demonstration implemented in 1998
- ❖ 12 state replication projects began in 2004

Source: www.cashandcounseling.org

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Cash & Counseling Program

- ❖ Original States
 - ❖ Arkansas
 - ❖ Florida
 - ❖ New Jersey
- ❖ Expansion States
 - ❖ Alabama
 - ❖ Illinois
 - ❖ Iowa
 - ❖ Kentucky
 - ❖ Michigan
 - ❖ Minnesota
 - ❖ New Mexico
 - ❖ Pennsylvania
 - ❖ Rhode Island
 - ❖ Vermont
 - ❖ Washington
 - ❖ West Virginia

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Cash & Counseling Program

- ❖ Demonstration program found:
 - ❖ Improves quality of life
 - ❖ Reduces unmet care needs
 - ❖ Does not increase costs
- ❖ State adoption of program now easier:
 - ❖ 2006 reauthorization of the Older Americans Act (OAA) makes it possible to include a C&C option in the provision of OAA-funded services
 - ❖ 2007, federally-approved waivers are no longer required for states to offer flexible budgets to eligible Medicaid consumers and their families

Source: www.cashandcounseling.org

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Intentional Communities

“Neighbors helping neighbors”

- ❖ Non-profit organizations founded by residents
- ❖ Provides support to residents who wish to stay in their homes as they grow older
- ❖ Members email or call a single telephone # to arrange assistance or to participate in a variety of activities
- ❖ Services: Transportation, home maintenance, assistance with paperwork, occasional meal preparation & companionship, regular check-in, weekly grocery shopping, assisted living, etc.
- ❖ Provides programs and services more cost-effectively than most conventional retirement communities

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Intentional Communities

- ❖ Services provided by neighbors, volunteers, or vetted vendors (often at discounted rate)
 - ❖ Average cost per year for membership
 - ❖ \$550 per individual
 - ❖ \$800 for household > 1 person
 - ❖ Most offer discounted rate for low-income households.
- Beacon Hill Village offers yearly memberships of:
- ❖ \$100 per individual or \$150 per household
 - ❖ \$250 credit for programs and/or services

Source: www.beaconhill.org

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Intentional Communities

- ❖ Beacon Hill Village (Boston, MA)
- ❖ Capitol Hill Village (Washington, D.C.)
- ❖ Cambridge at Home (Cambridge, MA)
- ❖ Avenidas Village (Palo Alto, CA)
- ❖ Transition in Place Services (TIPS)
(Clifton-Fairfax Station, VA)
- ❖ Mount Vernon at Home (Mount Vernon, VA)

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Intentional Communities

- ❖ **ElderSpirit Community (Abingdon, VA)**
- ❖ A unique intentional community of 29 homes, a common house, and a Spirit Center. 13 owner homes. 16 renter homes.
- ❖ Commitment to spirituality, mutual support, service to outside community, simple lifestyle and respect for the earth, arts & recreation, health, care during illness & dying
- ❖ Senior independent living (not an assisted living or nursing facility)
- ❖ Renter homes reserved for individuals who meet Virginia's guidelines for government financed housing
- ❖ Second community in Abingdon planned

Source: www.elderspirit.net

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Support for Family Caregivers

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Support for Family Caregivers

*"There are four kinds of people in the world:
those who have been caregivers,
those who are caregivers,
those who will be caregivers,
and those who will need caregivers."
– Rosalynn Carter*



Importance of Family Caregivers

- ❖ Provide help with household chores, personal care, transportation, medication, companionship, paying bills, and coordinating services outside the home
- ❖ In U.S.: 44 million Americans (1 in 5 adults) provide unpaid care, valued at a cost of \$350 billion a year.*
- ❖ In Virginia: 740,402 caregivers provide 793 million hours of unpaid care, valued at a cost of \$7.8 million a year.**

*AARP Public Policy Institute, 2006.

**National Family Caregivers Association & Family Caregiver Alliance (2006).

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Virginia Family Caregivers

- ❖ Average age: 43 years
- ❖ Female: 55%
- ❖ Age 50 or older: 36%
- ❖ Employed: 77%
- ❖ \$5,531: Average annual out-of-pocket expense for caregiving

- ❖ 80% provide transportation related help
- ❖ 71% assist with grocery shopping, managing finances, or help with housework
- ❖ 60% prepare meals
- ❖ 46% give medicines, pills, or injections
- ❖ 34% aid with mobility in and out of beds and chairs
- ❖ 29% supervise caregiving services
- ❖ 23% help with activities of daily living (ADLs) such as toileting, dressing, and bathing

Source: *Caregiving in the U.S.: Spotlight on Virginia*. 2004. National Alliance for Caregiving and AARP.

Family Caregivers: What they spend, what they sacrifice. 2007. Evercare and National Alliance for Caregiving.

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Unmet Needs of Family Caregivers

- ❖ Finding time for myself -- 35%
- ❖ Keeping the person I care for safe at home – 30%
- ❖ Balancing work and family responsibilities – 29%
- ❖ Managing emotional and physical stress – 29%
- ❖ Easy activities I can do with the person I care for – 27%
- ❖ How to talk with doctors – 22%
- ❖ Making end-of-life decisions – 20%
- ❖ Moving or lifting the person I care for – 16%
- ❖ Managing challenging behaviors – 14%
- ❖ Choosing an assisted living facility – 13%
- ❖ Choosing a home care agency – 13%
- ❖ Managing incontinence or toileting problems – 11%
- ❖ Choosing a nursing home – 8%
- ❖ Finding non-English educational materials – 5%

*Caregiving in the U.S., National Alliance for Caregiving and AARP. 2004. Survey of 1,247 caregivers in the U.S.

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Stress Factors of Caregiver Role*

- ❖ Unrelieved caregiver burden
- ❖ Exhaustion
- ❖ Financial pressures
- ❖ Health risks
- ❖ Emotional strain
- ❖ Mental health problems
- ❖ Workplace issues
- ❖ Retirement insecurity
- ❖ Lost opportunities
- ❖ Legal concerns

Result in earlier nursing home placement and subsequent increase in public expenditures for nursing home costs.**

*Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support. 2006. Feinberg, Lynn Friss et al.
**Delivering on the Promise. U.S. Department of Health and Human Services. 2002.

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Impact of Caregiving on Family & Leisure Activities



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Addressing Caregiver Needs

Caregivers need greater:

1. emotional support,
2. access to information and resources,
3. guidance in the decision making process,
4. support from employers, and
5. relief from the financial burden of caregiving

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Primary Funding Sources for Family Caregiver Support

- ❖ National Family Caregiver Support Program
- ❖ Virginia Caregivers Grant
- ❖ Virginia Respite Care Initiative Grant
- ❖ Home and Community Based Care waivers

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National Family Caregiver Support Program

- ❖ Part of Older Americans Act, 2000 Amendment
 - ❖ Services delivered through Area Agencies on Aging:
 - ❖ Information about available services
 - ❖ Assistance with accessing support services
 - ❖ Individual counseling, support groups, training to help with problem solving and decision making
 - ❖ Respite care for temporary relief from caregiving role
 - ❖ Supplemental services like home modifications, assistive technology items, and emergency response systems
 - ❖ FY 2008 Virginia Budget = \$4,012,742

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National Family Caregiver Support Program

- ❖ Eligibility: Adult informal caregiver to an individual who is 60 years of age or older (and to receive respite or supplemental services, must also require help with 2 ADLs or require substantial supervision due to mental impairment) or 55+ year old relative caregiver to a child 18 years old or younger
- ❖ Priority given to older individuals with greatest social and economic need, preference given to low-income minority individuals and persons living in rural areas

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Virginia Caregivers Grant

- ❖ DSS program providing annual grants of up to \$500 to caregivers who provide unpaid care to a person requiring assistance with 2 ADLs
- ❖ Caregiver must have joint income of <\$75,000 (\$50,000 for single caregiver) and provide care for at least 6 months of the previous calendar year
- ❖ 2007 funding: Initially \$700,000, reduced to \$640,000
- ❖ 1,280 applicants received \$500
- ❖ Eliminated from 2008-2010 state budget

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Virginia Respite Care Initiative

- ❖ Established by the 1988 General Assembly to provide respite for elderly (60 and older), and persons with Alzheimer's Disease or related illnesses
- ❖ Virginia Department for the Aging program, administered through 13 AAAs and 2 non-profit organizations
- ❖ Client must have a 24 hour caregiver
- ❖ Respite care limited to 35 hours per month per client

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Virginia Respite Care Initiative

- ❖ FY 2005: \$879,695 Budget, 395 Clients
- ❖ FY 2006: \$1,238,052 Budget, 350 Clients
- ❖ FY 2007: \$1,142,039 Budget, 410 Clients

- ❖ Must have at least 45% matching funds from locality. As a result, only 55% of localities can afford to participate in the program.
- ❖ Client fees are on a sliding scale.

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Virginia Respite Care Initiative

- ❖ 60,579 hours of respite provided in FY 2005
- ❖ State funding has not increased since 2000
- ❖ Waiting list: 75-80 people
- ❖ Many caregivers are 60-80 years old with mental and/or physical challenges

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Selected Caregiver Resources

VIRGINIA

Virginia Association of Area Agencies on Aging (www.vaaaa.org)

Virginia Department for the Aging (www.vda.virginia.gov)

Virginia Easy Access (www.easyaccess.virginia.gov)

UNITED STATES

Administration on Aging (www.aoa.gov)

Agenet Eldercare Network (www.agenet.com) (888-404-4242)

Alzheimer's Association (www.alz.org) (800-272-3900)

AARP (www.aarp.org/caregiving) (800-687-2277)

"Ask Medicare" (www.medicare.gov/caregivers)

Children of Aging Parents (www.caps4caregivers.org) (800-227-7294)

Eldercare Locator (www.eldercare.gov) (800-677-1116)

Family Caregiver Alliance (www.caregiver.org) (415-434-3388)

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Selected Caregiver Resources

UNITED STATES

Full Circle of Care (www.fullcirclecare.org)

National Alliance for Caregiving (www.caregiving.org) (301-718-8444)

National Caregivers Library (www.caregiverslibrary.org)

National Council on Aging (www.ncoa.org) (202-479-6653)

National Family Caregivers Association (www.nfcacares.org) (800-896-3650)

Rosalyn Carter Institute (www.rosalyncarter.org)

Today's Caregiver on-line Magazine (www.caregiver.com)

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Model Caregiver Support Programs

- ❖ **California:** Family Caregiver Alliance and Caregiver Resource Centers
- ❖ **North Carolina:** Family Caregiver Support Program
- ❖ **New Jersey:** CaregiverNJ
- ❖ **Georgia:** Rosalynn Carter Institute for Caregiving & Georgia Caregiver Coalition
- ❖ **Pennsylvania:** Family Caregiver Support Program

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Key Elements of Model Programs

- ❖ Single coordinating organization for all services
- ❖ Central point of entry to caregiver resources & information
 - ❖ On-line resource center
 - ❖ Standardized call center
- ❖ Caregiver assessment
- ❖ Consumer direction
- ❖ Family caregiver education and training programs

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Policy Options

Option 1: Take no action.

Option 2: Continue study for one additional year to research options for improving “aging at home” services and support for culture change initiatives in Virginia.

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Policy Options

Option 3: Restore funding for Caregiver Grant when budget allows.

Option 4: Partner with local Chambers of Commerce to educate Virginia business owners about caregiver workforce issues and encourage owners to provide caregiver support programs.

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Public Comments

- ❖ Written public comments on the proposed options may be submitted to JCHC by close of business on November 10, 2008. Comments may be submitted via:
 - ❖ E-mail: sareid@leg.state.va.us
 - ❖ Facsimile: 804/786-5538 or
 - ❖ Mail to: Joint Commission on Health Care
P.O. Box 1322
Richmond, Virginia 23218
- ❖ Comments will be summarized and presented to JCHC during its November 24th meeting.

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Study Work Group Members

- ❖ Edward Ansello. Virginia Center on Aging, VCU
- ❖ Mary Lynne Bailey. Virginia Health Care Association
- ❖ Dale Belrose. TLC4LTC
- ❖ Carrie Eddy. Virginia Department of Health
- ❖ Melissa Fortner. Virginia Mennonite Retirement Community
- ❖ Ilene Henshaw. AARP and TLC4LTC
- ❖ Joani Latimer. Virginia Association of Area Agencies on Aging
- ❖ William Lukhard. AARP
- ❖ Kathy Miller. Virginia Department for the Aging
- ❖ Gail Nardi. Virginia Department of Social Services
- ❖ Ellen Nau. Virginia Department for the Aging
- ❖ Dana Parsons. Virginia Association for Nonprofit Homes for the Aging
- ❖ George Phillips. Riverside Health System
- ❖ Bill Peterson. Virginia Department for the Aging
- ❖ Jane Woods. Driftwoods Consulting

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