MONITORING CAREGIVER HEALTH:

SURVEILLANCE FROM THE BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

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State-Based Public Health

- Three levels of organized public health
  - National: set many policies, funds, agencies, research
  - State: provide much of the relevant funding, uniform policies, & infrastructure for activities like surveillance
  - Local: county/city departments of public health responsible for the local core services & actions in partnership with state
- State programs relevant to caregiving
  - Chronic disease (division); Aging; AAA's caregiving
  - Children's Medical Services; Disability programs

Data-Driven Public Health

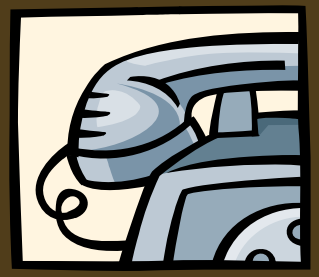
- At all levels, information (data) is key
  - Policy development
  - Program funding
  - Program & policy evaluation
- Data should be state-based to change relevant policies & program funding
  - Some data may be needed at smaller local levels. Area Agencies on Aging; there are 11 Florida AAA's

Public Health Surveillance

- Regular, ongoing data collection about health or health-related issues
  - Information about the prevalence of health behaviors/ health outcomes
  - Used in policy development & planning
- *Healthy People 2010* objective 6-13: Increase public health surveillance & health promotion programs for people with disabilities & their caregivers

State Public Health Data: The Behavioral Risk Factor Surveillance System (BRFSS)

- A surveillance system used in all US states & territories (http://www.cdc.gov/brfss/)
  - Telephone surveys of random community living adults represent the state, including broad health topics like health behaviors, healthcare access
  - If we identify caregivers on the BRFSS, we can compare their health to others, consider target groups for support programs



History of Caregiver Surveillance

- In 2000, two questions on the BRFSS
  - Do you provide care to someone age 60 or older?
  - Who would you call if a family member or friend needed in-home care?
- Results
  - 15.6% of US adults provided care, ranging from 13% in the West to 17% in the Southeast
  - 30% said they did not know who to call
  - The states/regions report is on-line at RCI

History of Caregiver Surveillance

- In 2000-2001, optional questions from perspective of people who need assistance
  - Do you need assistance with routine or self-care?
  - Who provides this care?
  - Is this care adequate?
- Results
  - 31% of people with a disability needed assistance
  - Having a caregiver improved use of some preventive health services (vaccination, Pap test, mammogram, colonoscopy, prostate screening)

Jamoom EW, et al. Effect of caregiving on preventive care for people with disabilities. Disability Health J 2008; 1: 51-57.

State Public Health Caregiving Data

- More detail necessary to support state-based caregiving programs & policies
- Caregiver Module: 10-questions states can choose to add to the BRFSS
  - Developed with national caregiving organizations & researchers

Identifying Caregivers 2009

- **BRFSS caregiver screening question:**

  "People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?"

Identifying Caregivers 2009

- 2009: the single screening question was asked of all BRFSS respondents in all states & territories
  - A state-based report on prevalence is forthcoming from the CDC
  - States can examine details of their own populations for the health of caregivers using these data
    - E.g., compare "days mental health was not good" between caregivers & others, look at preventive behaviors, etc.

The Full Caregiver Module

- Care recipient age, gender, relationship to caregiver, major health problem/disability
- Duration of caregiving
- Hours per week of caregiving
- Area with which care recipient needs most help
  - Self-care, transportation, seeing/hearing, etc.
- Greatest difficulty faced by caregiver
- Change in care recipient's thinking or memory in past year

Use of the Full Caregiver Module

- 2005
  - Pilot: North Carolina
- 2007
  - State-added: Hawaii, Kansas, Washington
- 2008
  - State-added: Florida, Michigan, Minnesota, Texas
- 2009
  - Approved module: Illinois, Louisiana, Ohio, Washington D.C.

Using CG Module Data

- Caregiver policy briefs
  - Washington
  - Florida
- Reports on caregiving within states
  - Overall prevalence, health behaviors
- Reports on specific types of caregivers
  - Caregiver of persons with cognitive impairment/Alzheimer's disease/dementia
  - Caregivers who report a financial burden, stress
  - Caregivers who provide full-time care

Results from the Caregiver Module

- **Caregivers of persons age 60+ with cognitive impairment in North Carolina were more likely than other caregivers to have a disability themselves & had provided care for longer.**

DeFries EL, et al. Caregivers of older adults with cognitive impairment. Prev Chronic Dis 2009;6(2).

- **Caregivers who felt they did not have a choice in becoming caregivers were more likely to report stress associated with caregiving.**

Winter KH, et al EM. Lack of choice in caregiving decision & caregiver risk of stress, North Carolina, 2005. Prev Chronic Dis 2010; 7(2).

2008 Florida Caregiver Module

- 13.4% of adults aged 18 & older provided care to someone, representing 1.8 million Floridian caregivers.
- Common care recipient health problems included
  - cancer (19%),
  - arthritis (8%),
  - Alzheimer's disease or dementia (7%)
- Caregivers provided most help with Activities of Daily Living
  - moving around (31%)
  - self-care (27%)
- 41% of caregivers said stress was the greatest difficulty they faced in caregiving

Florida Caregiver Health Examples

Health measure	Caregivers	Non Caregivers
Current smoker	21.2%	17.0%
Flu shot if 65+	68.0%	63.2%
Could not see doctor due to cost last year	21.0%	14.5%
Has disability themself	27.4%	20.1%

Specialty Report Example

- We produced a report for our Florida Department of Elder Affairs, restricting data to only caregivers and/or recipients of client ages of our Area Agencies on Aging (60+)
- State reports may require additional resources above & beyond what the BRFSS office has as State Departments of Health have experienced considerable staffing stresses in recent years, including mandatory furloughs

Interest in Caregiving Data

- State offices on caregiving or aging
  - National Family Caregiver Support Program of Administration on Aging
- Departments of health
  - Chronic disease, aging, disability branches
- Physicians & health care providers
  - Raising awareness of caregiver needs
- Policy makers
  - Evidence of need for caregiver support programs

Use the Caregiver Module for a State

- State BRFSS coordinators are responsive to the needs & interests of the state
  - Engage as many groups/organizations as possible
  - Most states charge $2,000 to $4,000 per question on the BRFSS, but may be able to cover part of the cost
- Timeline: contact state BRFSS coordinator by early summer to propose next calendar year
- List of state BRFSS coordinators on BRFSS website: http://apps.nccd.cdc.gov/BRFSSCoordinators/coordinator.asp

For More Information

- Contact

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- Visit the Florida Office on Disability & Health website for links to state & other caregiving reports: http://fodh.phhp.ufl.edu

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Questions & Discussion