MONITORING CAREGIVER HEALTH: SURVEILLANCE FROM THE BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

Elena M. Andresen, PhD & Erin DeFries Bouldin, MPH
University Of Florida

October, 2010
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/](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)

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.

- Caregivers who felt they did not have a choice in becoming caregivers were more likely to report stress associated with caregiving.
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.
<table>
<thead>
<tr>
<th>Health measure</th>
<th>Caregivers</th>
<th>Non Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current smoker</td>
<td>21.2%</td>
<td>17.0%</td>
</tr>
<tr>
<td>Flu shot if 65+</td>
<td>68.0%</td>
<td>63.2%</td>
</tr>
<tr>
<td>Could not see doctor due to cost last year</td>
<td>21.0%</td>
<td>14.5%</td>
</tr>
<tr>
<td>Has disability themself</td>
<td>27.4%</td>
<td>20.1%</td>
</tr>
</tbody>
</table>
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
For More Information

- Contact
  Elena Andresen andresen@phhp.ufl.edu
  Erin Bouldin edefries@phhp.ufl.edu

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

- **Funding**
  - Centers for Disease Control & Prevention (NCBDDD; NCCDPHP)
  - Rosalynn Carter Institute for Caregiving
  - Alzheimer’s Association

- **Survey Workgroup**
  - Mary Jo Gibson; Wendy Fox-Grage; Gerry Adler; Lynda Anderson; Joy M. Cameron; Joe Canose; John Crews; Jennifer Dexter; Tim Elliott; Ziya Gizlice; Rick Greene; Arlene Greenspan; Gail Hunt; Cathy Kluttz-Hile; Samantha J. Lasky; Carol Levine; Karen Luken; Lisa McGuire; Jaya K. Rao; Richard Schulz; Ronda Talley; Bonnie Teschendorf; Meg Ann Traci

- **Graduate Students & Staff**
  - Wajiha Akhtar; Brad Cannell; Amanda Crawford; Eric Jamoom; Claudia Kusano; Sarah McKune; Britta Neugaard; Claudia Tamayo; Katie Winter
Questions & Discussion