Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern. According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 100,000 households had someone with ICML in Planning and Service Area (PSA) 1, which serves the counties of Jo Davies, Stephenson, Winnebago, Boone, Carroll, Ogle, DeKalb, Whiteside, and Lee.

**INCREASED CONFUSION OR MEMORY LOSS**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of a set of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines a caregiver as someone who provides regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSA1 who have experienced ICML, there are many differences based on demographics and socio-economic status.

**ICML by Demographics, PSA 1, 2013**

Source: ILL. BRFSS, 2013
CAREGIVING NEEDS
The assistance and attention caregivers provide affects their everyday lives. According to BRFSS, three-fourths of caregivers in PSA1 identified the greatest difficulty they faced caring for a loved one. The difficulty reported most was that caregiving creates stress or aggravates health problems (39.3%). Other difficulties include lack of time for themselves or family, financial burden and interference with work.

Caregiver Relationship to Person They Provided Care, PSA1, 2013

- Parent or parent-in-law: 9.9%
- Spouse: 51.4%
- Other Relative: 33.0%
- Non-Relative: 5.7%

In PSA1, 19 percent of caregivers had provided care or assistance for a friend or family member within the past 30 days. The majority of caregivers provided care to individuals declared to have a major diagnosis of a physical problem (54.3%) rather than mental problem (21.3%). Most often the person for whom the caregiver provides care or assistance is a parent or parent-in-law (51.4%) or other relative (33.0%).

Source: ILL BRFSS, 2013

TIME SPENT PROVIDING CARE
Caregivers can spend years providing care to a friend or family member. About 30 percent of caregivers had spent more than five years providing care to one person. Annually, in PSA1, a total of 2,172 hours are spent by caregivers providing care for people with Alzheimer’s disease or dementia. This includes 1,092 hours spent providing care by spouses.

Providing care can be costly and it leaves less time for employment. Spouses are not eligible for disability benefits for providing care to their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

ICML MANAGEMENT
Individuals with ICML and those who share a household with someone who has it were asked questions regarding the impact ICML has on the person with ICML. According to BRFSS, in PSA1, ICML had affected people’s work or social activities always or sometimes in the past year (46.0%). Approximately 42 percent indicated ICML always or sometimes affects their ability to do household chores/activities. The areas of greatest need for assistance were household activities (42.7%) and transportation (16.9%). Other areas include safety and personal care. Approximately 17 percent indicated no assistance was needed.

Often the severity of ICML worsens over time. Two-thirds of individuals with ICML did not discuss an increase in memory loss/confusion with a healthcare professional in the past year.

December 2015
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern. According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 240,000 households had someone with ICML in Planning and Service Area (PSA) 2, which serves the counties of McHenry, Lake, Kane, Du Page, Kendall, Will, Grundy, and Kankakee.

**INCREASED CONFUSION OR MEMORY LOSS**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of a set of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines a caregiver as someone who provides regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSA 2 who have experienced ICML, there are many differences based demographics and socio-economic status.

**ICML by Demographics, PSA 2, Illinois, 2013**

Source: ILL. BRFSS, 2013
CAREGIVING NEEDS
The attention and assistance caregivers provide affects their everyday lives. According to BRFSS, 70 percent of caregivers in PSA 2 identified the greatest difficulty they faced caring for a friend or family member. The difficulty reported most was that caregiving does not leave enough time for themselves or family (27.8%). Other difficulties include creates stress or aggravates health problems, financial burden and interference with work.

In PSA 2, 19 percent of caregivers had provided care or assistance for a friend or family member within the past 30 days. A higher percentage of caregivers provided care to individuals declared to have a major diagnosis of a physical problem (46.4%) rather than mental problem (29.5%). Most often the person for whom the caregiver provides care or assistance to is a parent or parent-in-law (46.4%) or other relative (31.9%).

TIME SPENT PROVIDING CARE
Caregivers can spend years providing care to a friend or family member. In Illinois, more than 30 percent of caregivers had spent more than five years providing care to one person. Annually, in PSA 2, a total of 57,562 hours are spent by caregivers providing care for people with Alzheimer’s disease or dementia. This includes 10,712 hours spent providing care by spouses.

Providing care can be costly and it leaves less time for employment. Spouses are not eligible for disability benefits for providing care to their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

ICML MANAGEMENT
Individuals with ICML and those who share a household with someone who has it were asked questions regarding the impact ICML has on the person with ICML. According to BRFSS, in PSA 2, ICML had affected people’s work or social activities always or sometimes in the past year (41.6%). Approximately half (47.9%) indicated ICML always or sometimes affects their ability to do household chores/activities. The areas of greatest need for assistance were household activities (24.8), transportation (15.3%), and personal care (15.3%). Safety was also included. One-third indicated the individual with ICML did not need assistance.

Often the severity of ICML worsens over time. The majority of people with ICML did not discuss an increase in memory loss/confusion with a healthcare professional in the past year (62.7%).

Source: ILL. BRFSS, 2013

Greatest Difficulty Faced by Caregivers, PSA 2, 2013

Source: ILL. BRFSS, 2013
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern. According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 140,000 households had someone with ICML in Planning and Service Area (PSA) 3, which serves the counties of Rock Island, Henry, Bureau, La Salle, Mercer, Henderson, Warren, Knox, McDonough, and Putnam.

**INCREASED CONFUSION OR MEMORY LOSS**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of a set of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines a caregiver as someone who provides regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSA 3 who have experienced ICML, there are many differences based on demographics and socio-economic status.

**ICML by Demographics, PSA 3, 2013**

Source: ILL BRFSS, 2013
**CAREGIVING NEEDS**
The attention and assistance caregivers provide affects their everyday lives. According to BRFSS, 70 percent of caregivers in PSA 3 identified the greatest difficulty they faced caring for a friend or family member. The difficulty reported most was that caregiving creates stress or aggravates health problems (30.0%). Other difficulties include lack of time for themselves or family, financial burden and interference with work.

**Caregiver Relationship to Person They Provided Care, PSA 3, 2013**

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent or parent-in-law</td>
<td>36.5%</td>
</tr>
<tr>
<td>Spouse</td>
<td>37.1%</td>
</tr>
<tr>
<td>Other Relative</td>
<td>10.5%</td>
</tr>
<tr>
<td>Non-Relative</td>
<td>15.8%</td>
</tr>
</tbody>
</table>

Source: ILL. BRFSS, 2013

**Greatest Difficulty Faced by Caregivers, PSA 3, 2013**

- Doesn’t leave enough time for yourself or family: 26.3%
- Creates stress or aggravates your own health problems: 31.1%
- Mental problem: 30.0%
- Other: 12.8%
- None: 2.8%

Source: ILL. BRFSS, 2013

**TIME SPENT PROVIDING CARE**
Caregivers can spend years providing care to a friend or family member. In Illinois, more than 30 percent of caregivers had spent more than five years providing care to one person. Annually, in PSA 3, a total of 15,132 hours are spent by caregivers providing care for people with Alzheimer’s disease or dementia. Many of these hours are spent providing care by spouses.

Providing care can be costly and it leaves less time for employment. Spouses are not eligible for disability benefits for providing care to their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

**ICML MANAGEMENT**
Individuals with ICML and those who share a household with someone who has it were asked questions regarding the impact ICML has on the person with ICML. According to BRFSS, in PSA 3, ICML had affected people’s work or social activities always or sometimes in the past year (38.1%). Approximately 40 percent (39.3%) of people in the area indicated ICML always or sometimes affects their ability to do household chores/activities. The areas of greatest need for assistance among people with ICML were household activities (20.2%) and transportation (20.2%). Other areas include safety and personal care. A total of 30 percent indicated the individual with ICML did not need assistance.

Often the severity of ICML worsens over time. The majority of people with ICML did not discuss an increase in memory loss/confusion with a healthcare professional in the past year (56.0%).

*December 2015*
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern. According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 110,000 households had someone with ICML in Planning and Service Area (PSA) 4, which serves the counties of Stark, Marshall, Peoria, Woodford, Fulton, and Tazwell.

**INCREASED CONFUSION OR MEMORY LOSS**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines a caregiver as someone who provides regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSA 4 who have experienced ICML, there are many differences in demographics and socio-economic status.

**ICML by Demographics, PSA 4, 2013**

- Total: 9.6%
- Male: 12.7%
- Female: 7.3%
- Age 25-44: 10.9%
- Age 45-64: 10.6%
- Age 65+: 6.3%
- White/Non-Hispanic: 6.90%
- No Disability: 5.4%
- High-School Grad: 6.4%
- High School: 11.2%
- < High School: 10.3%
- Annual income <$15,000: 14.7%
- $15,000-$34,999: 5.4%
- $35,000-$49,999: 6.7%
- $50,000-$74,999: 10.4%
- Employed: 22.3%
- Retired: 10.4%
- Have health plan: 20%
CAREGIVING NEEDS
The attention and assistance caregivers provide affects their everyday lives. According to BRFSS, approximately half (48.9%) of caregivers in PSA 4 identified their greatest difficulty in caring for a friend or family member. The difficulty reported most was that caregiving creates stress or aggravates health problems (20.6%). Other difficulties include lack of time for themselves or family, financial burden and interference with work.

In PSA 4, 16 percent of caregivers had provided care or assistance for a friend or family member within the past 30 days. A significantly higher percentage of caregivers provided care to individuals declared to have a major diagnosis of a physical problem (53.5%) rather than mental problem (22.7%). Approximately three-fourths of caregivers provide care or assistance to a parent or parent-in-law (58.0%) or other relative (19.8%).

TIME SPENT PROVIDING CARE
Caregivers can spend years providing care to a friend or family member. In Illinois, more than 30 percent of caregivers had spent more than five years providing care to one person. Annually, in PSA 4, a total of 5,576 hours are spent by caregivers providing care for people with Alzheimer’s disease or dementia. Many of these hours are spent providing care by spouses.

Providing care can be costly and it leaves less time for employment. Spouses are not eligible for disability benefits for providing care to their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

ICML MANAGEMENT
Individuals with ICML and those who share a household with someone who has it were asked questions regarding the impact ICML has on the person with ICML. According to BRFSS, in PSA 4, ICML had affected people’s work or social activities always or sometimes in the past year (40.4%). Approximately 44 percent of people indicated ICML always or sometimes affects their ability to do household chores/activities. The areas of greatest need for assistance among people with ICML were transportation (28.1%) and household activities (19.3%). Other areas include safety and personal care. One-third indicated no assistance was needed.

Often the severity of ICML worsens over time. Approximately 72 percent of people in PSA 4 with ICML did not discuss an increase in memory loss/confusion with a healthcare professional in the past year.
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern.

According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 110,000 households had someone with ICML in Planning and Service Area (PSA) 5, which serves the counties of Champaign, Clark, Coles, Cumberland, DeWitt, Douglas, Edgar, Ford, Iroquois, Livingston, McLean, Macon, Moultrie, Piatt, Shelby, and Vermilion.

**INCREASED CONFUSION OR MEMORY LOSS**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines a caregiver as someone who provides regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSA 5 who have experienced ICML, there are many differences based demographics and socio-economic status.

**ICML by Demographics, PSA 5, 2013**

Source: ILL. BRFSS, 2013
CAREGIVING NEEDS
The attention and assistance caregivers provide affects their everyday lives. According to BRFSS, two-thirds of caregivers in PSA 5 identified the greatest difficulty they faced caring for a friend or family member. The difficulty reported most was that caregiving creates stress or aggravates health problems (26.4%). Other difficulties include lack of time for themselves or family, financial burden and interference with work.

Greatest Difficulty Faced by Caregivers, PSA 5, 2013
- 33.7%: Doesn’t leave enough time for yourself or family
- 29.3%: Creates stress or aggravates your own health problems
- 26.4%: Other
- 10.6%: None

Source: ILL BRFSS, 2013

Caregiver Relationship to Person They Provided Care, PSA 5, 2013
- 44.7%: Parent or parent-in-law
- 12.2%: Spouse
- 38.8%: Other Relative
- 4.3%: Non-Relative

Source: ILL BRFSS, 2013

TIME SPENT PROVIDING CARE
Caregivers can spend years providing care to a friend or family member. In Illinois, more than 30 percent of caregivers had spent more than five years providing care to one person. Annually, in PSA 5, a total of 8,055 hours are spent by caregivers providing care for people with Alzheimer’s disease or dementia. This includes 1,352 hours spent providing care by spouses.

Providing care can be costly and it leaves less time for employment. Spouses are not eligible for disability benefits for providing care to their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

ICML MANAGEMENT
Individuals with ICML and those who those who share a household with someone who has it were asked questions regarding the impact ICML has on the person with ICML. According to BRFSS, in PSA 5, ICML had affected people’s work or social activities always or sometimes in the past year (35.3%). Approximately 40 percent of people in the area indicated ICML always or sometimes affects their ability to do household chores/activities (39.2%). The areas of greatest need for assistance among people with ICML were household activities (25.5%) and transportation (17.6%). Other areas include safety and personal care. Approximately 30 percent (29.4%) indicated the individual with ICML did not need assistance.

Often the severity of ICML worsens over time. The majority of people in PSA 5 with ICML did not discuss an increase in memory loss or confusion (62.7%) with a healthcare professional.

December 2015
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased memory loss or confusion (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern. According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 14,438 households had someone with ICML in Planning and Service Area (PSA) 6, which serves the counties of Adams, Brown, Calhoun, Hancock, Pike, and Schuyler.

**Increased Confusion or Memory Loss**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of a set of questions regarding ICML as well as a caregiver module with questions for caregivers. This module consisted of a set of questions related to cognitive health and impairment and another for caregivers of individuals in general. Respondents were asked if they had ever experienced ICML. For those Illinois adults who have experienced ICML, there were differences based on age, income and disability status. Adults with a disability (24.6%) were significantly more likely to have ICML than adults without a disability (5.1%).

**ICML by Demographics, Illinois, 2013**

<table>
<thead>
<tr>
<th>Category</th>
<th>ICML Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>9.1%</td>
</tr>
<tr>
<td>Male</td>
<td>9.3%</td>
</tr>
<tr>
<td>Female</td>
<td>8.9%</td>
</tr>
<tr>
<td>18-24</td>
<td>8.1%</td>
</tr>
<tr>
<td>25-44</td>
<td>8.2%</td>
</tr>
<tr>
<td>45-64</td>
<td>8.9%</td>
</tr>
<tr>
<td>65+</td>
<td>11.2%</td>
</tr>
<tr>
<td>White/Non-Hispanic</td>
<td>8.0%</td>
</tr>
<tr>
<td>Black/Non-Hispanic</td>
<td>15.5%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>8.3%</td>
</tr>
<tr>
<td>Other/Non-Hispanic</td>
<td>7.6%</td>
</tr>
<tr>
<td>Multiracial/Non-Hispanic</td>
<td>6.7%</td>
</tr>
<tr>
<td>Have Disability</td>
<td>5.1%</td>
</tr>
<tr>
<td>No Disability</td>
<td>24.6%</td>
</tr>
</tbody>
</table>

Source: ILL. BRFSS, 2013
Illinois adults who were employed (6.3%) or homemakers or students (5.0%) were significantly less likely than adults who were out of work (18.2%) or retired or unable to work (15.6%) to experience ICML. Adults who earn less than $15,000 a year (16.1%) or between $15,000 and $34,999 a year (12.5%) were significantly more likely to have ICML than those who earn $35,000 to $49,999 (6.7%) or $50,000 to $74,999 (9.9%). Adults who earn $75,000 or higher were least likely to have ICML (4.7%).

### ICML by Demographics, Illinois, 2013

<table>
<thead>
<tr>
<th>Total</th>
<th>&lt;HS</th>
<th>HS</th>
<th>$50,000+</th>
<th>$75,000+</th>
<th>Employed</th>
<th>Out of Work</th>
<th>Retired</th>
<th>Have health plan</th>
<th>No health plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.1%</td>
<td>7.9%</td>
<td>9.4%</td>
<td>7.9%</td>
<td>16.1%</td>
<td>12.5%</td>
<td>6.7%</td>
<td>9.9%</td>
<td>4.7%</td>
<td>6.3%</td>
</tr>
<tr>
<td>6.3%</td>
<td>5.0%</td>
<td>8.6%</td>
<td>11.4%</td>
<td>15.6%</td>
<td>18.2%</td>
<td>6.3%</td>
<td>5.0%</td>
<td>4.7%</td>
<td>6.3%</td>
</tr>
</tbody>
</table>

Source: ILL. BRFSS, 2013

### CAREGIVING NEEDS

The BRFSS classifies a caregiver as someone who provides care or assistance to a friend or family member who has a health problem, long-term illness, or disability. Caregivers can face many difficulties. The care and assistance they provide affects their everyday lives. According to BRFSS, in 2013, when caregivers in Illinois were given a list of difficulties often experienced by caregivers and asked which one was the greatest difficulty they have faced, the difficulty reported most was the stress it creates (24.4%).

A combined 14 percent of caregivers felt lack of time for themselves (10.7%) or family (3.7%) was most difficult. Approximately 6 percent felt the effect it had on family relationships was the greatest difficulty.

### Greatest Difficulty Faced by Caregivers, Illinois, 2013

- Creates a financial burden 33.5%
- Not enough time for yourself 10.2%
- Not enough time for your family 24.4%
- Interferes with your work 6.2%
- Creates stress 10.7%
- Creates or aggravates your own health problems 3.7%
- Affects family relationships 3.7%
- Other 2.9%
- None

Source: ILL. BRFSS, 2013

**December 2015**
According to BRFSS, in 2013, 20 percent of adults in Illinois had provided care or assistance to a friend or family member within the past 30 days. The majority of caregivers provided care to individuals declared to have a major diagnosis of a physical problem (47.3%) rather than mental problem (22.7%). Most often the person for whom the caregiver provides care or assistance is a parent (38.4%) or non-relative (16.1%).

**Time Spent Providing Care**

Caregivers can spend years providing care to a friend or family member. More than 20 percent of caregivers had spent more than five years providing care to one person. According to BRFSS, in 2013, an estimated 121,334 hours were spent by caregivers in Illinois providing assistance to someone with Alzheimer’s disease or dementia. Approximately 8 percent of caregivers were spouses providing an estimated 19,292 hours spent providing care by spouses, leaving less time for employment. To compound the complexity of caregiving, spouses serving as caregivers are not eligible for disability benefits for providing such care, reducing household earnings to create a large financial burden.

**Self vs. Household Member Assessment**

The 2013 Illinois BRFSS included questions to be answered by individuals with ICML and for people who have a household member with ICML. When individuals with cognitive impairment were asked in which area most assistance is needed, the most frequent response was no assistance needed. The percentage of individuals with ICML who reported no assistance needed in any area (38.3%) is significantly higher than reported by a household member (15.7%).

<table>
<thead>
<tr>
<th>Area Assistance is Needed Most</th>
<th>Self</th>
<th>Household member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety</td>
<td>7.6</td>
<td>10.6</td>
</tr>
<tr>
<td>Transportation</td>
<td>15.4</td>
<td>21.4</td>
</tr>
<tr>
<td>Household activities</td>
<td>20.6</td>
<td>30.4</td>
</tr>
<tr>
<td>Personal care</td>
<td>12.4</td>
<td>17.7</td>
</tr>
<tr>
<td>Needs assistance, but not in above areas</td>
<td>3.9</td>
<td>1.</td>
</tr>
<tr>
<td>No assistance in any area</td>
<td>38.3</td>
<td>15.7</td>
</tr>
</tbody>
</table>

Source: ILL. BRFSS, 2013

*December 2015*
When asked how often ICML affects household chores or activates in the past 30 days, more individuals with ICML themselves than those sharing a household with an individual with ICML reported never (63.2% and 55.3% respectively) than always/usually (9.2% and 15.5% respectively), and sometimes (27.4% and 28.3% respectively). A significantly higher percentage of individuals with ICML themselves reported sometimes/rarely (27.4%) than always (9.2%). When asked how often ICML has affected ability to work or social activities, 37 percent of people with ICML reported always or never and 45 percent of people who share a household with someone with ICML reported always or never.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Always</th>
<th>Sometimes/Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self</td>
<td>HH</td>
<td>Self</td>
</tr>
<tr>
<td>During the past 12 months: How often did ICML affect household chores/activities?</td>
<td>9.2</td>
<td>15.5</td>
<td>27.4</td>
</tr>
<tr>
<td>During the past 12 months: How often has ICML affected ability to work/social activities?</td>
<td>12.3</td>
<td>15.7</td>
<td>24.2</td>
</tr>
</tbody>
</table>

Source: ILL. BRFSS, 2013

**WORKING WITH PROVIDERS**

Often the level of ICML increases over time. The majority of caregivers reported the person for whom they provided care experienced changes in thinking/remembering within the past year (55.9%). Individuals with ICML and individuals who have a household member with ICML were asked if ICML or medication for ICML were discussed with a health care professional. Significantly more individuals with ICML reported not discussing increase in ICML with their health care professional (68.3%) than discussing it (30.3%). The majority of individuals who have a household member with ICML reported discussing medication for ICML (61.0%) than not discussing it (36.3%). Keeping health care providers informed of changes in the status of the cognitive impairment is essential to maintaining or to improving the health of the individual. Having a household member advocate for their health management can increase the chance these changes are being discussed and help to ensure they are receiving proper treatment.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self</td>
<td>HH</td>
</tr>
<tr>
<td>Discussed increase in ICML with health care professional</td>
<td>30.3</td>
<td>42.3</td>
</tr>
<tr>
<td>Discussed medication for ICML with health care professional</td>
<td>45.0</td>
<td>61.0</td>
</tr>
</tbody>
</table>

Source: ILL. BRFSS, 2013

December 2015
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern.

According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 60,000 households had someone with ICML in Planning and Service Area (PSA) 7, which serves the counties of Cass, Christian, Greene, Jersey, Logan, Macoupin, Mason, Menard, Montgomery, Morgan, Sangamon, and Scott.

**INCREASED CONFUSION OR MEMORY LOSS**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of a set of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines a caregiver as someone who provides regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSA 7 who have experienced ICML, there are differences based on gender, age, race, ethnicity, and presence of a disability and socio-economic status such as education, income and employment.

**ICML by Demographics, PSA 7, 2013**

![Graph showing ICML percentages by demographic categories.]

Source: ILL. BRFSS, 2013
TIME SPENT PROVIDING CARE
Caregivers can spend years providing care to one person. In Illinois, more than approximately 15 percent (15.6%) of caregivers had spent more than five years providing care to one person. Annually, in PSA 7, a total of 6,383 hours are spent by caregivers providing care for people with Alzheimer’s or dementia.

Providing care can be costly. It leaves less time for employment. Spouses are not eligible for disability for providing care to their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

Much of the BRFSS data for PSA 7 could not be used due to sample size. Data that was available closely resembled that of other PSAs. The information below is taken directly from the state-wide Healthy Brain Initiative Burden Update.

CAREGIVING NEEDS
The BRFSS classifies a caregiver as someone who provides care or assistance to a friend or family member who has a health problem, long-term illness, or disability. Caregivers can face many difficulties. The care and assistance they provide affects their everyday lives. According to BRFSS, in 2013, when caregivers in Illinois were given a list of difficulties often experienced by caregivers and asked which one was the greatest difficulty they have faced, the difficulty reported most was the stress it creates (24.4%).

A combined 14 percent of caregivers felt lack of time for themselves (10.7%) or family (3.7%) was most difficult. Approximately 6 percent felt the effect it had on family relationships was the greatest difficulty.

Greatest Difficulty Faced by Caregivers, Illinois, 2013

- Creates a financial burden
- Not enough time for yourself
- Not enough time for your family
- Interferes with your work
- Creates stress
- Creates or aggravates your own health problems
- Affects family relationships
- Other
- None

Source: ILL. BRFSS, 2013

December 2015
In Illinois, 20 percent of caregivers had provided care or assistance for a friend or family member within the past 30 days. The majority of caregivers provided care to individuals declared to have a major diagnosis of a physical problem (47.3%) rather than mental problem (22.7%). Most often the person for whom the caregiver provides care or assistance is a parent (38.4%) or non-relative (16.1%).

**Self vs. Household Member Assessment**

The 2013 Illinois BRFSS included questions to be answered by individuals with ICML and for people who have a household member with ICML. When individuals with cognitive impairment were asked in which area most assistance is needed, the most frequent response was no assistance needed. The percentage of individuals with ICML who reported no assistance needed in any area (38.3%) is significantly higher than reported by a household member (15.7%).

<table>
<thead>
<tr>
<th>Area Assistance is Needed Most</th>
<th>Self</th>
<th>Household member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety</td>
<td>7.6</td>
<td>10.6</td>
</tr>
<tr>
<td>Transportation</td>
<td>15.4</td>
<td>21.4</td>
</tr>
<tr>
<td>Household activities</td>
<td>20.6</td>
<td>30.4</td>
</tr>
<tr>
<td>Personal care</td>
<td>12.4</td>
<td>17.7</td>
</tr>
<tr>
<td>Needs assistance, but not in above areas</td>
<td>3.9</td>
<td>1.8</td>
</tr>
<tr>
<td>No assistance in any area</td>
<td>38.3</td>
<td>15.7</td>
</tr>
</tbody>
</table>

When asked how often ICML affects household chores or activates in the past 30 days, more individuals with ICML themselves than those sharing a household with an individual with ICML reported never (63.2% and 55.3% respectively) than always/usually (9.2% and 15.5% respectively), and sometimes (27.4% and 28.3% respectively). A significantly higher percentage of individuals with ICML themselves reported sometimes/rarely (27.4%) than always (9.2%). When asked how often ICML has affected ability to work or social activities, 37 percent of people with ICML reported always or never and 45 percent of people who share a household with someone with ICML reported always or never.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Always</th>
<th>Sometimes/Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self</td>
<td>HH</td>
<td>Self</td>
</tr>
<tr>
<td>During the past 12 months: How often did ICML affect household chores/activities?</td>
<td>9.2</td>
<td>15.5</td>
<td>27.4</td>
</tr>
<tr>
<td>During the past 12 months: How often has ICML affected ability to work/social activities?</td>
<td>12.3</td>
<td>15.7</td>
<td>24.2</td>
</tr>
</tbody>
</table>

Source: ILL. BRFSS, 2013
WORKING WITH PROVIDERS

Often the level of ICML increases over time. The majority of caregivers reported the person for whom they provided care experienced changes in thinking/remembering within the past year (55.9%). Individuals with ICML and individuals who have a household member with ICML were asked if ICML or medication for ICML were discussed with a health care professional. Significantly more individuals with ICML reported not discussing increase in ICML with their health care professional (68.3%) than discussing it (30.3%). The majority of individuals who have a household member with ICML reported discussing medication for ICML (61.0%) than not discussing it (36.3%). Keeping health care providers informed of changes in the status of the cognitive impairment is essential to maintaining or to improving the health of the individual. Having a household member advocate for their health management can increase the chance these changes are being discussed and help to ensure they are receiving proper treatment.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self</td>
<td>HH</td>
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<tr>
<td>Discussed increase in ICML with health care professional</td>
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</tbody>
</table>

Source: ILL. BRFSS, 2013
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern. According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 1650,000 households had someone with ICML in Planning and Service Areas (PSAs) 8-11, which serves all counties in southern Illinois south of Interstate 70.

**INCREASED CONFUSION OR MEMORY LOSS**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of a set of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines caregiver as someone who provides regular care or assistance to a friend or family member with a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSAs 8, 9, 10, and 11 who have experienced ICML, there are many differences based on demographics and socio-economic status.

**ICML by Demographics, PSAs 8, 9, 10, and 11, 2013**

![Bar chart showing ICML by demographics for PSAs 8, 9, 10, and 11 in 2013.](chart.png)

*Source: ILL. BRFSS, 2013*
CAREGIVING NEEDS
The attention and assistance caregivers provide affects their everyday lives. According to BRFSS, seventy percent of caregivers in PSAs 8, 9, 10, and 11 identified their greatest difficulty in caring for a loved one. The difficulty reported most was that caregiving creates stress or aggravates health problems (35.8%). Other difficulties include lack of time for themselves or family, financial burden and interferes with work.

In PSAs 8, 9, 10 and 11, almost one-fourth (23.2%) of caregivers had provided care or assistance for a friend or family member within the past 30 days. More caregivers provided care to individuals declared to have a major diagnosis of a physical problem (56.1%) rather than mental problem (27.6%). Most often the person for whom the caregiver provided care or assistance is a parent or parent-in-law (49.6%) or non-relative (23.5%).

TIME SPENT PROVIDING CARE
Caregivers can spend years providing care to a friend or family member. In Illinois, more than 30 percent of caregivers had spent more than five years providing care to one person. Annually, in PSAs 8, 9, 10, and 11, a total of 12,248 hours are spent by caregivers providing care for people with Alzheimer’s or dementia. This includes 5,616 hours spent providing care by spouses.

Providing care can be costly. It leaves less time for employment. Spouses are not eligible for disability for providing care for their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

ICML MANAGEMENT
Individuals who have ICML and those who share a household with someone who has it were asked questions regarding the impact ICML has on the person with ICML. In PSAs 8, 9, 10 and 11, ICML has affected people’s work or social activities always or sometimes in the past year (31.5%). Approximately one-third (32.9%) of people in PSAs 8, 9, 10 and 11 indicated ICML always or sometimes affects their ability to do household chores/activities. The areas of greatest need for assistance among people with ICML were household activities (35.1%) and personal care (27.4%). Other areas include transportation and safety. Almost 20 percent (18.1%) indicated the individual with ICML did not need assistance.

Often the severity of ICML worsens over time. Two-thirds of people in PSAs 8, 9, 10, and 11 with ICML did not discuss an increase in memory loss or confusion with a health care professional within the past year.
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person’s everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern. According to the Illinois Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 75,000 households had someone with ICML in Planning and Service Area (PSA) 7, which serves Cook county.

**Increased Confusion or Memory Loss**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines caregiver as someone who provides regular care or assistance to a friend or family member for a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSA 12 who have experienced ICML, there are many differences based on demographics and socio-economic status.

**ICML by Demographics, PSA 12, 2013**

![ICML by Demographics, PSA 12, 2013](chart.png)

Source: ILL. BRFSS, 2013
CAREGIVING NEEDS
The attention and assistance caregivers provide affects their everyday lives. According to BRFSS, two-thirds of caregivers in PSA 12 identified their greatest difficulty in caring for a loved one. The difficulty reported most was that caregiving creates stress or aggravates health problems (33.7%). Other difficulties include lack of time for themselves or family, financial burden and interference with work.

Caregiver Relationship to Person They Provided Care, PSA 12, 2013

![Chart showing the relationship of caregivers to the person they provided care for.](chart)

In PSA 12, 18 percent of caregivers had provided care or assistance for a friend or family member within the past 30 days. More caregivers provided care to individuals declared to have a major diagnosis of a physical problem (47.1%) rather than mental problem (12.8%). Most often the person for whom the caregiver provided care or assistance is a parent or parent-in-law (46.1%) or other relative (28.8%).

TIME SPENT PROVIDING CARE
Caregivers can spend years providing care to a friend or family member. In Illinois, more than 30 percent of caregivers had spent more than five years providing care to one person. Annually, in PSA 12, a total of 10,201 hours are spent by caregivers providing care for people with Alzheimer’s disease or dementia. This includes 520 hours spent providing care by spouses.

Providing care can be costly and it leaves less time for employment. Spouses are not eligible for disability benefits for providing care to their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

ICML MANAGEMENT
Individuals with ICML and those who share a household with someone who has it were asked questions regarding the impact ICML has on the person with ICML. In PSA 12, ICML had affected people’s work or social activities always or sometimes in the past year (33.3%). Forty percent of people in the area indicated ICML always or sometimes affects their ability to do household chores/activities. The areas of greatest need for assistance among people with ICML were personal care (19.8%), transportation (18.5%), and household activities (18.5%). Other areas include safety. Approximately one fourth (27.2%) of people indicated the individual with ICML did not need assistance.

Often the severity of ICML worsens over time. Seventy percent of people in PSA12 with ICML did not discuss an increase in memory loss or confusion with a healthcare professional.

Greatest Difficulty Faced by Caregivers, PSA 12, 2013

![Chart showing the greatest difficulties faced by caregivers.](chart)

Source: ILL. BRFSS, 2013

December 2015
Cognitive health, like physical and mental health, is associated with living independently, quality of life and social engagement. In contrast, the lack of cognitive health can have profound implications for a person's everyday life as well as the lives of their friends and families. Persons living with increased confusion or memory loss (ICML) may be unable to care for themselves or to engage in necessary activities of daily living, such as preparing meals or bathing. Limitations in the ability to effectively manage medications and existing medical conditions are of particular concern. According to the Behavioral Risk Factor Surveillance System (BRFSS), in 2013, about 140,000 households in Planning and Service Area (PSA) 13, as defined by the Older Americans Act, had someone with ICML in Planning and Service Areas (PSAs) 8-11, which serves Suburban Cook County.

**INCREASED CONFUSION OR MEMORY LOSS**

The 2013 Illinois BRFSS included a cognitive impairment module consisting of questions regarding ICML as well as a caregiver module with questions for caregivers. BRFSS defines a caregiver as someone who provides regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. BRFSS is used to survey households and does not include residents of nursing homes, group homes, or other facilities. Respondents were asked if they had ever experienced ICML. For those adults in PSA 13 who have experienced ICML, there are many differences based on demographics and socio-economic status.

**ICML by Demographics, PSA 13, 2013**

![Chart showing ICML by demographics in PSA 13, 2013]
CAREGIVING NEEDS
The attention and assistance caregivers provide affects their everyday lives. According to BRFSS, 54 percent of caregivers in PSA 13 identified the greatest difficulty they faced caring for a friend or family member. The difficulty reported most was that caregiving creates stress or aggravates health problems (16.6%). Other difficulties include lack of time for themselves or family, financial burden and interference with work.

Greatest Difficulty Faced by Caregivers, PSA 13, 2013

In PSA 13, approximately 20 percent (21.1%) of caregivers had provided care or assistance for a friend or family member within the past 30 days. More caregivers provided care to individuals declared to have a major diagnosis of a physical problem (50.8%) rather than mental problem (10.1%). Most often the person for whom the caregiver provided care or assistance is a parent or parent-in-law (42.2%) or other relative (26.3%).

TIME SPENT PROVIDING CARE
Caregivers can spend years providing care to a friend or family member. In Illinois, more than 30 percent of caregivers had spent more than five years providing care to one person. Annually, in PSA 13, a total of 2,784 hours are spent by caregivers providing care for people with Alzheimer’s disease or dementia. Many of the hours are spent providing care by spouses.

Providing care can be costly and it leaves less time for employment. Spouses are not eligible for disability benefits for providing care to their spouse. The combination of reduced capacity to earn money by the person afflicted with ICML and lack of time for the spouse to earn money creates a large financial burden.

ICML MANAGEMENT
Individuals with ICML and those who share a household with someone who has it were asked questions regarding the impact ICML has on the person with ICML. According to BRFSS, in the PSA 13, ICML had affected people’s work or social activities always or sometimes in the past year (36%). Approximately 30 percent (29.3%) indicated ICML always or sometimes affects their ability to do household chores/activities. The areas of greatest need for assistance among people with ICML were household activities (22.7%) and transportation (21.4%). Other areas include safety and personal care. Approximately one third (34.7%) indicated the individual with ICML did not need assistance.

Often the severity of ICML worsens over time. Two-thirds of people in the PSA 13 with ICML did not discuss an increase in memory loss or confusion with a healthcare provider.