Family Caregivers: Needs and Wants
IOM Study: Family Caregiving for Older Adults
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Isn’t caregiving just something families have always done?
Yes…and…No

What has changed in the last 50 years…
• Increased life expectancy
• Increased complexity in health care and costs
• Radical change in women’s roles
• Decrease in number and size of families

Expectations of unpaid caregivers are greater now and growing
If you have seen one caregiving family, you have seen one caregiving family….families differ in:

• Size

• Cohesion and quality of relationships

• Culture

• Socio-economic status
Family Caregiver Needs

- **Information**: most cross-cutting; topics cover extensive range; dynamic over time as to what information is needed
- Emotional Support: impacts of health and functional changes in person you are caring for, past and current relationship with the care receiver and other family members, expectations for the future, mortality
- Decision Support: for current challenges and for those difficult situations that may be in the future
- Linkage to formal and informal/unpaid services
Family Caregiver Needs

- Training: skills range from care planning to direct care to self care
- Financial Information and Benefits Counseling
- Wellness and Prevention: self care for those who provide care
- Respite: everyone deserves a break
Family Caregiver Wants

- Recognized for the value and complexity of the work they do
- Not to be ignored within the health and social service systems
- Honesty in health care discussions with providers
- Not to suffer significant financial setbacks as a result of providing care to a family member
- Health care interactions to be truly “person and family centered” and to prize convenience in service delivery
- Have a consistent points of contact across the care continuum

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Family Caregiver Needs and Wants Summary

- The world has changed and with it, the capacity, ability and expectations of families to be the sole providers of long term care in the home needs to change.
- If we as a society hold the expectation of increasingly complex care is to be provided over the long term by unpaid caregivers, then society must also provide the support necessary for family caregivers to be successful not only in their current role as a care provider but also secure their return to the workforce or to a financially sound retirement.