



# CELEBRATING FAMILY CAREGIVERS

*A presentation to the Money Follows  
the Person Roundtable*

*November 10, 2014*

# Presenter

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# Proclamations: November is Family Caregiver Month!

**“NOW, THEREFORE, I, BARACK OBAMA**, President of the United States of America, by virtue of the authority vested in me by the Constitution and the laws of the United States, **do hereby proclaim November 2014 as National Family Caregivers Month**. I encourage all Americans to pay tribute to those who provide for the health and well-being of their family members, friends, and neighbors.”

&

**“WHEREAS**, the State of North Carolina acknowledges and supports family, friends, and neighbors who are helping those who are in need; support of family caregivers is not only the right thing to do, but also an essential investment for the future of North Carolina’s long-term care system;  
**NOW, THEREFORE, I, PAT McCRORY**, Governor of the State of North Carolina, do hereby proclaim November 2014, as **“FAMILY CAREGIVER MONTH”** in North Carolina and commend its observance to all citizens.”

- See more at: <http://www.governor.state.nc.us/newsroom/proclamation/20141101/family-caregiver-month#sthash.1EBmz7mw.dpuf>

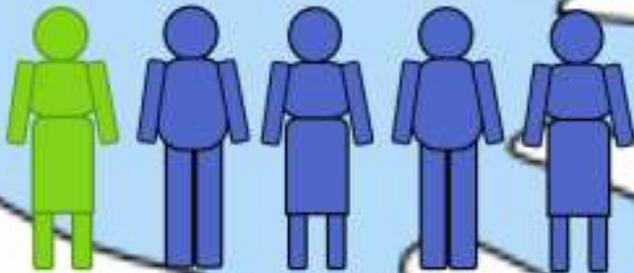
# During this session, you will...

- Discover the role family caregivers play in our nation's health care & economy
- Find out why family caregivers are often called the “silent care coordinators”
- Consider ways to engage caregivers as a catalyst to support better transitions
- Explore strategies to assist family caregivers
- Gain knowledge about and access to “Planning and Using Respite: Supporting Family Caregivers Across the Lifespan” online training modules in North Carolina.

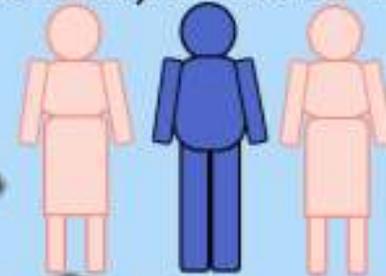
# How many caregivers are there?

According to the 2011 BRFSS,

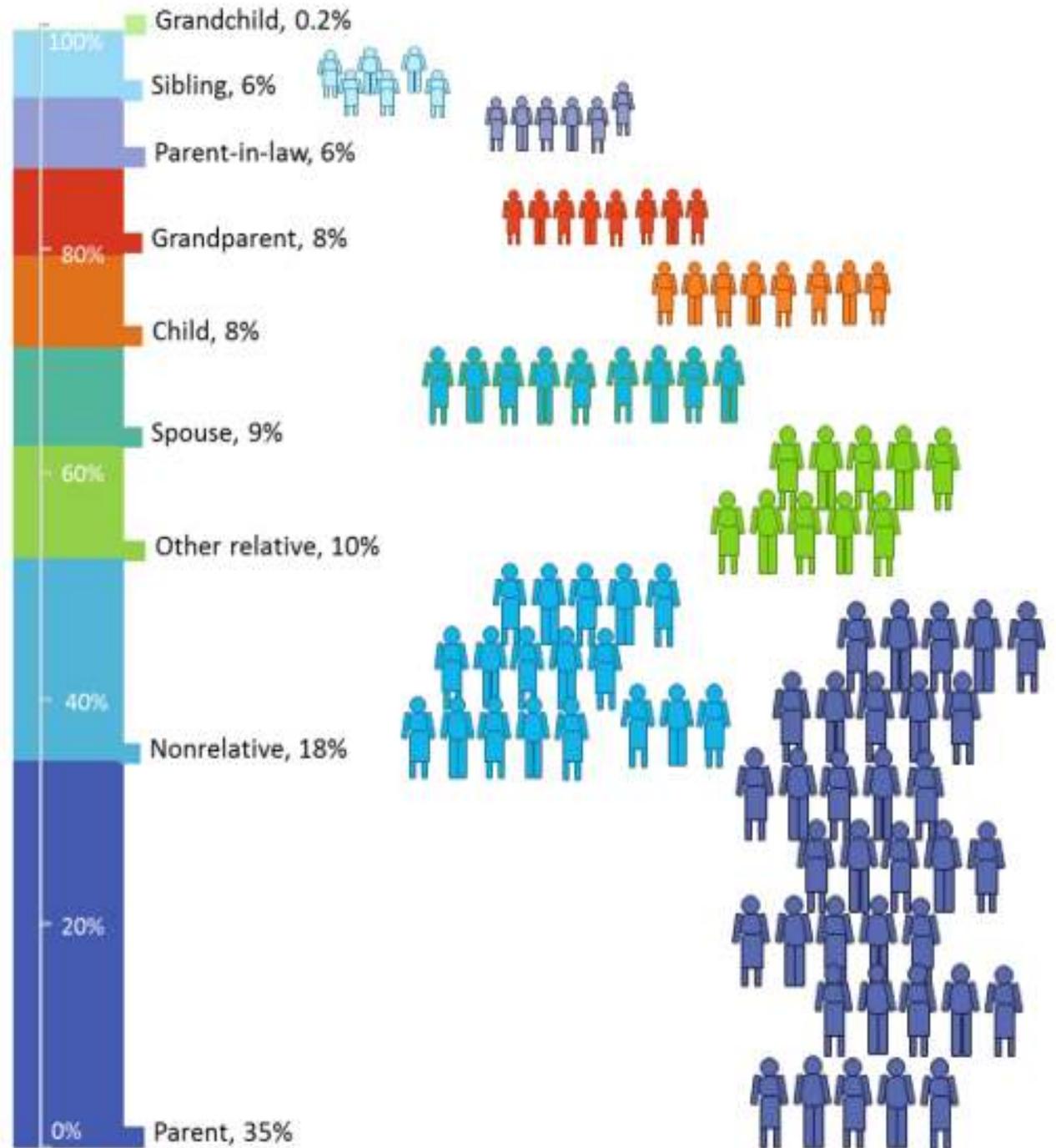
20% of North Carolinians  
are caregivers



65% of NC caregivers are  
women, almost 2 in 3



# Who receives the care?



## Why Do You Want to Know Whether There's a Caregiver?

Providing care is both physically and emotionally challenging.

Although the most recent NAC survey of US caregivers (2009) found that a majority were doing well, they also found that

- 26% spent 21 hours or more each week providing care
- 56% helped with ADLs
- 100% helped with IADLs
- 31% said they were emotionally stressed
- 17% said caregiving had made their own health worse.

The physical and mental health of the caregiver may be critical to the plan of care for the person who needs support.





## Why support family caregivers?

Our country's entire system of long-term services and supports for people with disabling conditions depends on them.

In 2009, to replace their work with paid care would have cost \$450 billion, according to AARP. By comparison, that year Medicaid paid about \$119 billion for long-term services and supports, and about \$184 billion came from other sources.

If for no other reason, preserving the well-being of family caregivers preserves our country's economy.

## Framing the need...

Everyday, thousands of people seek and receive health care and social services in community settings, hospitals, clinics and long term care facilities.

Often, there is a family caregiver in the picture, providing essential supports to a child or adult with disabilities or an elder parent or spouse.



Yet, these caregivers may remain largely invisible to the service professional, thus hiding important needs that are important to both the caregiver and care receiver.



# Common Roles of Caregivers

- Accompany patients to doctor visits; participate in patient-physician communication
- Serve as “walking medical records”
- Manage behavioral problems
- Spot early warning signs of symptom changes and medication errors/interactions
- Gatekeepers to decide who and when to call medical providers, or seek emergency care
- Identify needs for community-based services, medical equipment, and assistive devices
- Advocate for patients
- Monitor costs and deal with insurance issues
- Help express patient preferences for care

# Increasingly, they are also providing complex care

- Almost half of family caregivers performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions
- 3 out of 4 who provided this assistance were managing medications, including administering intravenous fluids and injections
- Many were providing wound care and more than a third (38%) wanted more training

- Results from an online survey from the AARP Public Policy Institute and the United Hospital Fund

# Families play a critical role in transitions

## MFP Rebalancing Fund 2014 Survey Results:

Second only to safe, affordable, accessible housing, **support to family caregivers, such as “respite” and other caregiver support options**, was cited as the most important factor to keeping people out of facilities and helping someone leave a facility.”

*“Transitions between settings are recognized as the most vulnerable points in the delivery of health care and long-term services and supports. (LTSS)”*

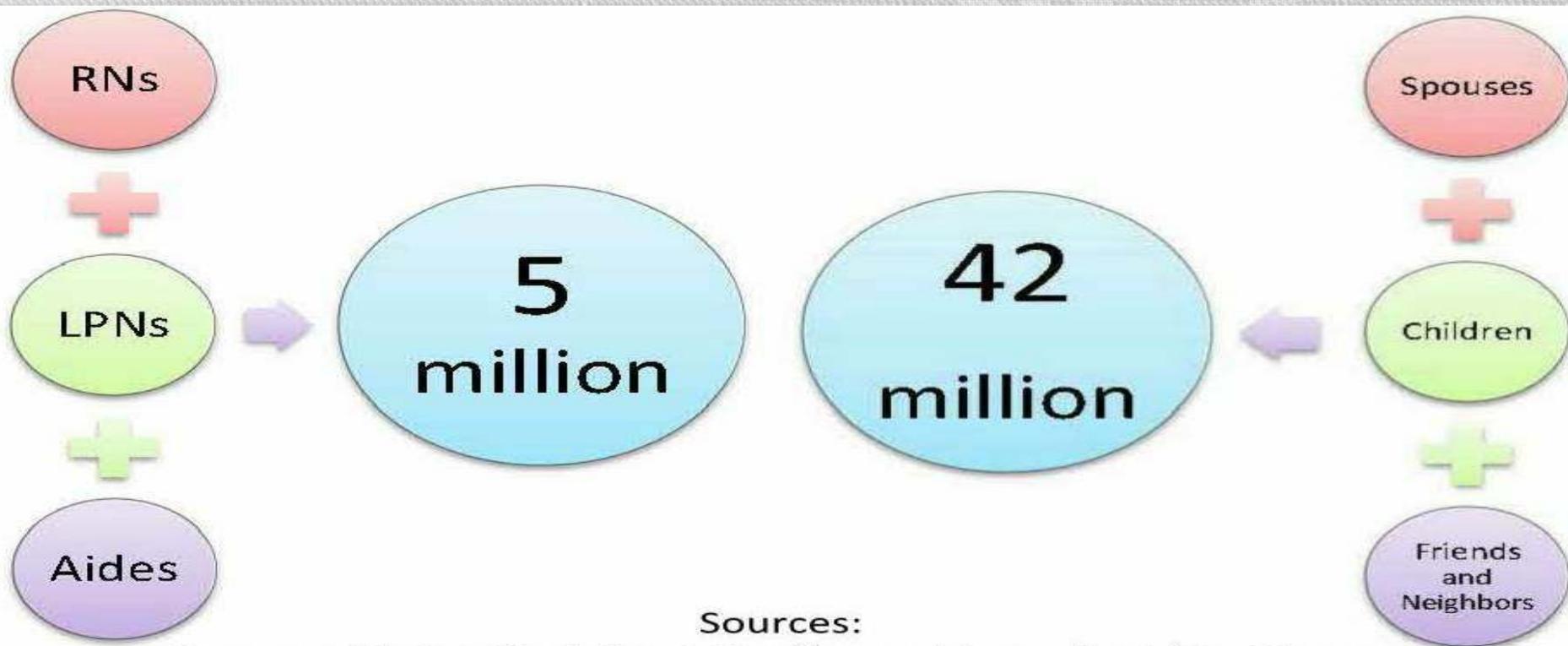
Reinhard, S., L. Feinberg, and R. Choula, “A Call to Action: What Experts Say Needs to Be Done to Meet the Challenges of Family Caregiving.” AARP Public Policy Institute, 2011.

# Major Findings from *Family Caregiving and Transitional Care: A Critical Review*

- Family caregivers receive inadequate support
- Family caregiver involvement can improve outcomes and continuity of care
- Health/human service professionals are recognizing the need to work with family caregivers
- Many transitional care programs do not actively engage family caregivers
- A greater focus on long term services and support is needed
- New teaching guides and programs are available but often not accessible
- Barriers to greater engagement with family caregivers need to be recognized

# 4 Questions About Engaging Family Caregivers

## 1. *Why are family caregivers important to transitions?*



Sources:

Bureau of Labor Statistics, <http://www.bls.gov/ooh/Healthcare>  
AARP Public Policy Institute, Valuing the Invaluable: 2011 Update

## 4 Questions About Engaging Family Caregivers

### ***2. How can I identify family caregivers?***

Points to Consider: Who is the hands-on family caregiver? If there are multiple family caregivers, which ones handle which caregiving tasks? Will this arrangement continue after the participant transitions to the next care setting?

Many family caregivers have never thought of themselves as "caregivers." Recognition of this role can be important for obtaining services, gaining support, and reducing guilt or stress.

## 4 Questions About Engaging Family Caregivers

### ***3. If the patient is alert and oriented, why involve anyone else? Isn't that more work?***

- Studies have shown that even independent, cognitively intact adults retain less than half of the instructions they receive in the hospital/health care setting.
- An informed family caregiver can supplement and reinforce the patient's understanding

## 4 Questions About Engaging Family Caregivers

### ***4. What about HIPAA and family caregivers?***

- HIPAA states that health care providers should use their own best judgment in working together with people who provide care to the patient or responsible for patient bills
- Only restriction is if patient (or legal guardian) specifically refuses sharing information

# Assume Less, Ask More

It should not be automatically assumed that families will somehow manage to do it all without help or that they can afford to hire someone to help. They should be asked in the discharge process exactly what they can and cannot do, with and without training.

- M.J. Gibson, K.A. Kelly, and A.K. Kaplan. Family Caregiving and Transitional Care: A Critical Review. October 2012

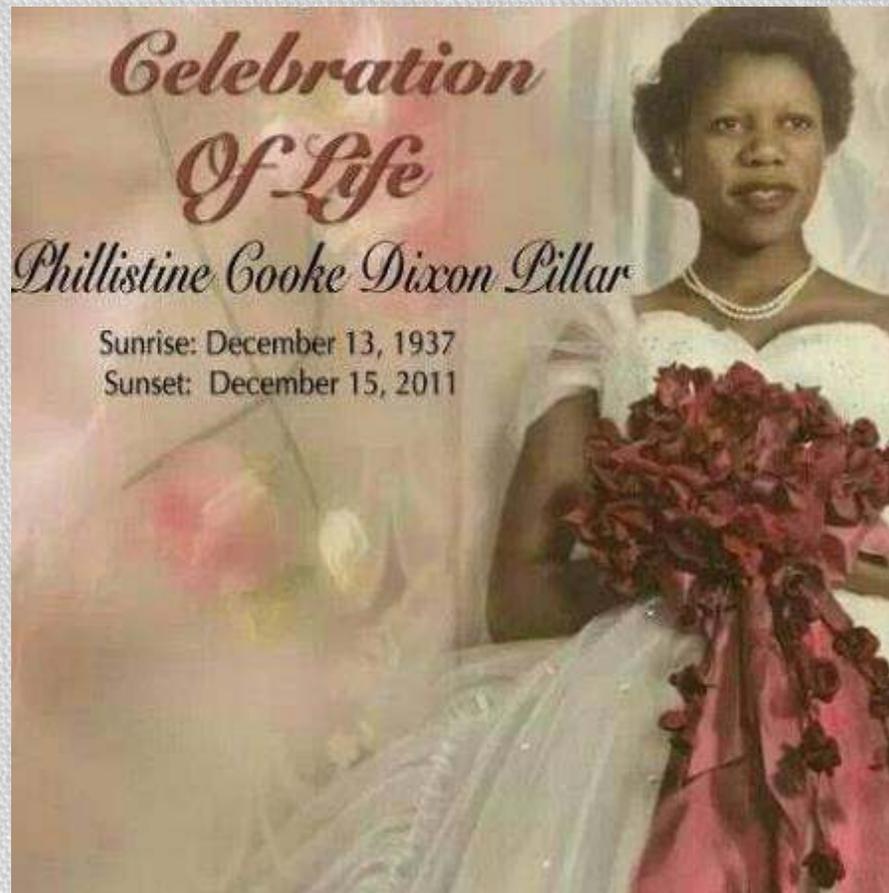
# If I were a family caregiver, I would want health care professionals to:

- Be more patient and compassionate
- Keep me informed
- Tell me the truth about care needs
- Listen to what I need, feel, want
- Respond to phone calls in a timely fashion
- Give me info. in a language I understand
- Treat me with respect
- Try to understand my culture and family background



# Stories from MFP Families

Phyllis (shared by Catherine and Lakeisha)



Alex (shared by Marianne)



# Strategies to Support Family Caregivers

- Caregiver Support Groups
- Powerful Tools for Caregivers (6 week class)
- Chronic Disease Self Management, Matter of Balance
- Online Caregiver Trainings, Support Groups
- Education and Trainings available through Area Agencies on Aging and other local Providers
- Limited respite, SHIP counseling, ombudsman, connection to application for services also at AAAs
- Connection to Certified Options Counselors

# North Carolina's Lifespan Respite Grants

- 2009 Lifespan Respite Care Grant
- 2011 Expansion Supplement Programs
- **2012 *Building Integrated & Sustainable Programs***
- 2014 Building Long-term Sustainability in State Programs



The logo for the North Carolina Lifespan Respite Project is centered on a white rectangular background. It features two thick, teal-colored curved lines that form a wide, shallow arch. Inside this arch, the text "NORTH CAROLINA" is written in a smaller, black, serif font, and "LIFESPAN RESPITE PROJECT" is written in a larger, bold, black, serif font below it. At the bottom center of the arch, there is a small green icon of a plant with three leaves and two swirling stems.

## NORTH CAROLINA LIFESPAN RESPITE PROJECT

In order to raise awareness among service professionals and embed a caregiver & respite focus...

...the North Carolina Lifespan Respite Project created web-based, on-demand training modules entitled,

**“Planning and Using Respite:  
Working with Family Caregivers  
across the Lifespan.”**

## Training Aimed at:



- Options Counselors
- Medical and Health care providers
- Department of Social Services Workers
- Transitions Coordinators
- 2-1-1 Information and Referral Specialists
- Others in private and public sectors
- Helpful to family caregivers too!

## Modules include:

1. Introduction: Caregivers, Caregiving and Respite
  2. Engagement and Screening
  3. Assessing Caregivers
  4. Planning Principles and Tools
  5. Planning Examples and Following Up.
- About 3 ½ hours in length when completed.

# “Planning and Using Respite” Trailer

[http://ssw.unc.edu/cares/lifespan respite/trailer/story.html](http://ssw.unc.edu/cares/lifespan%20respite/trailer/story.html)



# How to Access Training?

To register and access the modules,

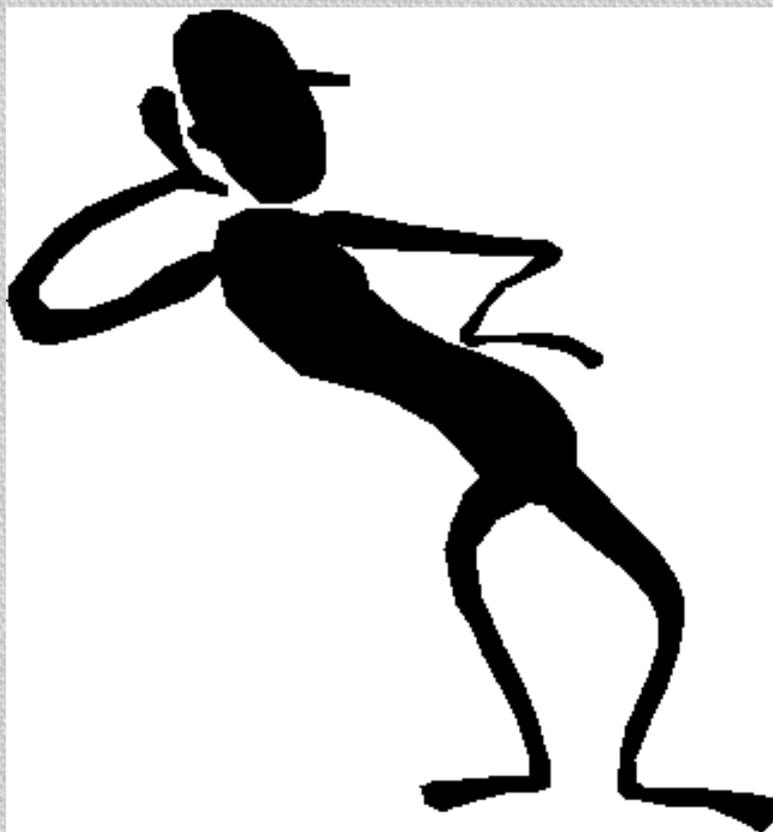
- Click this link:

<https://tmslearn.unc.edu?keyname=LifespanRespiteKey&keypass=bywNTvT6&autologin=true>

- Enter the requested information.
- You will be prompted to create your own unique username and password.
- When you complete this enrollment page you will see a message that confirms your new username and password. This message will also be emailed to you so that you have a copy of it in case you forget.
- The last step is to log in with your new username and password.
- If you return at a later date to start training or to continue a partially completed course, you **must log in with your unique username and password. If you use the enrollment key again you will be creating a duplicate account and will have to start your training from the beginning. Your duplicate account will also incur a charge for the module developer, so please be sure to sign up for just one account.**



Questions? Comments?





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