COMMUNICATIONS QUESTIONNAIRE

The Louisiana Lifespan Respite Coalition distributed a descriptive survey to the March 2013 Summit to solicit information about how to communicate to the caregiver in Louisiana.

Twenty surveys were returned, representing about 10 percent of attendees. Most of the respondents felt they were somewhat familiar with care-giving services in their area, they received occasional questions about care-giving supports, and they were most likely to find out about available services from an organization familiar with this type of help and most often one that served the elderly.

When the respondents received a call for help, it was nearly always from the actual caregiver, a person they perceived as already in a crisis, wherein the request for help was a personal “emergency” for one on the verge of “losing their mind”. In fact, respondents felt that the biggest obstacle to reaching the caregiver was their state of crisis, which inhibited the caregiver’s ability to plan. Additionally, respondents were aware of a lack of actual respite resources in the state and no central source of information to find respite resources.

Respondents felt the best way to reach the family caregiver was through social media, church bulletins, a news story, a doctor’s office or an organization dealing with the elderly.

Respondents felt it was important for the Coalition to define respite as a service that offers “relief” and support for the caregiver, so they can step away from the daily stress of providing care. The actual definitions provided to relevant questions are below:

**HOW DO YOU DEFINE RESPITE?**

- Planned or emergency **care** provided to a person to **relieve** their primary caregiver of natural or familial **support**

- Emergency or periodic **care**, providing **relief** or a **break** for the caregiver that allows him or her to continue providing care to parents or delays out of home placement

- Sitter **services** for “down” time

- Caregiver **relief**

- Temporary **relief** from some strenuous or **stressful** situation or responsibility

- Getting a **break**

- A **service** that will allow the family to **support** needed to avoid **stress** and burn out while offering safe and competent **care**

- The take a step back philosophy of caregiving, that everyone can be their best self (patient, caregiver) with some degree of **rest** from caregiving
System of care providers, the support network and the services provided to children and adults in need of care to improve their daily lives

Care for the caregiver

Relief for a family caregiver

Care for me and others

Services and supports designed to give relief to a caregiver in their caregiving duties for a set period of time

Temporary break from the ongoing care of a person with a disability

Planned or unplanned break for short duration to provide services to an individual while giving the caregiver a break

WHAT, IN YOUR OPINION, IS THE RIGHT WAY TO DESCRIBE RESPITE CARE TO A FAMILY CAREGIVER WHO HAS NOT YET SOUGHT HELP?

An ability to do what needs to be done for “you”
Period of relief or giving them a break so they can continue to provide care when they return from that break
Someone to help give you a break
Caregiver relief
Giving yourself permission to enjoy some time away from the responsibility of caregiving to rejuvenate, which allows for better caregiving
Let me help you
Relief to care for you’re loved one in their own home assist them with social and recreational activities
Help so you can take a break
It’s okay to ask for help
Relief
Support
An opportunity to take care of yourself
enjoy the simple things again
take care of yourself too
An opportunity to receive support for caregiving needs, that will allow some personal time to take care of their personal needs
That to best serve their loved one they need self care
Respite will be support to assist you with caring for your loved one and free some of your time to take care of yourself, household, other family members
Time off
Renew energy
Respite is an opportunity to help you be healthy so you can give the care your family needs.
Helps prevent burnout

WHAT WORDS ARE “HELPFUL”?

Break
Respondents were very concerned that communications not be negative, demoralizing or judgmental. They also believed language should not sound like you were replacing the caregiver due to personal failure, guilt or feeling overwhelmed.

WHAT WORDS WOULD YOU AVOID?

- Burden, planned stay, relief of responsibility
- Don’t use any language that sounds like we’re replacing you or implies you failed
- Get away from
- Don’t feel guilty
- Crazy
- You’re upset
- Sitter, baby sitter, worker, always use people/person, first centered language
- Guilty, burnout, overwhelmed, broken, selfish
- Anything negative
- It’s a person not a disability
- Demoralizing words that would lead to notion that things cannot be better
- Only in emergency
- Break for you
- You deserve it