Lifespan Respite Data Workgroup Notes from July 19, 2012

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1. Welcome & Introductions

2. Overview of workgroup objectives by Greg Link

3. Overview of the Lifespan Respite Care Act by Jill Kagan

4. Performance measurement vs. evaluation by Elena Fazio

Elena provided an overview to help everyone get on the same page and use similar language as we proceed forward as a workgroup.

ACL is mandated to demonstrate that their programs have value and it is also good for future planning. It's part of the annual budget process. Information goes to Congress. Therefore they're mandated to report on the Lifespan Respite Program.

Performance Measurement vs. Program Evaluation:
Do you know where the folks in your program are coming from; do you know where you would like your program to go?

Program data – pieces of standardized information we collect; for example client's age. The quality of the data is essential. Any kind of analysis depends on high quality data.

Performance measurement – how well the program, service or agency is working? The data are typically collected by program management and they're generally conducted periodically over the course of the program. We must be mindful of burdens on those giving you the information.

Performance management is the ongoing review of a program's activities to see that objectives are being met.

Performance measurement is the ongoing review of how a program is doing and it may also alert us to a problem.

Program evaluation is an individual systematic objective study to see how a program is doing - it demonstrates causality.

Elena provided a basketball analogy to help us remember the definitions. For example *program data* would be the number of minutes played or the number of free-throws attempted. *Performance measurement* might be the final score or who won and who lost. *Evaluation* is like the post game analysis and probably focuses on the whole season as opposed to just one game.

Both program measurement and program evaluation are complimentary and can be helpful in terms of planning and decision making. Performance measurement helps us see if we've

achieved our objectives. Evaluation provides more in depth information and helps us to understand the why and how.

This workgroup is focusing on performance measurement. Our goal is to want high quality program data to demonstrate, support and say good things about the Lifespan Respite Programs and to be mindful of baseline data and targeting into the future. Ultimately the data will end up in the ACL budget justification documents to OMB and ultimately to Congress, so the stronger the data, the better the program looks to Congress and to others.

Our efforts should remain grounded in the work of the grantees and to work toward grantee consensus on the final product. Recommendations that come out of this group are aimed at having a balance of feasibility and implementation and to be mindful of the burden on program personnel.

Elena and Jennifer will provide input on the fact sheet we're to produce as well.

5. Guided discussion
Greg said the focus of the grantees is on systems development and service provision. Some states provide direct services with some of their grant funds.

The focus areas of the data workgroup are on systems and consumers – are we on track or should we be looking at something different? Are there other focus issues?

Casandra mentioned looking at general public awareness about respite.
Greg thinks there is merit in that. What about the person who isn't a caregiver – do they know about respite, do they understand it; do they see the value in it?

For our purposes the consumer (the person getting the break) is the caregiver. We do need to collect data on the care recipient as well in order to demonstrate a lifespan approach.

Broad awareness is a double edge sword with limited finances. How do you collect information about how people find out about the program or what the referral source was? It's a difficult issue because the law mandates the systems side and then who provides the service becomes less of an issue.

Hopefully programs will come together to share referral mechanisms and outreach activities. Some of the funds are used for gap filling and who provides the service, or how, is not the issue.

Lifespan respite is a referral source in itself. It's about making all resources work together more effectively and seamlessly and improving access to services.
Which caregivers are getting the services that they're currently eligible for? To what extent are people being referred to resources they aren't currently using? What about the gap population – serving the unserved?

It is all right to create waiting lists if they're not able to serve everyone. It demonstrates need. It's good from a policy perspective as well.

Who are you not serving and why aren't you serving them? It might mean engaging more providers to help meet the needs of providers. Public awareness can go both ways (recruiting more providers and educating caregivers) or may walk hand in hand of engaging and making the public more aware.

Perhaps we should be Identifying and labeling respite –for example, dropping a child off at a recreation program is respite. It might be helpful if people had a broader awareness of how to access respite.

Collecting data on the systems side is going to be more complex because there are many more moving parts and variables.

In South Carolina they've found a fundamental lack of knowledge of what respite means. Caregivers don't self identify; they don't know the word 'respite.' It is all in how it's explained to people.

What are the most effective ways to get that message out to those who don't self identify and who don't understand the concept? Evaluate the referral sources - Do people internalize it in different ways depending on how they hear it – for example a PSA late at night vs. a referral from a family physician. Some methods might be more effective than others.

Look at referral paths on the systems' side. It's kind of the chicken and the egg approach. It has to have meaning for the consumer. It's a balancing act of too many people and not enough resources. We can't overwhelm the system either. Then people get turned off if they call and there are no services.

So far we've been discussing descriptive data. There is value in having data on types of families or caregivers that need the services before having large public awareness campaigns. It's good for program design and for Congress to know where the money went. Then the next step is to go beyond descriptive into effectiveness. Defining the service itself – a week of camp, an hour in-home, etc. What is a unit of service? It's essential when you get into evaluation.

It's hard to agree on a common definition of respite.

Maybe collect data in a different way, for example what about collecting data on what people use – day care, in home care vs. how much and then why? It may be that it's the only thing available. What professionals think caregivers should have and what people get. Also what people do with their respite? What the experts think and what the consumers themselves want. It may be that people aren't happy with that list – how many never walked through the door because what they wanted wasn't on the list? Something that would get at that would be good although difficult to collect.

Some of the expansion grant states put money toward developing voucher programs. What really works best for some families is the synergy between informal care and formal care.

Barb Snyder described that Delaware's program was designed with private money. People can use friends and family – 60% of the families do that.

Perhaps we should profile what people are using in the open systems and how do the characteristics of those families vary from those who use a closed system.

Jill mentioned Oklahoma's statewide consumer-directed voucher program. Most families do use family and friends many times because there aren't formal programs available in many parts of the state. We don't have a good handle on what's out there and what families are choosing from.

If you create a system with formal services but none of them exist or aren't very good. You can look at people who live in a service-rich vs. a service-poor area.
Some places are just more service-rich than others. Rural areas tend to be service-poor which creates a problem in serving those in rural areas.

Consumers – respite service use. In addition to hours and money it's what it is that helps to tell the story. Don't we want to know "are lives being improved?" are caregivers seeing a reduction in stress; are we delaying out of home care; are we saving the system money?

Mary Jo said we need parameters around what we mean by 'life is improved;' 'decrease in stress levels'; or that caregivers can use the time in ways they find meaningful or however we interpret that.

Joe mentioned telling the story of respite. The National Alliance of Caregiving has some interesting information from some of the surveys they've done as well as financial impact. They looked at social participation and friends. How respite can help with that. We need to consider health as well as social and economic factors. It's quality of life – health and social connections but social and economic factors too.

Can we cross analyze data between care recipient and caregiver? What type of family caregiver they are – caring for someone with Alzheimer's or caring for a child with Autism. In other words tie the care recipient's condition to the caregiver. It might be too difficult for the little programs to collect that. We also need to know that all programs are serving care recipients across the lifespan.

Some states are already collecting these data but it isn't universal. It would be really important from a policy perspective as well. You do need to take a lifespan approach though. Tying the care recipient condition to the caregiver is an important thing to consider.

On the systems side, a lot of the work that has been done by all of the grantees has focused on systems improvement. How do we make our systems more effective for delivering respite services for caregivers to access services?

Some domains to consider are how do we measure if this program is effective in building systems? Is it looking at increasing stakeholder involvement in coalitions? Is it actual entries of actual providers in respite data bases?

Joe suggested identifying the gaps and then filling the gaps (although filling the gap requires more money). It sets up why you need more money to fill the gaps. Greg said a lot of states have begun to look at that data. He emphasized that any recommendations that AoA puts forward to the grantees is that we only look at things that are pretty straight forward and easy to collect but helps us to know that the programs are having an impact.

Are there data on volunteer programs vs. paid providers? That might be very interesting to look at. Tennessee is a good example. Their program is built on volunteers. Part of their grant funds are used to train volunteers.

Why do programs decide to use a volunteer model? Is it for economic reasons or is it that it creates a different kind of relationship or is it to give some positive experiences to the volunteers (especially via universities or faith-based volunteers)?

Carol asked if on the federal level is there any way to encourage or create opportunities for the unemployed or under-employed to get some training across federal agencies – more training to more people - perhaps through the new ACL. It's an opportunity to provide more services in the long run by training more people to provide respite services. A person could start out as a volunteer and then that may lead to meaningful employment.

What does the ideal lifespan respite program look like? ASPE has research that there is a predictive factor that if a caregiver is highly stressed because the person they're caring for was very disabled and they had financial hardships and physical strain, especially for older caregivers, those care recipients tend to end up in a nursing home. However that might be difficult to measure.

One could say that a successful program is one that prevents out of home placement. How do you find the people for whom this intervention would be the most helpful?

A number of the expansion states have done some pre and post tests for those who receive the services. How do you know who is out there that never heard about it? How do you get to those who didn't know that the program exists?

Does the frequency and dose of the respite make a difference? Are people getting sufficient amounts and types or respite? We need to learn what kind of questions do we ask people up front? If people have a support network that is accessible and available they may need some periodic 'vacation' respite as opposed to someone without a social network who many need frequent, regular respite.

Joe commented that the concept of the lifespan is important. It's the coordinated infrastructure that kind of brings that all together.

One measure on the systems side is can they document to what extent they connect a caregiver to a provider and to the funding source? If they can't do that then they can't be successful. It's a referral issue, but not just to providers but to the funding source as well.

Jennifer commented that the conversation has been very useful. It's useful that people don't hold back with their ideas because a comment might be more evaluative but we can think that domain or area is of importance. Can we construct indicators that are easy to measure that may be administrative data wise but can we collect data in a regular quarterly, annual basis?

What data should we be collecting?
We'll pull together some kind of a summary document that will provide ACL with the beginnings of a framework to what types of outcome measures and performance measures are important for this program.

Casandra: It would be nice to know what consumers are expecting when they begin the service. What are their expectations? Were they realistic? Were they achieved?

Greg: As we think of operationalizing this would there be any merit in constructing a logic model - for the national level, not the state level. Perhaps to develop a conceptual framework or a one page map that defines our thinking might work just as well.

Ray commented that at this stage of development, or the conversation, it might be too soon to jump into a logic model. At some point it should be up to the states to define their program and design their logic model. Otherwise it might be distracting and difficult to achieve at this time. Perhaps some guidance around the framework would be extremely helpful.

Greg thanked everyone and said how helpful the call was.
He said we'll be developing a factsheet or something of the sort that will be pulled together and sent out to the data workgroup for their feedback. Then we'll share that with as many of the grantees as possible to get their input.

Look for something from Greg and Jill in the next few weeks.