

Chat Transcript:

Deana Prest: Hi, Deana Prest from New York

Miriam Rose: Miriam Rose - Ohio

Cory Lutz: Cory Lutz - Nevada

Jennifer Gant: Jennifer Gant - SD

Jennifer Abernathy: Hi Everyone! Jennifer Abernathy from Tennessee.

Deb Petersen: Deb Petersen - South Dakota

Jeff Duncan: Jeff Duncan, Nevada

Sharon Johnson, NE: Sharon Johnson - Nebraska

KenYada Washington: Hi, KenYada Blake-Washington, Mississippi

Julie Waters: This is Julie, from AL and we are further along and actually providing respite with the grant funds. This year we are collecting data on who receives respite, how many hours and pre and post survey of training and respite received. We are basing our collection on the same demographics and data we collect for Title III E. We use similar measures as the form one for our quarterly reporting. I hope this makes sense.

Julie Waters: Can the outcome be the same and the indicators be based on the specific grantee activities?

Miriam Rose: Similarly, maybe the indicators could be related to each grantee's specific goals and objectives.

Miriam Rose: Or the type of goals and objectives that each grantee has chosen.

Cindy Findley: Yes, reporting should align with grant goals.

Cindy Findley: Perfect. Suggestions, thanks.

Lisa Schneider: This is Lisa Schneider from Wisconsin. I too entered the call after it started and I'm curious about the phrase 'promoting community-based respite services'. Is this different than 'promoting in-home respite services'?

Cindy Findley: Can you explain that question, please?

Sharon Johnson, NE: Voting on resources but tally not displayed

Cindy Findley: excellent idea on the polls

Cindy Findley: Increase of paid caregivers

Chat Transcript and polling results from 1/11/18 ARCH Meeting

Cindy Findley: increase of family caregivers wanting respite

Cindy Findley: we have a caregiver crisis in Arizona

Cindy Findley: can't find paid caregivers

Deb Petersen: Can I send them in to Jill?

Pam Oliason: I need to make sure that the indicators I track are related to our work plan. I will need to think about this. Pam in Idaho

Courtney Smith: We also have a hard time finding respite and paid caregivers in RI

Julie Waters: I think you should look at the RFP and start from the point of goals that we all wrote our grants to accomplish the objectives, focus on the requirements of the grant as indicators for everyone.

Casandra asked if she could call individuals for clarification.

Cindy Findley: absolutely

Courtney Smith: sure

Jennifer Abernathy: Yep! Anytime!

Pam Oliason: Of course.

MaryJo Caruso: Sure

Cindy Findley: Not reactive, proactive approach

Julie Waters: Then maybe everyone should have a standardized way to report their individualized objectives that were proposed in grants. I also think we could all track respite and education provided through these grants and increase in partnerships.

Sharon Johnson, NE: Is it possible to provide additional detail about number of respite providers versus available respite providers actually being used by families. Trained providers, skill sets, etc. It is one thing to have people identified as respite providers but may not be delivering care.

Sharon Johnson, NE: Access to respite varies by funding source eligibility requirements.

Jen Doris: NH would have no way to track those indicators unless it is in a survey for families

Julie Waters: Outcome 3 could possibly be tracked by results from ADRC assistance to caregivers. Caregiver surveys have been done throughout our grant processes.

Vicki Clear: Our caregivers choose their own provider so we do not track available respite providers in any way.

Chat Transcript and polling results from 1/11/18 ARCH Meeting

Courtney Smith: We have some pre and post surveys we are doing with both our families and some RN's who are providing some respite training. I think we'd be ok to share some of that data

Sharon Johnson, NE: Agree with Alicia's comments regarding provider type

Vicki Clear: We also don't require our respite providers to have any training since the family is the employer so not sure what appropriately trained would be.

Jen Doris: we ask it on our biannual family survey for our program

Vicki Clear: We ask our caregivers if they find it easy, somewhat easy or not at all easy to find a respite provider on a satisfaction survey.

Christine Schoenberger: # of inquiries rec'd

Julie Waters: An increase in the number of respite providers in the state.

Deb Petersen: What about increase in the number of counties.

Vicki Clear: We actually have a harder time finding respite providers in the urban areas more than in the rural areas which surprised us.

KenYada Washington: Not realistic for Mississippi

Julie Waters: ADRC Staff are trained on respite resources and provide this information statewide to all who enter the "no wrong door"

Alicia Blater: What specifically do you mean by increased access? Is this just number of providers available across the state, or does it imply affordability, availability of a qualified worker, etc.? In our voucher program, we are having some vouchers returned, particularly in services for children with complex health needs, because the agency does not have a qualified worker available when the family wants him/her.

Nadine Walter: Very well said!

Lisa Schneider: In Wisconsin we are in the process of developing a survey related to system navigation, i.e. people knowing where to go to find resources such as respite. We are surveying social service agencies, schools, hospitals, etc. on one survey. And then doing a separate but related survey targeted at at-home/private caregivers

Jennifer Abernathy: Thanks Nadine!

Sharon Johnson, NE: Respite providers may be individuals, agencies, camps, adult day health care, facilities and advocacy organizations

Vicki Clear: We track age groups, how many counties we are serving and types of needs and disabilities.

Miriam Rose: Increase in number of caregivers who can access an appropriate respite provider.

Chat Transcript and polling results from 1/11/18 ARCH Meeting

Cindy Findley: No way to find the caregivers.

Jennifer Abernathy: We count number of caregivers who are calling to access respite.

Cindy Findley: We can only report on those who contact us.

Cory Lutz: In Wisconsin, how are you conducting these surveys?

Vicki Clear: We do track referral sources by asking on the application who told them about the program and track phone calls from other agencies

Julie Waters: I agree with systems change.... measure advocacy efforts to increase awareness of importance of respite and then track if there are additional public policy changes, budget increases, etc. to track some measure of public policy changes, which increase access.

Jennifer Abernathy: Yes, we do track all those demographics.

Alicia Blater: Our State's United Way 2-1-1 call center collects data on the services callers/email users are seeking. This may be a source of numbers of people seeking respite several states could look to.

Hilarie Hauptman: Yes we track age groups in WA State

Nadine Walter: I think the survey data will be skewed if we are only able to survey those caregivers that access our respite

Christine Schoenberger: Agree with Nadine.

Christine Schoenberger: maybe per capita measure of # of providers?

Lisa Schneider: To Cory Lutz: In Wisconsin we just created a Wisconsin Family and Caregiver Support Alliance consisting of numerous statewide organizations collaboration with State DHS, The ARC Wisconsin, long term care providers (We have IRIS and Family Care), and a slew of others. We are in the process right now of developing the survey for organizations via a specific sub-committee of the overall Alliance

Cory Lutz: Thank you, WI!!

Christine Schoenberger: this could be satisfaction with process

Julie Waters: Again increase the number who access the ADRC and that should cut down on Steps.

Julie Waters: I agree with this statement about No Wrong Door and grant requires that all grantees work with ADRC

Miriam Rose: Also, an increase in access to providers means the number of steps is not as much of a barrier.

Chat Transcript and polling results from 1/11/18 ARCH Meeting

Pam Oliason: When I talked about aligning with my work plan I was saying that no matter what is decided here I will always only be able to report on what we have in our work plan. These global indicators are significant but at my office we don't have the means to collect the data across systems. Our projects are planned to incrementally increase access to respite across the lifespan across systems, but other systems are increasing respite independent of our project. Court case significantly increased respite to families of kids with SED for instance. This program administered by another division of government.

Julie Waters: The concept of No Wrong Door is for all to work with ADRC and then ADRC get the individual to the right resource with follow-up.

Deb Petersen: Increase in the number of caregivers accessing lifespan respite through ADRC

Julie Waters: It is ok to contact me at Julie.waters@adss.alabama.gov or 334-353-9285.

Alicia Blater: Our State has struggled with growing the ADRC network. We have furthered the concept by trying to get as many providers across health and human services to adopt the functions of an ADRC, even though we wouldn't call most of them an actual ADRC and they are not connected and promoted that way.

Sharon Johnson, NE: Nebraska ADRC refers callers to the NE Lifespan Respite Network.

Alicia Blater: Using this ADRC "network" as a partner in data collection would be very challenging because of this.

Alicia Blater: That is one of the reasons why we are helping our United Way 2-1-1 call centers become more robust in helping caregivers seeking services, and specifically respite services.

Pam Oliason: Great conversation, thanks all.

Cory Lutz: The issue with the 211 system in Nevada is that the "key" words doesn't always get people where they need to be.

Alicia Blater: True! So much work and time has to be dedicated to the taxonomy.

Cory Lutz: And training the agencies to use the correct terms!

Hilarie Hauptman: Thank you, very helpful conversation.

Jennifer Rosenbaum: Taxonomy review is part of our QA plan for our NWD/ADRC Resource directory, and may be a good tie-in...

Alicia Blater: True also! There are many hurdles and we certainly haven't found all the answers.

Jennifer Rosenbaum: Thank you for the opportunity to review and comment!

Polling Results:

An annual increase in financial and/or in-kind contributions to the state's Lifespan Respite project

Yes: 40% (6 votes)

No: 46.6% (7 votes)

Yes, w/changes: 13.3% (2 votes)

An increase in funding distributed to caregivers

Yes: 35.3% (6 votes)

No: 52.9% (9 votes)

Yes, w/changes: 11.7% (2 votes)

An increase in the number of stakeholders who actively promote, fund, provide, or otherwise support respite services.

Yes: 46.6% (7 votes)

No: 0%

Yes, w/changes: 53.3% (8 votes)

An increase of faith-based, community-based agencies...

Yes 47% (8 votes)

No: 35.2% (6 votes)

Yes, w/changes: 17.6% (3 votes)

Decrease in caregivers unable to locate an appropriately trained provider

Yes: 5.56% (1 vote)

No: 66.6% (12 votes)

Yes, w/changes: 27.7% (5 votes)

Increase in number of respite providers in each county/state

Chat Transcript and polling results from 1/11/18 ARCH Meeting

Yes: 10.5% (2 votes)

No: 26.3% (5 votes)

Yes, w/changes: 63.1% (12 votes)

Increase in public and private organizations

Yes: 29.4% (5 votes)

No: 64.7% (11 votes)

Yes, w/changes: 5.88% (1 vote)

Lifespan Respite activities result in increased access to respite resources across the state

Yes: 60% (12 votes)

No: 15% (3 votes)

Yes, w/changes: 25% (5 votes)

Resources are secured for the continuation of the grant

Yes: 55.5% (10 votes)

No: 16.6% (3 votes)

Yes, w/changes: 27.7% (5 votes)

There is a decrease in the number of steps caregivers report having to take prior to accessing Respite

Yes: 0%

No: 72.2% (13 votes)

Yes, w/changes: 27.7% (5 votes)