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2018 LIFESPAN RESPITE TRAINING AND TECHNICAL ASSISTANCE NEEDS ASSESSMENT REPORT

PREPARED FOR ARCH NATIONAL RESPITE NETWORK AND RESOURCE CENTER

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Executive Summary

Periodically, the ARCH National Respite Network and Resource Center conducts a national needs assessment from a broad array of constituents seeking guidance on the use of its resources to develop the most relevant services and materials for its training and technical assistance activities. The primary focus of this inquiry is the Lifespan Respite grantees, their primary partners and State Respite Coalitions, although other constituents are invited to participate.

In 2018, the process for conducting the needs assessment was different than the process used in previous years. The 2018 needs assessment was designed to narrow the possible topics for focus and to encourage a greater number of open-ended responses: it was conducted in two phases. The first phase surveyed Lifespan Respite grantees and primary partners during the 2017 National Lifespan Respite Grantee and Partner Learning Symposium in Huntsville, Alabama (which occurred in October 2017). During this phase, 16 possible topics for inclusion in the needs assessment were considered, including: 1) Administration/Implementation of your State Lifespan Respite Program grant; 2) Advancing/Maintaining the ARCH National Respite Locator Service and State respite registries; 3) Building/Sustaining Statewide Coalitions; 4) Best practice steps in building/enhancing a statewide coordinated system of community-based respite Services; 5) Basic principles of respite; 6) Direct delivery of respite services; 7) Increasing stakeholder involvement; 8) Marketing/Public Awareness; 9) Engaging caregivers; 10) Identifying special populations in need of respite; 11) Lifespan Respite Program sustainability; 12) Respite provider recruiting and training; 13) Recruiting/managing volunteers; 14) Working with faith-based grantees; 15) Performance measurement/data collection; and 16) Other (with specification).

The second phase consisted of a web-based survey using SurveyMonkey that focused on the five topics identified to be of greatest interest to Lifespan Respite grant stakeholders responding to the original poll: 1) Marketing/Public Awareness; 2) Performance Measurement/Data Collection; 3) Increasing stakeholder involvement and diversity; 4) Best practices for building/enhancing coordinated statewide respite systems; and 5) Sustainability for Lifespan Respite grant activities, coalitions, and respite services. The final needs assessment survey also provided an opportunity at the end for respondents to list and rank other topic areas of importance as well as to provide answers to a series of open-ended questions intended to solicit more qualitative information.

A total of 80 persons responded to the survey. The current online survey was distributed to a wider audience than just Lifespan Respite grantees and partners, and included other state respite coalitions not affiliated with Lifespan Respite grantees, national organizations with a relationship to ARCH, including members of the ARCH Advisory Committee and the Expert Panel on Respite Research, members of the ARCH network, individuals on the ARCH email list for the monthly newsletters and notices of ARCH products, and respite providers.

This executive summary presents the major findings from the needs assessment, with those findings and recommendations based on the responses from all 80 respondents. In the full body of the report, a separate analysis of the responses of Lifespan Respite grantees and partners (identified in this analysis as primary constituents), including individuals representing state respite coalitions is included. There are also differences between the responses from our primary constituents when compared to the general population of respondents. Caution must be exercised when interpreting these differences because many respondents serve in multiple capacities in their states, and therefore also when responding to the needs assessment. However, the apparent differences are instructive with respect to anticipating request for training and technical assistance as well as vehicles for providing training and technical assistance.

Major Findings

The major findings from the Training/TA needs assessment are:

Training/TA Needs in Five Focus Areas Remain High

- Relative to previous ARCH training/TA needs assessments, the five focus topics (*Marketing/Public Awareness, Performance Measurement/Data Collection, Increasing Stakeholder Involvement and Diversity, Best Practices for Building/Enhancing Coordinated Statewide Respite Systems, and Program Sustainability*) remain very highly rated in terms of importance. However, there were some changes in relative importance of each topic as we solicited responses from a much broader audience than had been surveyed in the past and provided the opportunity respond to a greater number of questions.

ARCH's Existing Resources Ranked Highly

- ARCH's existing library of resources appears to contain quality items that are favorably received by most respondents who access them. This speaks well to directing those requesting

T/TA to the existing library of resources as a first response, to be followed up with a more detailed response if the existing resources proved to inadequately address the request

- Even though the large majority of respondents who accessed the existing resources rated them highly, the proportion of respondents accessing those resources ranged only from 37% to 56%. This number definitely related to the fact that our primary constituents are more likely to access these resources than are some other constituents who responded to the needs assessment survey. However, we would be remiss if we did not encourage more of our constituents to access and make use of these materials. Perhaps some updating or tweaking of the materials might be necessary, but the overall reactions to these materials are highly favorable.
- Due in large part to the new needs assessment process to gather this information, asking respondents to consider and rate the quality and helpfulness of ARCH resources (and listing several examples of resources relating to each topic area), resulted in a new awareness by many respondents that the resource library is as large and varied as it is. Several respondents commented that they were excited about making this realization and were looking forward to accessing these resources.
- Among Lifespan Respite grantees or partners, the recently launched ACL/ARCH Data Workgroup and the ARCH Sustainability Learning Collaborative appeared to be highly effective and efficient vehicles for the delivery of technical assistance. These technical assistance vehicles are also popular among other respondents to the needs assessment survey.

Likelihood of Requesting TA

- The proportion of respondents likely to request T/TA presents an interesting mix. Specifically, although *Marketing and Public Awareness* (topic number one) retained its number one ranking among all respondents in terms of importance, only 30% of respondents indicated that they will request T/TA. Our primary constituents also rated this topic as number one in importance; however, 38% of primary constituents are likely to request T/TA on this topic, quite a bit higher than among the general population of respondents.
- Conversely, *Best Practices for Building/Enhancing Coordinated Statewide Respite Systems* ranked fifth among these five highest-ranking topics in terms of importance with a summed proportion of 69%, but it received the highest number of respondents likely to request T/TA on any topic, at 44%. However, among our primary constituents, a combined 80% of respondents found the topic to be extremely important or very important, with 50% identifying it as extremely important. Furthermore, 75% of primary constituents have accessed ARCH resources on the topic, and 55% of primary constituents indicated that they are either extremely likely or very likely to request T/TA in the next 18 months. Therefore, this topic is the most likely of the top 5 for anticipated requests for T/TA and is also the topic with the largest difference between our primary constituents and the general population of respondents.

- Even though the five highest-rated topics identified above continue to be highly rated in terms of importance and are likely to be associated with the preponderance of requests for T/TA, the top three topics among the remaining topics identified in Figure 6.1 (*Engaging Caregivers to Use Respite*, *Respite Provider Recruiting and Training*, and *Building/Sustaining Statewide Coalitions*) each received a majority of number one or number two readings from all respondents, ranging from 51% to 58%. Therefore, there are likely to be requests for T/TA on these items as well. Based on comments provided by respondents, this is particularly true with respect to recruiting, training, and retaining respite providers.
- There are notable differences among the ratings of topics outside of the top five topics when responses from primary constituents and responses from the general population of respondents are compared. Whereas 51% of general respondents identified *Building/Sustaining Statewide Coalitions* as extremely or very important, 60% of primary constituents so identified. Conversely, whereas 58% of the general population of respondents identified both *Engaging Caregivers to Use Respite*, and *Respite Provider Recruiting and Training* as extremely or very important, only 47% and 53%, respectively, of primary constituents rated these as extremely or very important. In fact, 37% of primary constituents rated *Respite Provider Recruiting and Training* as of little or no importance. This appears to be an important disconnect between the perceived roles of our primary constituents and the general population of respondents.
- In order to bridge this disconnect, it may be advisable to use the National Lifespan Respite Conference as a venue for offering workshops on these topics and to encourage our primary constituents to attend those workshops with constituents from their own states who are attending the conference.

Specific TA Topics Requested

- Across several topic areas, respondents expressed the need for more information on respite models to improve services for caregivers of children with disabilities.
- There were several requests for guidance on how to construct PSAs, and even on how to start a non-profit foundation to support respite coalitions and/or respite services. While these activities are not ARCH-specific activities, there may be generic information on these topics that could be assembled, slightly tweaked with respite-oriented language, and made available to respite constituents from ARCH. Among our primary constituents, their comments suggested that they are seeking hands-on, practical technical assistance such as toolkits and “how-to” manuals with content focused on public awareness using PSAs and distributable brochures based on adaptable templates.
- Some of the comments relating to convincing caregivers to utilize respite suggest that there may be a need for assistance in developing “advance” messaging to caregivers who do not yet need or don’t think they need respite, but who are likely to need it in the future, either as the needs of their care-receivers increase, or the burden of providing care increases. In theory, this

type of messaging is more likely to be received and processed by caregivers before they have become overwhelmed, depressed, or are experiencing feelings of inadequacy or guilt about failure as a caregiver to their loved ones, thus laying the groundwork for readily accepting respite when the need arises.

- There were numerous references and even a few requests relating to the use of social media to reach caregivers, especially younger caregivers, such as those caring for children or Gulf War injured veterans. These caregivers, largely by virtue of their ages, are likely to be more “tech savvy” than caregivers of the frail elderly or those suffering from Alzheimer’s and other forms of dementia. Perhaps one or more states has had success using social media for this purpose and could provide a webinar on the topic, or provide seminal materials that could be more fully developed into an ARCH resource on the topic. The appropriate use of available technology will be increasingly important and our primary constituents should be well prepared to assist their state programs to take maximum advantage of that available technology. This may require the development of new T/TA resources in the ARCH library of resources, or the adaptation of existing models using lifespans respite-related terminology.
- There were requests for focused technical assistance on constructing a logic model. This issue is being discussed in the Sustainability Learning Collaborative in some depth.
- There were several requests for technical assistance in the form of reviewing “homegrown” surveys for form, content, question construction, scale construction, and the like. There were also at least two requests/suggestions relating to technical assistance on research/evaluation design. Given ARCH’s current initiative on advancing respite research, it may be possible to provide technical assistance on study (research or evaluation) design, or to review draft surveys or needs assessments and respond to grantees or coalition members as a form of technical assistance provided by ARCH. This possibility would be particularly helpful to primary constituents in their efforts to assist participants in their state program with the collection of reliable and valid information, and for advancing the topics of performance measurement and program evaluation, are generally.
- *Increasing Stakeholder Involvement and Diversity* is another area that revealed differences between primary constituents in the general population of respondents. Whereas 83% of the general population of respondents rated this topic as extremely or very important, 91% of primary constituents did so. Furthermore, 77% of primary constituents had accessed information from ARCH’s resource library on this topic compared to 56% of the general population of respondents. Both groups of respondents requested toolkits and “how-to” manuals as the vehicles for receiving T/TA on this topic, but notably, the focus among primary stakeholders was weighted towards increasing involvement of other government agencies with funding capabilities, and in government agencies or NGOs with shared or overlapping client responsibilities. Among the general population of respondents, the waiting was towards specific client groups such as ethnic minorities, caregivers for children with disabilities, and families with autistic family members.

Recommendations for ARCH Training and TA Activities

- Conduct a “constituent awareness” campaign to inform or remind constituents of ARCH’s resource library and encourage them to access these resources as a first line of inquiry for respite program development and management, and to help them make focused and explicit requests for training and technical assistance.
- Given the significant need for T/TA in both performance measurement and in sustainability planning, continue to operate and support both the Data Workgroup and the Sustainability Learning Collaborative and encourage more Lifespan Respite grantees and partners to participate in them.
- Prepare for numerous requests for training and technical assistance on each of the “top five topics” of the 2018 Needs Assessment, and in particular the topic of *Best Practices for Building/Enhancing a Coordinated Statewide Respite System* from Lifespan Respite grantees and partners. Offer to host additional State Lifespan Respite Summits to help meet this need.
- The notable difference between the survey responses of Lifespan Respite grantees and partners and the general population of survey respondents on the topics *Engaging Caregivers to Use Respite*, and *Recruiting and Training Respite Providers*, suggests that efforts should be made to bridge the differences and achieve greater alignment of views. To this end, it is recommended that webinars be made available to the ARCH network or workshops on these topics be conducted at the National Lifespan Respite Conference and that Lifespan Respite grantees and partners attend these workshops with other constituents from their own states who are attending the conference. This would help foster discussion intended to achieve greater alignment on the approach to these topics within each state’s Lifespan Respite program.
- There is growing interest, particularly among Lifespan Respite grantees and partners, to take advantage of available technology and social media, using both of these as vehicles for fundraising, achieving financial stability, and public awareness activities. There is also interest in mass media applications as evidenced by requests for assistance in developing Public Service Announcements for radio and television. Efforts should be made to identify and adapt training and technical assistance models and resources from other disciplines that could be adapted to the Lifespan Respite environment.
- Related to the previous recommendation, there is an ever growing population of younger caregivers often referred to as millennial caregivers (e.g., spouses/children of Gulf war veterans; parents of young children with disabling conditions), who are more likely to be tech-savvy than caregivers of the populations of older adults (e.g., caregivers of persons with Alzheimer’s and other dementias, caregivers of the frail elderly, caregivers of adult children with disabling conditions). It is recommended that ARCH poll state grantees who are focusing

on these populations of caregivers and identify successful models or approaches to using technology and social media as they identify and engage caregivers, conduct public awareness activities, engage in advance messaging about respite (i.e., messaging in advance of caregivers needing respite so as to prepare them to request respite when they do need it), and other applications identified during the polling process.

- Explore the possibilities and implications of a new service to Lifespan Respite grantees and partners by offering to review draft surveys and questionnaires as to design, substance and form in order to help increase the reliability and validity of local program evaluation and performance measurement efforts.

Summary of Needs Assessment Polling

This section presents a summary of the needs assessment polling data relating to the top five topics of inquiry. The analysis includes interpretive comments based on trends, rankings of ratings and information provided by respondents associated with their use of currently existing ARCH resources, their reaction to those resources, and the likelihood of respondents to request T/TA on these topics over the next 18 months. Table 1 has been constructed to present summary statistics relating to the analyses and comments.

The leftmost column in the table presents the topic titles in decreasing order of “popularity” based on polling data from the 2017 Lifespan Respite Grantee and Partner Learning Symposium. The columns to the right of the topic column present, from left to right:

- the proportion of respondents who ranked the topic as being extremely important;
- the proportion of respondents who ranked the item as being very important;
- the sum of the proportions from the preceding two columns, thus yielding the combined proportions of respondents ranking the topic as being extremely or very important;
- the nature of the balance of responses, with the term “somewhat” indicating that the large majority of remaining responses rated the topic as “somewhat important,” as well as any trends towards being “not important” if there were a number of responses in the two “unimportant” categorical options;
- the proportion of respondents who had accessed any of the existing ARCH resources relating to the topic; and,
- the proportion of respondents who stated that they are either extremely likely or very likely to request T/TA from ARCH on this topic over the next 18 months.

Table 1. Summary of needs assessment polling data from the top five topics of interest to respondents.

Topic	% Who Rated Extremely Important	% Who Rated Very Important	% Summed Ext + Very	Balance of Responses	% Accessing Resources	% Likely to Request T/TA
1. Marketing and Public Awareness	52	37	89	Somewhat	40	30
2. Performance measurement and data collection	38	33	71	Somewhat	37	29
3. Increasing stakeholder involvement and diversity	39	44	83	Somewhat	56	25
4. Best Practices for Building/Enhancing a Coordinated Statewide Respite System	37	32	69	Somewhat to not important	48	44
5. Sustainability for LR grant activities, coalitions, respite services	56	30	86	Somewhat	49	36

NB: All numbers in table are expressed as percentages of *n*. Out of a total of 80 respondents, between 58 and 61 respondents assigned ratings to each of these topics and completed the remaining questions associated with that topic. Thus, the percentages in the rightmost column represent the proportion of about 60 out of 80 respondents, rather than all 80 respondents.

Not surprisingly, each of these five topics remains highly rated in terms of its importance and the level of need expressed by respondents relating to each topic. The number one topic, *Marketing and Public Awareness*, received the overall highest proportion of respondents rating the topic as either extremely or very important, the summed proportions being 89%. The balance of responses loaded on the rating of “somewhat important” with only 3% of respondents indicating less than that. In addition, a majority of respondents ranked it as being extremely important.

A bit surprising is the observation that topic number five, *Sustainability for Lifespan Respite Grant Activities, Coalitions, and Respite Services*, received the second highest summed proportions indicating importance with 86%. Similar to topic number one, this topic also had a majority of respondents rating the item as extremely important.

Topics number two, three and four achieved summed proportions indicating importance of 71%, 83%, and 69%, respectively, but there was less difference between the total proportion of respondents rating the items as extremely important versus very important. As in the case of topic number three, *Increasing Stakeholder Involvement and Diversity*, more respondents rated the item as very important rather than extremely important (this item also received the lowest proportion of respondents likely to request T/TA on the topic).

With respect to resources, the proportion of respondents accessing resources currently in ARCH's resource library ranged from 37% to 56%. The highest percentage, 56%, related to topic number three, *Increasing Stakeholder Involvement and Diversity*. The high rating of these accessible resources may explain, at least in part, why only 25% of respondents indicated a likelihood of requesting T/TA on this topic over the next 18 months.

The topic presenting the most intriguing results is topic number four, *Best Practices for Building/Enhancing a Coordinated Statewide Respite System*. Although still highly rated, this topic had the lowest summed proportions of importance at 69%. Furthermore, although the balance of responses to the question of overall importance was largely centered upon "somewhat important", this is the only topic in which the balance of responses skewed towards readings of "not so important" or "not at all important". However, about half of respondents (48%) accessed existing ARCH resources. Again, some number of respondents did not find the resources particularly helpful, or at all helpful, even though the large majority of respondents who access those materials rated them as very helpful or extremely helpful (in this case "very helpful").

In general, reactions of respondents to the resources that they accessed are quite positive, with the large majority of respondents finding them either to be very helpful or extremely helpful.

The Needs Assessment Survey Process

Periodically, the ARCH National Respite Network and Resource Center conducts a national needs assessment from a broad array of constituents seeking guidance on the use of its resources to develop the most relevant services and materials for its training and technical assistance activities. Although the primary focus of this inquiry is the Lifespan Respite grantees, their primary partners, and State Respite Coalitions, ARCH also encourages participation in the needs assessment from other constituents, including respite care and other health and social services providers, ARCH paid network members, national organizations, and caregivers who may be recipients of respite services or in need of respite services.

In 2018, the process for conducting the needs assessment was different than the process used in previous years, which utilized a very broad and inclusive checklist of possible topics the ARCH Respite Network might be interested in and the preferred T/TA formats. Historically, the contents of the needs assessment were taken from authorizing legislation and funding opportunity announcements relating to the Lifespan Respite Program from the Administration for Community Living. The 2018 needs assessment was designed to narrow the possible topics for focus and to encourage more open-ended responses. It was conducted in two phases, the first of which surveyed only Lifespan Respite grantees and partners during the 2017 National Lifespan Respite Grantee and Partner Learning Symposium in Huntsville, Alabama (which occurred in October 2017). This first phase enabled the subsequent needs assessment survey to focus on a smaller number of items identified by participants in the Learning Symposium to be of greatest importance in the present context of lifespan respite services, and to delve into that smaller number of topics in greater depth than had historically been possible.

A total of 16 possible topics for inclusion in the needs assessment were presented to Lifespan Respite grantees and primary partners attending the October 2017 Symposium. The topics were ranked by 37 symposium participants in order of level of need, interest and relevance. The 16 topics included: 1) Administration/Implementation of your State Lifespan Respite Program grant; 2) Advancing/Maintaining the ARCH National Respite Locator Service and State respite registries; 3) Building/Sustaining Statewide Coalitions; 4) Best practice steps in building/enhancing a statewide coordinated system of community-based respite Services; 5) Basic principles of respite; 6) Direct delivery of respite services; 7) Increasing stakeholder involvement; 8) Marketing/Public Awareness; 9) Engaging caregivers; 10) Identifying special populations in need of respite; 11) Lifespan Respite

Program sustainability; 12) Respite provider recruiting and training; 13) Recruiting/managing volunteers; 14) Working with faith-based grantees; 15) Performance measurement/data collection; and 16) Other (with specification).

Of the 16 possible topics included in the poll, 5 topics were identified to be of greatest interest to Lifespan Respite grant stakeholders responding to the poll. These 5 topics include: 1) Marketing and Public Awareness; 2) Performance Measurement and Data Collection; 3) Increasing Stakeholder Involvement and diversity; 4) Best Practices for building/enhancing coordinated statewide respite systems; and 5) Sustainability for Lifespan Respite grant activities, coalitions, and respite services. Although the subsequent, more broadly distributed needs assessment survey focused on those five topics, the final needs assessment survey also provided an opportunity at the end of the survey to list and rank other topic areas of importance to the respondent as well as to provide answers to a series of open-ended questions intended to solicit more qualitative information from needs respondents.

The survey was constructed to be completed anonymously via SurveyMonkey. Potential respondents were notified via email of the distribution of the survey and were provided an active link taking them to the survey. All data were analyzed by ARCH's external evaluator, and all results are reported in this document in the aggregate without attribution to individual respondents.

A total of 80 persons responded to the survey. This is the most respondents ever to a national ARCH needs assessment by nearly a factor of two. This is interpreted to be a result of increased interest in responding to the survey generated by the polling of critical topics conducted at the October 2017 symposium and the distribution of the survey to a broader list of individuals. Among those 80 respondents, about one third (31%) had attended the 2017 Grantee and Partner Learning Symposium, and among those attending about two thirds (64%) were sure or reasonably sure that they had attended the Needs Assessment polling session. A broad range of types of respondents is reflected in the demographic data describing respondents (Note: the following proportions sum to greater than 100% due to some respondents representing more than one demographic category):

- State Respite Coalition Representative 28%
- Respite Program/Service Provider 28%
- Lifespan Respite State Government Grantee 23%
- National Organization 14%
- Caregiver/Respite Service Recipient 13%
- Other 16%

The distribution of respondents reflects the fact that no one category is dominant over the entire group, and that a broad array of constituent interests is reflected in the survey responses.

During the presentation of findings, each of the five topics identified as most important by those attending the Learning Symposium polling session is presented in a separate subsection with three figures summarizing the needs assessment data. These questions relate to “how important” the topic is to the respondent; “how helpful” ARCH’s training and technical assistance (T/TA) resources have been to respondents trying to improve their Lifespan Respite programs in the specified topic area up until the time of the survey; and, “how likely is the respondent to request T/TA” in the specified topic area over the next 18 months.

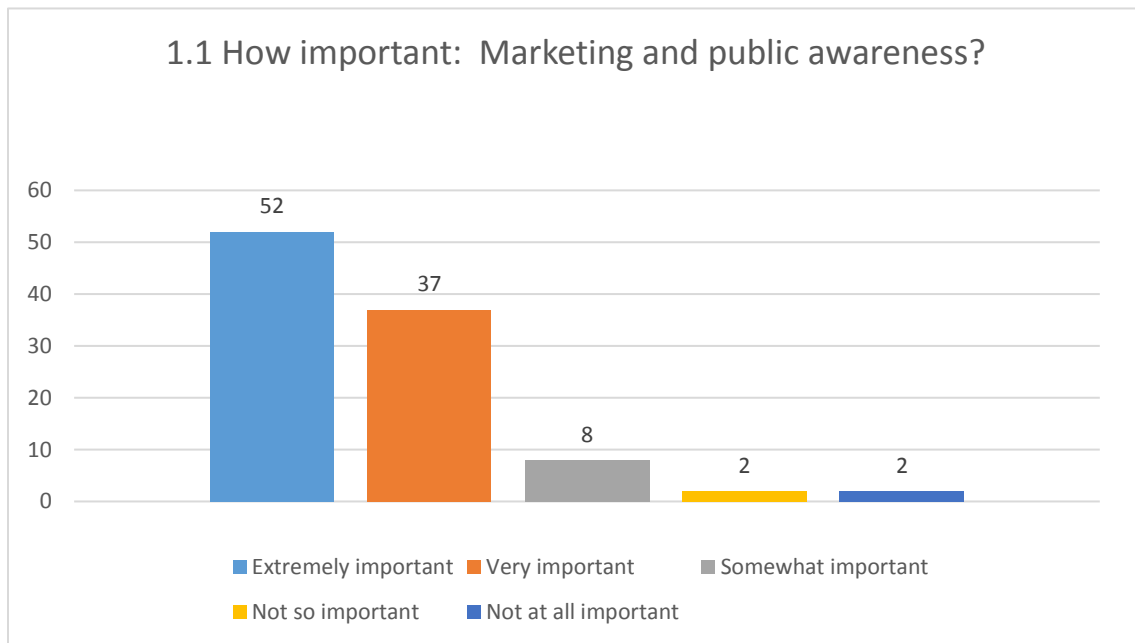
Each of the sections in the SurveyMonkey survey making inquiry about one of the five topics contained additional questions relating to things like the preferred mechanisms or receiving T/TA; awareness of outside resources that might help ARCH provide assistance to other states working on the same issues; and opportunities to offer individual comments or suggestions relating to the topic area.

A separate analysis of the responses of Lifespan Respite grantees and partners, including individuals representing state respite coalitions, is included. Thirty-eight of the survey respondents met these definitions. These respondents are considered to be our Primary Constituents and their responses are presented in bullet-list format in a text box at the end of each of the subsections in the following section titled Detailed Polling Responses.

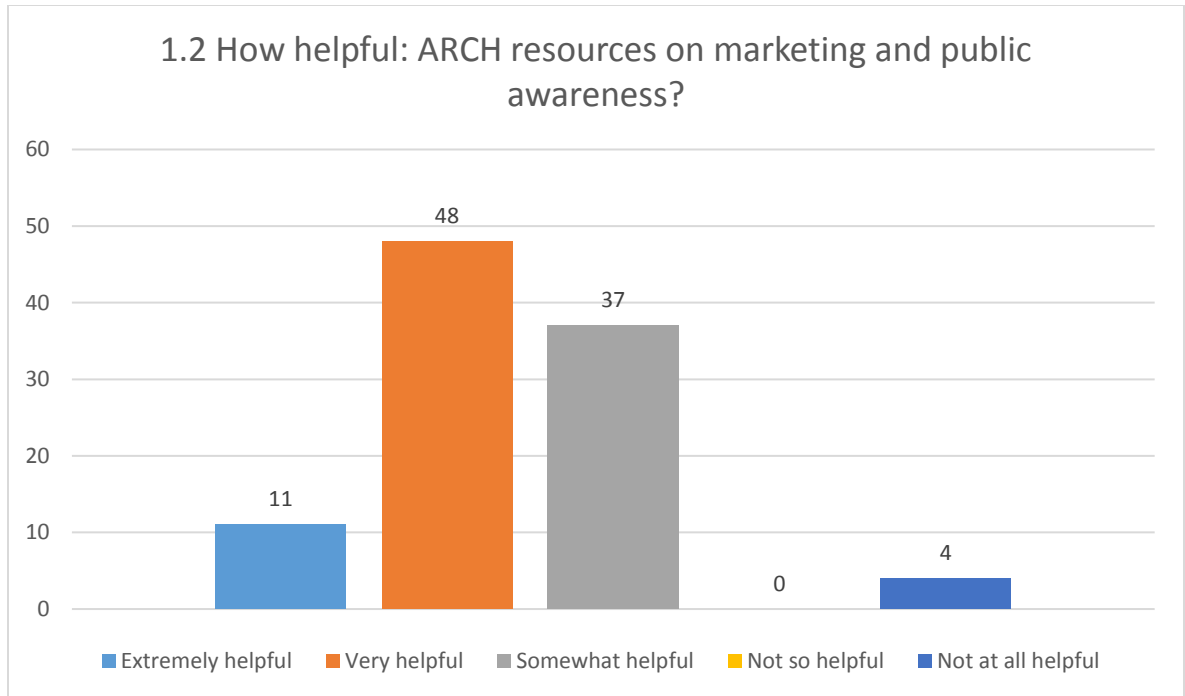
Detailed Polling Responses

1. Marketing and Public Awareness

It is clear from the polling response data presented in Figure 1.1 that the majority of respondents (52%) identified marketing and public awareness as extremely important, and an additional 37% identified this topic as very important; thus the top two categories account for 89% of all respondents.



On each of these topics, ARCH maintains a library of free, downloadable or viewable resources in its technical assistance library. In the case of marketing and public awareness, these resources include a number of archived webinars, recorded teleconferences, and various tools for engaging employers of caregivers about the value of respite, and “how to” tools on marketing and public awareness. Somewhat surprisingly, only 40% of respondents stated affirmatively that they had accessed any of these resources. About half, 49%, said that they had not, and an additional 11% could not remember whether they had done so. Among the 27 respondents who had accessed these resources, only one respondent did not find them to be at least somewhat helpful, with the majority of respondents (85%) finding these currently-existing materials to be somewhat helpful or very helpful. A small number, 11%, found them to be extremely helpful. These data are presented in Figure 1.2.

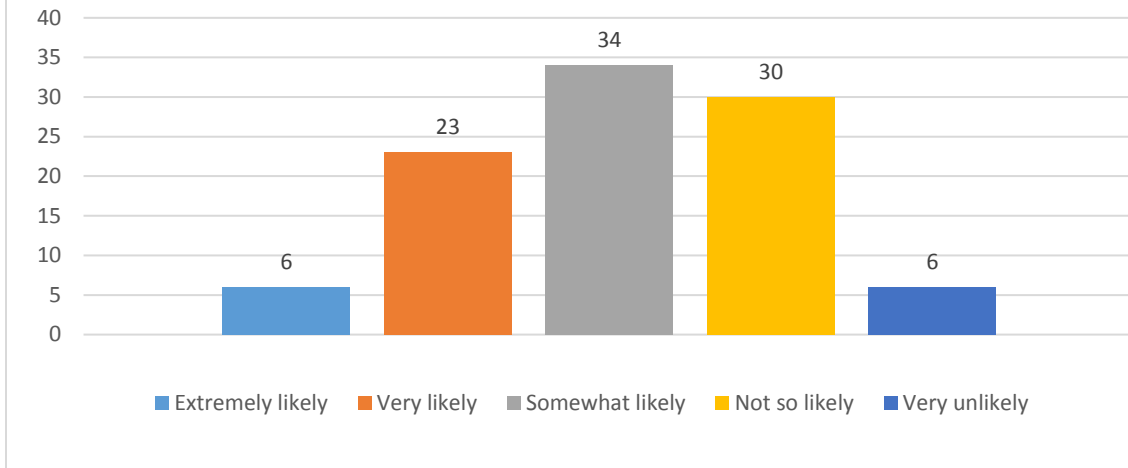


Comments on ARCH Resources: Marketing and Public Awareness

Respondents were given the opportunity to offer comments about ARCH’s resources on marketing and public awareness. Eleven comments were offered, most of which were favorable and generally worded, such as, “Relevant and well-organized,” and “Helpful information that can be used for planning.” Some respondents simply stated that they had not used any of the materials, and two respondents found the materials hard to access. Perhaps the pithiest comment was: “The materials bring up what your intentions are, and match those with the types of publicity, marketing, advertising, etc., and assist with talking through who we are trying to reach and whether there needs to be different messages created, and more. Very helpful. Thank you.”

Given the level of importance that this topic commands among respondents, it is a bit surprising that only about 30% of respondents stated that they are either very likely or extremely likely to request technical assistance on marketing and/or public awareness over the next 18 months. By contrast, 36% indicate that they are not very likely, or very unlikely to request T/TA on this topic. The ambivalent or “neutral” response option of “somewhat likely” accounted for the largest number of respondents at 34%. These data are presented in Figure 1.3, below.

1.3 How likely to request T/TA on marketing/public awareness in the next 18 months?



When asked about the preferred mechanisms for receiving the/TA, four categories stood out with more than 60% of respondents: webinars (62%), downloadable guidebooks or “how to” manuals (62%); fact sheets (60%); and toolkits (60%). Other vehicles or information less likely to be requested included telephone/email consultation (36%); online training (40%); and workshops held in association with the annual Lifespan Respite Conference.

Comments on External Resources

Respondents were asked to provide information on any external resources associated with marketing and public awareness, including things like public awareness videos, marketing slogans, or specific marketing strategies. About one-fifth (21%) of respondents were aware of models or resources in their state or other states that they thought would be helpful for ARCH to review and possibly disseminate to other state programs.

Eleven comments were offered, and while some were fairly general such as “We are working on incentives,” or “We are in that process,” some others were quite intriguing. For example, SC has developed a tagline “Take a Break SC!” which is associated with their Lifespan Respite Initiative. They intend to use it in PSAs, infographics and short videos to convey information on respite.

Texas was cited as having a great campaign on caregivers. Florida was noted for having an animated respite informational video that was shared at the national conference in Huntsville that could be adapted to other states. Another state (unknown) recently updated all of its marketing materials, created a website and logo, and are working on marketing techniques to increase overall awareness among families and professionals. Another respondent suggested that ARCH examine the Wilder Foundation's Minnesota state-based media campaign titled "What Is a Caregiver?" The respondent was sufficiently impressed with this initiative to provide the URL to the project: <http://www.wilder.org/Programs-Services/caregiving-resource-center/Pages/default.aspx>.

Given that a number of states have already developed or are developing their own marketing strategies to address the unique respite needs of caregivers in their states, it is not as surprising that there is high interest in this topic, but also some ambivalence about the need to seek additional technical assistance from ARCH on this topic.

Comments on Specific Needs: Marketing and Public Awareness

Respondents were encouraged to provide more information about specific needs they have relating to marketing and public awareness if this topic was among their most important concerns. Thirty-two comments were offered. As is typical of qualitative comments of this type, many were vague, such as, "We're in the beginning stages so we can't answer this question yet." Some were not within the purview of ARCH's mission or resources, such as "We need money to support our work." However, also typical, there were some substantive suggestions made and some clearly stated needs. These included:

- Outreach to families identifying the importance of respite in supporting healthy families.
- Tools and examples of successful marketing plans, and "how tos" on constructing PSAs.
- Examples of information to post to clients who may need resources.
- Information, perhaps through webinars, about referral systems to identify caregivers and help them recognize the benefits of respite BEFORE they are desperate for assistance, so as to prepare them to access respite more deliberately.
- Information on cost sharing with partners, and put forth consistent messaging.
- How to work with families of veterans and serve veterans with disabilities.
- State-of-the-art marketing and public awareness for recruitment and training of quality respite care providers.

- Information on how to approach Native American tribes within the lifespan respite grant geographic area of coverage.
- Examples of marketing and public awareness efforts that have NOT worked well, so that we don't repeat others' mistakes.
- How to use social media to access caregivers, particularly younger caregivers such as those caring for children with disabilities or disabled veterans.
- A library of videos and Facebook posts that have a record of good messaging; something that can be adopted with our logos and respite campaign.

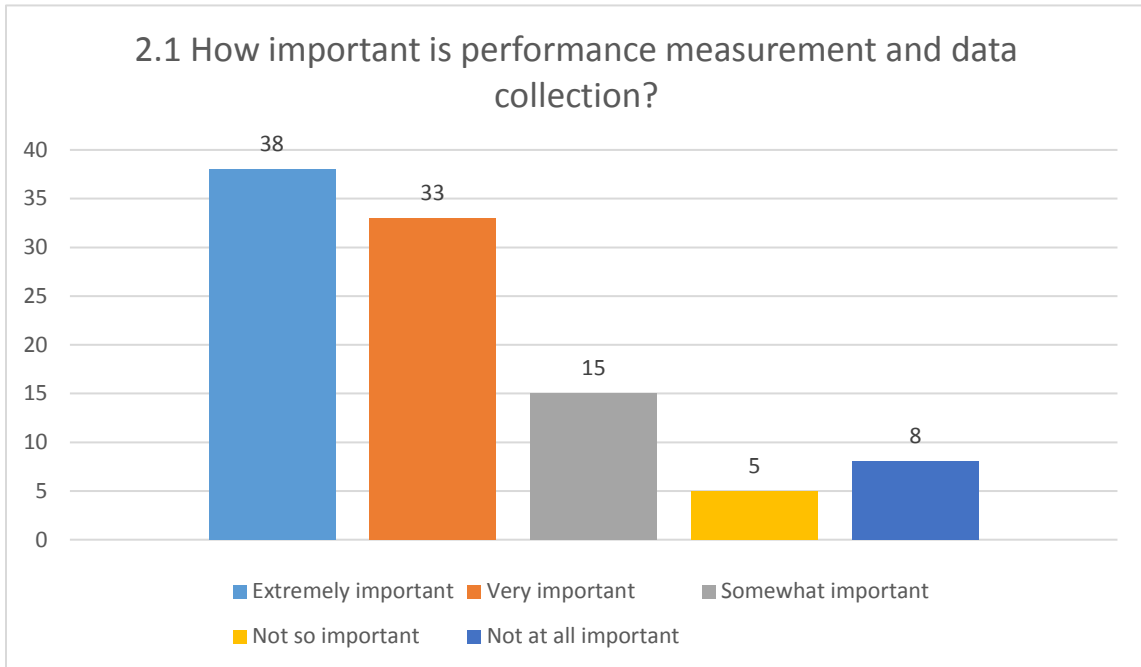
The preceding list contains some good ideas and actionable suggestions. Among the most interesting comments, however, which did not contain specific statement needs was: "Wow, I realize I have not done a good job in seeking out resources already available from ARCH. Just reading these questions and seeing this information has broadened my knowledge. Thank you."

Marketing and Public Awareness: Responses from Lifespan Respite Grantees and Partners

- 88% of primary constituents rated marketing and public awareness to be either extremely important or very important, with the distribution of responses being approximately evenly balanced.
- Of these respondents, 53% had accessed the existing ARCH resources devoted to this topic.
- 66% found those resources to be extremely helpful or very helpful with the preponderance of respondents (61%) rating the resources as being very helpful.
- 38% of these respondents who rated the topic as extremely important or very important are likely to request T/TA during the next 18 months, with the preponderance (25%) being very likely to make that request.
- The top three mechanisms for receiving the T/TA likely to be requested include toolkits, downloadable guidebooks and "how to" manuals, and webinars. Each of these was indicated by 60% or more of those responding.
- The content of comments made by primary constituents tends towards practical items such as PSAs that can be tailored to individual state's lifespan respite programs, or other materials (e.g., distributable brochures). A few respondents were new to the process of marketing and unsure how to proceed.

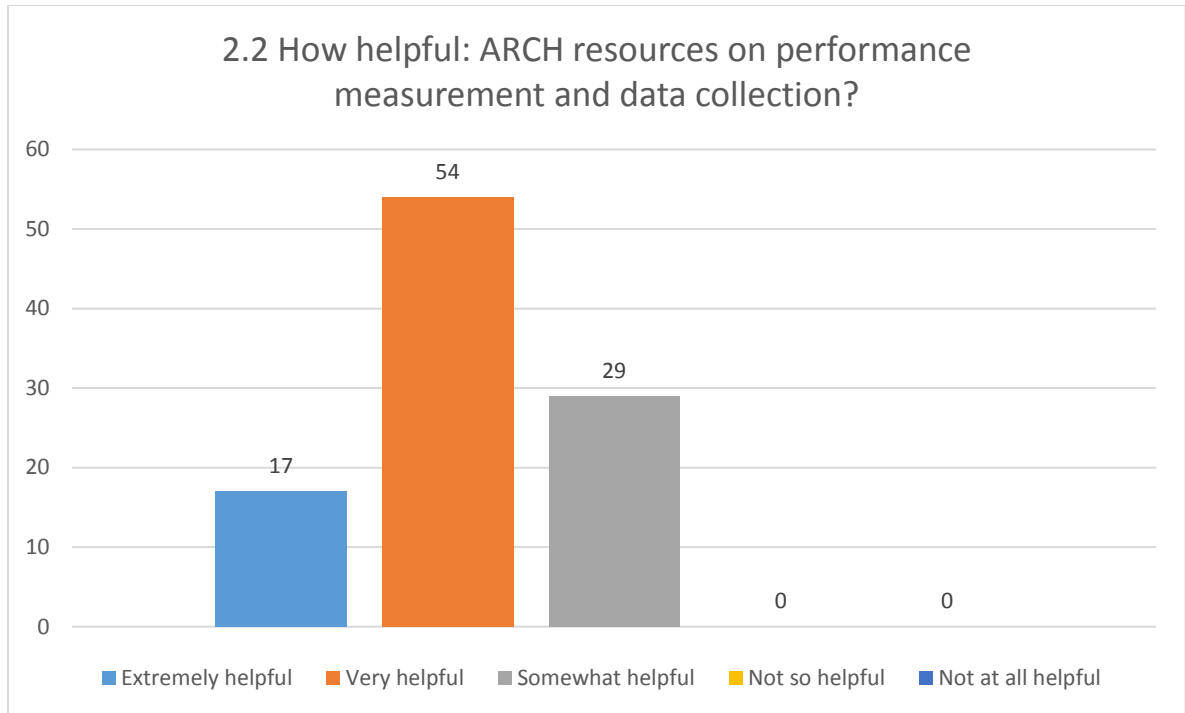
2. Performance Measurement and Data Collection

Figure 2.1 presents data on responses with respect to performance measurement and data collection. While not quite rising to the same level of perceived importance as marketing and public awareness, performance measurement and data collection is still a compelling category, with 71% of respondents rating it as either very important or extremely important.



Over the past several years ARCH has developed and made available through its resource library a number of tools devoted to this topic, including: *Measuring Systems Change in Consumer Outcomes or Recommendations for Developing Performance Metrics or State Lifespan Respite Programs*; *Evaluating and Reporting Outcomes: a Guide to Respite and Crisis Care Program Managers*; *Evaluating Outcomes for Children and Families*; *A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates, and Funders*; and, *Respite Goals: State Performance Measurement and Data Tools*.

Given the level of interest in this topic, overall, it is somewhat surprising that only 37% of respondents had accessed or downloaded any of these materials. However, among those who did access them, the large majority found them either to be very helpful (54%), or extremely helpful (17%). An additional 29% found them to be somewhat helpful. These data are presented in Figure 2.2.



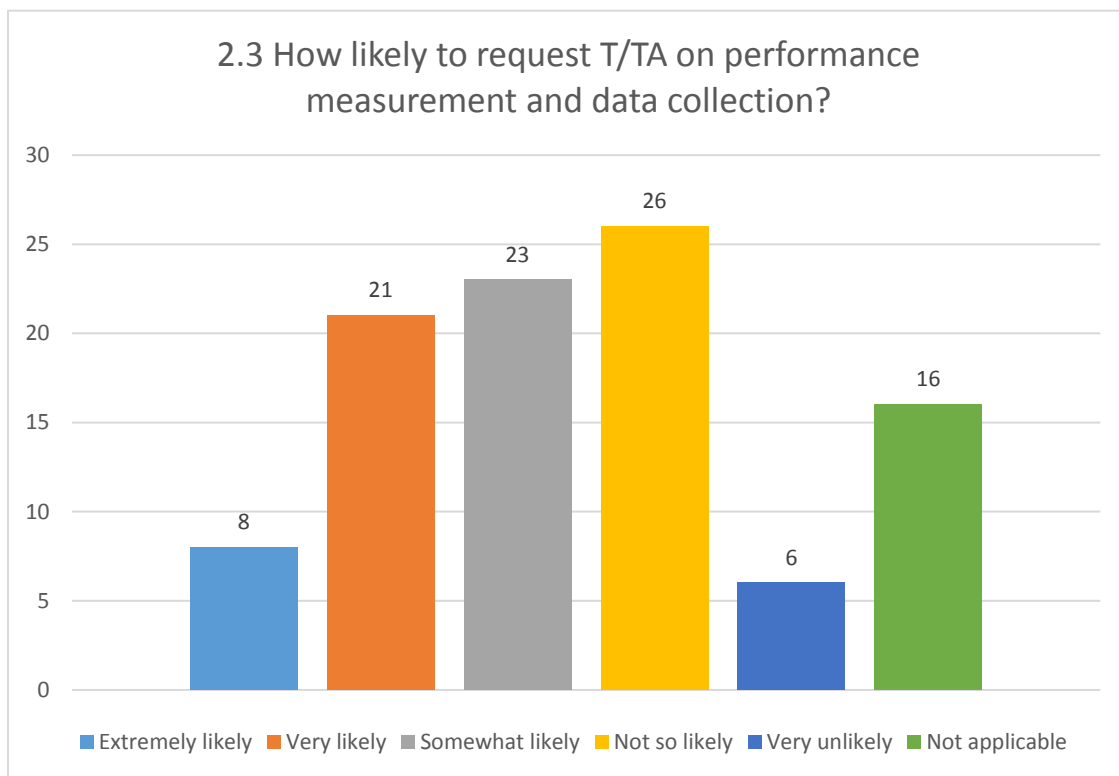
Comments on ARCH Resources: Performance Measurement and Data Collection

Consistent with each topical subsection, respondents were asked to comment on the ARCH resources available from ARCH’s resource library. Eleven comments were offered. Dismissing the generally worded, nonspecific and apologetic (e.g., “Sorry, I haven’t looked at any of these.”) comments, the most meaningful included:

- These resources bring attention to topics that should be on our radar as we establish our coalitions; information seems accessible and gives good background for professionals who are not ordinarily involved in data collection.
- These documents sometimes become quite complex for me, but the reality is that both funding and justification for services are all data-driven.
- ARCH’s resources are my “go to” documents. They have nearly everything I need to make progress.
- This information gave me a high level of understanding of what has been developed so far.
- These resources served as a starting point for adopting measurable outcomes.
- Assisted me in data collection and outcome accountability tool creation for use within our state.

Taken as a whole these comments suggest that the contents of ARCH’s existing resources related to performance measurement and data collection are serving their intended purpose and meeting the needs of people who access them and process their information.

Given the level of interest in performance measurement and data collection, it is somewhat surprising that only 29% of respondents indicated that they would be very likely (21%) or extremely likely (8%) to request T/TA on performance measurement and/or data collection in the coming 18 months. The largest single response category was “not so likely” accounting for 26% of respondents. These data are presented in Figure 2.3.



In spite of the lower-than-expected number of respondents indicating that they would be seeking T/TA in the near future, 52 of the 80 respondents indicated vehicles of choice for receiving T/TA. Among them, downloadable guidebooks and ARCH’s “how to” manuals were the most frequently indicated (71%), but a number of others were also well represented with respect to preferences: online training (62%), toolkits (60%), fact sheets (56%) and webinars (52%).

Comments on Specific Needs: Performance Measurement and Data Collection

Thirty-two comments were entered in response to an opportunity to state specific needs relating to T/TA on performance measurement and data collection. A number of these comments were simply “Not applicable” or variations on the theme of “We’re not ready for this yet.” However, a number of comments were provocative and actionable, including:

- Measuring satisfaction and behavioral/emotional change is easy. But getting quality performance measures on respite delivered by many different providers is difficult. How does one gauge the value of the respite dollar spent when the service delivery models can be so different?
- We have developed a basic survey. How can we have it reviewed to be sure we are asking the right questions?
- How do we develop logic models that support respite?
- I hope the data collection work group that was established at the Huntsville conference will help us all to collect more reliable data.
- Interested in data collection methods that result in high response rates, and suggestions on how to analyze data and use the results. It would be nice to establish a nationwide database with each state collecting similar information.
- I value ARCH staff to be a sounding board and an advisor on new measurements.
- We are seeking funding to conduct research and would like collaboration with ARCH if we receive funding.
- Help in survey design appropriate for SurveyMonkey following a gathering of lifespan family caregivers ascertain the benefit of the gathering of the components that need improving.
- Constructing tools on quality indicators to document establishing effective community-based respite and caregiver support services.
- Replicable models from other states that have been successful.

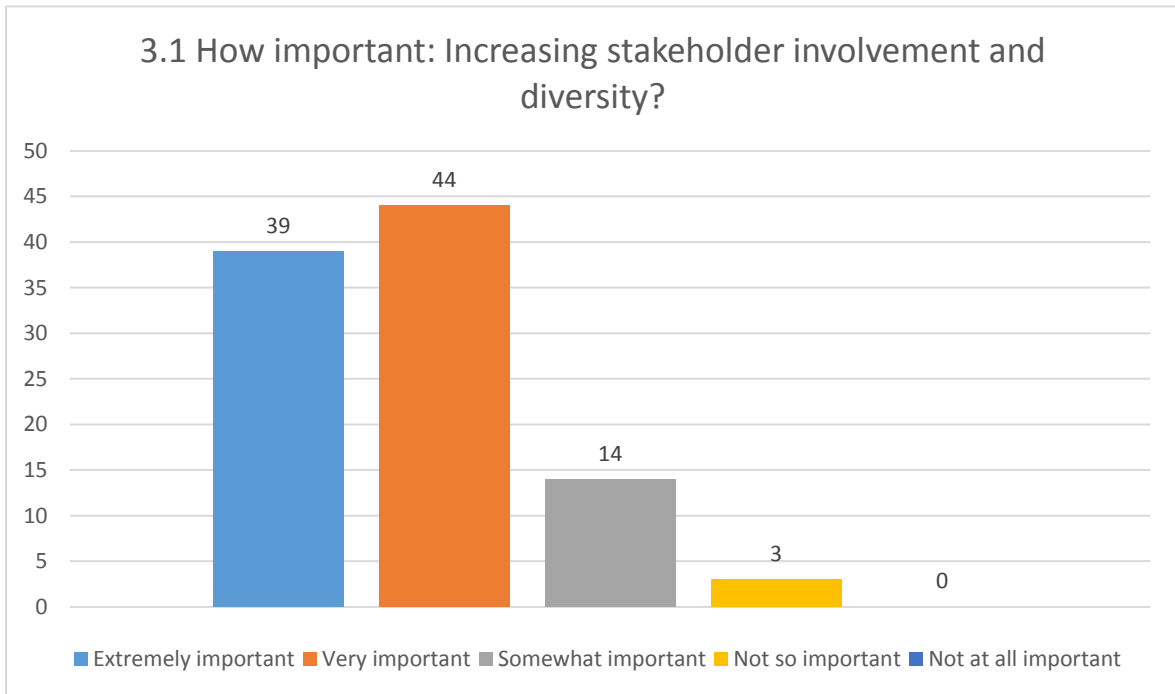
Several additional comments praised the existing resources available from ARCH, and some echoed comments from the previous section that participating in the needs assessment made them aware of resources that they had heretofore failed to access.

Performance Measurement and Data Collection: Responses from Lifespan Respite Grantees and Partners

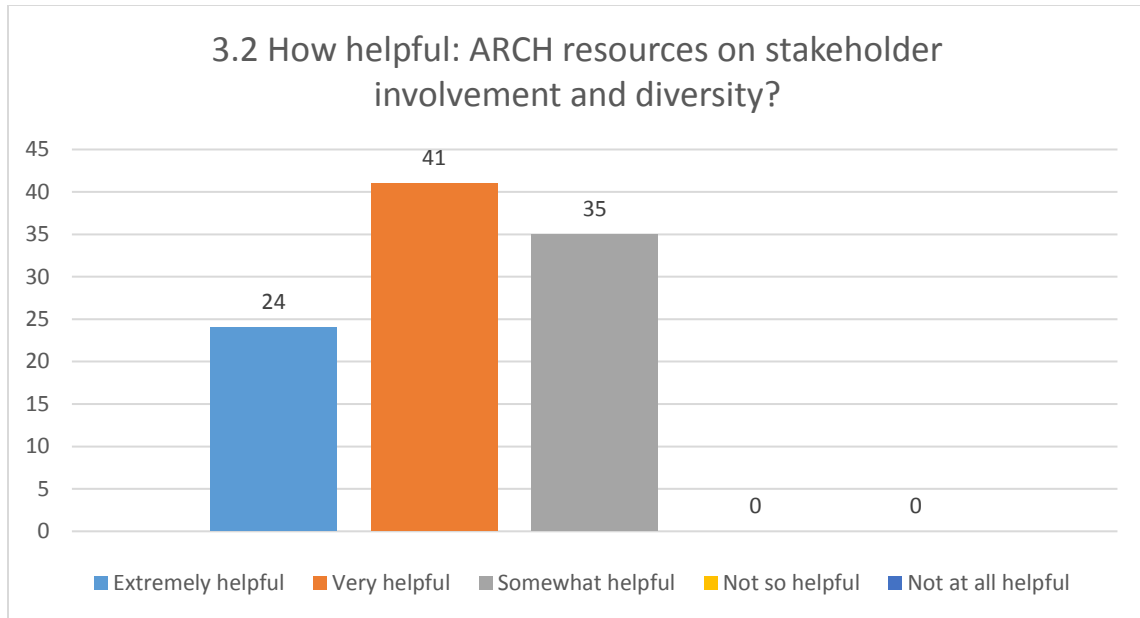
- 84% of primary constituents rated this topic as extremely important or very important, about evenly split between those two categories.
- Of these respondents, 53% had accessed the existing ARCH resources associated with this topic.
- The very large majority of those who had accessed these materials (82%) found them to be extremely helpful (24%) or very helpful (58%).
- Although 84% rated the topic as extremely important or very important, only 38% indicated that they would be extremely likely (13%) or very likely (25%) to request T/TA on this topic during the next 18 months.
- Among those who will likely request T/TA, the preferred mechanisms for receiving T/TA include downloadable guidebooks and “how to” manuals, and toolkits (79% and 75%, respectively) but on-line training emerged as the third most preferred mechanism for receiving T/TA with 64%.
- The comments from primary constituents generally recognize the importance of performance measurement, but were unsure what to do or what to ask for. Some frame their comments as advice to ARCH, such as “set national standards,” or “build a tool including quality indicators,” and continue the Data Workgroup.
- The very high rate of participation in the Data Workgroup by primary constituents suggests that it is a very effective vehicle for the provision of T/TA to this group.

3. Increasing Stakeholder Involvement and Diversity to Your Respite Activities

Diversity, in general, is a topic of increasing and sustained interests across most of human services today. This is no less true for family caregivers and other stakeholders in the domain of lifespan respite. In this instance, diversity refers to not only diversity in ethnic and cultural terms, but in the type of organizations represented in the coalition or among primary partners beyond the traditional disability and aging organizations. Many states are working to ensure coalition participation from employers, businesses, foundations, legislators, the media, various state governmental agencies, Veterans and military associations, the faith and volunteer communities, and the informal or nontraditional service providers in the community. Among respondents to ARCH’s needs assessment survey, 83% felt that increasing stakeholder involvement and diversity in their respite programs was either extremely important or very important (39%, 44%, respectively). These data are presented in Figure 3.1.



ARCH’s existing T/TA resources on this topic include: a variety of webinars, recorded teleconferences, fact sheets and tools for collaboration. Survey participants had accessed these materials with greater frequency than in some other topic areas, with 56% having accessed one or more of these T/TA resources. Among all respondents, none found resources to be either unhelpful or not very helpful. These data are presented in Figure 3.2.



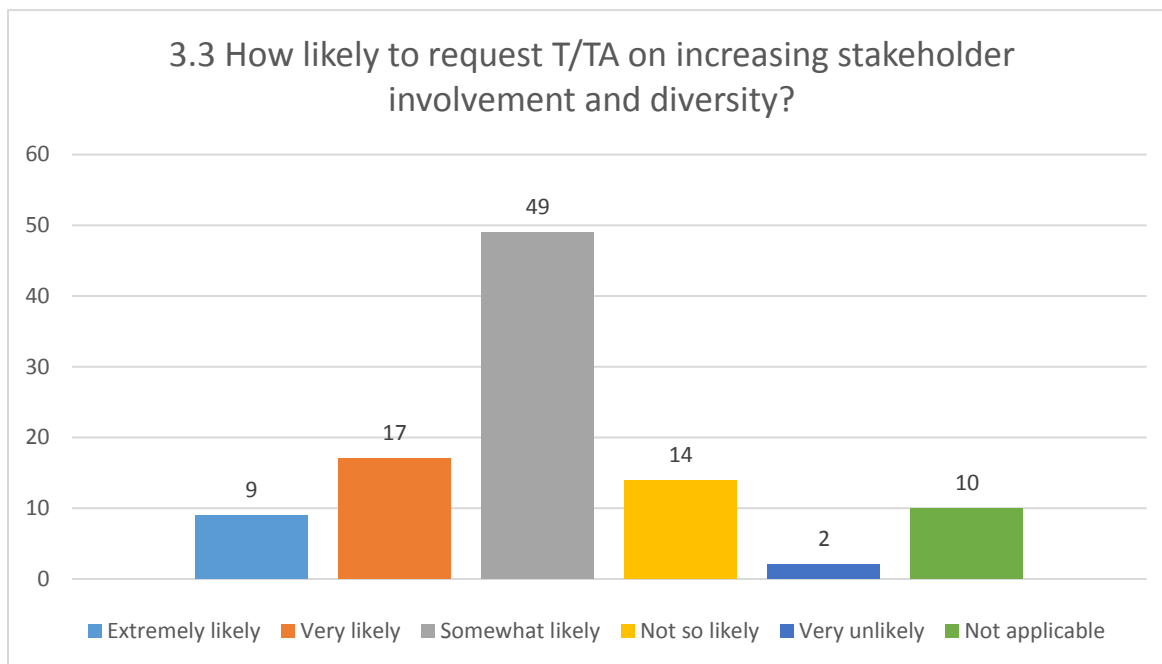
Comments on ARCH Resources: Stakeholder Involvement and Diversity

Seventeen comments were offered in response to this question. Again, discarding the vague and apologetic, some positive observations were made. They include:

- Our coalition needed better organization and a definitive sustainability plan. We are currently reorganizing and rebranding our coalition. ARCH tools have provided a good roadmap for our goal of establishing a more effective coalition.
- Offered innovative ideas and concrete approaches.
- Understanding what’s important and why it is important.
- Helpful and accessible resources.
- Participation in several ARCH webinars provided helpful information and perspective.
- Recorded webinars are helpful. Also the infographic is great and we often pull it out and discuss.
- These resources are great to share with coalition members, respite providers and stakeholders.

In spite of the high level of interest among respondents, both with respect to interest in the topic and the rate at which the respondents had already accessed resources from ARCH, this does not seem to be a topic associated with a large demand for T/TA over the next 18 months. A combined 25% of respondents indicated that they would be very likely or extremely likely to request T/TA in the

coming 18 months, with nearly half responding ambivalently (49% responding “somewhat likely”), and the remaining 26%, combined, indicating a very low or no probability of requesting T/TA in this area. These data are presented in Figure 3.3.



Among those likely to request TA, however, the response pattern of chosen vehicles for sharing that information is somewhat different than among other topics. Two-thirds (67%) indicated webinars as being among their more desired presentation formats, followed closely by downloadable guidebooks and how-to manuals (63%), followed, in turn, by fact sheets (56%) and toolkits (50%).

Due to our experience with varying definitions or assumptions about the term “diversity,” respondents were given the opportunity to provide additional information on particular stakeholders who are of primary interest to respondents to attracting or engaging them in their lifespan respite programs and activities. Three-fifths (60%) of respondents offered comments.

Comments on Specific Stakeholders Respondents are Interested in Accessing

Respondents were asked to briefly describe particular stakeholders of interest and to explain why these stakeholders are so important. Thirty-five comments or offered, the most useful include:

- Employers have historically been missing from the respite discussion.
- Local legislators for awareness and support.

- Partnering with other service providers of the care receiver so that we can provide simultaneous services to the caregiver. This may increase funding opportunities for our services.
- Engaging the medical community to develop partnerships.
- Family's and persons with disabilities from non-Caucasian backgrounds; Caucasian families often access respite, but we struggle to connect persons from other ethnic backgrounds.
- Mental health partners, veterans' groups, and other minority groups.
- Parents of children with significant disabilities because those parents seem to be unlikely to be aware of respite opportunities in their communities.
- Other organizations serving persons with disabilities in the state; smaller caregiver coalitions that exist around the state that are not connected to one another; employers who may not realize that their employees are caregivers in need of respite.
- Caregivers working with children with disabilities and other populations besides the elderly with dementia.
- Easterseals and United Cerebral Palsy to participate in our lifespan respite coalition as they are key players in the state and other states, and these organizations could benefit from being part of our state respite system as well as being an asset for all of us.
- Families of children and adults with autism.
- Faith groups and other community groups that have more longevity and trust within the community to facilitate access to caregivers.
- Legislators, state government agency heads, local politicians, etc., who can influence public opinion about respite and also provide access to the programs that they administer or for which they advocate [8 such comments].

Comments on Specific Needs: Stakeholder Involvement and Diversity

Respondents offered 30 comments articulating specific needs they have for T/TA relating to stakeholder involvement and diversity. These include:

- Guidance on how to most successfully approach other organizations. A framework for building a partnership.
- Models describing successful partnerships.
- How to close the gap between stakeholders and funders; money does the talking, but we need to involve stakeholders in the ownership of the outcomes of respite in our state.
- How to influence state leaders and policymakers understand the importance of securing federal grant opportunities to support efforts to meet respite care demands in our state.

- Hosting a Respite Summit with ARCH’s assistance to bring together caregivers and organizational leaders to bolster our coalition.
- Strategies that might be successful in politically conservative states.
- How to garner national media attention on the benefits of respite.

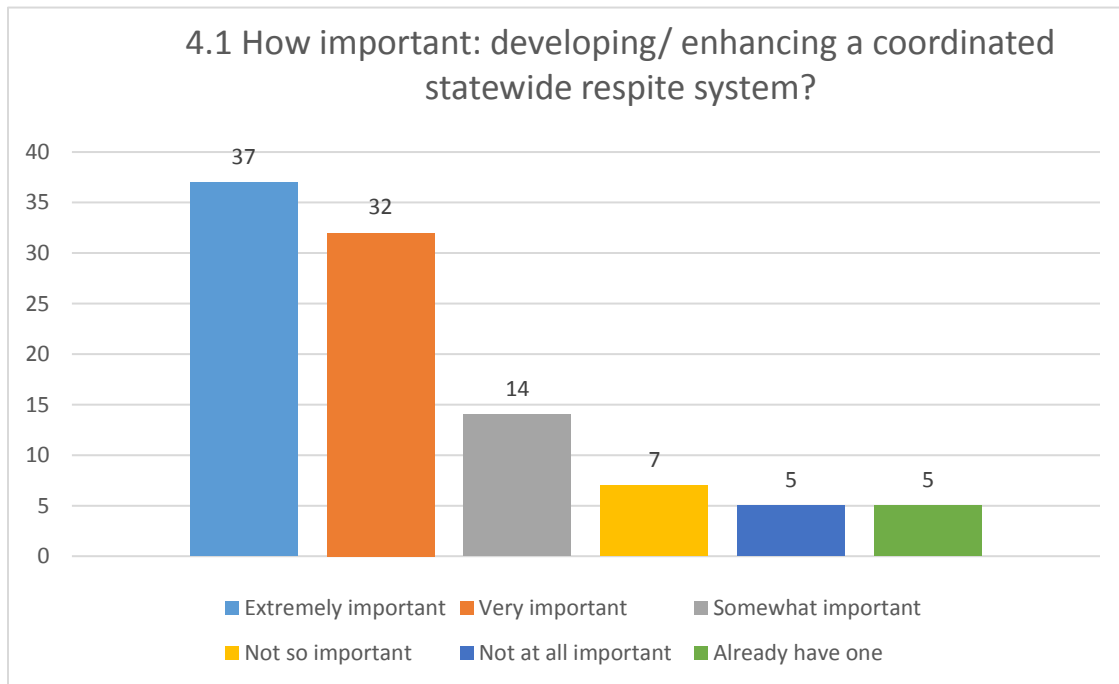
Increasing Stakeholder Involvement and Diversity: Responses from Lifespan Respite Grantees and Partners

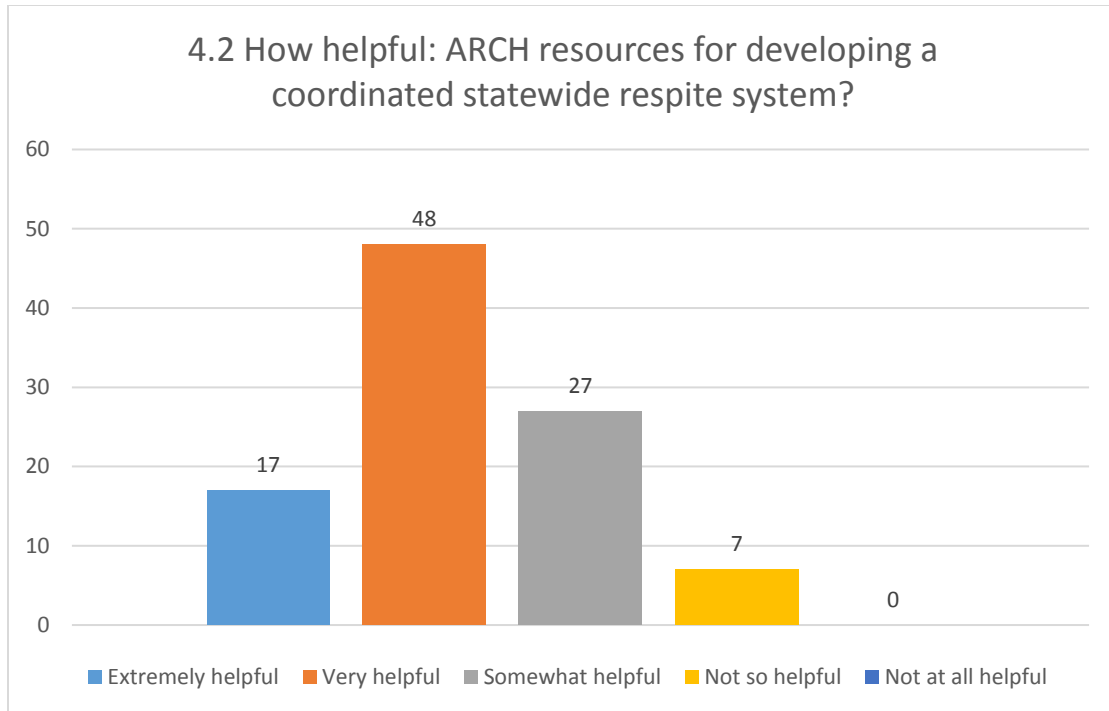
- The very large majority of primary constituents (91%) rated this topic either extremely important (47%) or very important (44%).
- Lifespan Respite grantees and partners have been quite active on this topic, with more than three quarters (77%) having accessed existing arch resources on the topic.
- A large majority (72%) found these resources to be either extremely helpful (32%) or very helpful (40%).
- A majority also likely feel that they have been successful in addressing this topic as only 32% indicated that they would be extremely likely or very likely to request T/TA over the next 18 months; respondents were evenly split at 16% each.
- Among those few likely to request T/TA, webinars were the most frequently cited mechanism for receiving T/TA (68%), with downloadable guidebooks and “how to” manuals and toolkits closely following (64% and 61%, respectively).
- About two thirds (68%) of primary constituents indicated that they would like to target specific stakeholders or stakeholder groups, generally clustering around care providers, financial partners, including government agencies with funding capability as well as legislative bodies, and other government agencies or organizations with shared client responsibility (services for populations with disabilities, Multiple Sclerosis Society, Easter Seals, etc.).

4. Best Practices for Building/Enhancing a Coordinated Statewide Respite System

A combined total of 69% of respondents rated building/enhancing a coordinated statewide respite system as either very important or extremely important. This is slightly less than the three previous topics, but notably only 14% identified it as somewhat important, whereas a combined total of 17% found the topic to be either unimportant or the respondent claimed to already have established a coordinated statewide respite system. However, the combined 69% in the high importance categories suggests that this is a very important topic. These data are presented in Figure 4.1.

A large number of the resources maintained by ARCH in its resource library relate directly to this topic of developing a coordinated statewide respite system. These include the *Lifespan Respite 101 Toolkit*; *Linking Lifespan Respite to Your States Long-Term Services and Supports*; *State Lifespan Respite Tools: Examples of Integrating Respite into Your States System*; and several archived webinars and recorded teleconferences. Nearly half (48%) of respondents said they had accessed one or more of these resources; 42% had not, and 10% were not sure. The majority of those respondents who had accessed the materials (65%) found the materials to be very helpful or extremely helpful. These data are presented in Figure 4.2.





Comments on ARCH Resources: Developing a Coordinated Statewide Respite System

Only eight comments were offered by respondents describing the actions or helpfulness of ARCH resources relating to developing a coordinated statewide respite system. Several were generally laudatory (e.g., “helped us identify opportunities, best practices, and provides us with tools and resource information”), but two were constructively critical:

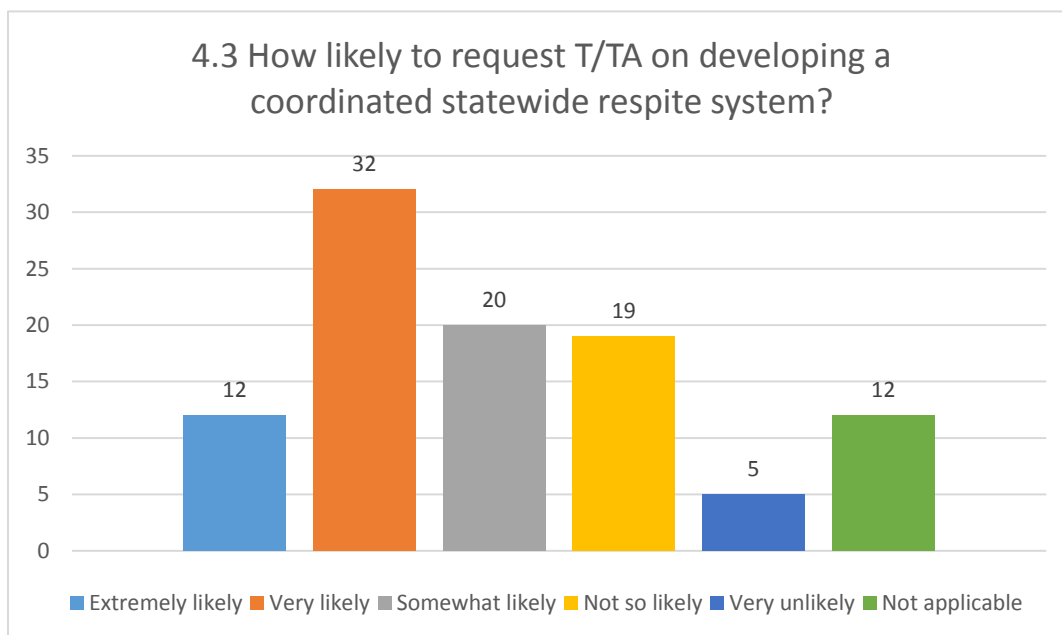
- We need more specific information about the respite model and services for caregivers of children;
- Resources on this topic are not comprehensive; it is almost impossible to keep current due to the constant changes.

One comment offered a rather unique perspective from a community service provider without a history of providing respite services:

- Our organization was recruited into the coalition at the end of our jurisdiction’s grant. [?] Respite is not our area of expertise and ARCH tools have provided helpful background as we help our coalition in its mission.

Although ranking fifth among respondents rating a topic as extremely or very important (69%, combined), developing/enhancing a coordinated statewide respite system ranked first among

respondents with the highest number indicating that they are extremely likely (12%) or very likely (32%) to request T/TA on the topic over the next 18 months. These data are presented in Figure 4.3.



Among the vehicles for receiving T/TA on this topic, the most preferred by those respondents likely to seek T/TA are webinars and downloadable guidebooks or how-to manuals. Each of these registered at 65%, but all other categories except phone/email consultation also reflected desirability registering at 45% to 50%; phone/email consultation registered at 40%.

Comments on Specific Needs: Developing/Enhancing a Coordinated Statewide Respite System

Twenty-three respondents offered comments on their specific needs in relation to T/TA on this topic. A few are not actionable by ARCH (e.g., “We need access to funding”), and several suggested assistance for collaboration and engagement with state government organizations or their state’s administration. This suggests a level of T/TA commensurate with the Lifespan Respite summits that ARCH periodically cosponsors with individual state lifespan respite grantees. In fact, one respondent said that their state is engaging with ARCH in a Sustainability Summit for this purpose.

More than one-fifth of the comments (5 respondents) indicated that they did not know what to ask for, were unsure, or were undecided at the time of the survey. This suggests that some respondents, while recognizing the high importance of this topic, are unsure of what to do about it or unsure of how ARCH might be able to help. However, several comments are informative:

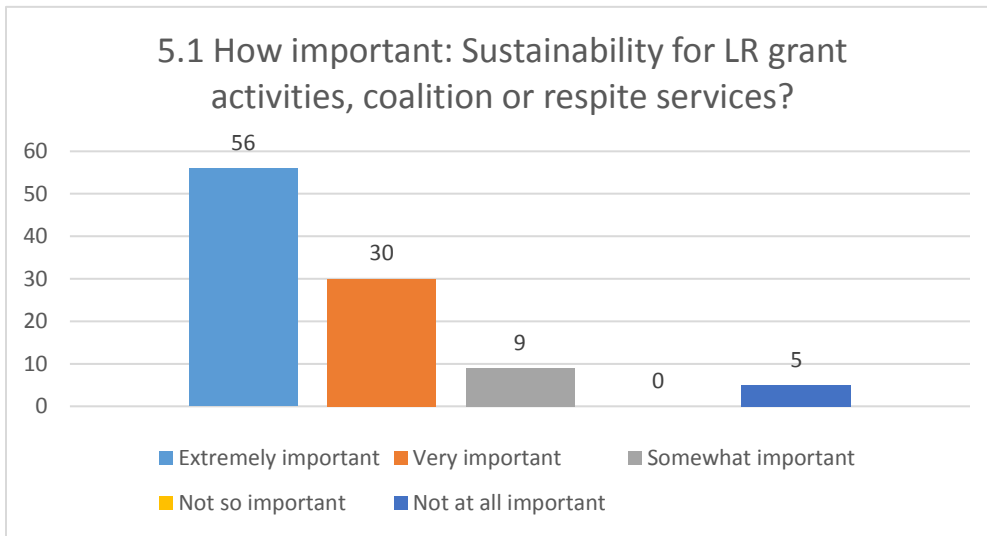
- Perhaps a listing [catalog?] of other organizations that take part in coalitions in other states. These would be partners with whom to coordinate.
- Examples of strategies that have worked well in practice.
- Communicate best practices from other states that have developed statewide coordinated respite systems, and outcomes that have resulted. People seem to be working in isolation.
- We need information on specific resources that are available to caregivers of children. This is especially important; this population needs to be included in our coalition. Also, better marketing strategies about their availability so that those working with this population can make resources available to them in their network.
- Continue to have regular webinars to provide information in real time from other states that have been working on respite projects for longer than we have.
- We will be developing a respite-specific online resource directory in the coming months. We will be reaching out for guidance.
- Facilitated contacts from national organizations willing to work with their state chapters to engage with state coalitions in a meaningful way. Looking for ways to simplify weaker procedures; remaining support best practices, particularly in serving rural communities.

Building/Enhancing a Coordinated Statewide System: Responses from Lifespan Respite Grantees and Partners

- 80% of primary constituents rated this topic as either extremely important (50%) or very important (30%).
- This is another topic area where primary constituents have been active, with 75% having accessed ARCH resources associated with this topic.
- Three quarters (74%) found these resources to be helpful, with 17% rating them as extremely helpful and 57% rating them as very helpful.
- A majority (55%) of Primary Constituents are extremely likely (13%) or very likely (42%) are likely to request T/TA on this topic in the next 18 months.
- Preferred mechanisms for receiving T/TA are downloadable guidebooks and “how to” manuals (65%), but webinars emerged as a strong second choice (58%) and, for the first time among primary constituents, the mechanism of workshops at the National Lifespan Respite Conference was cited by 54% of those responding.
- Comments among primary constituents were varied in a manner similar to those of the total population of respondents.

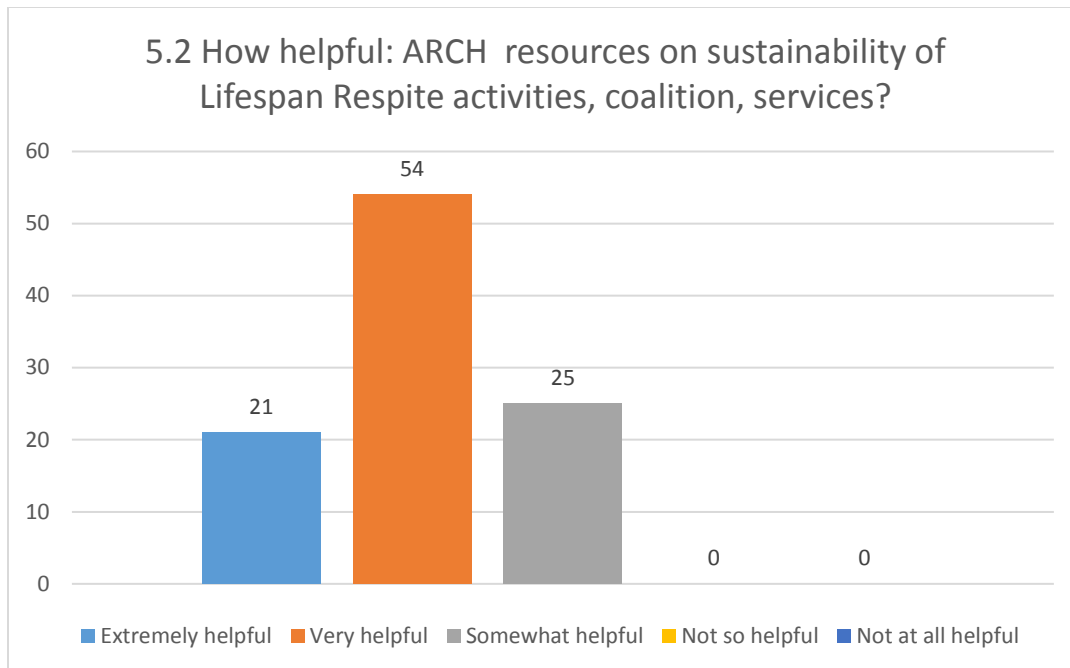
5. Sustainability for Your Lifespan Respite Grant Activities, Coalition or Respite Services

The topic of sustainability for lifespan respite grant activities, coalition or respite services ranked second overall with respect to the total number of respondents rating it as extremely important or very important (86%, combined), but ranked number one among those rating it as extremely important (56%). The remaining 14% of respondents rated the topic as either somewhat important (i.e., neutral) or not at all important, presumably because they have a sufficient and stable funding base or sustainability plan. These data are presented in Figure 5.1.



ARCH’s current and archived resources pertaining to this topic include the *Sustainability Learning Collaborative* (comprising recorded webinars, conference calls, and other resources), *Sustaining Lifespan Respite Systems: Lessons Learned and Practical Applications with a Checklist for Success*; *InfoGraphic: What’s the Key Ingredient for a Successful Sustainable Coalition?*; *The Lifespan Respite Sustainability Toolkit*; and at least four archived webinars conducted between 2012 and 2017 specifically devoted to this topic.

Half of those responding (49%) had accessed one or more of these resources; 46% had not, and 5% were not sure. Among those who had accessed one or more of these resources, the majority (54%) found the resources to be very helpful, and an additional 21% found them to be extremely helpful, for a combined majority of 75%. The remaining 25% found the materials to be somewhat helpful, and no respondents found them to be of little help or of no help. These data are presented in Figure 5.2



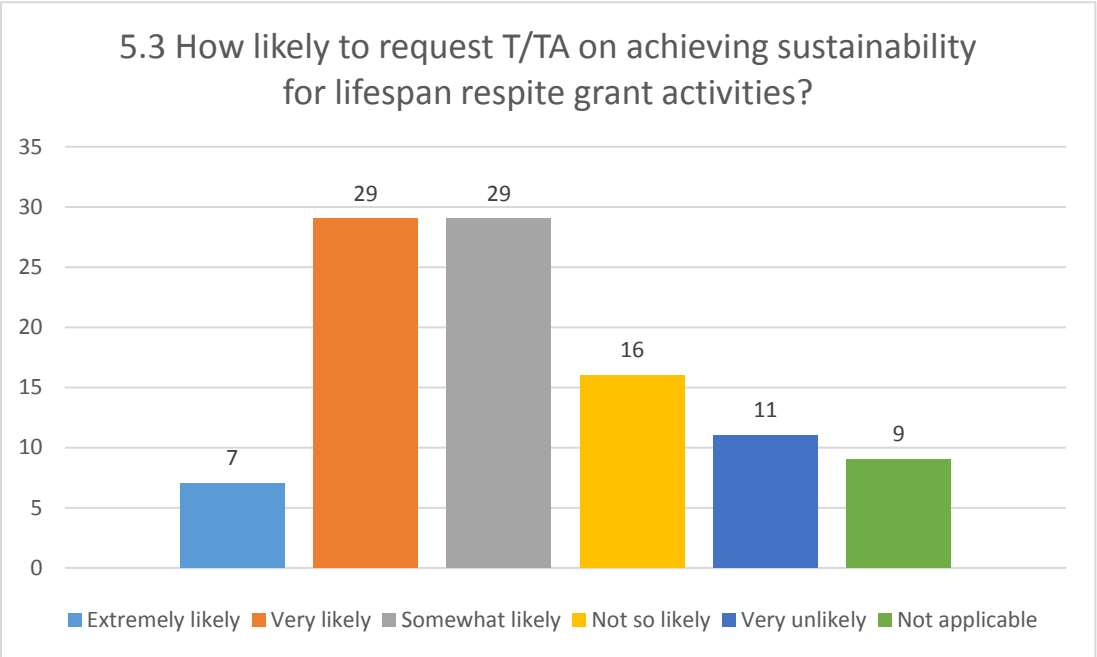
Comments on ARCH Resources: Sustainability of Lifespan Respite Activities and Services

Ten respondents offered comments on ARCH resources relating to this topic. All comments of substance are generally laudatory:

- The Learning Collaborative and other tools provide the user-friendly roadmap which is especially important to us since our coalition has no dedicated staff.
- Good guidance and a thorough examination of the topic.
- A little overwhelming, but extremely helpful.
- Visual materials are great. Facilitated conversations (the learning collaborative) have been extremely informative.
- We shared many of these resources with coalition members, respite providers and stakeholders.
- I was unaware of these resources, but will be researching them.

Several comments referenced the Sustainability Learning Collaborative that was convened at the 2017 Lifespan Respite Grantee and Partner Learning Symposium. It is interesting to note that 60% of respondents were aware of the Learning Collaborative, and more than half of them (54%) participate in the Collaborative.

In keeping with its rank of number two in overall importance, and its rank of number one on being extremely important, sustainability ranks number two with respect to the number of respondents expected to request T/TA over the next 18 months. About 35% of respondents may be expected to do so. This estimate may be influenced to some degree by the fact that 9% of respondents indicated that T/TA on this topic would not be applicable to them, presumably, again, because they had achieved sustainability or had a concrete plan for doing so. These data are presented in Figure 5.3.



Among the most likely requested vehicles for presenting or receiving T/TA on achieving sustainability lifespan respite grant activities are webinars and downloadable guidebooks or how-to manuals, each registering at 63%. All other vehicles for delivery or receipt of T/TA registered at about 45% to 55%, with the exception of workshops associated with the National Lifespan Respite Conference, which registered at 37%.

Comments on Specific Needs: Sustainability for Lifespan Respite Grant Activities

Twenty respondents offered comments. This is another topic area that it is very important to respondents, accompanied by a high likelihood of requests for T/TA. However, the information in the comments suggests that respondents are quite unsure of what to ask for or how to proceed. There were a number of general requests for things like education, training, networking, and continued access to downloadable materials. Only a few were more substantive:

- Identify possible funding options for the state’s lifespan respite needs.
- Need to learn practical steps on how the lifespan respite leaders can implement reasonable efforts regarding sustainability, particularly outside of federal and state funding.
- We are still gathering information and developing a thorough understanding of what sustainability involves and what is required, practically speaking. ARCH has been very supportive and helpful and we anticipate having a better idea of what we need as we progress with the Collaborative and with the toolkit.
- Perhaps a webinar or conference call with states that have successfully used the toolkit to share experiences as we identify challenges using it.

On the general issue of workshops that might be conducted at the National Lifespan Respite Conference, respondents were very consistent across all topics with one exception. All topics were identified as appropriate or desirable for workshops at the Conference by about 35% of respondents except for Developing/Enhancing a Coordinated Statewide Respite System, which registered 50%.

Sustainability of Lifespan Respite Grant Activities: Responses from Lifespan Respite Grantees and Partners

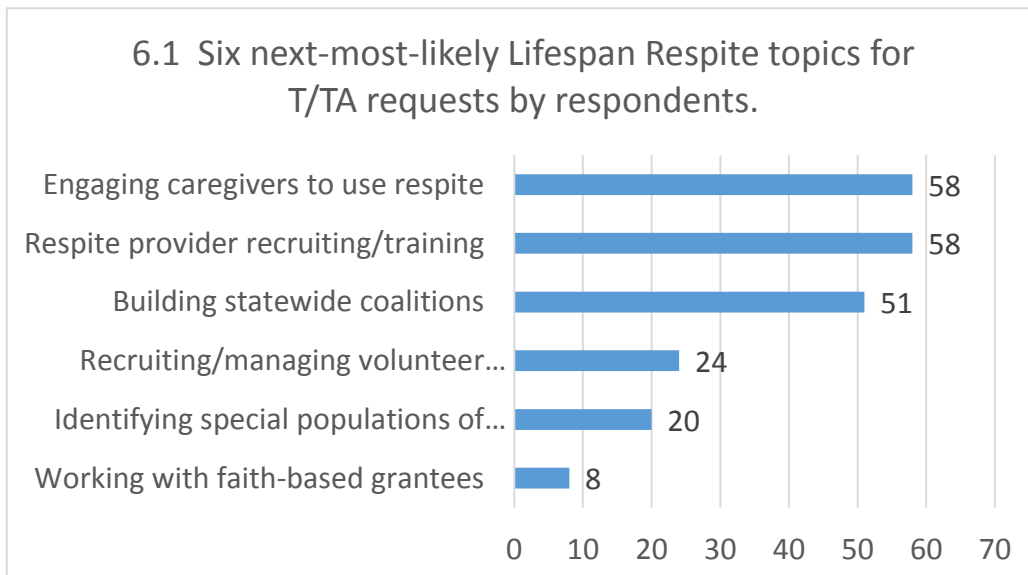
- 100% of primary constituents rated this item as either extremely important or very important, with a large majority (73%) rating it as extremely important.
- The large majority of primary constituents (78%) have accessed ARCH resources on this topic.
- 80% found these resources to be extremely helpful (24%) or very helpful (56%).
- 42% of primary constituents indicated that they would be extremely likely (10%) or very likely (32%) to request T/TA over the next 18 months.
- The preferred mechanisms for receiving T/TA are downloadable guidebooks and “how to” manuals (73%), toolkits (60%). Webinars and on-line training were tied for third place (53%).
- Virtually everyone among these constituents (94%) is aware of the Sustainability Learning Collaborative, and two thirds (65%) are participating in the collaborative. A sustained or even increased emphasis of the Learning Collaborative may be warranted as it is both a direct and efficient vehicle for delivering TA to primary constituents and even to members of the general population of respondents (54% of whom are participants in the collaborative).
- Comments among primary constituents were varied and did not differ substantially from comments made by the larger group.

6. Other Topics of Interest to Lifespan Respite Grantees and the Lifespan Respite Community

Subsections one through five presented the results of a follow-up needs assessment asking about the top five ranked items identified by attendees at the 2017 Lifespan Respite Grantee and Partner Learning Symposium. Those are the top five from a list of 16 potential topics. However, they were not the only items of interest. The six next-most-requested items during the symposium were: 1) Building/Sustaining Statewide Coalitions; 2) Engaging caregivers to use respite; 3) Respite provider recruiting and training; 4) Recruiting/managing volunteer respite providers; 5) Working with faith-based grantees; and, 6) Identifying special populations of family caregivers and their respite needs.

Survey respondents were given the opportunity to rank order the six items in importance to their lifespan respite activities. Figure 6.1 presents the findings from this inquiry. The data in the figure represent the summed proportions of respondents ranking the item as either number one or number two out of the group of six. Thus, in the case of the first item, *Engaging Caregivers to Use Respite*, 58% of respondents ranked that item as either number one or number two out of the six items in the group.

The top three topics (*Engaging caregivers to use respite*; *Respite provider recruiting and training*; and *Building/Sustaining Statewide Coalitions*) each received a majority of number one or number two rankings ranging from 51% to 58% of all respondents. The remaining three topics (*Recruiting/Managing volunteer respite providers*, *Identifying special populations of family caregivers and their needs*; and *Working with faith-based grantees*) each received less than one quarter of all respondents' rankings of one or two, ranging from 8% to 24%.



As with all preceding topics, respondents were given an opportunity to make comments or provide qualitative information relating to their selections and rankings. They were asked in particular to comment if they had selected any of the six items as being very important even though not included in the top five topics determined by the Learning Symposium polling.

Comments on Specific Needs: Other Topics of Interest

Respondents offered 29 comments on other topics of interest. Because the comments do not all relate to the same topics, there is a great deal more variety than in previous subsections. Therefore, all substantive comments are presented below:

- We are interested in ideas for funding caregiver needs assessments.
- We frequently have caregivers of persons with special needs who require specially trained respite providers. There is a very shallow pool of those providers in our state. Likewise, caregivers need information and education on respite and self-care.
- We have a training program but need to recruit volunteer respite providers as well as increase the number of paid respite providers.
- We need to attract, train and retain providers. It is a huge issue in our state or turnover is high and wages are low.
- We have a tremendous need to expand the pool of qualified, trained respite care providers.
- How can social media be used for outreach to families across the lifespan? When and where does it work? Coalition and Respite Service Delivery - can it work when competition among members is strong?
- My top concern is finding out how to start a non-profit to sustain the voucher program. It is important that coalition members begin to figure out ways to sustain the program, perhaps through memberships or other means. Another big issue is recruiting, not just respite provider agencies, but also helping them increase training and maintain their work force to meet lifespan needs.
- Ongoing training of providers is essential, but keeping the training fresh and new is a challenge. Are there models of recurrency training that address this issue?
- We need to get our legislators involved in order to build our state respite coalition and statewide respite system. Legislative support is essential.
- Many advocates working with caregivers of children are not aware of resources that lifespan respite providers can share with them. Highlighting this population of caregivers [of children with disabilities] and identifying what advocates can do to find and share current and future information in fact sheets, list serves, toolkits would be great.

- Tools for start-up community-based respite project.
- We need help with strategic planning to get everyone in our inclusive caregiver coalition to identify the needs of caregivers statewide. We have leaders from other organizations, and attendees representing caregivers in many support programs and agencies. All of them are worried about sustainability.
- We need to develop methods/strategies for recruiting respite providers, providing ongoing relevant training to address hard-to-serve populations such as those with physical and cognitive disabilities including mental illness, Alzheimer's, autism and brain injuries. We need to create/maintain a statewide registry of providers.
- At this time, we do not recruit for training respite providers. We support families who find their own respite provider that meets our requirements for support. We need to develop the capacity to have volunteer respite providers for our families.
- We need to know how to properly vet new providers that meet the needs of our families and special populations. We're considering mandating a statewide training requirement for respite providers.

Some common themes throughout these comments include the need to recruit, train, and retain providers, both volunteer and paid. There are variations on this theme, such as volunteer versus paid providers; basic training, recurrency training, specialized training, mandated training, etc.; and vetting new providers and retaining current providers. Some comments relate directly to topics in other sections focusing on sustaining the lifespan respite program.

There are also some recurrent themes such as engaging legislators and administrator support, increasing the knowledge base and focus on caregivers of children with disabilities, and emerging populations such as Veterans with brain injury or physical disabilities. However, there are some unique and interesting potential T/TA needs presented in these comments, including ideas like starting a nonprofit foundation to fund coalition activities and even direct services, and conducting/funding caregiver needs assessments.

General End-of-Survey Comments

All respondents were given the opportunity to offer any concluding thoughts, express any additional needs, and offer any other ideas to the ARCH National Respite Network and Resource Center. Sixteen respondents took advantage of that opportunity. Several of the comments are "merely" congratulatory or laudatory (e.g., "You guys are the best!", "ARCH is terrific", "Thank you for all you do to support the state Coalitions"). Some respondents reiterated recurrent themes, such as the

desire to include children in every conversation relating to respite, including resources, tools, suggestions, recruiting and training; and holding a Respite Summit each year for enhancing statewide program development. Two commented on their emerging knowledge of ARCH as a resource and a commitment to make greater use of ARCH in the future:

- I need to learn more about who you are and what you offer.
- I am just grateful for what was shared in the survey and will be taking a closer look at the resources mentioned. I would love to be as well-prepared/knowledgeable for the calls that I receive from professionals and families. I know that this is a lofty goal, but that is why I am here and if I can succeed in that goal a little more with the help of ARCH and its program/resources... I will. Thank you again for your continued support and ongoing efforts.