

Texas Respite Summit After Action Report

This After Action Report (AAR) is intended to provide the Texas Respite Coalition an overview of the responses from the participants of the 2014 Texas Respite Summit (TRS). The information provided will assist the Coalition in reviewing the effectiveness of the Texas Respite Summit and identifying next steps.

Questions posed for the TRS evaluations were provided by ARCH and the Coalition. Data that has been included within the AAR serves as a snapshot of the responses submitted by TRS participants. A total of 63 participants submitted their evaluations at the Summit. One additional participant submitted their feedback through a web link distributed after the Summit (*See evaluation summary beginning on page 5 of this After Action Report*). In total, 105 registered to participate in the Summit.

ACTIVITY: 2014 Texas Respite Summit

LOCATION: Embassy Suites San Marcos, TX

DATE OF ACTIVITY: June 12, 2014



DESCRIPTION OF THE ACTIVITY:

The Texas Respite Summit was a strategic planning session to assist the Texas Respite Coalition and the Texas Department of Aging and Disability Services (DADS) in determining needs and priorities for improving respite care in Texas.

BACKGROUND INFORMATION:

A planning committee consisting of members from the Texas Respite Coalition and the Texas Respite Coordination Center (TRCC) was designated to coordinate the Summit and assist in providing the Coalition updates regarding the Summit. Members of the planning committee included representatives from the following: Department of Aging and Disability Services (DADS), Department of Family and Protective Services (DFPS), AARP, Department of Assistive and Rehabilitative Services (DARS), Texas Department of State Health Services Children with Special Health Care Needs Program, Easter Seals Houston, Respite Care of San Antonio, and Texas Parent to Parent, Texas Association of Regional Councils.

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In an effort to maximize participation, the TRCC with guidance from the planning committee partnered with Texas Parent to Parent to coordinate the Summit with their annual conference. The planning committee worked with the TRCC and DADS to ensure the Summit was well coordinated.

A pre-registration process was used to ensure key stakeholders, representing a diverse set of interests, had the first opportunity to attend. Several stakeholder groups were actively recruited, including the Veterans Administration, representatives of state mental health services and caregivers of individuals of different ages. Registration was later opened to a wider audience of individuals who learned about the summit through the Take Time Texas website.

WHAT TOOK PLACE:

In the spring of 2014, the Texas Respite Summit Planning Committee began to meet monthly via teleconference. Decisions regarding invited guests, participants, and the priorities of the Summit were established by the planning committee. Members of the planning committee devoted their time to coordinating an event that was beneficial to attendees and helped build a foundation of a strategic plan for respite care in Texas.

2014 Texas Respite Summit

BUILDING THE FOUNDATION OF A STRATEGIC PLAN FOR RESPITE IN TEXAS

June 12, 2014 | 9 a.m.-4 p.m. | San Marcos, Texas

9:00 a.m. **Welcome & Introductions:**

Cara L. Magrane, Chief Operating Officer, Respite Care of San Antonio
The Honorable John Davis, State Representative, House District 129

9:15 a.m. **Panel of Family Caregivers: Challenges, Rewards and Needs**

Rosemary Alexander
Diane Kearns
Laura Warren, Executive Director, Texas Parent to Parent
Heather Hansen
Moderator: Dr. Martha Diase, Coordinator, Aging Texas Well Initiative, Texas Department of Aging and Disability Services

9:45 a.m. **Panel: The Texas Lifespan Respite Care Program and Resources for Respite**

Joyce Pohlman, Grants Coordinator, Community Access and Grants Unit, Access & Intake Division, Texas Department of Aging and Disability Services
Manda Hall, Title V Children and Youth with Special Health Care Needs Director, Assistant Medical Director, Purchased Health Services Unit, Texas Department of State Health Services
Christian Wells, Executive Director, Alzheimer's Association, Capital of Texas Chapter
Stella C. Newberger, LCSW, Social Worker, Contract Adult Day Health Care and Respite Care Programs Coordinator, Veteran Directed Home and Community-Based Services, South Texas Veterans Health Care System

10:30 a.m. **The State of Respite in Texas**

Deputy Commissioner Chris Traylor, Texas Health and Human Services Commission

10:45 a.m. **Break**

10:55 a.m. **Facilitated Breakout #1 - Respite Needs**

1. What is respite? Do you offer respite services in your area or are you a family caregiver who uses or needs respite?
2. What are your respite needs? For example, do you need more respite? More affordable respite? A specific type of respite? Respite that better fits your schedule?
3. What is missing from respite care services? What are your challenges, barriers and unmet needs?

11:40 a.m. **Breakout Session Report**

12:00 p.m. **Lunch & Special Guest Speaker**

Moderator: Joyce Pohlman, Grants Coordinator, Community Access and Grants Unit, Access & Intake Division, Texas Department of Aging and Disability Services.
The Honorable Judith Zaffarini, State Senator, Senate District 21
Kim Sulter, Executive Vice President, National Multiple Sclerosis Society

1:15 p.m. **The Lifespan Respite Program: Supporting Families with Better Access to Respite**
Greg Link, Administration for Community Living (ACL)

Engaging Collaborative Partners in Lifespan Respite Programs

Jill Kagan, ARCH National Respite Network

2:00 p.m. **Facilitated Breakout #2 - Creating a Respite Roadmap**

1. If you had a magic wand, what would a "dream" respite care system in Texas look like? What would it offer?
2. What needs to be done to make this "dream" respite care system happen? Brainstorm major goals or next steps for improving respite care.
3. Based on what you learned today, what can the state do to better assist caregivers? What should the Texas Respite Coalition do?

2:45 p.m. **Breakout Session Report**

3:15 p.m. **Next Steps/Action Plan**

4:00 p.m. **Adjourn**



Health and Human Services Chief Deputy Commissioner Chris Traylor addressed the Summit about the efforts being made by HHSC to expand public knowledge of respite care, the agency's goals, and the anticipated direction of respite care in Texas. Chief Deputy Commissioner Traylor voiced the continued need for respite care in Texas due to the growing population and extended gratitude to the caregivers that have assisted the State of Texas in ensuring the safety and care of those in need.



Lunch was provided to attendees who also heard from Kim Suiter, Executive Vice President, National Multiple Sclerosis Society who spoke on the importance of respite care.

Breakout Sessions

The Summit was promoted as a planning summit in which participants would provide input on needs, gaps and priorities for respite care in Texas. Two facilitated breakout sessions were conducted to gather participants' ideas. In the first session, in which participants examined the current state of respite, what is missing and what attributes an ideal respire system would include. In the second session, participants discussed strategies for achieving an ideal respite system. Breakout groups shared findings at the conclusion of each session. The information that was provided was recorded and will be distributed by DADS to the Coalition for further discussion and inclusion in the strategic planning process.

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The following is a sample of positive aspects and possible improvements that were derived from the evaluations. Of the 105 registered participants we received 64 responses. The total response rate for this forum is 61%.

POSITIVE ATTRIBUTES:

- Diversity of interests represented among participants (Please refer to question #14 for affiliation breakdown.)
- Active engagement of participants in breakout sessions. Many wanted more time for this part of the summit.
- Speakers and attendees included high level officials who can impact public policy.
- Partnership with P2P helped advertise the summit to family caregivers of children.
- The Summit provided a great opportunity for participants to network and share information.
- Participants overwhelmingly supported the use of diverse workgroups to provide input and recommendations for the Coalition.
- The Coalition has been encouraged to conduct forums regionally and take place annually.

THINGS TO CHANGE IN THE FUTURE:

- A common suggestion received from participants was to reduce the number of speakers or to increase the length of the Summit. This would allow participant to have more time to network and share ideas. Participants also felt additional time would have provided additional information to be included in the strategic planning process.
- Participants asked to hear more input from caregivers and state agency personnel. It was important for the state to share its vision and goals for respite care.
- Regarding logistics the addition of an afternoon snack/coffee break, utilizing multiple rooms during the breakout sessions, and ensuring the room temperature accommodates participants.
- Incorporation of a statewide perspective to the training.
- Participants should be provided the program prior to attending to allow time to thoroughly evaluate and answer questions.
- Participants encouraged better time management and scheduling of the events.

- Handouts would assist participants in following presentations and provide reference materials.

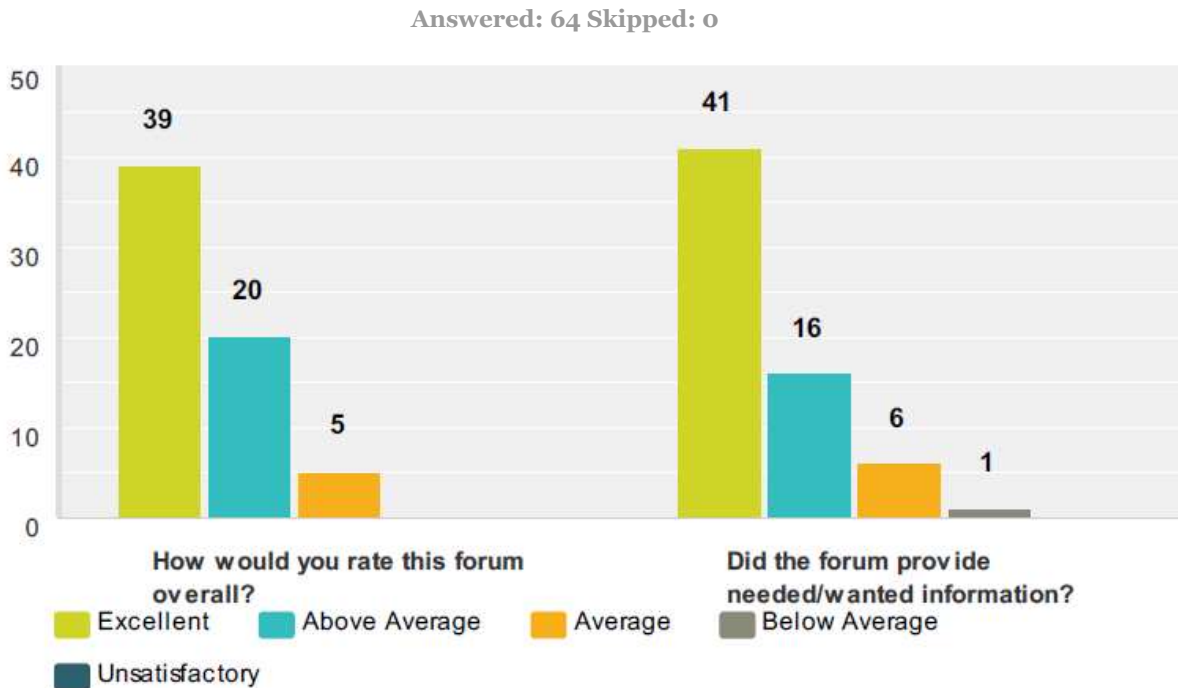
NEXT STEPS:

The Texas Respite Coalition will develop the information provided by Summit participants to develop a strategic plan for respite care in Texas. This strategic plan will assist in addressing the current issues facing respite care and utilizing the input from Summit participants to formulate and recommend innovative ideas. In addition, the Coalition will continue to be a diverse representation of respite care in Texas and will begin accepting new members to provide insight and solutions.

Texas Respite Summit Evaluation Summary

The following data is an accumulation of the 64 total evaluations received following the 2014 Texas Respite Summit.

1. We would like to have your opinions on the summit overall.



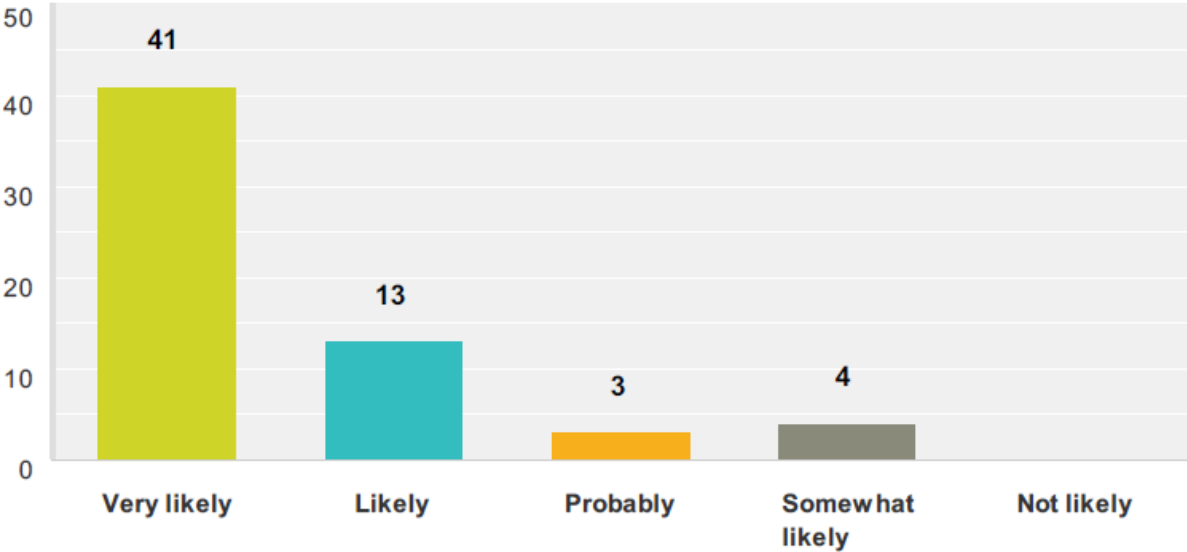
If one or more of your answers to the above questions were "below average" or "unsatisfactory," please tell us why.

Answered: 8 Skipped: 56

1. For a 1st Summit, well laid out and executed! Loved the way time running out was worked out so full time frame kept. BRAVO!
2. Wanted more information from HHSC
3. My interest in Veterans' resources. Very little info for PTSD/TBI.
4. Too many speakers about "policy." Not enough time devoted to sharing resources and learning about respite needs from caregivers i.e. too much 30,000 ft view not enough ground work
5. Good number of participants to allow for dialogue on subject
6. Great info for organizations, not a lot of info for the caregiver tho.
7. I don't think we hit the mark or "the goal" but maybe I was dreaming too high. Jetti is amazing - good talker, presenter and cheerleader.
8. I was here looking for my families that have children with mental health needs I did not find a lot of hope.

2. How likely are you to attend a summit like this in the future?

Answered: 61 Skipped: 3



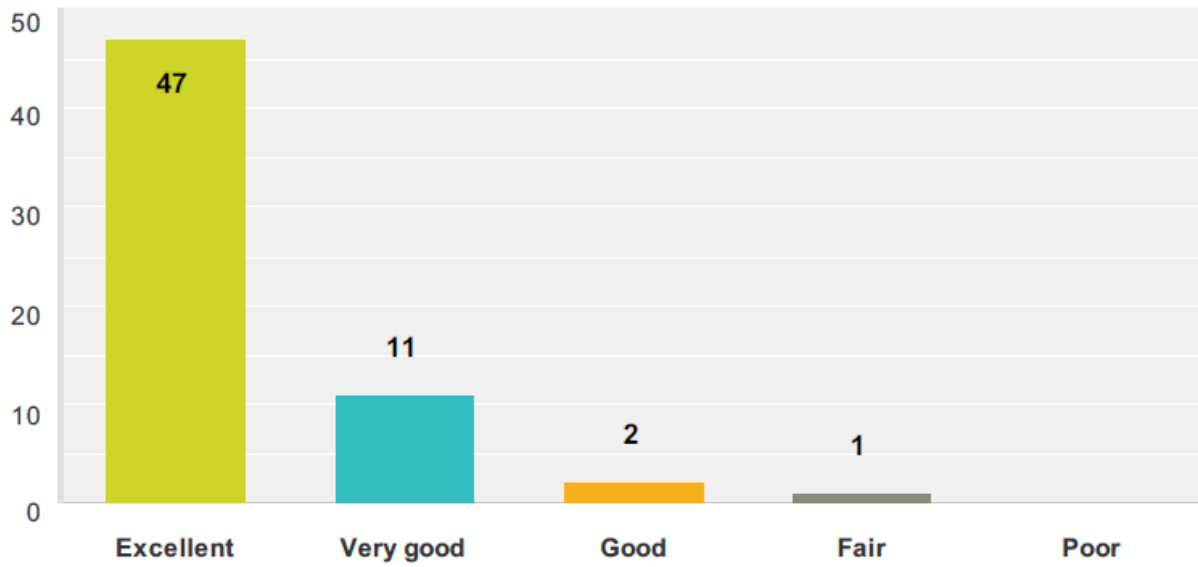
3. Do you have any comments or feedback you would like to share about the keynote or other general sessions?

Answered: 23 Skipped: 41

1. Chris was personable and relate-able. Many of the sessions seemed to be geared toward more of the professional. Hope caregivers present could relate.
2. Thank you!
3. -more breaks -a little time management -break outs worked out better than expected
4. Excellent info on severely disabled. However respite care for TBI that can physically do most/some ADL's but cannot remember to do them. Home safety while alone is a real risk. I've been told to "quit being needy," "get over it," and "quit thinking I deserve help." On bad days they need help almost total care.
5. Would have liked more discussion groups and possibly 1 panel, not 2 with focus on caregivers. Really liked Jill's presentation with strong data component.
6. Shout outs to John Davis and Kim Suiter. Great leaders who speak from the heart and understand.
7. More Brainstorming- best local practices. Less "State of the Union" while important should not be the meat of the day
8. Maybe offering a digital way includes opinions in outside areas. FB groups, etc, could be used as an easy way to gather more individuals.
9. Have 1 or two more short breaks and a more balanced room temperature. The panels were very helpful I learned and understand the needs of family caregivers well. The panel of family caregivers was perfect as the first option. The panel on Texas Lifespan care program is a good option. I'd say for the next summit, invite 2 -3 speakers to share the benefits and successes of their program.
10. Would like to have more specific information presented on the lifetime respite program.
11. I think the audience was so filled with actual caregivers (which is great!) that the federal perspective was lost on them a little bit.
12. Very enlightening and informative. A great opportunity to network with other like-minded folks.
13. Excellent choice of speakers
14. Need to allow time for all speakers to answer questions.
15. Really enjoyed John Davis! How nice to get a legislator who is committed to respite.
16. Increases my awareness of respite care.
17. Since communication is one of the areas lacking with regard to respite, ensuring key information is made available on the web or via handouts.
18. Speakers went over time and moderators. Poor schedule - 1st 2 panels used Deputy Commissioner's time so that his talk happened when everyone was expecting a break. In other words, you took away our needed respite time! Less talk by moderators.
19. Great/ very informative
20. The federal and ARCH speakers were in the wrong place on the agenda. It broke the momentum of the small group discussions.
21. The Resources for Respite panel was too long - each speaker shared too much detail.
22. They were very good on presenting information for IDD and physical disabilities.
23. Enjoyed the federal updates and presentations by agency leadership. Also enjoyed the VA info. She could have had more time.

4. How would you rate the venue/location?

Answered: 61 Skipped: 3



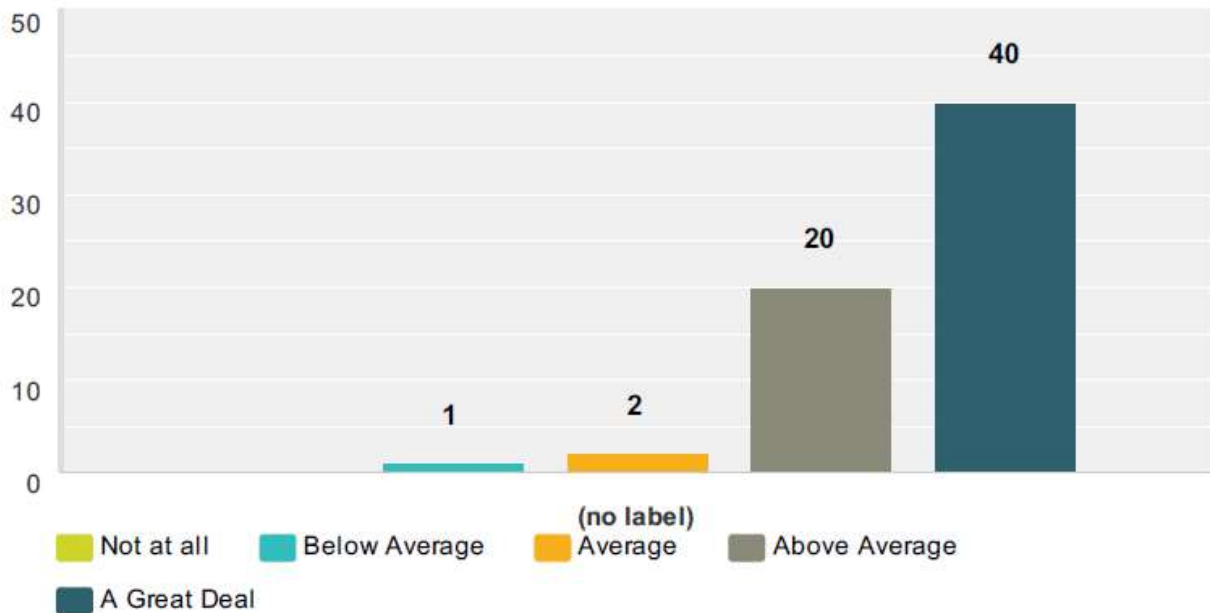
5. Do you have any additional comments, recommendations, or suggestions for how we can improve next year's summit?

Answered: 19 Skipped: 45

1. Make it 1/2 day. Have resources available for caregiver attendees.
2. Actual break out sessions and topics, move around, not just be in one room the whole time.
3. Thank you for being so proactive with my dietary allergies and illness. I appreciate it. Food was fabulous.
4. More breaks
5. Joyce Pohlman - great ambassador with great customer service...Made me feel welcomed as soon as I walked up to the registration table.
6. Provide/teach. lead self care activities for caregivers while they are here. " Breaks that are meaningful" to drive home what respite is -stretching- art-music-hand massage-singing-meditation.
7. The location was decent to request a warmer lunch option e.g. sandwiches & chicken with vegetables or pasta
8. Room was very cold.
9. Groovy lunch!
10. Have more organizations join collation and collaboration.
11. Keep inviting a wide range of attendees- caregivers, professionals, trainers, lawmakers. I learned a lot from people at my table.
12. Encourage gender diversity of attendees
13. No need to freeze people.
14. Room cold! Schedule consistent breaks, please. Very tasty lunch- thank you.
15. Room too cold most of the day.
16. Email Reminder 48 - 72 hours prior instead of less that 24 hours.
17. Cold! I would suggest box lunches, it goes faster and people don't wait.
18. The "color sticks" on the table really blocked the view of the panel speakers and screens. Was very distracting. Maybe lie the color circles flat on table. Revisit the breakout sessions location. Having everyone in the same room was very distracting and difficult to hear group discussions. A lot of important sharing was missed.
19. Snacks/ on going coffee service after lunch.

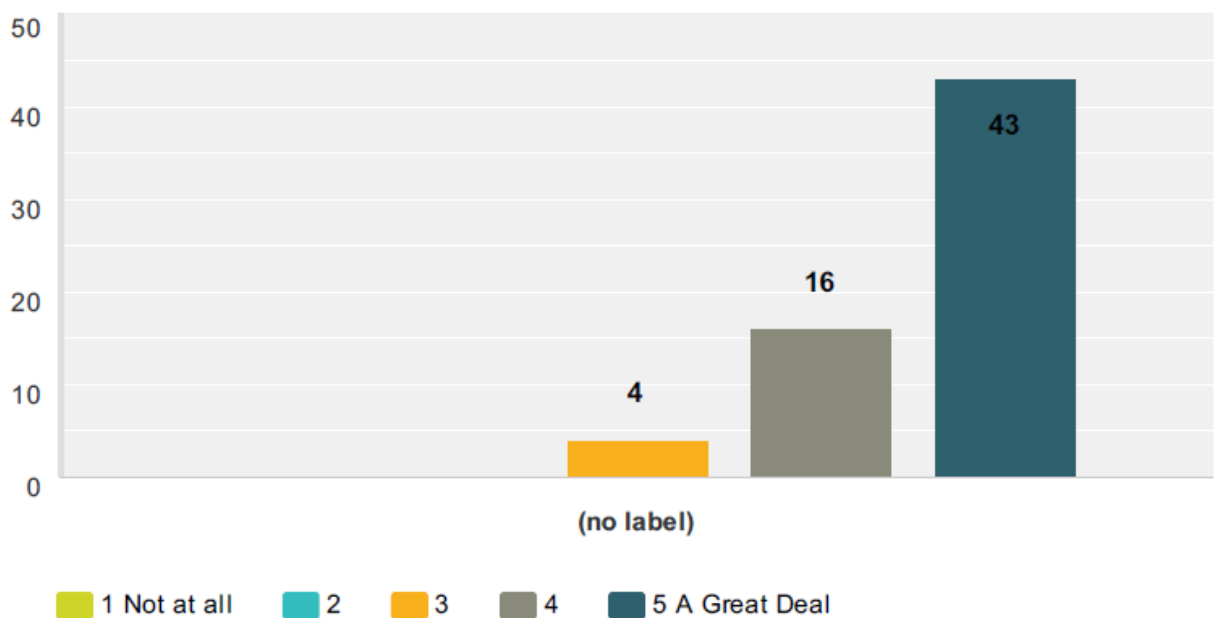
6. Providing presenters who were knowledgeable about the subject matter and effective in presenting information?

Answered: 63 Skipped: 1



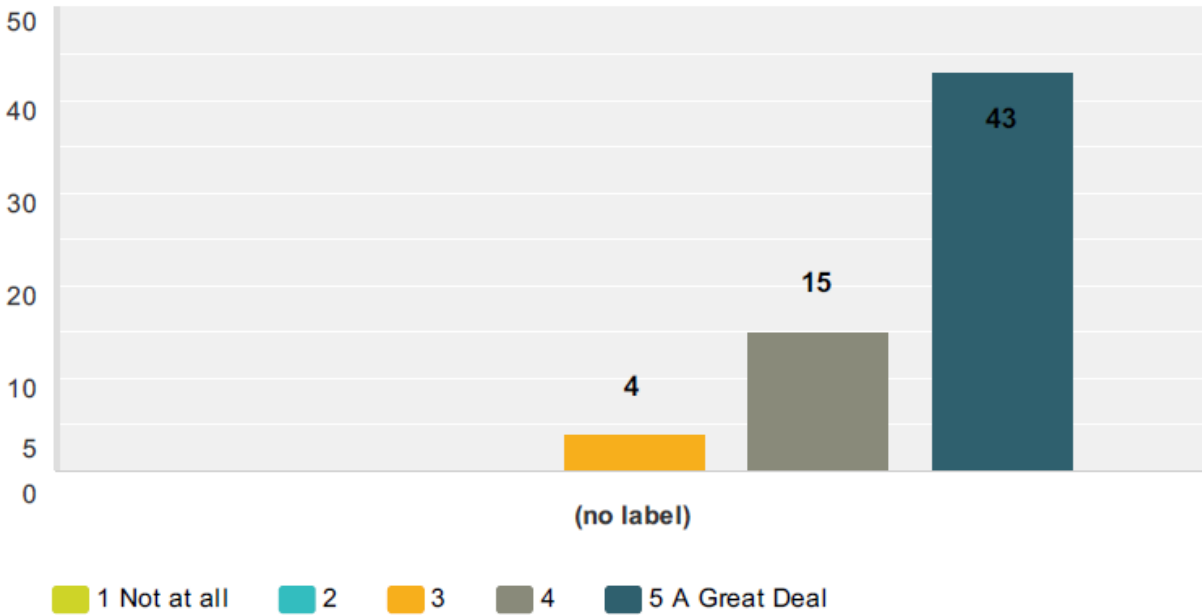
7. Introducing information in an understandable manner?

Answered: 63 Skipped: 1



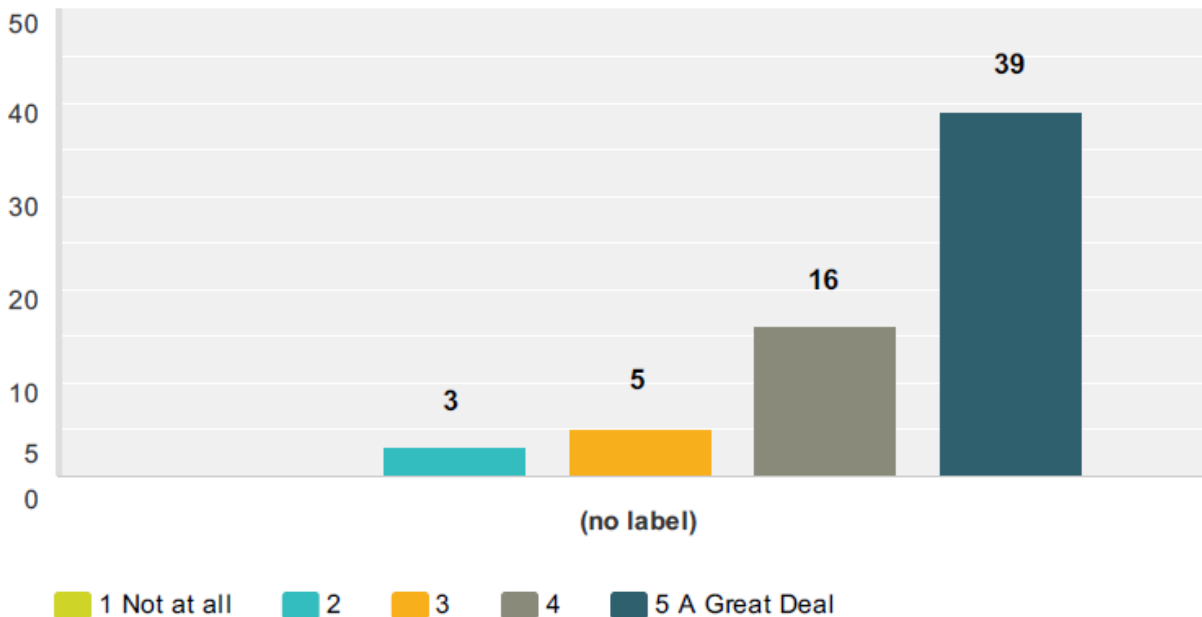
8. Presenting material in an organized fashion?

Answered: 62 Skipped: 2



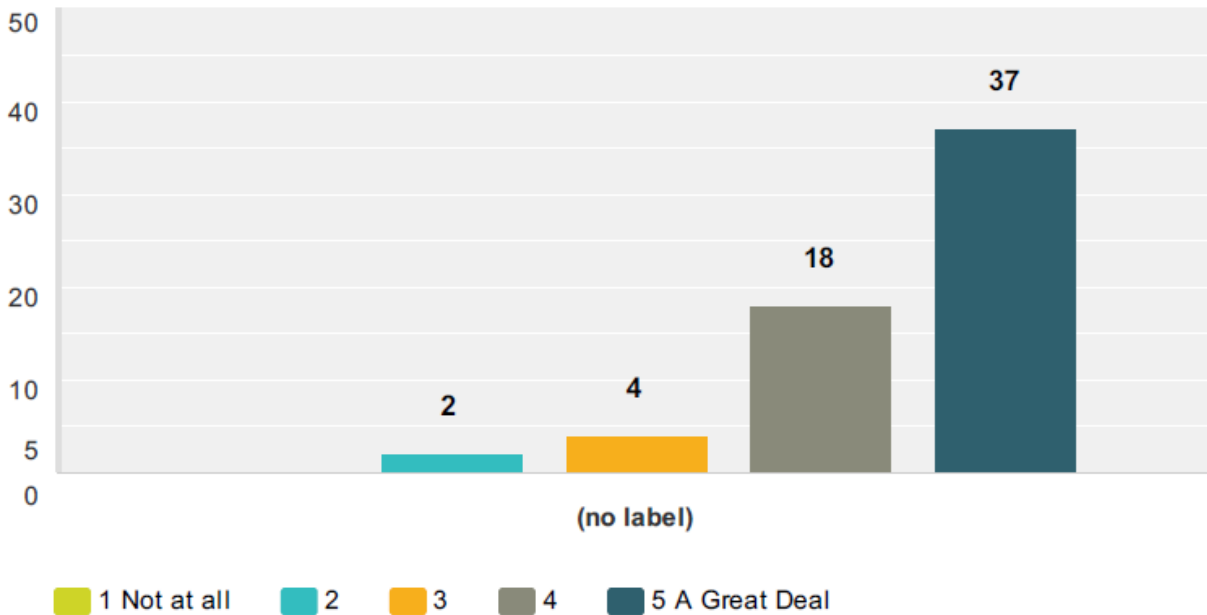
9. Providing effective handouts and/or visual aids?

Answered: 63 Skipped: 1



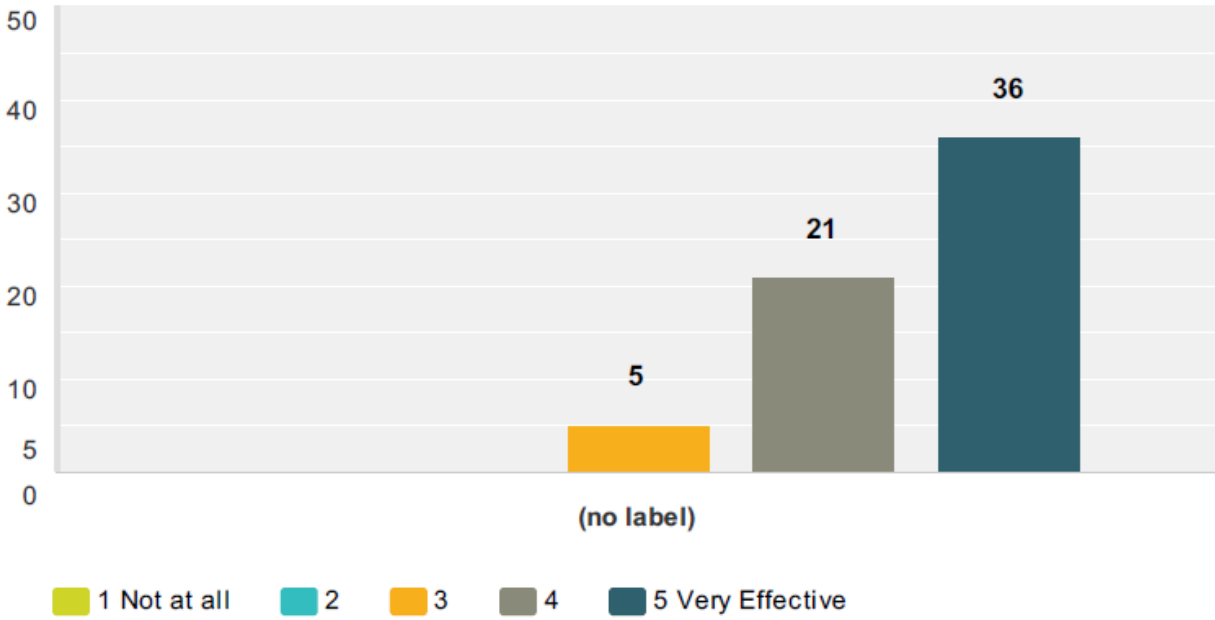
10. Increasing your knowledge of the subject matter?

Answered: 61 Skipped: 3



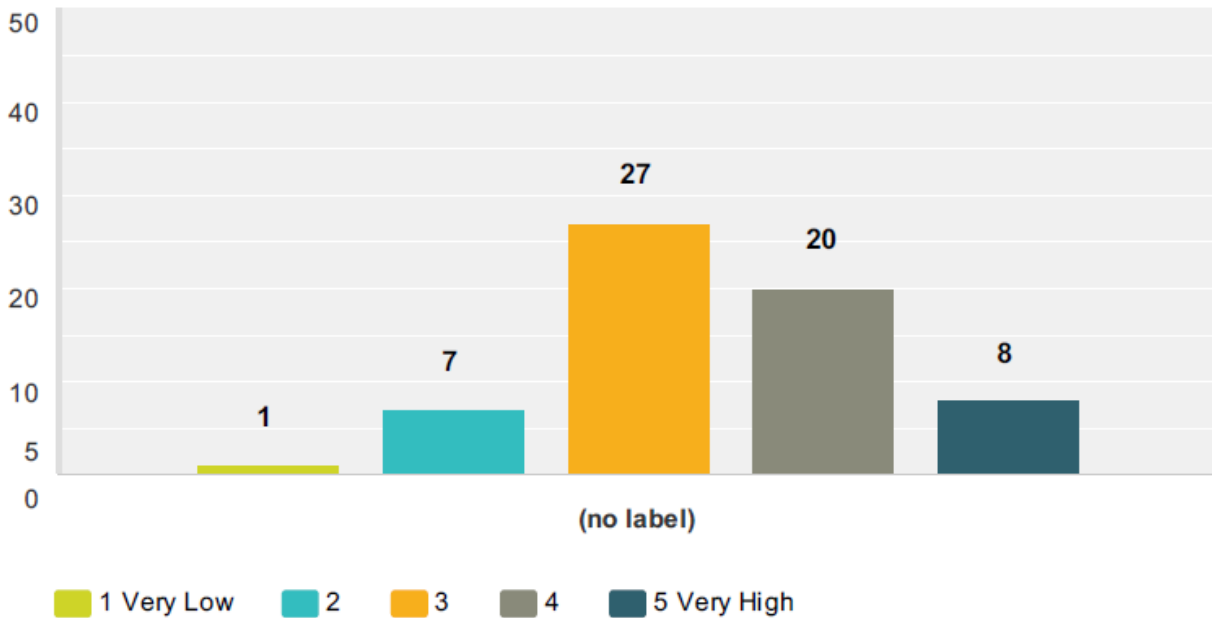
11. Overall, how effective was this summit?

Answered: 62 Skipped: 2



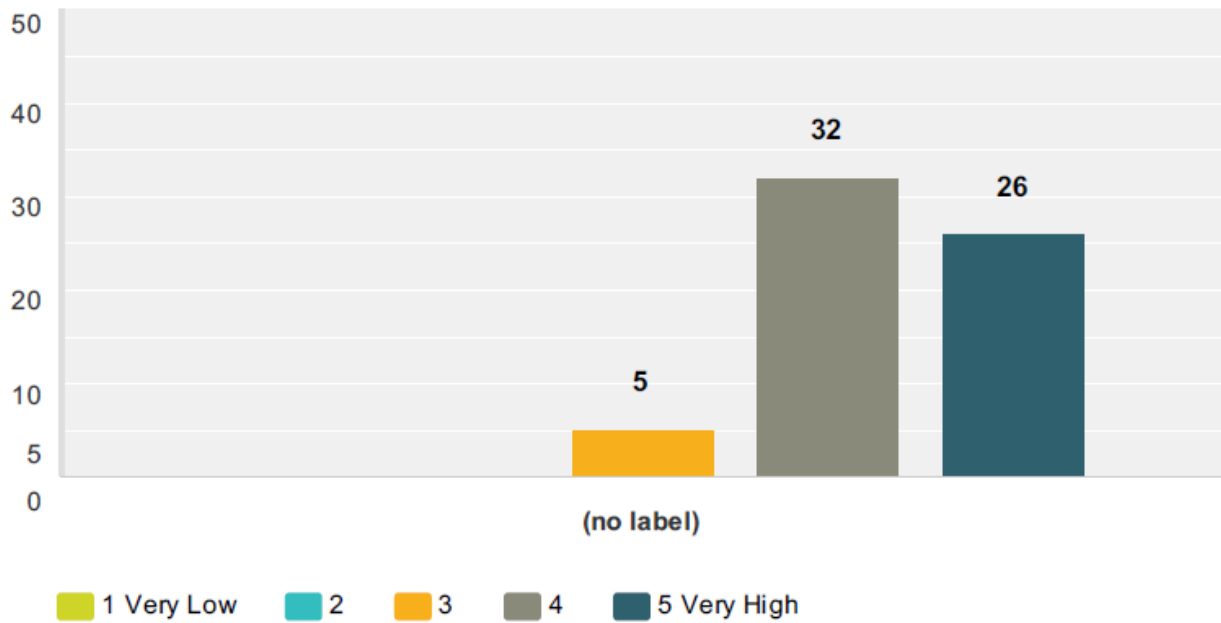
12. Before participating in the Summit, how would you have rated your knowledge of the subject matter?

Answered: 63 Skipped: 1



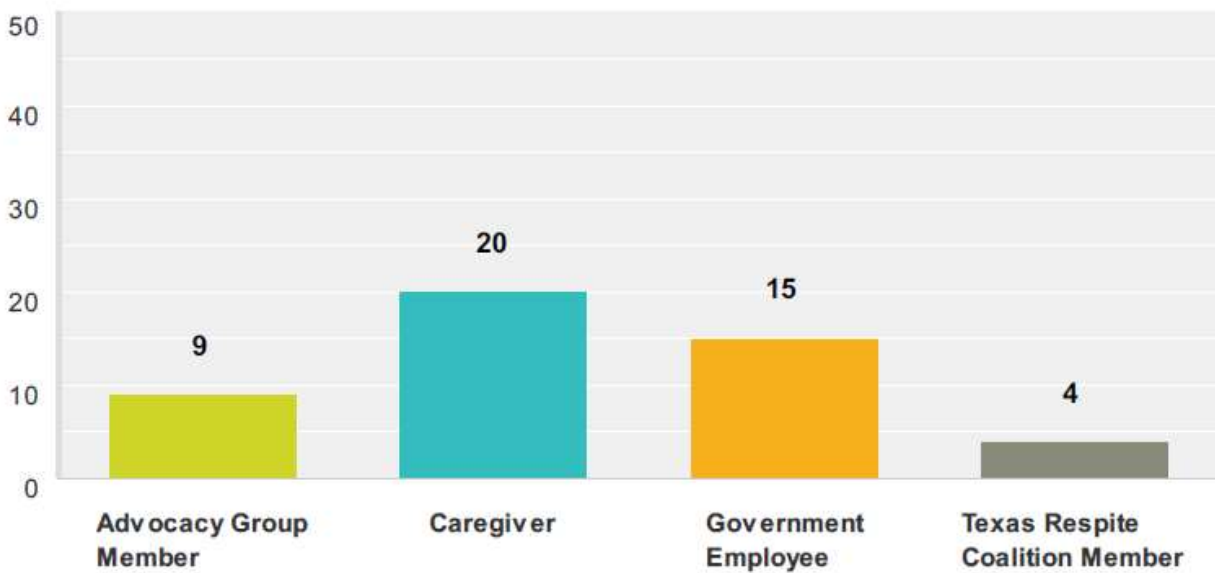
13. Now that you have participated in this Summit, please rate your knowledge of the subject matter.

Answered: 63 Skipped: 1



14. What best describes your affiliation?

Answered: 48 Skipped: 16



15 attendees provided specific responses regarding their affiliation.

1. Work with Active Caregivers through the AAA
2. Caregiver*
3. Care manager
4. Registered Nurse
5. Non Profit
6. MCO Provider Relations Manager
7. VA Federal Agency
8. AAA
9. Nurse, researcher, faculty
10. Non-profit agency
11. Caregiver Ministry
12. Non Profit
13. Non Profit
14. School District
15. Respite Provider

*Participant marked multiple affiliations.

15. Were there any advocates and/or professionals that were not in attendance that you believe would have benefited from a summit like this?

Answered: 31 Skipped: 33

1. Profits/nonprofits who provide assisted living; memory care challenge to offer respite options. They need to see the need.
2. not sure where there hospice representations
3. possibly other nonprofit like cancer, MDA
4. Yes
5. VA Caregiver Program
6. Not at the moment
7. More respite care providers - Professionals
8. Yes, National Kidney Foundations! Texas Certified Health Workers. Dialysis patient caregivers.
9. Hospital/Nursing Homes - Doctors (geri, family and pedi)
10. Easter Seals
11. More respite care providers – Professionals
12. Medical Providers
13. Unknown
14. AARP, providers of respite care
15. Perhaps tap into resource groups such as interagencies and healthcare marketing organizations.
16. HR professionals from some of the big Texas corporations
17. Physicians, directors of hospice services, nursing coordinators/discharge planners; Nurses from: ICU, stroke units, spinal cord injury, rehab, hospice, neuro units, home health; intake in all settings; parish nurses; community health nursing faculty!!; public health professionals; Texas Nurses Association!
18. Hispanic Families
19. residential care home, nursing home owners/managers
20. Texas Disability Rights, (CACTX) Children's Advocacy Centers of Texas Inc
21. Yes ARC board members, I am a board member on the ARC of the Hill Country in New Braunfels and we need to get this information out to out member families.
22. More non-profits ie ARC, Easter Seals, MDA, ALS, Parkinson, ALS
23. Non profits who provide local respite services in Austin.
24. ARC, more non profits, church orgs, faith based
25. Yes
26. Medical personnel/nurses and doctors/ rehab professionals
27. Medicaid Community, HMO's
28. Cancer Society
29. The mental health professionals were missing.
30. This needs to be open to the general public, not invite only. Held in several locations around the state. Maybe go back to multi-location town hall events. Use live webcast technology, etc.
31. No

16. Do you have any comments or suggestions for improving future summits?

Answered: 23 Skipped: 41

1. Not necessary every year, maybe every 3 years!
2. More discussion on resources in the community
3. Big and better
4. This was quite wonderful but it seemed geared toward children and elderly.
5. More planning time. 1 panel of caregivers.
6. More planning time. 1 panel of caregivers.
7. Assigned seating is great but not in this situation...Visual aids were too far as I was assigned in the back of the room...preference is always up close
8. Highlight the best practices for us to take back to our communities. More emphasis on learning for caregivers
9. Have 2 - 3 speakers/ caregivers come that are dealing with issues that are hot topics in media but very important for public to know of.
10. Do in different cities- San Antonio, Austin, Houston
11. Look at specific case studies and scenarios of need.
12. Shorten length of summit. More info on caregivers for caregivers.
13. Directory of attendees with affiliations is very helpful opportunity for networking
14. Consider more time for better planning
15. Keep Rep. Davis coming back! Chris Greg & Jill
16. This was very well organized so I can't imagine what you could do differently. Possibly hold these seminars throughout the state.
17. Suggestions in the group breakout sessions
18. Seemed that the speakers went too long. The breakout sessions allowed for networking, brainstorming; real work
19. Get the word out to providers.
20. Provide business cards of speakers
21. Two days!
22. More input from caregivers, it was still too bureaucratic.
23. No

17. Are there any topics and/or speakers you would like to recommend for next year's summit?

Answered: 17 Skipped: 47

1. Coops, intergenerational programs, village concept.
2. TARRC could invite Dennis Debloudt on Autism Risk and Safety Management if there are any allowed funds not just for all but all disabilities and out elders
3. Specific with Veterans with PTSD and TBI
4. Dr. Mark Kunik to speak to conversation. Re: h/c providers also addressing needs of the caregivers. Also to inform the strategic planning process.
5. Less speakers more group work
6. Maybe bring in actual provider
7. 2 faith based ministries or organizations
8. Same choice of congressional people, caregivers and public/ private organizations.
9. Role of nurses educating about respite: referrals, cultural and linguistic implications
10. Make panels more diverse related to gender, color, religion, etc
11. Dell Children's Michelle Mirskey family liaison
12. A professional health care provider such as a doctor that is knowledgeable about medical consequences of not taking care of one's self.
13. Members of the legislature that could help fund respite.
14. Joyce did an excellent job!
15. Thank you!!!!
16. I have good knowledge on IDD, cognitive waiver programs and respite for this population. I need help with mental health. I know the YES waiver, but they are even having difficulty locating providers that are willing to serve those with mental health disorders.
17. No

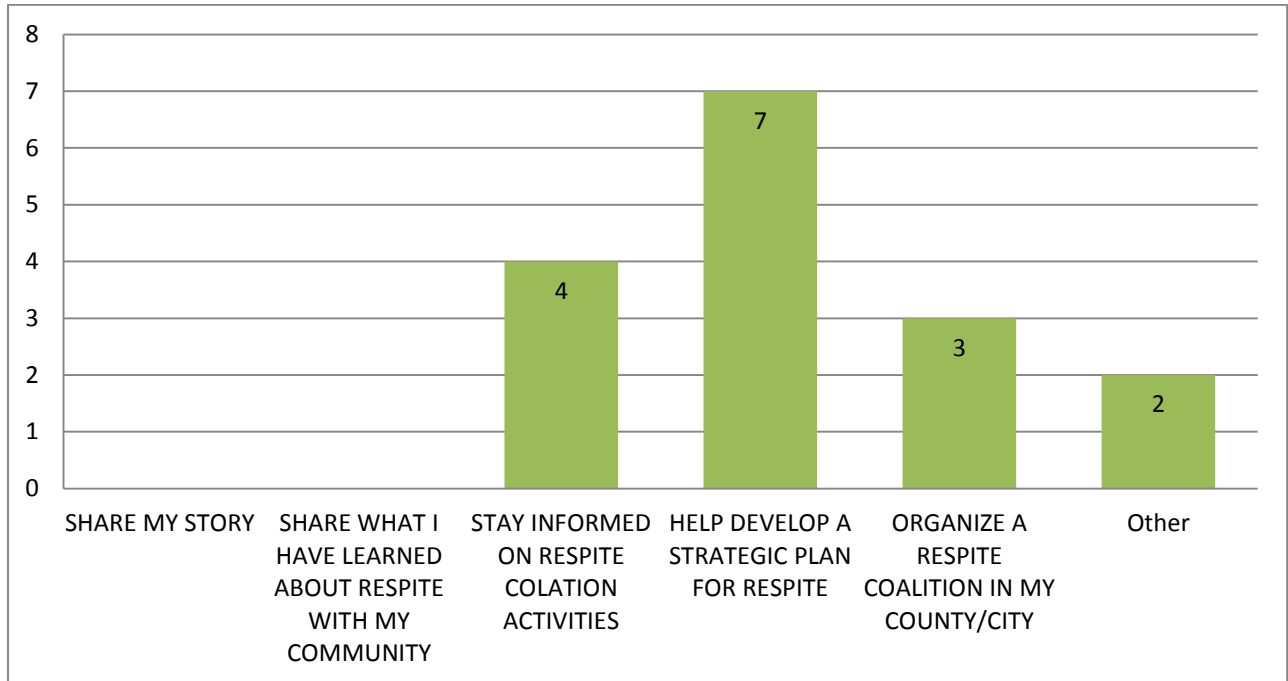
Additional Comments

Answered: 22 Skipped: 42

1. Thanks for all the hard work! Well done!
2. encourage caregiver coalitions to promote respite when they present or provide outreach.
3. Networking opportunities were priceless. Excellent topics/ speakers.
4. Thank you!!!!
5. We are blessed beyond measure, believe me I know this. But some days I want to be away from home. Love keeps me there. But it's hard. Thank you for your kindness in managing the meal around my diet and allergies.
6. This summit was geared mainly towards the professional. I did learn a lot especially the sources of help, as a caregiver. I just hope the "Dream Respite" comes
7. Wonderful day of respite and great opportunity to impact public policy for the unfortunate growing group of care providers. Thanks!
8. Breakout sessions were huge eye openers for me! Learned a great deal during these sessions. Great 1st Annual Texas Respite Summit! Perhaps have caregivers speak after lunch to re-energize speakers was very important to respite care!
9. Great 1st effort! I "assumed" we would spend majority of time working in small groups. Was really looking forward to learning from others and problem solving
10. Need to use media to publicize the respite care summit. Recruit well known seniors (President Bush- Elder) or children to push recognition of respite care needs
11. Very enjoyable and informative! Thank you! P.S. A little too cold.
12. Increased knowledge of the coalition and how things have worked
13. I accept that presenters are knowledgeable on material presented, but what about the person I talk to when I make that phone call or access that website? How well does it work in practice? I have been in a situation where a neighborhood tried to take care of one elderly person. In spite of our best efforts, the task proved too great & he had to go to a nursing home. Without training & with families of our own to take care of, we simply didn't have the resources.
14. Room was too cold, otherwise very educational summit
15. The Summit broadened my knowledge of the array of respite needs and challenges.
16. Joyce & the event team & workgroup did an amazing AWESOME job today for the FIRST of many Texas Respite Summits to come!
17. Great discussions in small groups.
18. Deputy Commissioner should have had more time. City on name tags. Add poster session for speakers/agencies before and after sessions.
19. People started bailing out of the last break so I would restructure it next time. Cookies at the afternoon break would be good.

Texas Respite Summit Post Card Responses

The following data represents responses received from participants regarding possible future collaboration with the Coalition. A total of 16 response cards have been received.



Texas Lifespan Respite Summit

Respite Theme Categories

1. Increased outreach and marketing about respite

- People can't imagine asking for respite- don't think about it
 - Education is needed on term "respite" and benefits
 - It makes a difference how a message is framed
- Top Priorities
 - \$ - value driven program with metrics
 - Education and Awareness
 - People do not know what respite is until they really need it
 - Develop an elevator speech
 - People have internal turmoil about seeking respite
- Community Outreach (students, churches, nonprofits)
- Accessibility to respite – get the word out
- State agency websites that are easy to find and navigate – accessible
- People need to understand what respite is
- Easier way to find respite (customer friendly)
-
- Awareness
 - Educate the public through outreach forums for families to learn about respite and available respite
- Public awareness
- Getting word out about respite
- Clear message about respite
- Close trust and knowledge gaps about respite
- Terminology
-
- More marketing, outreach
 - "Don't mess with Texas"
- Respite – Demystify!
- Make sure caregiver KNOWS it is necessary and acceptable to ask for and receive HELP
- Awareness
- Brand Respite or find a word that is the "Kleenex" of facial tissue
- Messaging
- More marketing
-
- Legislative advocacy
 - Including on regts.
 - Needed for healthcare professionals
- Collect family stories and share
- Educate

- What is respite
- Where are resources
- Data – all of us are impacted
- Family caregivers
- Health care providers, including Community Health Workers
- Legislators
- Employer sensitivity training/publications
- AAAs advisory councils
- Bi-partisan approach to addressing the need for respite
- Volunteer groups need to communicate about respite
- Respite needs to be “front and center”
- Get respite stories heard by public (public awareness campaign)
- Education
- Change the word “respite”

-
- Fund Public Service Announcements (PSAs) to increase awareness of needs of caregivers, and for respite
 - PSAs and Outreach
 - AAA/ADRC staff training
 - Webinar on respite
 - Increase staff training on what is respite
 - Get the word out
 - Communicate to broader Texas community
 - More communication with community by TRC
 - Continuous public awareness campaign
 - E.g. don’t mess with Texas
 - Materials, brochures, flyers
 - Be advocate and voice (funding)
 - Family needs permission to accept care
 - People don’t know they need to plan/didn’t have the ability to plan
 - 2nd respite summit to build on this one
 - Include CEUs to attract healthcare professionals
 - Include full spectrum of population affected (Cancer, Easter Seals, MDA, Autism, ARC)
 - Support development of strategic plan
 - Involve all areas of the state in strategic planning process (Regional Groups/Meetings)
 - Coalition can be voice for caregivers

-
- Caregivers recognizing need for respite, having trust and confidence in respite services and using the services
 - Routine, systematic public awareness campaigns
 - Public education on how to access existing services
 - Make more information in how to contact you

- Connect with corporate employee assistance programs/HR
 - Some major corporation join Task Force
 - EAPs guide employees on where to get support when things are going well/impacting work
- Education
- Planning
- 2nd respite summit to build on this one
 - Include CEUs to attract healthcare professionals
 - Include full spectrum of population affected (Cancer, Easter Seals, MDA, Autism, ARC)
 - Include full spectrum of populations – a lot of nonprofits
- Need to make use of respite champions

a. Use culturally sensitive approaches to reach caregivers of various backgrounds (5)

- People don't know what respite is, or how to ask for help
- Hispanic culture- Family is 1st
- It is very hard for individuals in the Hispanic culture to understand respite
- Need to target Hispanic community
 - Translations are awful
 - Cultural resistance
 - Family support is strong but hardest to recognize
- Think about cultural emphasis and meeting needs of diverse populations
- Culturally sensitivity message on respite
 - Electronic mail, verbal communication in services
 - When is it being communicated and what sort of follow up?

-
- Cultural/Demographics (Age, Hispanic, etc.)
 - Availability
 - Marketing
 - Language and cultural barriers
 - Generational differences

-
- Culturally, linguistically appropriate
 - Culturally sensitive respite
 - Culturally sensitive

-
- More literature in more languages and for hearing impaired
 - Follow federal standards (CLASS) for cultural competency

b. Educate health care professionals on caregiver needs and respite (6)

- Doctors and other professionals need to “prescribe it”; educate families on needs
- Care Coordination Physicians

- Medical Home Program with respite as a priority on the referral list
- Disconnect with
 - Coming out of the hospital/medical/non-medical disconnect
 - Care Transition Coaching and Discharge planning

-
- Educate health care professionals
 - Absence of knowledge about respite in health care community
 - MDs, social workers, hospitals

-
- Doctors ask caregiver how they are, not just the person with the need
 - First responder advocate – from diagnosis
 - Social Workers, nurses pastoral care, M.D.s
 - Hospital Discharge Planning
 - Hospital/Senior Centers/Physicians/Pharmacy
 - Open doors of hospitals to all providers of respite care
 - Care Plan by all hospitals, doctors and nursing homes for caregivers

-
- Training for health care professionals on respite
 - Make it mandatory
 - Community Health Workers/Promotoras
 - Collaborate with them to further awareness of respite
 - Expand medical home model
 - Will receive better care and needs of caregiver will more likely be addressed
 - Hospital policy change to allow assessments before discharge
 - People need to walk out of the doctor’s office with a prescription for respite
 - Social worker training
 - Bring in Medical community – top down
 - Care plan in place before discharge

-
- Mandate – every health care professional receive education on caregiver needs and respite upon license renewal
 - Bring together businesses and organizations that are big and educate them about respite (HMOs, AAA, Hospitals, Social Workers, etc., WellMed)

Start respite early (with diagnosis)

-
- **Better discharge planning**

2. Develop One Stop Shop for information on respite

- One stop shop to access all services
- One stop respite request and service
 - Increase selection on website
 - Clearinghouse phone number like 2-1-1

- One/No wrong door respite
- Access to increased knowledge of services = connect
- Not duplicating services
- Be an information repository and pull it together
- More than just a website, answers needed
- 1 Phone call to get appropriate respite care
- All-in-One (under one roof) Care Center – child and person who needs respite
- Multi-tiered support – web/phone

-
- Centralized information
 - ID players, places, populations – no duplication

-
- Develop One Stop Shop
 - Crisis lines need respite information and 211
 - Clearinghouse number/website
 - Like 211 respite
 - Apps, etc.
 - Respite included I distributed letters, e.g. HHSC (DADS, DSHS, TMHP, DARS, etc.)
 - Maximus list

-
- **One-stop respite shopping**

3. Increase funding to make respite more affordable

- There isn't enough respite/funding for respite available
 - We need to know what is already available
 - Respite is not affordable
 - Funding availability based on financial situation – access to waivers
 - People lose access to waivers and Medicaid (\$2 over SSI= lost Medicaid)
- Low cost/ Free
- More and more affordable
- Flexibility and cost
 - Can't pay for respite when patient is sleeping
 - Very costly –won't provide if less than 4 hours

-
- Money/Resources
 - Affordable and accessible respite
 - Adequate respite provider system
 - Funding
 - Financial barriers
 - Funding to cover/provide respite
-

- Affordable
 - Sliding scale with consideration of total health expenses
- Relief when needed without cost concerns
- Affordable
- Income requirement free
- Bottomless pit of \$\$
- Affordability
- Unlimited funding

-
- \$\$
 - ID \$\$ - educate funders on the imperative of respite
 - Collaboration of funding sources to support respite
 - Increase funding for respite
 - No cost, no limit
 - Funding to programs that pay for respite workers
 - Administrative cost **
 - Training, liability, facility
 - Backup plan when funding stops
 - Buy-in from leaders and consumers
 - Need to make use of respite champions
 - SUSTAINABILITY?

-
- What is missing is low or no cost respite for people who fall just above the poverty level
 - Some financial relief so we could stop having to work past retirement age to meet family needs
 - So aged people could stay with families – less costly than nursing homes
 - Affordable rates and lots of family being together
 - No limitations (age, financial, etc.)
 - Affordable respite in every Texas county
 - All citizens get 20 hours paid-AAA
 - All citizens are educated early that past 20 hours they must pay for care
 - Waivers/vouchers/ \$ to assist all who need it
 - Combination public/private funded
 - Less paperwork, processes of eligibility for subsidized assistance
 - The necessary economic help
 - Re-direct resources (\$ and manpower) from projects like light rail to human needs, not legacy projects to satisfy political ambitions
 - Funding
 - Innovative financial model that is not full Medicaid spend down – tiered program
 - Buy-in from leaders and consumers
 - Need to make use of respite champions

- Work to make it easier to keep aging parents, grandparents home with family by creating access to funding for family- min. hours to be paid for care

4. Improve the quality, skills, and pay of paid care providers (training)

- Lack of caregivers to give the direct family caregiver a break
 - How certify caregivers = job skills
 - Reliable/Retention
 - Provider availability
 - Educate the person/provider
 - Higher quality trained providers – behavioral health
 - Wages – low wages, contractors (no benefits) life change of provider to seek better position
 - Wages are not as competitive with other jobs such as restaurant or retail
 - Retention
 - Difficult to put effort into training providers and they leave
 - Have to trust the caregiver
 - Stressed out
 - Trust
 - Guaranteed confidence
 - Training issues
 - Having someone come into your home must trust caregiver
 - One bad apple ruins it all and makes caregiver scared to use respite
-
- Difficult to find staff that can be TRUSTED and that staffing levels are adequate
 - Staff/Staff education (specific conditions)
 - Age appropriate activities
 - Encourage more and better for profit care providers- this would increase # of programs
 - Increase careers, colleges, tech schools
 - Education for caregivers
 - Paid caregiver – give a living wage
 - More providers
 - Training for advanced needs
 - Trust
-
- Livable wage for all staff supporting, advising on respite
 - Trained professionals with incentives for retention
 - Caregiving recognized as a career field with proper pay
 - Trustworthy attendants
 - Accreditation
 - Wages for caregivers
 - Trained professionals paid with incentives

-
- Funding to pay more appropriate wages
 - Funding for more than minimum wage
-

- Need to pay for the care families want for their loved ones
 - Should not be competing with Bill Miller or Bucees for workers
 - State needs to pay a rate that allows employers to offer benefits
 - Spend time training paid caregivers on how to identify, approach and connect the family care giver to resources/help
 - Practitioners (Medical Doctors, Nurse Practitioners)
 - Social Services
 - Direct Care Workers
 - Accessible training for specialized health care needs
 - Licensing requirements
 - CNA Training requirements
 - Respite provider requirements
 - Require credentialing for behavioral health training
 - Education for caregivers about how to hire respite care providers
 - Respite that is predictable
 - # hours/#days
 - Reliable, consistent
 - Quality – honest, trustworthy, competent providers
 - Employers - Go to employers to incentivize employee attendance
 - Difference between a paid caregiver and a family caregiver and they both should be valued
 - Distinguish “family caregiver”: paid caregiver
 - Performance Measures – incentive programs
-

- Staff who really care
- Respite care as a career choice and college, tech school, university degree plans
- Everyone would have good care, great place to stay, great programming
- Unlimited trained staff and volunteers

5. Address issues with Medicaid funded respite and waivers

- Less paperwork determining eligibility
- Cross Agency eval-eligibility and enrollment (standardized)
-
- Not enough hours in waiver programs
 - Finance Standardization of Rates
- #1 unmet need is finance standardization of rates
- Need more flexibility in all the waivers
-
- Waivers, vouchers, \$ assist to all ages, remove gap 22-60
- Medicaid funded respite should be flexible
- CMS needs to fund respite care and make sure it is not a huge ball of red tape
 - Possibly uneducated care providers left out – not all CNAs
-
- Explore options for more flexibility with Medicaid waiver dollars
- Fix billing issues
- More options for Medicaid dollars
-
- State needs to figure out how to use funds to reduce waits on Medicaid waiver list
- Providers are reluctant to provide services as needed in group homes intermittently vs. full time due to Medicaid audit
-
- **Alternative to Medicaid spend down**
- **Less paperwork, processes of eligibility for subsidized assistance**

6. Provide respite that is family/person centered

- Safe, secure, good care, affordable, family oriented
- Level of Need/LOC may change day to day
 - How to find a “true picture”?
- Respite is for the family
 - Family caregiver and the attended are NOT mutually exclusive
-
- Respite consider needs of whole family
- Sibling needs?
-
- **Respite care for the “normal kids” in a special needs family**
- **All inclusive – help entire family**
-
- a. Enhance flexibility of current programs (8)**
 - Portability/flexibility
 - Family Centered/Driven need

- Each family is different

-
- No cost, No limit on hours offered. Can be used on flexible schedule
 - Flexible programs based on need

-
- Explore options for more flexibility with Medicaid waiver dollars
 - Ongoing respite: food prep, housekeeping, toileting

7. **Make respite more available**

- Hours sufficient for family needs
- No cost, No limit on hours offered. Can be used on flexible schedule
- Easy, friendly, available offer at 1st day of caregiving
- Equal availability for all ages
- 24/7 availability
- Immediate access routine and emergency respite: Caregiver and care recipient
- Immediate emotional support
- No interest list/waiting list
- Access to respite for all families, no matter what need

-
- Ensure families in the financial gap have access
 - Respite services allowing parents to let go
 - Distinguish “family caregiver”: paid caregiver
 - Primary caregiver lives out of town/state
 - Easier to obtain
 - No services/funds for middle aged and middle class
 - 20-40 year old middle income fall through the cracks – no waiver
 - Accessible and flexible transportation
 - 30 day-60-day-90 day

-
- Need time off, of course
 - To be able to leave town- take a break, visit my own aging mother and sister who cares for her
 - Have everyone be safe, secure
 - Available equally to all who need it
 - Remove gap from 22 years old – 60 years old
 - Access

a. Increase respite for caregivers of persons with behavioral health needs, especially children (7)

- Care for
 - Children with mental health issues

- Tri-occurring diagnoses
- Veterans
- Respite to provide another set of hands
- Behavioral health
- Respite for kids with a mental health disorder

-
- Providers for children with special needs
 - Children with mental/behavioral needs
-

- Inclusion of providers who can support clients with mental health/illness
-

- Require credentialing for behavioral health training
 - Behavioral component to all respite providers
-

- Respite care for mentally or emotional disabilities
 - Trust is a huge issue
 - Need one to council my patient
-

b. Increase availability of emergency/crisis respite (9)

- Crisis
 - Lack of Emergency Respite
 - Emergency respite
-

- Services for families in crisis/emergency situations
-

c. Increase availability of respite in rural areas (11)

- Hard to get respite in rural areas
-

- Equal availability in rural areas
 - Non-urban services/location
 - Not enough service providers in rural areas
-

- Meet needs in rural and urban areas
 - Accessible for urban and rural
-

- Accessible for urban and rural
-

- Available equally in rural counties

8. Explore best practices and alternative models for providing respite

- Respite “system” should include a network of peers for support
 - Alternative solutions
 - Care coordination for whole family
 - Increase collaboration among providers and partners
 - Copy what other people are doing
 - Caregiver training/peer support for new caregivers
 - Built in support from the beginning of caregiving experience
 - Respite Ombudsman
 - Include network of peers for support
 - Instead of hourly, monthly rate to fit needs
 - Alternative approaches available
-
- Use best practices from other successful programs/efforts
 - Use Care.Com to find paid caregivers
 - Include cost of membership in benefit
 - Explore ways to simplify Consumer Directed Services by using existing sites (Care.com) and services, such as payroll taxes, background checks
 - Creating volunteer base for Respite Coalition
 - Collaboration between partners and providers
 - Collaboration of nonprofit and for profit
-
- Increase parent to parent = “sisterhood factor”
 - Develop metrics
 - Access-easy
 - Family caregiver satisfaction
 - Home Care Foundation
 - PAS – elder, New Braunfels
 - Let’s not re-invent the wheel – use existing resources
 - Partner with AoA and other coalitions for performance measures
-
- Have VA respite be a special event (as well as nursing homes, etc.)
 - A meal, a skeet shoot, a movie, something that is not sitting in a room of droolers and poopys
 - Have an “in-home” respite of a massage, pedicure, etc. for the disadvantaged or the caregiver. It would be cost effective
 - Entertainment
 - Hobby opportunities and education for caregivers during their respite time
 - Health care
 - Entertainment
 - A forum for caregivers to share (pool) their resources
 - Fun activities, age appropriate, for those receiving care
 - Encourage volunteerism in our youth and young adults
 - Innovative financial model that is not full Medicaid spend down – tiered program

- Let's not re-invent the wheel – use existing resources

9. Develop and enhance family and community collaboration

- No need for formalization...people helping people
 - The care/service of people drives
 - NOT a system – true community support
- “The Village” concept/co-ops/people helping people – community spirit
 - Village concept/Co-op/Service Array
- More understanding that is a family/community joint effort
- Address isolation of caregivers
- Building natural supports / true “gift” of time
- “The business”; decrease the commercialization of the gift/caregiving
- Collaboration
- Integration nonprofit/for profit

-
- People to visit
 - Involve