



Nevada Lifespan Respite

Summit Report

Friday, June 29, 2012

Submitted by: Cheryl Dinnell, Coordinator,
Nevada Lifespan Respite Care Program

To: ARCH National Respite Network & Resource
Center

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Executive Summary

The Nevada Lifespan Respite Summit held on Friday, June 29, 2012, was successful in bringing stakeholders together, sharing information, and providing a networking opportunity for participants, despite encountering technical difficulties with videoconferencing between three sites. Otherwise, Nevada had an incredibly successful, highly prepared and well organized summit. Our national guests were impressed by the level of commitment, engagement and energy that emerged at the end of the day among participants (as illustrated by the large number of individuals who stepped forward to assume leadership positions in various workgroups.) In total, 102 attendees participated in the Summit, attending one of the three sites in Elko, Las Vegas, or Reno.

The Summit opened with Welcoming Remarks & Introductions by Rique Robb, President of the Nevada Lifespan Respite Care Coalition. At the beginning of the Summit, five caregivers shared their personal stories and described their need for respite. These were very moving stories, and several Summit participants were eager to receive copies of the Caregiver Panel comments. Since the Summit, all the panelists have supplied their written comments and signed media releases so that their personal stories can be added to the Family Stories section of the NevadaADRC.com/Lifespan Respite site.

The Summit also included presentations on the status of respite in Nevada, and updates on the activities related to the Lifespan Respite grants. Mary Liveratti, Administrator, Aging & Disability Services Division, Betsy Aiello, Deputy Administrator, Division of Health Care Financing & Policy, and Robin Williams, Director of Community Services, Rural Developmental Services, spoke of respite programming and the funding currently available in Nevada. Cheryl Dinnell, Coordinator, Nevada Lifespan Respite Care Program, spoke about Nevada caregivers and what the program has learned about them, and Cheyenne Pasquale, ADRC Project Manager, Aging & Disability Resource Centers, gave an overview of the ADRC programs, the NevadaADRC.com website and the lifespan respite resources that will be available there. These presentations helped set the stage for group discussion on the current status of Lifespan Respite in Nevada.

In the afternoon, presentations on Lifespan Respite from the national perspective were given. Greg Link, Program Officer, Administration on Aging, spoke on the future structure and funding of Lifespan Respite grants, and Jill Kagan, Program Director, ARCH National Respite Network & Resource Center addressed best practices and models of Lifespan Respite from across the nation. With these ideas and perspectives to consider, participants were prepared for further discussion about the future of Lifespan Respite in Nevada, and engaged in identifying the next steps forward.

The Summit's primary purpose was to generate the thoughts and ideas of participants in breakout sessions where groups of approximately 15-25 people each met to discuss and share personal perspectives on several questions. In the morning breakout session, 6 different discussion groups identified existing supports and services, and identified strengths, barriers and unmet needs. In the afternoon these same groups discussed the role of the Nevada Respite Care Coalition, identified others who need to be a part of the Coalition, identified characteristics of the Lifespan Respite system they wanted for Nevada, and discussed what steps needed to be taken to achieve it.

These discussion groups were facilitated by teams of facilitators, who lead the discussion and captured the information generated by the group. Each group reported back to all the full audience of Summit participants, via video-conferencing technology. Facilitators also worked together to generate a list of commonly mentioned themes, which were then presented and voted on by the participants at each site. Each selected theme required a “champion” to help continue the future work and discussion on that theme, and several individuals stepped forward to accept those roles. Each site generated a different set of priorities, as would be expected by the diversity at each site and the geographical realities of people residing in different parts of the state.

Evaluations and discussion summaries have been prepared and tallied, and are included in this report. Overall, participants rated the Summit on effectiveness as a 4.22 on a 5-point scale. Based on participant feedback, the Summit was very effective and increased the participants’ knowledge in the subject matter.

In follow-up meetings after the Summit, planners and participants hoped that everyone who participated would recognize that the one-day Summit could not provide enough time to fully process the information provided, nor generate more than major themes for future activity. The Summit provided a beginning to Nevada’s future activities. Any indication that the goals identified or selected at the Summit represented consensus or represented all the ideas generated in the discussion groups would be incorrect. These major themes are only developed as starting points for future discussion and work.

In addition to the work of the Summit, Nevada submitted its third proposal to the Administration on Aging for Lifespan Respite funding, and recently received notification that Nevada received one of the awards. The Summit report will also provide useful information and guidance to those future efforts.

Summit Agenda

Nevada Lifespan Respite Summit Agenda

8:30-9:00 AM Registration

9:00-9:15 AM Welcome/Introductions

- Rique Robb, President, Nevada Lifespan Respite Coalition

9:15-9:45 AM Panel Presentation – Respite from a Caregiver Perspective

- Camilla Downs, Marge Purdy, Bonnie Timmreck, Nora McGinley, Robbin Vasquez

9:45-10:00 AM Status of Respite in Nevada

- Mary Liveratti, Administrator, Aging & Disability Services Division

- Betsy Aiello, Deputy Administrator, Division of Health Care Financing & Policy

- Robin Williams, Director of Community Services, Rural Developmental Services

10:00-10:30 AM What Nevada knows about Caregivers

- Cheryl Dinnell, Coordinator, Nevada Lifespan Respite Care Program

10:30-11:00 AM Lifespan Respite & ADRC Portal

- Cheyenne Pasquale, ADRC Project Manager, Aging & Disability Resource Centers

11:00-11:10 AM Break

11:10-11:50 AM Morning Breakout Session

- Share your role/connection to respite services

- What already exists to assist families in accessing respite?

- What is missing? Challenges, barriers, and unmet needs

11:50 AM-12:15 PM Breakout Session Report

12:15-1:00 PM LUNCH PROVIDED BY:

- Silver & Blue Catering
- Nevada Center for Excellence in Disabilities
- Great Basin Coffee
- Aging Services Director's Organization—Las Vegas
- Joe's Lunchbox

Nevada Lifespan Respite Summit Afternoon Agenda

- 1:00-1:30PM Lifespan Respite in Nevada: Three Years of Growth & Progress
- Greg Link, Program Officer, Administration on Aging
- 1:30-2:15 PM Engaging Collaborative Partners in Lifespan Respite Programs
- Jill Kagan, Program Director, ARCH National Respite Network & Resource Center
- 2:15-2:25 PM Break
- 2:25-3:05 PM Afternoon Breakout Session
- What should Lifespan Respite look like in Nevada?
 - What needs to be done to move forward?
 - Who else needs to be part of this Coalition to ensure that all family caregivers are served, regardless of age or disability?
 - What role should the Respite Coalition take?
- 3:05-3:30 PM Breakout Session Report
- 3:30-4:00 PM Select Goals
- 4:00-4:30 PM Future Steps in Respite for Nevada
- 4:30-4:50 PM Committees Formed
- 4:50-5:00 PM Final Addresses

Background

The ARCH Lifespan Respite Technical Assistance Center, funded by the US Administration on Aging, assists a limited number of states each year with on-site training events or “Lifespan Respite Summits”. One of the purposes of a Summit is to bring state respite coalitions or organizations, Aging and Disability Resource Centers, and state agencies together to collaborate with each other and with private and public state and community-based agencies, respite providers, and family caregivers to strengthen a grantee state’s implementation efforts and build collaborative partnerships after a Lifespan Respite grant has been received. Nevada has received two Lifespan Respite grants, both in the final year of operation.

In December 2011, the Nevada Aging & Disability Services Division requested a grant from the ARCH National Lifespan Respite Technical Assistance Center to hold a Lifespan Respite Summit in Nevada. The sustainability of any Lifespan Respite programming would depend largely on the collaboration of the Nevada Lifespan Respite Care Coalition, its members, the Nevada Aging & Disability Resource Center, and the Nevada Aging & Disability Services Division. Bringing these key stakeholders, and others vested in the future of respite, together in a forum to discuss the future of Lifespan Respite was considered an important next step.

The Nevada Aging & Disability Services Division, in cooperation with the Nevada Lifespan Respite Care Coalition, chose to hold the Summit on June 29, 2012, via video-conferenced sites in Elko, Las Vegas, and Reno. This would facilitate greater participation of key stakeholders who would otherwise be unable to travel long distances necessary to join the event. The three sites were hosted by the Cleveland Clinic in Las Vegas, and the Nevada University Center for Excellence in Disabilities in Reno and Elko.

The Summit was organized and coordinated by Cheryl Dinnell, Nevada Lifespan Respite Care Program Coordinator. The agenda was developed with assistance from Jill Kagan and Maggie Edgar of the ARCH National Lifespan Respite Coalition, members of the Nevada Lifespan Respite Care Coalition, and representatives from the Nevada Aging & Disability Services Division. Summit planning was accomplished with the assistance of Diana Rovetti of the Nevada Center for Excellence in Disabilities, several members of the Respite Coalition, and representatives of various state agencies.

Summit registration was available online through support by Jill Kagan at ARCH. Registrants were asked to identify themselves by role as a caregiver, respite care provider, non-respite caregiver services, or interested others. Twenty-nine individuals identified themselves as caregivers; 39 registrants listed themselves as respite providers; 28 people stated they provide non-respite caregiver services; and 49 individuals said they were “interested others.” Descriptions used to designate these categories are included in the appendix.

Promotion of the Summit was supported by Coalition members, the Nevada Aging & Disability Services Division, and through presentations by Cheryl Dinnell at various organizational meetings. Efforts were made to have representation from a broad list of agencies, programs, and caregivers representing all ages and disabilities, and Summit planners did their utmost to encourage attendance from across the state to ensure geographic representation. Interest in the Summit was actually higher than could be accommodated by the various sites, so Reno and Elko were closed to new registrations in the week before the Summit. In total, 145 registrations were received.

Lunches and snacks were provided by a variety of donors, as neither Nevada Aging & Disability Services Division nor ARCH could pay for food. Nevada Senior Services provided their status as a 501(c)3 tax-exempt

organization to assist with fundraising efforts, and the Coalition applied for funding from the Aging Services Directors Organization. A grant for \$750.00 was received, as well as gift card donations from corporate sponsors (Safeway, Costco, and Walmart). The Nevada University Center for Excellence in Disabilities generously provided lunch in Reno and Elko. Other Coalition members donated water and other snacks at the various sites. Appropriately, all donors, volunteers, and invited guests received a personal thank you card for their contribution to the event.

Parking permits, special accommodations, and caregiver stipends were provided to make it possible to participate in the Summit. ARCH funding provided the caregiver stipends, as well as some of the supplies needed. Caregiver stipends ranged from \$100-150, depending on need.

Meeting content was designed to include information about the Lifespan Respite law, existing sources of federal respite funding sources, and model state Lifespan Respite programs, with the goal of preparing the state agency to work in collaboration with the state respite coalition and the ADRC to apply for future federal Lifespan Respite grants.

The potential impact of the Summit would be in the statewide networking and coalition building, the results of collaborative efforts to improve Lifespan Respite in Nevada, the valuable education of other stakeholders on respite and its related issues, and the maximization of existing resources for respite and the development of new respite resources. The Respite Coalition wanted the Summit to help it develop priorities for its activities, and generate potential legislative priorities for the upcoming 2013 legislative session.

Breakout Session Discussion

What are some of the strengths of the respite system in Nevada?

When participants considered what already exists to assist families in accessing respite, the responses could be grouped in the following categories: Referral Sources & Information Outlets, Funding for Respite, Advocacy & Support for Caregivers, Programs of Professional & Volunteer Providers, and Informal Sources of Respite

Referral Sources & Information Outlets

While the Aging & Disability Resource Centers and Nevada 2-1-1/Crisis Call line were frequently mentioned, other referral sources included resource fairs, resource publications, the NevadaADRC.com website, the Caregiver Coalition of Northern Nevada, and the value of “word of mouth” promotion. Support groups and peer mentoring programs such as Family TIES of Nevada, and Nevada PEP were also identified as good sources. The Lifespan Respite Care Program and the Nevada Lifespan Respite Care Coalition were also listed as information and referral sources.

Funding for Respite

While some participants felt the funding resources for respite were not evenly distributed around the state (some areas are apparently deemed as not having as great a need for funding as other areas), there was recognition of several voucher programs and available respite funding under Older Americans Act, Title III-E,

Funds for a Healthy Nevada, through Nevada Mental Health and Developmental Services, and the Lifespan Respite Expansion Grant (LRBI). RAVE Family Foundation, Alzheimer's Association, and Elvirita Lewis grants were also mentioned under funding of respite.

Advocacy & Supports for Caregivers

Nevada Legal Services and Save Our Seniors were mentioned as advocacy organizations that serve people with special needs. Parent-to-parent and peer mentoring programs such as Family TIES of Nevada, Nevada PEP, Alzheimer's Association, and Multiple Sclerosis programs provide emotional support and guidance. Other resources mentioned were preventative programs through Health Maintenance Organizations and other insurance programs.

Programs of Professional & Volunteer Providers

This list includes Adult Day Health Care, Adult Day Care, and geriatric care centers, Personal Care Agencies (PCA), Home Health Care agencies, early memory loss programs, and children's programs such as Children's Cabinet, RAVE, Head Start, Easter Seals, Olive Crest Foster program, and the Foundation for Positively Kids. The Veteran's Administration Medical Center and skilled nursing facilities were also mentioned. These were all seen as having a role in assisting families in accessing respite.

Informal Sources of Respite

Participants identified many places and programs where someone other than the primary family caregiver were providing care and assistance for people with special needs, and were in effect providing respite by relieving caregivers temporarily of care. The list included transportation services, school districts, churches and faith communities, recreational programs and camps, in-state and out-of-state travel programs, and the efforts of extended family, friends, and neighbors. Self-sufficiency of the caregivers was cited as a reason these informal sources were utilized for respite.

What are the barriers, weaknesses and unmet needs of the current respite system in Nevada?

Participant responses have been grouped as follows: Funding & Respite Caregivers, Getting the Word Out, Programmatic Challenges, Overcoming Caregiver Resistance, and Building Partnerships.

Funding & Respite Caregivers

Finding personnel and having a way to support them was most frequently mentioned by participants. A pool of respite caregivers, either as volunteers or professionals, who are ready to serve, was seen as crucial. Volunteer resources still need some funding and infrastructure for recruitment and support, as volunteers still need stipends or reimbursement for food or transportation costs. The limited population base in frontier areas of Nevada makes it difficult to recruit volunteers.

Getting the Word Out

Highest mention went to having a central source for all the respite programs that really covers all parts of the state, although it was noted that the NevadaADRC.com website is currently in development and will hopefully help address this need. Very little currently listed is for rural Nevada.

Having a comprehensive list still does not address the need to promote respite, and that lack of promotion got the second highest mention among discussion groups. The visibility of respite programming, the education of caregivers about respite, the public education through TV, public forums, and public service announcements, were all considered as important but missing in the current system. Support for “word of mouth” promotion of respite should also have a place among hospitals, discharge planners, doctors, social workers, emergency services, support groups, during the intake/enrollment processes of many state services, and as part of the transition process between services.

Caregivers may recognize their own needs better and utilize respite more fully, if they were identified as caregivers earlier. Caregiver support groups do not promote respite. The lack of information on respite and the lack of up-to-date information on respite resources were both listed as problems in promoting respite. Social media outlets and other marketing strategies are not being used, and communication about respite with legislators is lacking.

Programmatic Challenges

When participants listed barriers to respite, programmatic challenges in the current system to qualify caregivers for respite were frequently mentioned. Eligibility guidelines, service categories, lack of clarity in defining respite or who gets it, lack of understanding and institutional support of a respite philosophy that all caregivers deserve respite - these all form hurdles in accessing respite. The turn-around time to receive additional respite funds after funding is depleted is too long. Participants stated that respite should be based on need, not income.

Participants complained about extensive paperwork demands, high turnover in staff, complex rules and red tape, insensitivity to language barriers and cultural differences as additional challenges. Some programs require information that stops potential clients from using the program. Nevada is geographically a rural state, but still has not overcome the challenges of transportation to receive or deliver services, or how to cover the large distances between communities. There currently is not a way to match fund sources to appropriate providers.

Programs need to treat the family, not just the specific member of the family. The “average Joe” family is as deserving of respite as the disease specific or income specific priorities placed by other programs.

Some participants cited a lack of coordination between respite programs to optimize utilization, eliminate redundancy in programs, and avoid the negative impact of program closures. Also mentioned was the need to be able to increase wages for respite caregivers, to make respite a career track that has some incentive to workers.

Gaps in Services & Coverage

Multi-generational or compound caregivers particularly have a need for a broad general respite program that covers all care recipients (instead of very specific subsection of the population), but all caregivers need to have consumer choice and flexibility in the use of the respite resources. People helping those who live alone cannot currently get respite at all. Too many people who should be served fall through the gaps.

The gaps in respite services represent lack of partnership in developing specialized resources. Lack of trained respite providers, including nursing staff, and lack of in-home respite care options for clients with specialized

medical care needs for dementia, autism, or medically fragile children and adults were also mentioned as missing or needed. There is also a need for emergency respite options and hospice respite care.

Overcoming Caregiver Resistance

Getting caregivers to use and accept respite requires strategies to overcome their resistance to it. Participants recognized that many issues around trust, denial, cultural pride, guilt, language barriers, and some of the personal information that is required to apply, stop potential clients from using respite programs. Lack of trust in the respite program staff or concerns about the quality of training they receive are other reasons respite resources are not utilized by caregivers.

The fears of caregivers, that the care recipient will be unhappy or poorly cared for during the separation, and all the planning involved in having someone else provide care create barriers for caregivers, even if they know they need it. Respite requires preparation, whether provided at home or away. It involves good communication and some navigation around other services. There are also not enough support groups or programs where caregivers are taught about respite and where caregivers can help other caregivers. Participants felt that more faith-based communities need to recognize the need for respite and render assistance, and might have more success in overcoming caregiver resistance to respite.

What should Lifespan Respite look like in Nevada?

The most often mentioned model was the Oklahoma Lifespan Respite program, probably because it seemed to represent a combination of several priorities for Lifespan Respite in Nevada. The discussion has been grouped in the following categories: One Simplified Place for Respite, New Partnerships, Marketing & Information Dissemination, and Data Driven Priorities.

One Simplified Place for Respite

Comments all referred to having one place, maybe the NevadaADRC.com portal, to shop for respite options, to apply for respite funding through one administrative portal, where information on all respite options existed. This one site would handle referrals and use one general application for all agencies, to simplify paperwork and capture data on an on-going basis. Since not everyone is Internet-savvy, alternatives would include downloadable information that could be distributed to potential clients. Through one administrative portal for respite, new funding amounts could be handled on a more frequent, quarterly basis, rather than having a long interval to wait once funds are depleted. Voucher programs were popular among participants, and if Lifespan Respite was all one program, multi-generational, with vouchers that allow for flexible, creative use, Nevada might see increased use of respite.

New Partnerships

Lifespan Respite generally needs more people to be brought to the table, and several new partnerships were recommended. The list includes partnerships with local businesses and web-based entities, healthcare providers, discharge planners, child welfare, faith-based organizations, casino groups, university systems, hospital case managers, AARP, rural communities, and all county, area, and state agencies. New partnerships could open programs between profit and nonprofit organizations, to serve more people with special needs. Lifespan Respite needs advocates everywhere and more evidence of community-agency collaboration around respite.

Marketing & Information Dissemination

Participants were frustrated that so much of the Lifespan Respite system could not be easily seen or understood. Requests for a comprehensive resource guide, a book shared between all agencies and disseminated to all service organizations, that provides a “family tree” on respite programming and puts all the pieces of the pie together in one place. One place suggested was the NevadaADRC.com portal where self-directed searches could be conducted and services could be arranged or determined via the Internet. An alternative suggestion would be to have Aging & Disability Resource Centers provide CDs/DVDs to assist potential clients in their search for respite resources.

Marketing of respite needs a focused communication plan, where resources are identified and marketed through public education platforms. Public service announcements on respite would help raise awareness, so caregivers would be encouraged to use respite before finding themselves in crisis. Since information is so lacking for both caregivers and respite care providers, making people aware of training opportunities that support respite would also be important use of a good marketing and communication system. Mention was also given to having “culturally sensitive” materials on respite.

Data Driven Priorities

While no one questions the importance of respite to specific groups of caregivers, most funding of respite seemed driven by the popularity or preference of only certain areas, income levels, or conditions, leaving the “average Joe” with a respite need without any options. Lifespan Respite needs a system where information is collected on the respite services used and available, where more research is done on respite and its relationship to caregivers, where accountability of respite provision is driven through data, where every caregiver is a priority, and where funding decisions reflect that. Other funding of respite would be possible if Nevada had data for projections on cost savings from respite. Any Best Practice Model that Nevada develops or adopts would need to be supported by data.

What are the Next Steps for Lifespan Respite in Nevada?

Summit participants engaged in lively discussion around the role of the Respite Coalition, expanding representation on the Respite Coalition, and what were the important next steps for Lifespan Respite. The Summit discussion led to the organization of several regional workgroups, around specific topics that were selected for further exploration and activity. Additional items were also mentioned as possible steps that Nevada might take, and are listed here:

1. Conduct research on Best Practice Models for Lifespan Respite. Oklahoma’s model was most frequently mentioned, but participants recommended a review of all other Lifespan Respite programs nationwide to see what might fit Nevada best.
2. Take action to eliminate the “must live in the same home as patient” provision which prevents some caregivers from getting respite.
3. Develop more support groups, or expand their reach (conference calls, webinars, etc.), so more caregivers are supported and helped by other caregivers.
4. University credit for “field experience” that provides respite for caregivers.
5. Investigate licensure issues around the provision of respite care.

Each Summit site generated their own list of goals, champions for those goals, and volunteers for future committee work. The Nevada Lifespan Respite Care Coalition would help organize and find support for these future efforts so that reports on future activities would be shared across the state. Some of the Summit groups may find it prudent to join with other groups on similar goals and objectives.

Elko Goals/Champions/Committees

Need for trained caregivers and respite providers - (13 votes)

Methods for recruiting respite providers – (5 votes)

Outreach and marketing – educating local communities and agencies about what respite is - (4 votes)

What is the respite coalition and how do we get rural representation? - (6 votes)

More representation from all areas/counties of rural Nevada. (13 votes)

I. RECRUITMENT & TRAINING OF PROVIDERS

Champion: Pam Wynes

Volunteers for committee: Martha Schott-Bernius, Karen Taufer, Jan Link, Mona Carter (available for consultation), Abby Wheeler, and Jan Brizee.

II. EXPANSION OF RURAL REPRESENTATION ON COALITION

Champion: Jan Brizee

Volunteers for committee: Darla Baldwin, Kimberly Schmeling, Michelle Huddleston, Martha Schott-Bernius, Mona Carter, Barbara Barrett

Las Vegas Goals/Champions/Committees

I. EXPAND AND BROADEN COALITION (DIVERSIFY) – (17 votes)

Champion: Sherlene Simpson

Volunteers for committee: Gina Jolliff, Judy Padilla, Alicia Davisson, Jan Brizee

II. COMMUNICATION/EDUCATION/MEDIA – (16 votes)

Champion: Stephanie Kuewa

Volunteers for committee: Gina Jolliff, Sue Cook, Ms. Lou Critchfield, Cory Lutz

III. (TIE) ADVOCATE LEGISLATION – (12 votes)

Champion: Jeff Klein

Volunteers for committee: Sherian Brooks, Joseph Brooks, Carol Matrone, Linda Nowell, Jan Crandy

(TIE) DIVERSIFY FUNDING SOURCES – (12 votes)

Champion: Melissa Thrower

Volunteers for committee: Creston O'Bryan, Joseph Brooks, Cheyenne Pasquale

IV. EXPAND SERVICES TO 19-64 YR OLDS –(11 votes)

Champion: Cheyenne Pasquale

Volunteers for committee: Jan Crandy, Linda Nowell, Donsetta Blakely, Carolyn McClune, Melissa Thrower, Carol Matrone, Sherrie Adams-Ambre (GAB)

V. DEVELOP STATEWIDE MARKETING PLAN – (7 votes)

Champion: Samantha Jayme

Volunteers for committee: Albert Chavez, Judy Padilla, Melissa Thrower

Reno Goals/Champions/Committees

I. DEVELOP COMMUNICATION & MARKETING PLAN (Education/ Develop Message)

Champions: Laura Coger, Jill Andrea, Lisa Bonie

Volunteers for committee: Diana Rovetti, Jeff Dold, Robin Williams, Amy Cinkovich, Roswell Allen, Renee Portnell

II. DATA BASE RESOURCE – updated (ADRC)

Champions: Evan Miller, Cheyenne Pasquale

Volunteer for committee: Wayne Alexander

III. EASY ACCESS TO INFORMATION AND RESOURCES LIVE!

Volunteers for committee: Vicki Puccinelli, Denise Hund

What role should the Respite Coalition take?

1. The Nevada Lifespan Respite Care Coalition needs to be more representative of all existing respite programs, and should E-blast all Summit registrants about coalition meetings with an invitation to attend. New partnerships should be developed, and many recommendations are included in this report.
2. Outreach and Marketing – Educate communities and agencies about what respite is, understanding cultural differences and targeting specialized information about respite to specific populations. Develop public service announcements to raise awareness.
3. Training and Education – Identify training needs for respite staff, including cultural sensitivity training. Utilize centers, libraries, or technology-based training to get to as many people as possible. Offer Continuing Education Credits. Provide training about respite for support groups, faith-based and other community organizations.

4. Challenge politicians (especially in voting years) about the priority placed on respite for caregivers and other caregiver supports. Illustrate the savings that caregivers create for Nevada. Involve legislators in Coalition activities.
5. Find new resources and funding for respite to increase funding pots, instead of splitting them up. Identify new funding partners (such as casino groups) to broaden the pool of resources for respite. Collect funds privately and distribute in grants or vouchers.
6. Direct the work of various taskforce, workgroups, and committees. Develop reports on these activities that can be shared and used for advocacy efforts.
7. Become directly involved in the recruitment of workforce – both direct support staff and volunteers. Provide orientation training for caregivers and respite workforce.

Who else needs to be part of this Coalition to ensure that all family caregivers are served, regardless of age or disability?

The list is long and varied, and new partnerships have already been recommended in this report, but mention was also made of: AARP, big corporations and their employee programs (regarding employed caregivers), politicians, pharmacy companies, faith-based organizations (Interfaith Council), school districts, children’s agencies, children day care centers, YMCA, Parks & Recreation programs, adaptive recreation programs, foster care, media, medical and insurance companies, veteran’s and military programs, university and public education programs, service organizations (such as Rotary), civic organizations, Boys & Girls Club, advocacy groups (ALS, Cancer Society), Brain Injury Association, Medicaid, county social services, Aging Services Directors’ Organization (ASDO), Division of Child & Family Services, legislators, other government offices, and the participation of many more caregivers.

This concludes the report of the Nevada Lifespan Respite Summit. Handouts from presentations, caregiver panel comments, and other materials distributed at the Summit are available upon request.

Appendix

List of Attendees & Registrants

Evaluation Results

Overall

Elko

Las Vegas

Reno

Definitions of Roles for Registration Purposes