

**DRAFT California Lifespan Respite Care Summit Notes and  
Interest Parties in Follow up Activities  
September 23, 2009 from 11am to 4PM  
Holiday Inn Burbank Media Center 150 E. Angeleno Ave., Burbank CA 91502**

Summit attendees were asked to complete a pre-test and post-test to assess their understanding of lifespan respite before and after Lifespan information was presented.

Jill Kagan with ARCH National Respite Network and the National Respite Coalition was introduced by Mike Huckins, President with the California Respite Association. She and the other sponsors of the summit were thanked for their generous support. Other sponsors included The Valerie and Jacob Langeloth Foundation, National Certified Insurance and Philadelphia Insurance Companies.

Rachel Ford, a parent to two young men with special needs and a daughter of a dad with mental health needs spoke of her family's journey and challenges in the search for respite.

Jill Kagan led us through the agenda to help us understand what Lifespan Respite is and how the Lifespan Respite Care Act of 2006 came to be. She summarized how other states are providing this lifespan system of care to provide relief care to primary caregivers who have family members with special needs: all ages, all disabilities and all chronic illnesses.

In the afternoon, the main group broke into three groups to discuss the 5 Breakout Session Questions as follows: Each group took turns reported back on each question and the other two groups filled in what had not been discussed already:

**Question 1:** Identifying State Respite Barriers: What is needed for families to access respite services in CA? Please identify existing barriers and unmet needs.

**Combined responses:**

Population size of California is over 10% of the nation's population  
Geographic size of California is also very large  
California has gigantic urban areas as well as rural areas which affects providing respite  
Financial ability to pay (on a sliding scale basis) as it relates to families with need  
Funding for Respite Agencies  
CA Lifespan Respite Legislation would have to be cost neutral due to current fiscal crisis  
Lifespan Respite Act funding is not enough yet to make it a serious federal program  
Lack of information (no one stop place)  
Fragmented services along age lifespan  
Language/cultural barriers  
Education: (What to ask for or to understand what respite can do for families)  
Families not connected to any agency (don't know who to call)  
Families do not identify as caregivers  
MediCal/Insurance Community is not working with Social Service (respite) community

## Health System

Service Systems do not communicate effectively

Competition toward limited funding

Caregivers having to leave the workplace to care for their person with special needs

California has yet to tap all resources (federal, etc)

Employer/IRS issues

Payment for Service alternatives to Voucher like Employer of Record respite

## Unmet Needs:

Mental Health, Severe physical disabilities, anything outside of developmentally disabled,

Traumatic Brain Injury that does not occur by age 18

**Question 2:** Strengthening the State Respite Coalition: Who else needs to be part or to collaborate/partner with the CA Respite Association to ensure that all family caregivers are served regardless of age or disability? Be as specific as possible, providing names, organizations and contact information (e.g. State Mental Health agency, child abuse agency, MS Society State Chapter)

AARP CA

Adult Day Programs

Adult Protective Services

ALS

Alzheimer's Association

APDA

Area Agency on Aging (Linkages; Multi-Service Senior Program)

Assisted Living or other facilities to help meet emergency respite needs

Autism Society

CAHSAH (California Home Health Aides Association)

California Caregivers Coalition

Child Protective Services

Community Childcare Council

Caregiver Resource Centers

Developmentally Disabled Services Agencies to Dept. of Dev. Services

Family Primary Caregivers and Clients with Special Needs

Grandparents as Parents

Health Services/Hospitals

IHSS/PASC

LGMF

Mental Health

Military (Respite funding now)

Multiple Sclerosis Society

National Association for Mental Illness

Olmstead Committee

Regional Centers

Stroke Victim Stakeholders

Targent Center USC  
Traumatic Brain Injury  
UCEDD the MIND Institute (Autism Research)  
Union Representation  
Universities (LE USD)  
Veterans Administration  
YMCAs

**Question 3:** Building the California Lifespan Respite System: Based on what you learned about other state lifespan respite programs, which structure would be best for your state's Lifespan Respite program? Do you think it should function like any of the programs in Arizona, Nebraska, Wisconsin, Oregon or Oklahoma Based on your identification of barriers and unmet needs, what services should CA's Lifespan Respite program provide to overcome these obstacles? (refer to state comparison chart for the different systems)

Two of the three groups concurred that California should be a collaborative effort between major stakeholder much like Oklahoma; One of these group felt that in order to collaborate with government agencies, the state coalition or association would need to be a non-advocacy group. One group felt we should be like Wisconsin and be the lead agency in the state.

Lead Agency possibilities:

Caregiver Resource Centers: 11 centers, 25 years experience

Aging and Disabilities Resource Centers: two agencies with 5 years experience (San Diego and Del Norte Counties) and several new So. Cal, SF ADRCs under development

California Respite Association: 25 years experience, but grassroots volunteer organization focusing mostly on respite for the developmentally disabled although mission is broadly defined to include any population with special needs

California Department of Health and Human Services(Agency) as it includes many of the major stakeholders (two groups suggested this)

A Coalition of Coalitions representing independent agencies

Larger questions: Do we want a state agency?;  
California infrastructure exists—let's use it

**Question 4:** Preparing for Federal Application: In the short term, what should the CA Respite Association and its collaborators be doing to prepare for federal funding of a statewide Lifespan Respite Program? Is state legislation necessary?

We already have infrastructure and some state legislature (Lanterman Act for DD populations)

Have brainstorm/summit with all stakeholders (go back to question number 2 and get groups)

Create feasible timeframe and standards

Formulate mission

Combine resources and statistics

Learn to supplement but not duplicate the service system that currently exists

Build caregiver awareness through a telephone access

Build a recruitment and training network to provide more qualified respite workers statewide

Expansion of CA Coalition—continued roll of coordinating stakeholder in planning

**Question 5:** Role of the State Coalition in Planning as well as Implementation (a) As a first step, with which federal application requirements can the CA Respite Association provide help or leadership? (b) In the long term, what role should the CA Respite Association play when it assumes joint responsibility for the State Lifespan Respite Program with the Aging and Disabilities Resource Centers and which tasks or responsibilities would you include for the CA Respite Association in the “memorandum of agreement”? (e.g., coalition could run the whole state program; provide I and R; train and recruit providers; conduct needs assessment; or be solely focused on advocacy)

In-kind match of Lifespan Respite Grant with volunteerism and office space

Respite Worker Training

Survey for unmet needs

Information and Referral

Assist in creating and maintaining collaboration

Assist in updating databases, telephone information and referral (multi-lingual) with respite resources

Advocacy as appropriate

Most of initial money will need to be used to create a coordinated statewide system of care for respite.

Waiting list for underserved populations to document need for future funding.

**Attendees interested in being involved with post Summit activities related to pursuing Lifespan Respite in California**

Katy Santillan, Imperial Valley Respite and Inland Respite

Mike Huckins, California Respite Association

Sue Wiggins, Sonia Corina dba Bay Respite

Louise Bruce, The LaChris Connection

Joy Scott, Tri-County Respite Care Services  
Kevin Rath, Manos Home Care  
Shelley Crayton, Family Support Services of the Bay Area  
Sharon Matland, ALS Association  
Rachel E. Ford, Solano County Mental Health  
Sharon Fallis, UCEDD The M.I.N.D. Institute