

Washington D.C.
Respite Summit Report

July 2012

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Table of Contents

Summit Announcement..... 3

Agenda.....4

Breakout Session Reports

Questions.....5

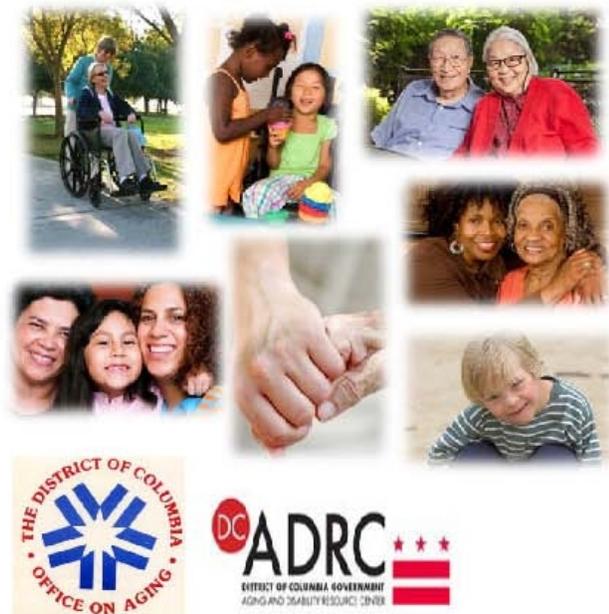
Next Steps.....9

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DC Lifespan Respite Summit

A Summit for Family
Caregivers, Parents, Respite
Providers, Community Groups
& Agencies

July 18th, 2012
9:00 AM – 4:00 PM
DC Office on Aging/
Aging Disability Resource Center
500 K Street N.E.
Washington, D.C. 20002
(202) 724-5626



The Lifespan Respite Program, funded by the US Administration on Aging, was established to help states expand, enhance, and coordinate respite services. The DC Lifespan Respite Program works to meet these goals and serve all family caregivers. This program includes, but is not limited to, individuals, families, and children affected by developmental disabilities, other disabilities, mental health issues, aging, chronic illness, or abuse.

Join us **July 18th, 2012**, for this **FREE *working meeting*** to learn about Lifespan Respite, coalition building, and to enhance and find continued support for a coordinated ***District of Columbia Lifespan Respite system***.

The event is **FREE**, but please register online at the **ARCH [DC Respite Summit Registration](http://www.arch.memberlodge.org/Events)** site (<http://www.arch.memberlodge.org/Events>)

Space is limited so register early! Limited stipends may be available for family caregivers. Lunch on your own. For more information, please contact Linda Irizarry at linda.irizarry@dc.gov or by phone at 202-724-5626.

With support from:



This project is supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services and endorsement by the Federal Government should not be assumed.

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**DC Lifespan Respite Summit:
Strengthening DC's Lifespan Respite Program
July 18, 2012
8:30 am - 4:00 pm**



- 8:30-9:00 am Registration**
- 9:00-9:15 Welcome and Introductions**
- *Camille Williams, Chief of Staff, DC Office on Aging*
 - *Chantelle Teasdell, Ph.D., Aging and Disability Resource Center*
 - *Kaseka Mukendi, Director, D.C. Caregiver's Institute*
- 9:15-10:00 Respite...What a Relief**
Respite from the family caregiver perspective
- *Mrs. Daniels, family caregiver of a child with a disability*
 - *Mr. Cain, family caregiver of an adult with a disability*
 - *Mrs. Parker, family caregiver of an aging person*
 - *Dr. Crewe, family caregiver of aging person with Alzheimer's*
- 10:00-10:30 The Lifespan Respite Care Program: Supporting DC's Family Caregivers**
- *Greg Link, Program Officer, Administration for Community Living/AoA, Washington, DC*
- 10:30-11:00 The Baseline: Status of Respite in DC**
- *Linda Irizarry, Project Lead, DC Lifespan Respite Program*
 - *Chantelle Teasdell, Ph.D., DC Aging and Disability Resource Center*
 - *Robin Exton, Medicaid, DC Department of Health Care Finance*
 - *DDS*
- 11:00 -11:30 Facilitated Breakout Session: *What is the status of respite services and funding in your community?***
- 11:30-12:00 pm Breakout Session Report**
- 12:00-1:00 Lunch on your own**
- 1:00-1:45 Engaging Collaborative Partners in Lifespan Respite Programs**
- *Jill Kagan, MPH, Program Director, ARCH National Respite Network and Resource Center*
- 1:45 pm-2:45 Facilitated Breakout Session: *What are the next steps for the DC Lifespan Respite System?***
- 2:45pm-3:15 Breakout Session Report**
- 3:15-3:45pm What have we learned today? Goals/Next Steps/Action**

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Morning Session

Question 1- Please share your connection to respite services. Do you offer respite services in your area or are you a family caregiver who uses respite?

The different groups consisted of service providers such as social workers, nurses, and other community based organizations. The other participants were caregivers across the lifespan that have used respite services within the District of Columbia.

Question 2- What systems or help already exist to assist families in accessing respite?

- Eight hours of respite under the state plan.
- 20 days of respite every year.
- D.C Caregivers Institute
- Adult Day Care Center
- Support groups and workshops
- Trainings at Caregiver Institute
- Flex spending account
- Court ordered support for neurological testing
- Overnight care outside the home(limited access)
- Medical based wellness skilled care

Question 3- What is missing? What are the challenges, barriers, and unmet needs?

There isn't a gap in resources in terms of case management for children. Also participants felt that there wasn't a proper definition of respite.

- The challenges regards to respite providers were:

- culture differences
- no quality assurance,
- the nursing assistants are not trained properly
- they believe some are using drugs
- the spend down is unfair
- Knowledge of respite resources and funding availability.
- waiting list are too long
- The unmet needs is therapeutic services to help release guilt
- Not enough hours
- Insufficient hours for children
- Training and recruiting of providers

Afternoon Break Session

Strengthening Collaboration- Who else needs to be part of or partner with the DC Respite Coalition to ensure all family caregivers are served regardless of age or disability? What should the role of the coalition be in the DC Lifespan Respite program?

The participants felt that these organizations/agencies should be a part of the coalition:

<ul style="list-style-type: none"> • Department of Mental health • Department of Human Services • Child and Family Services Agency • Health Care Finance • EPA 	<ul style="list-style-type: none"> • ODR • UCEED- Tony Fisher • The ARC • Children's Hospital • Bill Gates Foundation 	<ul style="list-style-type: none"> • Faith based organizations • Universities • Health Services for Children with special needs • Make a wish organization • DDS
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The role of the Coalition for the DC Lifespan Respite Program should be:

- To enhance the respite system by more program oversight, an advisory group, and program evaluations.
- Raise public awareness about caregiving issues and program.
- Helping with the affordability of respite care.
- Being a liaison between coalition and community agencies
- Information & referral

Question 2- Enhancing the DC Lifespan Respite System- What should a Lifespan Respite system look like in DC? Based on what you know and learned today, which overall infrastructure would be best for DC's Lifespan Respite Program?

- A clearer understanding of how to access services
- Increased available training and education
- Assessment for both caregiver and client & their environment
- Expand services to all families

Question 3- Building the Services- Based on identified strengths, barriers, and unmet needs, what services should the DC Lifespan Respite Program provide to overcome obstacles or build on strengths?

- Communication
- Training and recruiting providers
- Increasing involvement in advocating for higher standards
- Increase continuity of care
- More therapeutic services

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Question 4- Ensuring the Program's Future: What needs to be done to move forward and to find and sustain funding for the program when the federal grant expires?

- Increase advocacy

I think the groups ran out of time.

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Next Steps/ Suggestions:

- Have a complete list of respite providers
- Expand the network of respite providers to include non/for profit organizations and local universities.
- Have cultural trainings for nurses and personal care attendants.
- More understanding of the different diseases caregivers deal with
- Respite coalition to include more government agencies
- More advocacy and legislation for caregivers
- Assessment and case management for caregivers
- Consumer rating system
- An increase of community outreach
- Facilitate family meetings
- Coordinate with other DC government agencies to fundraise and raise awareness about caregiving.
- Give out flex spending vouchers
- Structured activities for the persons being cared for instead of just “babysitting”
- Services for the blind and/or hard of hearing.
- Buddy System

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