

**Florida Lifespan Respite Alliance (FLRA)**  
**Florida Lifespan Respite Summit**  
**Meeting Minutes for June 15, 2017 from 8:45AM – 4:30PM**

Prepared by: Kasey Cunningham, FLRA Program Coordinator

**ATTENDEES:**

Jean Sherman, FLRA Board President, FCC, FDCC  
Horton Townes, FLRA Board Vice-President, St Paul Handicapable Ministry  
Lisa Bretz, FLRA, Board Secretary, AAANF  
Christine Kucera, FLRA Board Member, DOEA  
Connie Siskowski, FLRA Board Member, AACY  
Kasey Cunningham, FLRA Program Coordinator  
Terry Rhodes, OPFF  
Jill Kagan, ARCH  
Victoria Wright, ACL  
Kathleen Cowan, DCF  
Valerie Breen, FDCC  
Michelle Cyr, AARP  
Jeff Smith, APD  
Representative Larry Ahern, FL House of Representatives  
Shayra Rosario, FL House of Representatives  
Jody Armstrong, Disability Achievement Center  
Cydnee Dennison, Special Olympics FL  
Beverly Burton, Area Agency on Aging – Pasco Pinellas  
Virginia Ruf, AFIRE, Family Caregiver  
Chris Eavans Ruf, AFIRE, Care recipient  
Evelyn Johnson-Taylor, Family Caregiver, author  
Kim Zeche, Family Caregiver  
Christine Brower, Family Caregiver, Handicapable Ministry  
Gena George, AAAPP, SHINE  
David Gollins, Alzheimer's Association  
Doug Long, FLUMC  
Amanda Singleton, Family Caregiver, Singleton Legal  
Pauline Lipps, Family Care Council  
Mary Smith, FND Manasota  
Jackie Tatsk, Retirement Living by Design  
Lil Collier-Balfanz, Family Caregiver, FUMC  
Nicole Day, Area Agency on Aging  
Bernadette Homan, Arden Courts  
Lenora Wynn, Devereux  
Jessica Wynn, Empowering Families and Communities  
Sally DePalma, The One Roof Initiative, Family Caregiver  
Elizabeth Perkins, FLCIC – USF  
Karen Berkman, CARD – USF  
Pamela Heyer, United Way- Palm Beach Community Coalition

Beth Potter, FL United Methodist Conference  
Pat Greely, Family Caregiver  
Brian Greely, Care recipient  
Paula James, Family Care Council  
Susan Fontaine, Bay Care Faith Community Nursing  
Karyn Rizzo-Jimenez, Aging in America

## DISCUSSION POINTS:

- **Update from Administration for Community Living – Victoria Wright**
  - An overview was provided on the Lifespan Respite Care Program
  - Development of the program as well as current work were discussed.
  - 35 states and the District of Columbia have been awarded the Lifespan Respite grant through ACL.
  - The initial 3-year grants have helped states develop or build upon respite infrastructure
  - An additional grant is available to current state grantees which will require states to provide gap-filling respite services to family caregivers, and to work with ACL to develop program performance and outcome measures.
  
- **Update from ARCH National Respite Alliance – Jill Kagan**
  - An overview was provided of family caregiving statistics from around the nation and in the state of Florida.
  - The Lifespan Respite Care Act definition of respite was shared
  - Discussion of respite, including benefits and barriers
  - The Lifespan Respite definition is: Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.
  - Discussion of systems building and examples from multiple states
  
- **Update on Current Grant Program- Kasey Cunningham, Christine Kucera**
  - Overview of FLRA development and current work, including website and public service announcement development
  - Overview of Florida's RELIEF program, current status and goals
  
- **Work Group Action Session:**
  - The whole group divided into 5 smaller, action groups to identify respite resources, and gaps in service.
  - Each group listed family respite resources, including the ages, types of disabilities served, where service is provided (home or center/facility), and the city/county where it is located.
  - Each group also discussed/listed next steps for improving the accessibility of respite services in the regions.
  
- **Family Caregiver Panel**

- Family Caregiver panelists: Amanda Singleton, Christine Brower, Evelyn Johnson-Taylor
- Panelist experience included – care of a parent with terminal illness, short term care of spouse with disability; long-term care of spouse with traumatic brain injury (stroke); long-term care of spouse with rare neurological disease.
- Each panelist provided a discussion of the following:
  - the person for whom care is provided including his/her age, condition and relationship to caregiver.
  - Type of care provided and how long doing it.
  - Experience with respite care and what respite care means to family.
  
- **Update from American Association of Caregiving Youth – Connie Siskowski**
  - Connie Siskowski provided an overview of the work of the AACY.
  - A brief video was shared showcasing the goals of the organization and several youth caregivers currently involved with the group.
  
- **Faith based panel**
  - Panelists included Horton Townes, Handicapable Ministry and Sally DePalma, OneRoof Initiative
  - Each panelist shared how their program started, as well as how long it has been in existence
  - They described the type of respite provided, the number of people served and the types of disabilities seen – both programs serve a diverse population of different ages and disability types
  
- **Community Coalitions Panel**
  - Panelists included Michelle Cyr of the Tampa Bay Community Coalition and Pamela Heyer of the Palm Beach Community Coalition. Peter Kaldes of the Broward Community Coalition provided a written overview of their development and current work.
  - Each panelist discussed the purpose/goals of their coalition and how respite is included.
  - Each coalition representative will continue to collaborate with the FLRA as the regional hub for their location.
  
- **General Discussion/Wrap Up**
  - The group came together as a whole to discuss the formation of regional hubs.
  - It was determined that the 3 community coalitions represented will serve as regional hubs for the FLRA.
  - Evaluations and surveys were completed.

## **ACTION STEPS**

- 1. Kasey Cunningham will follow up with all attendees to provide membership confirmation.**
- 2. Kasey Cunningham will meet with Lisa Bretz to coordinate the Northwest Florida Community Coalition/regional hub.**
- 3. All surveys will be submitted to Terry Rhodes.**
- 4. FLRA general membership meeting will be scheduled to take place after August 30. Kasey Cunningham will coordinate.**
- 5. Formalized scope of work/roles/responsibilities will be created by the FLRA board to be implemented with regional hubs.**
- 6. All partners will be invited to FLRA general membership meetings.**
- 7. Ongoing identification of respite resources to be added to the ADRC database will be continued. New resource information will be provided to Kasey Cunningham.**
- 8. Follow up with faith based initiatives and all identified resources will be conducted by FLRA.**