

Sustainability Planning Learning Collaborative



March 22, 2024

Susan Janko Summers
sjsummers@archrespite.org

Repurposing the Sustainability Learning Collaborative

1. Reach new Lifespan Respite grantees and leaders and support them in sustainability planning
2. Connect Lifespan Respite sustainability planning activities with National Strategy goals
3. Continue to provide peer-to-peer support in identifying and addressing challenges to sustainability planning, and to celebrate progress and successes

Sustainability Issues and Challenges

1. Everyone wants their good work to continue, but *few have committed* to do the *comprehensive long-term systems planning* that increases the likelihood that their good work will continue.
2. If respite leaders don't develop a *comprehensive and strategic written plan* that serves as a guide and working document, and that evolves over time, progress may be *piecemeal*, and will be *subject to threats*.
3. The National Lifespan Respite Network is welcoming many *new members* who are unlikely to have the connections, deep historical and experiential knowledge, or infrastructure available that will support them in sustainability planning.

A Systems Focus for Infrastructure and Sustainability

LIFESPAN RESPITE CARE ACT

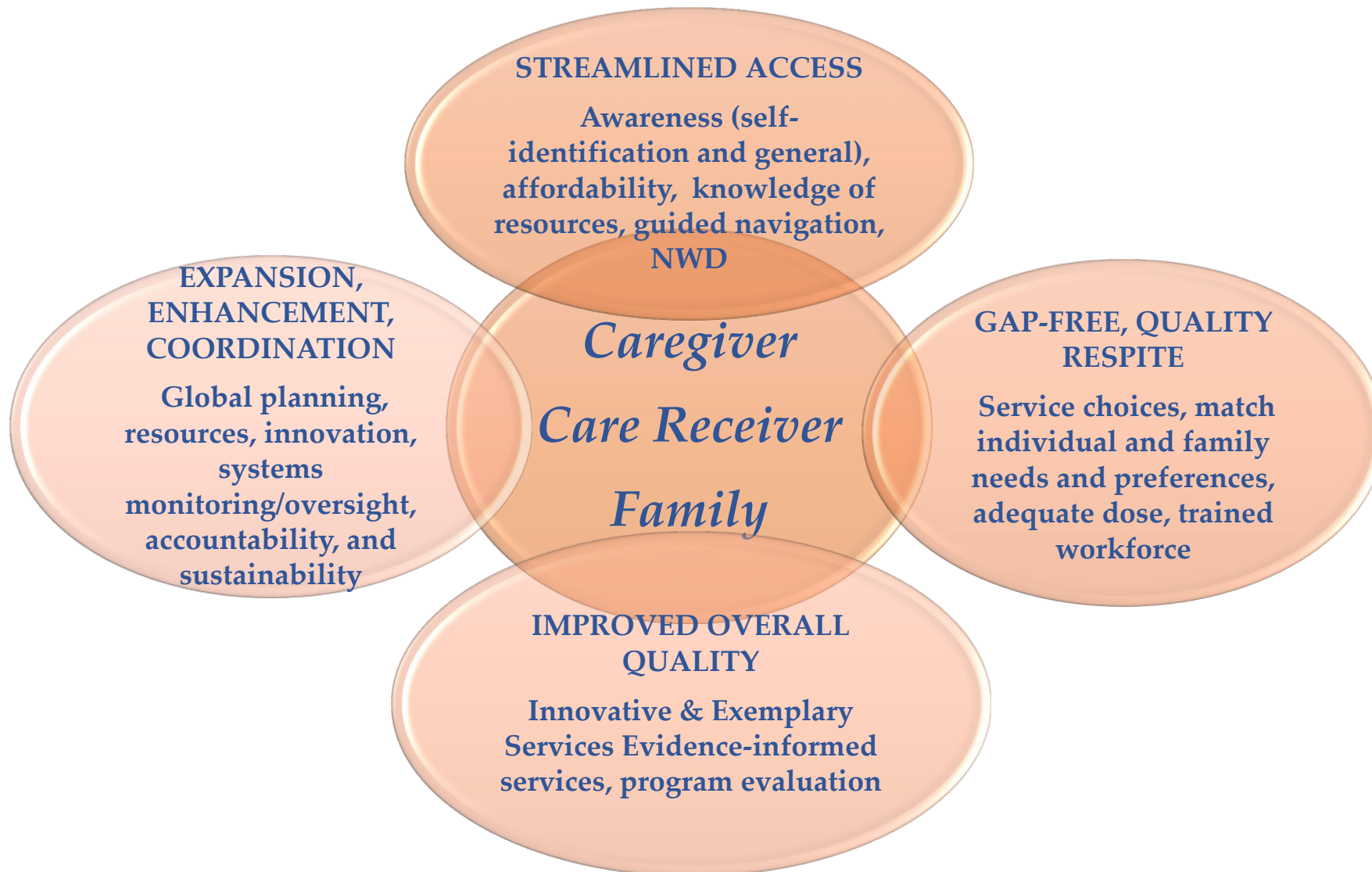
Defines lifespan respite care as:

Coordinated systems of accessible, community-based respite care services for family caregivers of children or adults with special needs.

FIVE OBJECTIVES

1. Expand and enhance respite services in the states;
2. Improve coordination and dissemination of respite services;
3. Streamline access to programs;
4. Fill gaps in services where necessary; and
5. Improve the overall quality of respite services where available.

Person- and Family-Centered Sustainable Systems



A Systems Focus for Infrastructure

NATIONAL STRATEGY

The Strategy, developed jointly by the Advisory Councils established by the **RAISE Family Caregiving Act** and the **Supporting Grandparents Raising Grandchildren Act**, with extensive input from family caregivers, the people they support and other stakeholders, includes nearly 500 actions that can be adopted at every level of government and across the public and private sectors to ensure that family caregivers—who provide the overwhelming majority of long-term care in the United States—have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others.

FIVE MAIN GOALS

1. Increase awareness and outreach;
2. Build partnerships and engagements with family caregivers;
3. Strengthen services and supports;
4. Ensure financial and workplace security; and
5. Expand data, research, and evidence-based practices.

The National Strategy

Strengthen Services and Supports



- Increased person- and family-centered, trauma-informed, and culturally competent services
- **FLEXIBLE AND ACCESSIBLE RESPITE CARE**
- Education, counseling, and peer support
- Access to safe homes, nutritious meals, transportation, and technology
- Leverage volunteers for family caregiver support
- Family caregivers' and care recipients' needs addressed in emergency response
- Resources to improve planning for future care needs
- Increased support for the direct care workforce
- A child welfare system that recognizes kin- and grandparent-led families

Aligning Lifespan Respite *and* The National Strategy

1. Expand and enhance respite services in the states;
 2. Improve coordination and dissemination of respite services;
 3. Streamline access to programs;
 4. Fill gaps in services where necessary; and
 5. Improve the overall quality of respite services where available.
1. Increase awareness and outreach; (LR 3)
 2. Build partnerships and engagements with family caregivers; (LR 2)
 3. Strengthen services and supports; Outcome 3.2: Family caregivers can obtain respite services that meet their unique needs. (LR 1, 2, 3, and 4)
 4. Ensure financial and workplace security; and
 5. Expand data, research, and evidence-based practices. (LR 5)

Threats to Sustainability

- No formal, written sustainability plan
- Piecemeal planning
- No historical record of respite work
- Isolated leaders
- Concentrated leadership
- Planning groups without broad representation
- Planning groups without clout
- Planning groups lacking shared purpose and meaning
- Changes in funding or resources
- Changes in government structure
- Unstable partnerships



Sustaining Lifespan Respite Systems:
Lessons Learned and Practical Applications
with a Checklist for Success

Lifespan Respite Network Resources *and* Forces for Change



- ❖ First-hand knowledge and expertise in legislative policy
- ❖ Deep knowledge from long-term successful grantees
- ❖ Archived ARCH resources (documents, webinars)
- ❖ Incentive from the National Strategy
- ❖ Need from new Lifespan Respite grantees and partners

Next Steps

How do we engage new grantees and Lifespan Respite Leaders ?

Are webinars a good way to support colleagues in engaging in comprehensive Sustainability Planning?

- If so, what content should webinars present, and in what order?*

Do we need a real-time problem solving learning collaborative in addition to webinars?