



Solidifying the Bedrock of Successful Lifespan Respite Care Programs

Delaware Division of Health and Social Services
Division of Services for Aging and Adults with Physical Disabilities
(DSAAPD)

a presentation by Kate Rasulova



40.6 million

53 million

341, 276, 740



43% of caregivers are the **sole providers of care**, typically spending **20 hours** per week on caregiving duties

53% of family caregivers work **full-time jobs**, meaning they must balance their caregiving and workplace responsibilities

Nearly half (**47%**) of caregivers receive **no formal support**, such as financial aid, counseling, or respite care, despite **88%** saying they **need more help**

Family caregivers suffer **≈2% higher rates of depression** than non-caregivers of the same age (statistically significant difference considering group sizes)

Family caregivers suffer a **63% higher mortality rate** than non-caregivers

Current Caregiving Situation

“High-quality respite is one of the most requested needs of caregivers, but gaps in the availability and affordability of access are significant. For family caregivers, respite can mean different things and be received in numerous ways. Input from the Advisory Council members and stakeholder listening sessions all agreed on **one fundamental fact about respite: it must be meaningful to the person receiving it.”**

Outcome 3.2: National Strategy

124,000+ people serve as **unpaid family caregivers** for their aging parents, spouses, and other loved ones

81% of caregivers belong to a **low-income** household

43 personal care and home health **aides per 1,000 adults** aged 65 and older



Caregiving in Delaware

“If you aim at nothing, you will hit it every time.”

ZIG ZIGLAR

FOUNDATION

2018 Recognize, Assist, Include, Support, & Engage Family Caregivers (raise) Act



"Family caregivers often say they **need a “break” from caregiving**." **"Respite services** give family caregivers that temporary break, so they can have time to care for their own well-being and mental health."

"Many caregivers have great need for support, which is often unaffordable or unavailable. Volunteers have long been a mainstay of the LTSS system providing respite, meal delivery, transportation, and social interaction while being relatively cost effective for both programs and families. **Expanding volunteer opportunities** can both increase the availability of direct supports and create a path for expanding the **direct care workforce.**"

FOUNDATION

2022 National Strategy to Support Family Caregivers

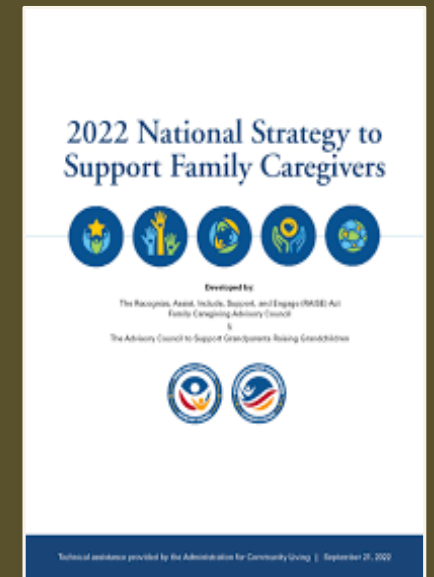
“Researchers can also **evaluate barriers**, such as operating hours, compliance with accessibility requirements under multiple federal disability civil rights laws, and legacy licensing requirements to look for ways to expand the number of community settings where respite can be provided.”

“Encourage clinicians and providers to conduct formal **assessments of family caregiving needs**”

“Goal 3: **Strengthen services and supports**”

“Goal 5: Expand data, research, and **evidence-based practices**”

“**Community-based providers** of long-term services and supports play a critical role in delivering essential services and supports for family caregivers. The recommendations and actions contained in this Strategy offer a roadmap for their own program development in support of family caregivers.”

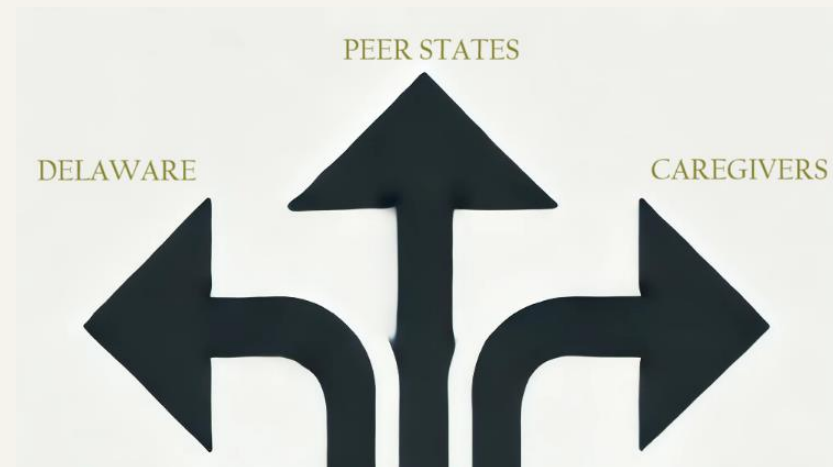


RESEARCH

FULL PROCESS



PHASE 2 DETAILS



DELAWARE ASSESSMENT

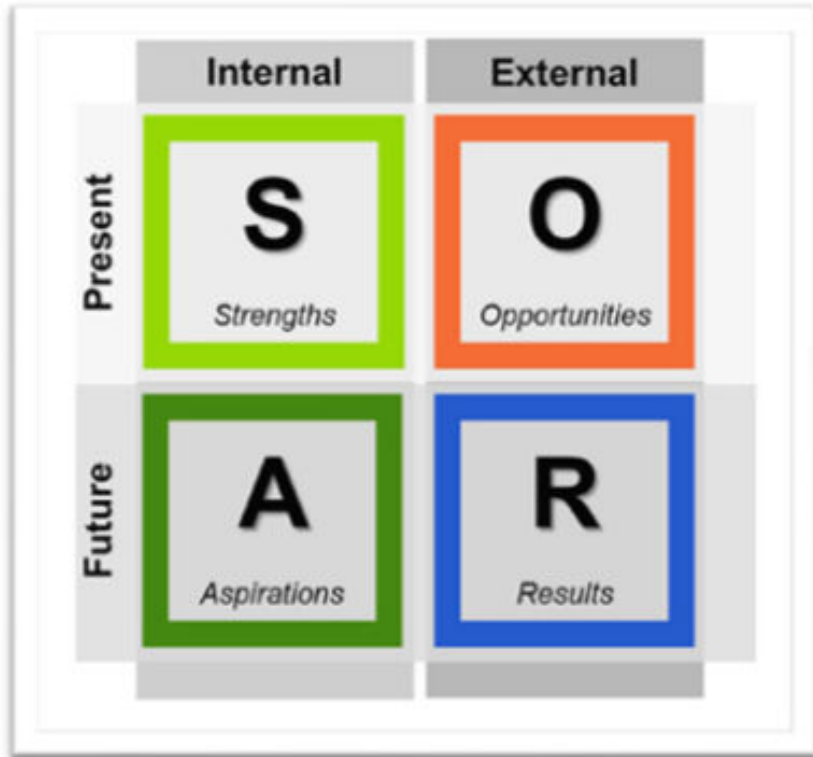
Delaware Respite Program Evaluation

Program	Population(s) Served	Respite Services Offered
For Pete's Sake	Cancer patients ages 21-55	<ul style="list-style-type: none"> Offers a Travel Respite Program for adult cancer patients, their caregivers, and their children to spend time together in an environment away from their home. Provides respite resources and financial support for families unable to travel due to advanced stage cancer through the Staycation Respite Program. Offers complimentary in-person events for respite recipients and donors / volunteers.
HarborChase	Older adults (ages not specified)	<ul style="list-style-type: none"> Provides services in Wilmington, Claymont, and Talleyville. Offers short-term respite in a congregate setting. Treats guests as full-time residents, given access to all the amenities, benefits, and experiences of the community.
Home Instead	Adults 18-plus	<ul style="list-style-type: none"> Offers respite care by sending an in-home care professional after an assessment, customized care plan, and caregiver match. Offers 24-hour home care and overnight caregiving services to the sick, disabled, or elderly. In-Home Senior Care Services include personal care, hospice support, meal prep and home helper, transportation, and companionship.

BEST PRACTICES ²

Document Type	Document Title by Best Practice State
Policies, Procedures, and Specifications	<u>Alabama</u> <ul style="list-style-type: none"> Alabama Lifespan Respite Resource Network, Voucher Guidance Document, 2010
	<u>Nebraska</u> <ul style="list-style-type: none"> NE Lifespan Respite Network- Crisis Respite Eligibility Criteria, 2013
Tools and Templates	<u>Alabama</u> <ul style="list-style-type: none"> Providing Breaks for Family Caregivers: A Toolkit for Volunteers and Faith Communities, 2013 Alabama Retrospective Pre and Post Test Survey Form AL Respite Survey Recruitment Letter to Agencies, 2010 Respite Survey Cover Letter for Family Caregivers, 2010 Respite Survey Cover Letter for Service Providers, 2010

1 PROGRAMS



Scope

Strengths

- What internal capabilities and resources does DSAAPD excel at?
- What elements can the DSAAPD team leverage and/or build on to achieve target goals?

Opportunities

- What areas can create new avenues of evolution and assist DSAAPD in meeting overall goals?
- What operational gaps exist that, if addressed, can help DSAAPD achieve quality outcomes for staff and program participants?

Aspirations

- What does DSAAPD want to achieve in the future that would build on its strengths and inspire staff and make life better for those served?
- What are DSAAPD's values, purpose, and vision for the future?

Results

- What are the outputs of achieving DSAAPD's vision for the future?
- What elements will indicate that DSAAPD is achieving its goals?

SOAR FRAMEWORK

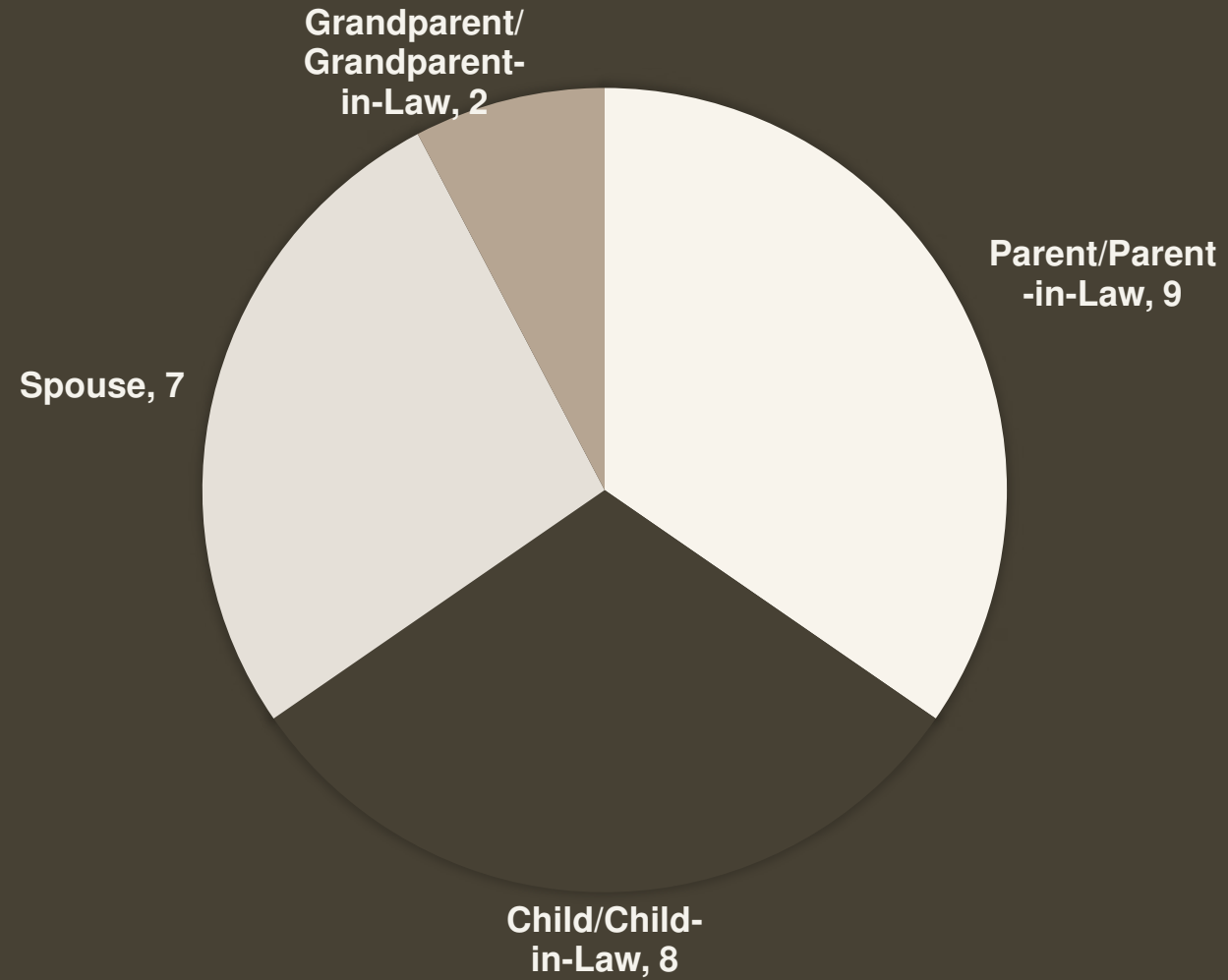
DE RESPITE PROGRAM EVALUATION

Evaluation Factor	Best Practice	Clear	Not Clear	Not Applicable
Clear Administrative and Operational Policies / Procedures	0	0	4 (80%)	1 (20%)
Resources / Training Available and Address Known Challenges and Caregiver Realities	0	0	4 (80%)	1 (20%)
Continuous Quality Improvement through Quality Data Collection and Reporting	0	0	4 (80%)	1 (20%)
Program Design Expands Access to Respite	0	0	0	5 (100%)
Voucher System that Effectively Provides Respite	0	0	3 (60%)	2 (40%)
Enhanced Service Menu	0	1 (20%)	2 (40%)	2 (40%)

CAREGIVERS



Caring For:



HIGHLIGHTED RESOURCES

Administrative

The Alabama Lifespan
Respite Resource Network
("Alabama Lifespan Respite")

Educational

Arkansas Lifespan
Respite Training

Promotional

Colorado Caregiver
Awareness Campaign

Interactive

Massachusetts Lifespan
Respite Coalition's Family
Caregiver Respite Service
Needs Questionnaire



Respite Knowledge

- Caregivers **lacked a clear understanding** of the Lifespan Respite Program
- One Caregiver used the Lifespan Respite program, a few others had heard of it and respite more broadly, and **all caregivers wanted to learn more**
- Caregivers reported feeling overwhelmed due to **challenges finding, navigating, and filtering through caregiving resources**



Benefits of Respite

- Most caregivers **discussed the emotional and mental drain** from caregiving, resulted in feelings of depression for a few
- Caregivers mentioned the possibility of **burnout from caregiving**
- Most caregivers identified their **lack of personal time** to get exercise and attending doctor's appointments as benefits for the respite program
- Several caregivers described their **lack of connection** to others and time to invest in relationships as reasons to take a break



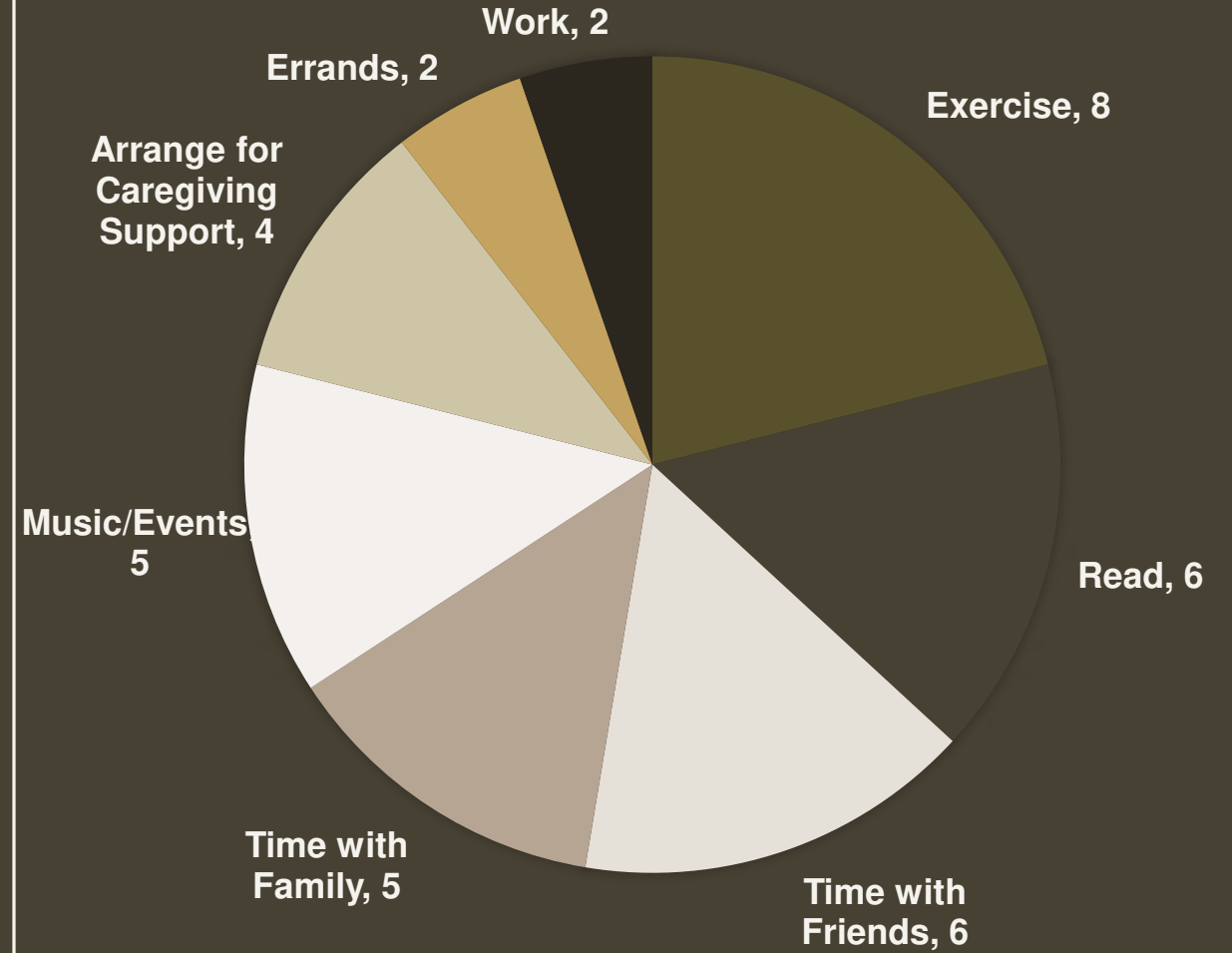
Additional Needs

- Caregivers expressed needing **counseling and mental support**, self-care and time management **trainings**, and a **volunteer caregiver registry**
- Caregivers expressed **difficulty finding trusted caretakers**, especially for overnight care
- All caregivers identified **challenges with managing schedules**
- **Limited transportation options** prevented caregivers from attending activities for loved ones
- Caregivers **benefited from social communities**

CAREGIVERS



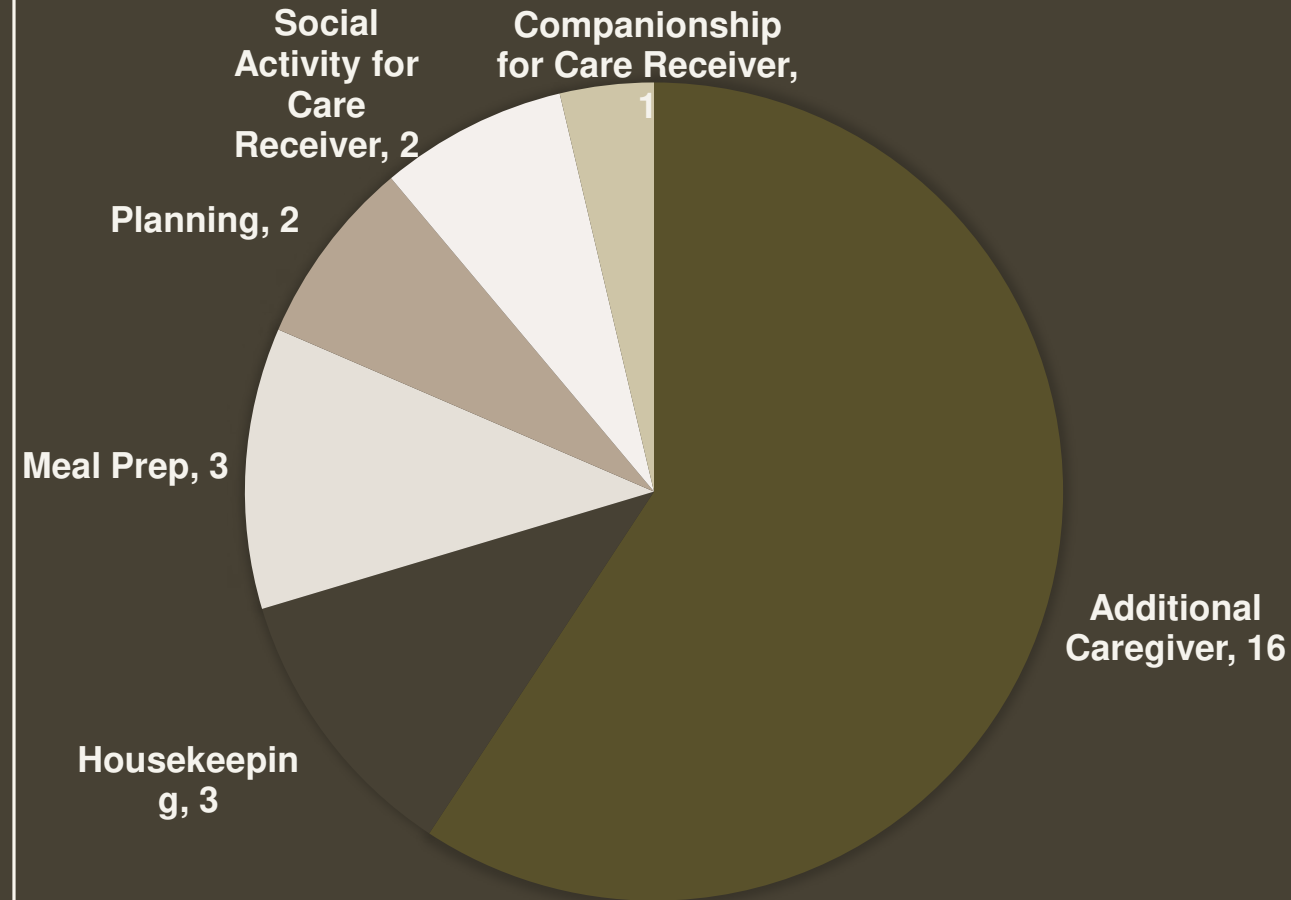
Respite Options:



CAREGIVERS



Support Needed:



RECOMMENDATIONS



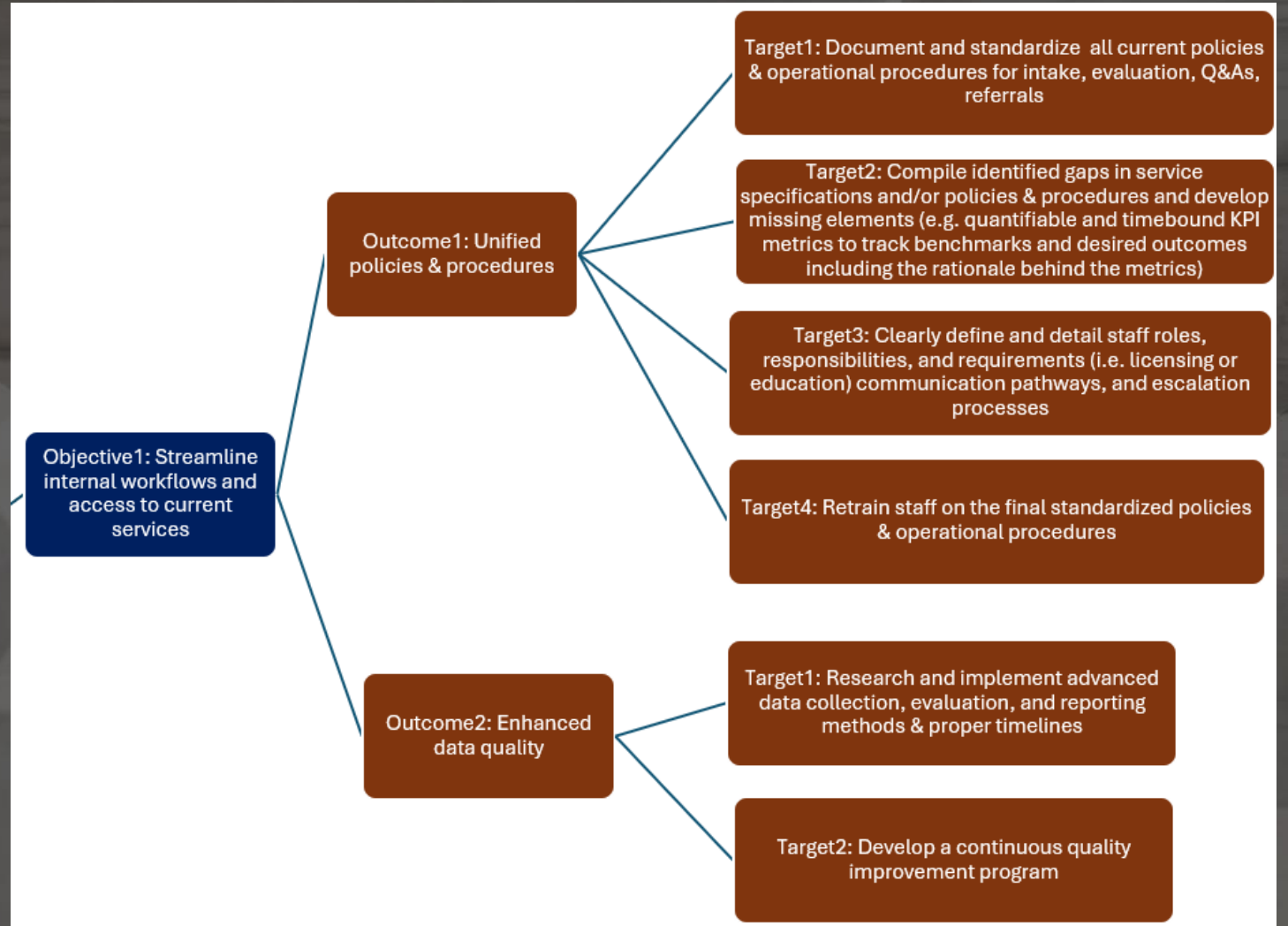
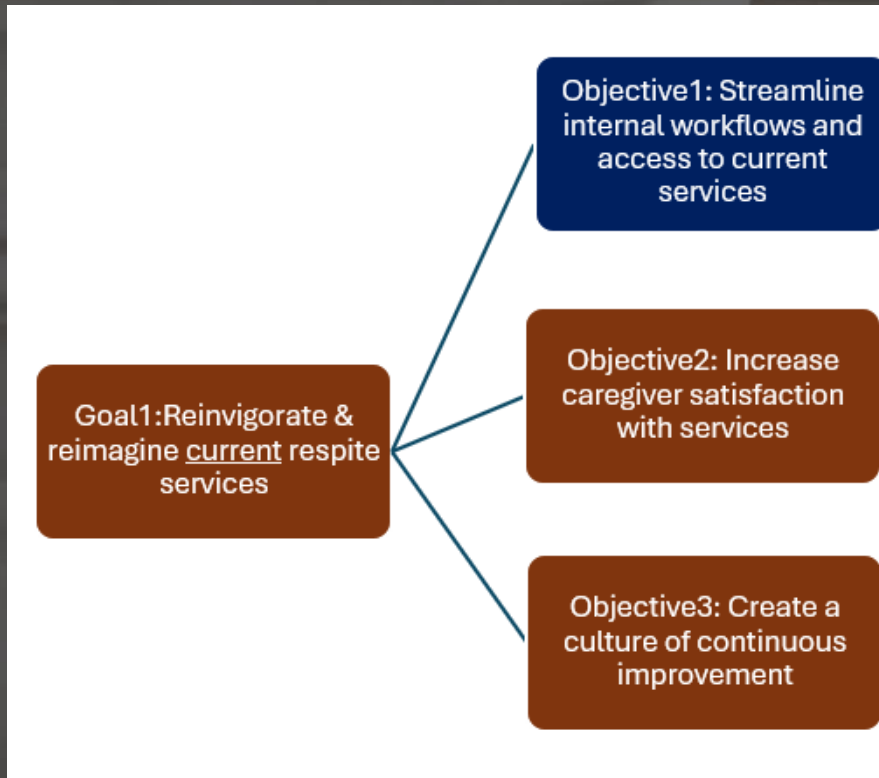
1. Develop and implement an **enhanced and unified menu of services** delivered through a person-centered, sustainable, coordinated statewide Lifespan Respite Program, which **includes Volunteer, Congregate, Emergency Respite Programs**.
2. Develop a **continuous quality improvement plan** that ties quality, impact, and data collection strategies to program goals and objectives.
3. Develop clear, comprehensive, and efficient **administrative and operational policies** to improve program operations.
4. Offer caregivers increased **access to trainings and resources** on topics relevant to caregiving, which are comprehensive and address known challenges consistent with practice and decision making.
5. **Expand respite offerings** that are person- and family-centered.
6. **Streamline processes for the respite voucher** application and reimbursement system.
7. Develop a **public education and outreach plan** to promote the Lifespan Respite Program to caregivers, providers, and particularly individuals in underserved communities.
8. Develop a **sustainability plan** for the Lifespan Respite Program to promote continuity and stability.

Major Objectives	Key Tasks	Year 1											
		7/23	8/23	9/23	10/23	11/23	12/23	1/24	2/24	3/24	4/24	5/24	6/24
1.0 Improvement of Respite Services through Program Evaluation	1.1 Contract with one of Delaware's State approved vendors.*	X	X										
	1.2 Vendor will conduct a comprehensive program evaluation of DSAAPD's respite services.		X	X	X	X	X	X	X	X			
	1.3 Vendor will provide an evaluation report and recommendations for action plan implementation.										X		
	1.4 Based on program evaluation outcomes, plan pilot programs for new and desired respite services.*										X	X	X

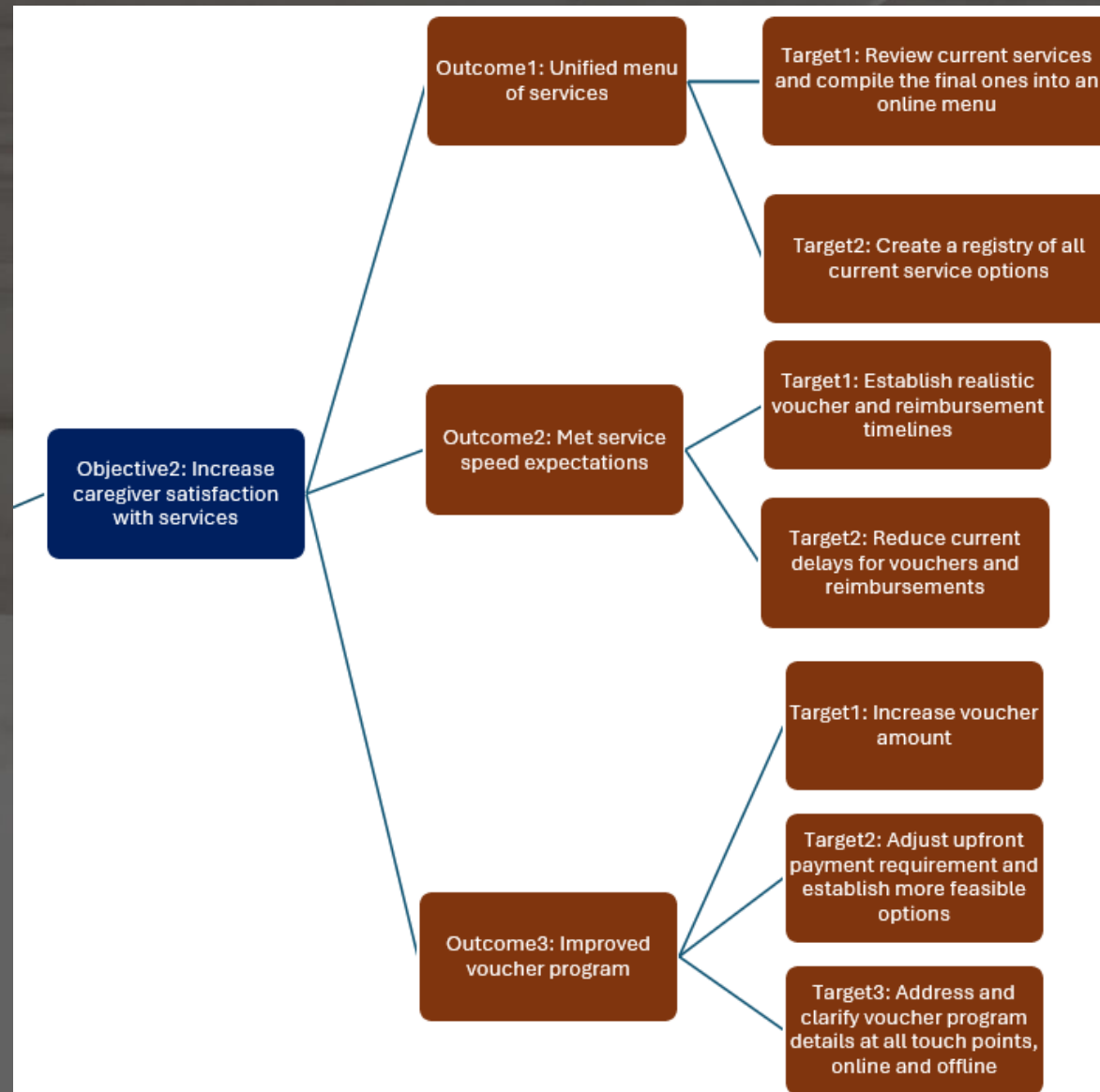
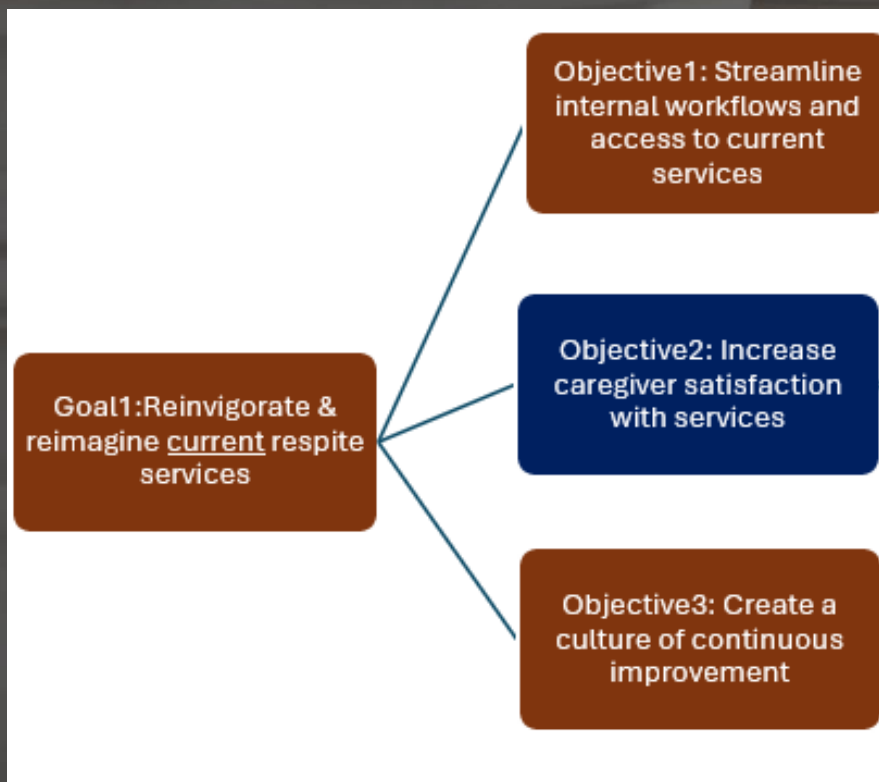
WORKPLAN

ALIGNMENT PLAN

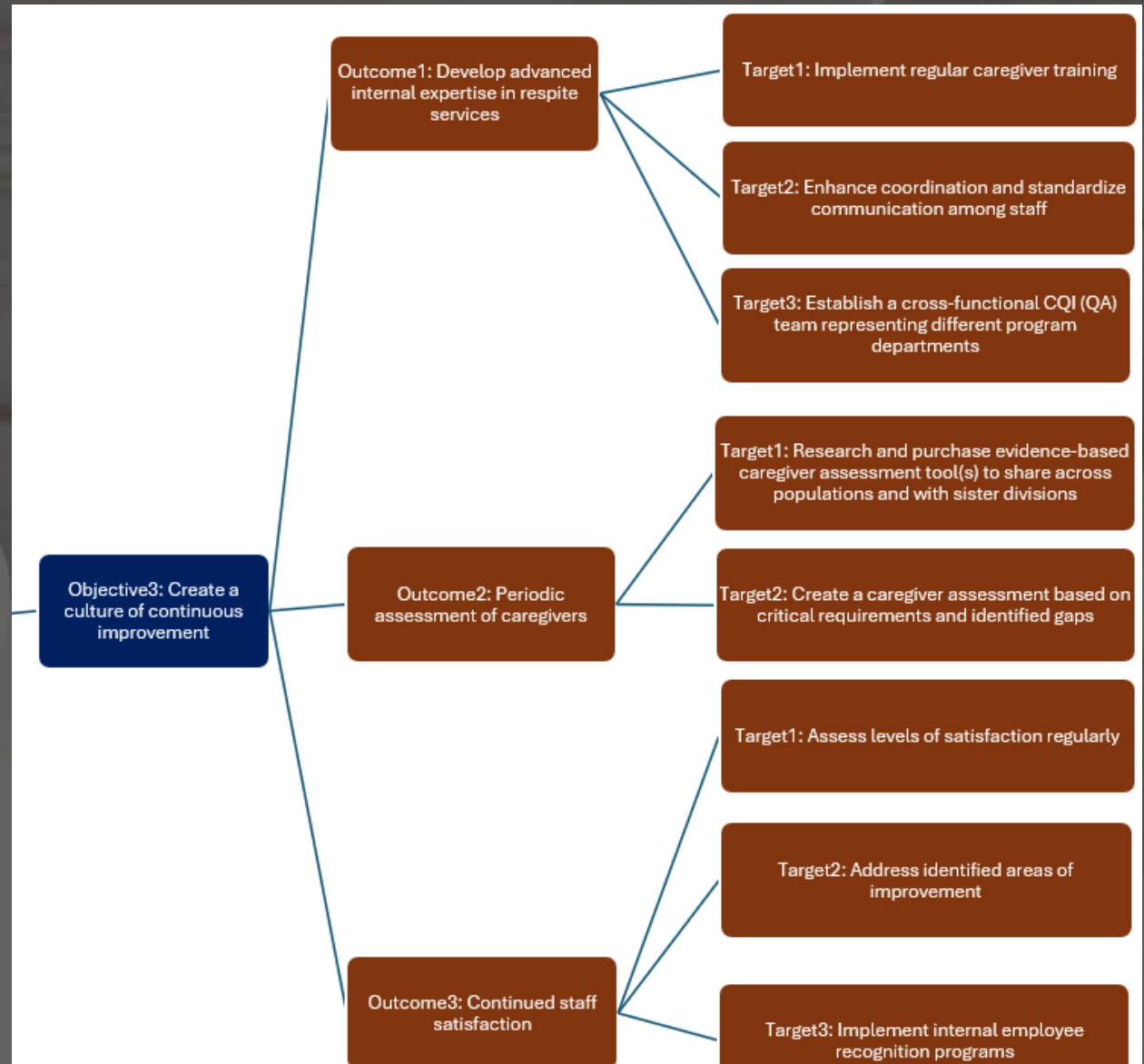
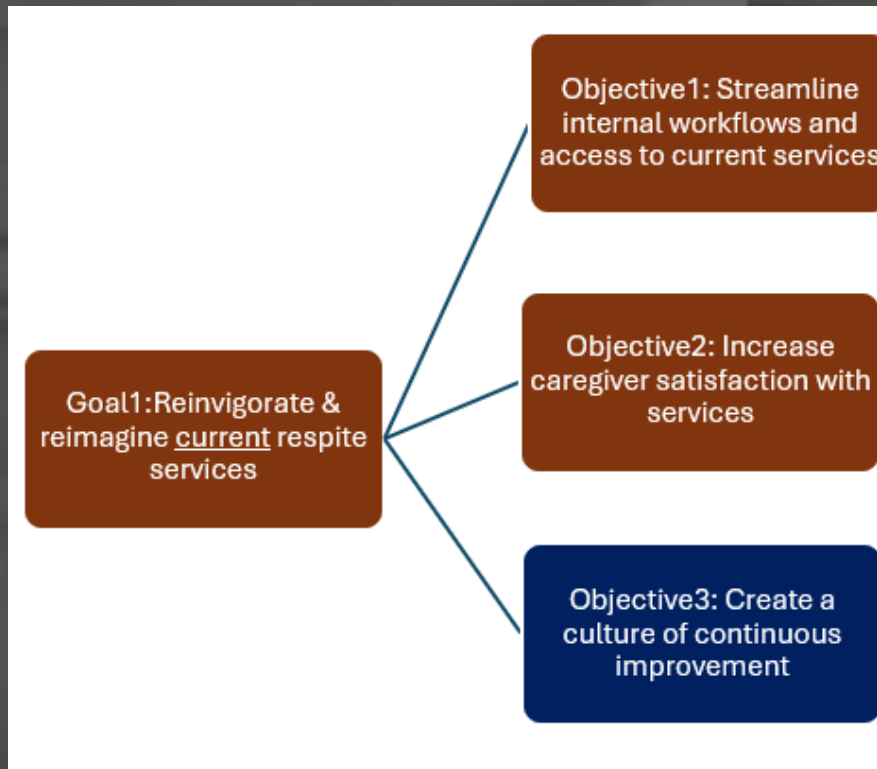
Strategic Objectives	What			
	Output or Outcome <input type="checkbox"/>	Target <input type="checkbox"/>	Measure Definition <input type="checkbox"/>	Data Sources <input type="checkbox"/>
Goal 1: Establish administrative and operational policies and procedures for DSAAPD's Lifespan Respite Program, that are clear, comprehensive, and up to date.				
Develop and implement administrative policies and procedures for the Lifespan Respite Program that refer caregivers to available resources.	Streamlined internal processes for respite service delivery	Developed and implemented standardized procedures for Lifespan Respite Program service intake, scheduling, and evaluation within 6 months of program initiation	Clear documented procedures for staff to follow during caregiver intake, evaluation, Q&As, referrals, and ensuring consistency and efficiency of information and service delivery	Internal policy and procedure documents, staff training materials, and feedback from staff members involved in the development and implementation process
	Aligned internal systems and processes to support streamlined data collection and enhanced data quality	Developed and implemented standardized procedures for Lifespan Respite Program continuous quality improvement involving data collection, evaluation, and reporting within 6 months of program initiation	Clear documented procedures on quantifiable and timebound KPI metrics to track benchmarks and desired outcomes and the rationale behind the metrics; the processes and timelines for data collection, evaluation, and reporting; and the processes for continuous quality improvements using program data	Internal policy and procedure documents, staff training materials, and feedback from staff members involved in the development and implementation process
	Streamlined understanding of partner roles, responsibilities, communication pathways, and escalation processes	Reviewed and revised the Lifespan Respite Program Service Specifications within 6 months of program initiation	Service Specifications clearly define and detail staff roles, responsibilities, and requirements (i.e. licensing or education) communication pathways, and escalation processes to ensure high quality service delivery and improved outcomes	Service Specifications, feedback from staff members and partners



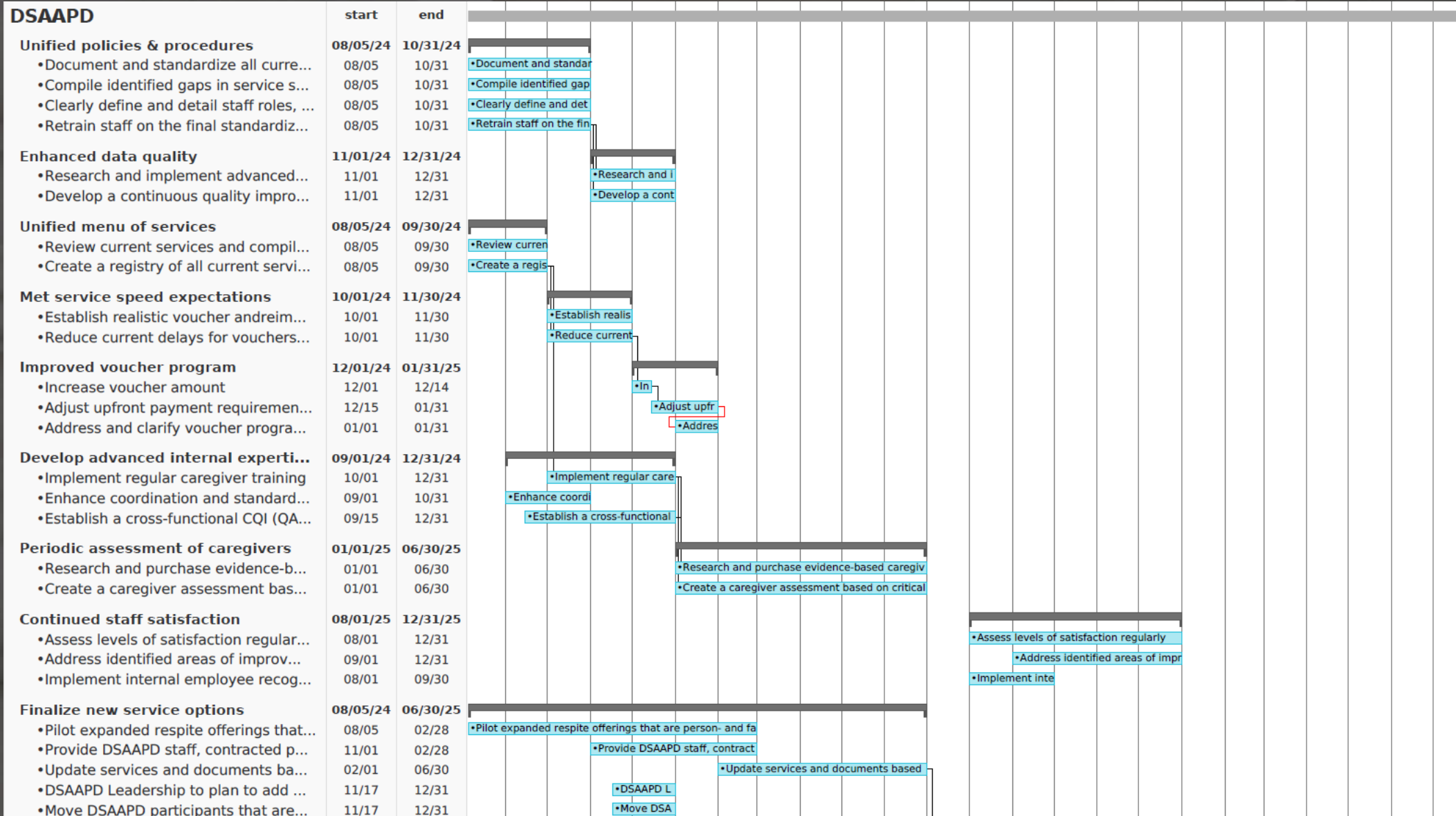
Organized Steps



Organized Steps



Organized Steps



Gantt Chart

Planning the Respite Volunteer Program5

Step 1: Establish an implementation team of team members who will be involved in establishing the Respite Volunteer Program at DSAAPD5

Step 2: Develop relationships and secure buy-in with external partners who can support DSAAPD in the development of the Respite Volunteer Program5

Step 3: Establish data collection and reporting processes for continuous quality improvement.....5

Step 4: Establish clear and documented policies and procedures for the Respite Volunteer Program6

Implementing the Respite Volunteer Program7

Step 4: Recruit volunteers for the Respite Volunteer Program (option 1) or partner with organizations that recruit and screen volunteers (option 2).....7

Step 5: Screen potential volunteers to determine appropriateness for respite volunteer program (if they decide to recruit volunteers directly).....7

Step 6: Recruit families to utilize volunteer registry7

Step 7: Leverage existing training materials for respite volunteers or develop training materials and resources for orienting respite volunteers and staff to the Respite Volunteer Program and policies and procedures8

Step 8: Conduct home assessments of care receivers.....9

Step 9: Develop a process to match families with volunteers.....9

Step 10: Supervise and provide ongoing support to volunteers.....9

Monitor and Evaluate Program9

Step 11: Develop a registry of available volunteers.....9

Step 12: Collect ongoing feedback from caregivers and key stakeholders10

Step 13: Evaluate the program according to its goals and all aspects of the program (i.e., volunteer training completion, matching process, effectiveness etc.)10

Step 14: Develop a sustainability plan.....10

Step 14: Communicate with and gather feedback from team, leaders, and external

ACTION PLAN FOR NEW PROGRAMS

Which resources do you think DSAAPD could leverage to create quick improvements in its programs?

<https://www.menti.com/al9uj3w8whcp>



Opinion Poll



WEAVING

DSAAPD journey

Unify documents

- Existing: Lifespan Respite and Grandparent-Relative Respite
- New: Congregate Respite, Emergency Respite, and Respite Volunteer
- Umbrella: Caregiver Support Programs

Internal changes

- Hire new personnel
- Restructured existing Voucher Program
- Began researching new digital technologies, such as a new caregiver assessment tool

partnerships

Emergency Respite:

- Respite Care Association of Wisconsin (RCAW)
- Family Caregiver Alliance

Congregate Respite:

- Pilot programs with Easterseals Delaware and Smyrna Opera House



MUSICAL MEMORIES CAFÉ (mmc)



- 1-hour gatherings
- Individuals with Alzheimer's and other dementias and cognitive disorders
- Therapeutic effect of music



THANK YOU

KATE RASULOVA

Layokat . rasulova@ Delaware . gov

Division of Services for Aging and Adults with
Physical Disabilities