

# Research on Respite Outcomes and Access

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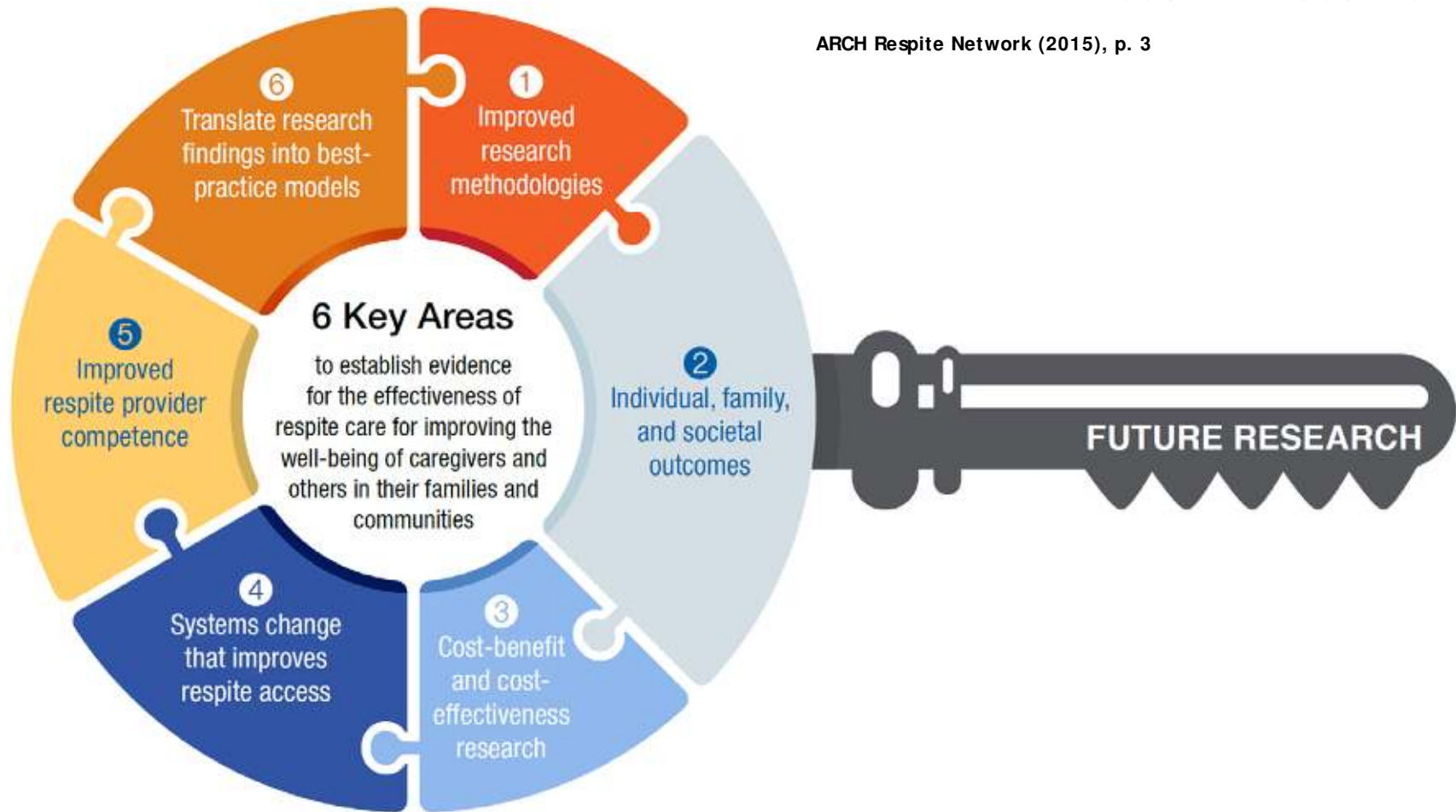
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# Objective

- Reflecting on the 2015 *A Research Agenda for Respite Care* report from ARCH
- Aligning with current research recommendations and initiatives emerging from multiple reports and summits on dementia care science
  - As well as our own work; e.g., Gaugler, Jutkowitz, & Gitlin, 2020, NASEM Decadal Project



# The Challenge of Researching Respite: Who Benefits

- “The most important researchable questions about respite is whether to take into account the needs of all family members when determining eligibility, or when designing and delivering services“ (ARCH Respite Network, 2015)
- The traditional methodology utilized to conduct research with caregivers/care partners

# The Challenge of Researching Respite: Defining and Categorizing Alongside Other Service Types

- “Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system” (ARCH Respite Network, 2015)
  - Appended definition
- The challenges of categorizing these and other non-pharmacological interventions (Gaugler et al., 2017)

- “Three systematic reviews (SRs) utilized similar definitions when grouping and synthesizing results of respite for dementia caregivers ([Cooper et al., 2007](#); [Olazarán et al., 2010](#); [Maayan et al., 2014](#)). Olazarán and colleagues included two studies of respite, while Maayan *et al.* included four and Cooper and colleagues included three. Only one study was consistent across the three reviews. In contrast, four studies were included in at least one review but not the others. Furthermore, one study was included in two of the reviews, but was classified as respite in one and not the other.” (Gaugler et al., 2017; p. 22)
- Improved reporting of the components/elements of respite in studies and evaluations (Gaugler et al., 2020; Schulz et al., 2010)
  - <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01542-7/tables/2><https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01542-7/tables/2>

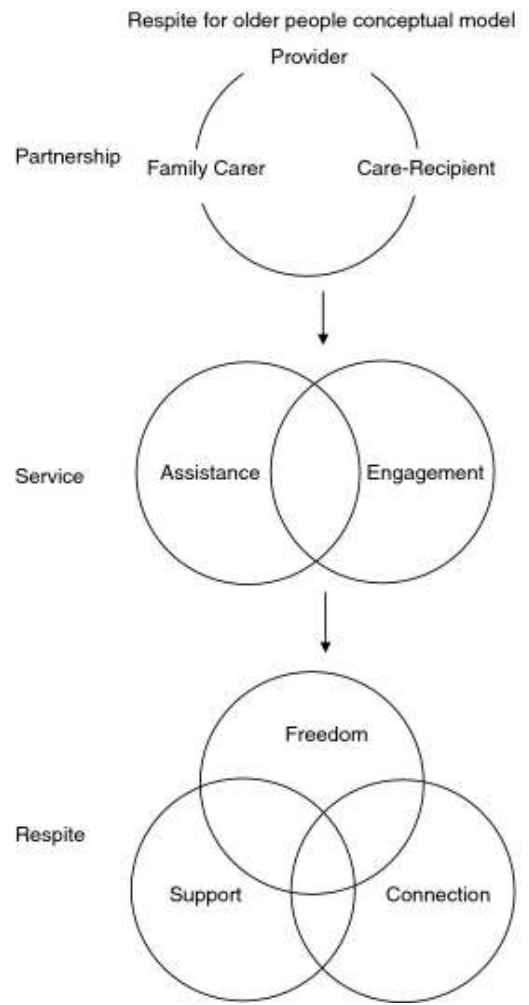
# Respite Outcome Measures

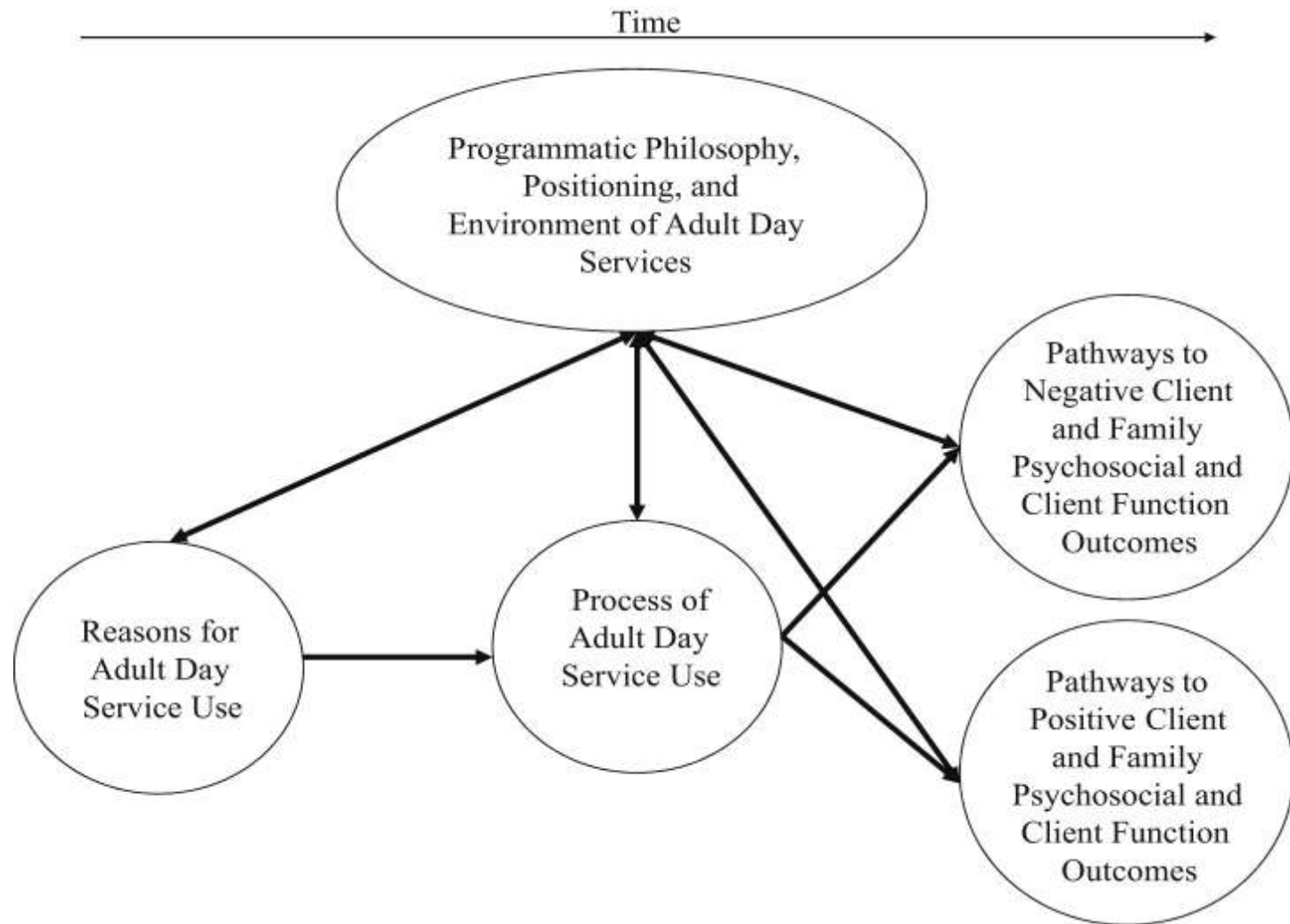
- Over-reliance on deficit oriented outcomes, in keep with biomedical perspectives
- Strengths-based measures, as applied in dementia care science (and other areas as well) (Gaugler et al., 2019)
  - Resilience
  - Successful aging domains
  - Goal attainment scaling (Jennings et al., 2018; Reuben & Jennings, 2019)
  - Social health per European research in optimal dementia care measures
  - LINC-AD

# Conceptualizing

- What are the “essential ingredients” of respite
- Core to dissemination and implementation success
- Evans, 2013; Gaugler, 2014







# Designing Respite Studies

- Are RCTs even possible in respite? Does it matter?
- Viewing respite less as a general “intervention” to be evaluated and instead as a context for innovation
- The ADS Plus Study (Gitlin et al. 2019; Roth et al., 2020; [https://nursing.jhu.edu/faculty\\_research/research/projects/ADS/index.html](https://nursing.jhu.edu/faculty_research/research/projects/ADS/index.html))

# What is the Adult Day Plus Research Study?

- Does augmenting adult day services with systematic, evidence-based caregiver support, education and skill building (ADS Plus), enhances wellbeing for persons with dementia and family caregivers?
- We will compare usual care at 23 adult day services to 26 adult day services providing usual care and ADS Plus on these outcomes:
  - Family caregiver depressive symptoms
  - Family caregiver overall well-being
  - Number of days adult day services are used
  - Nursing home placement

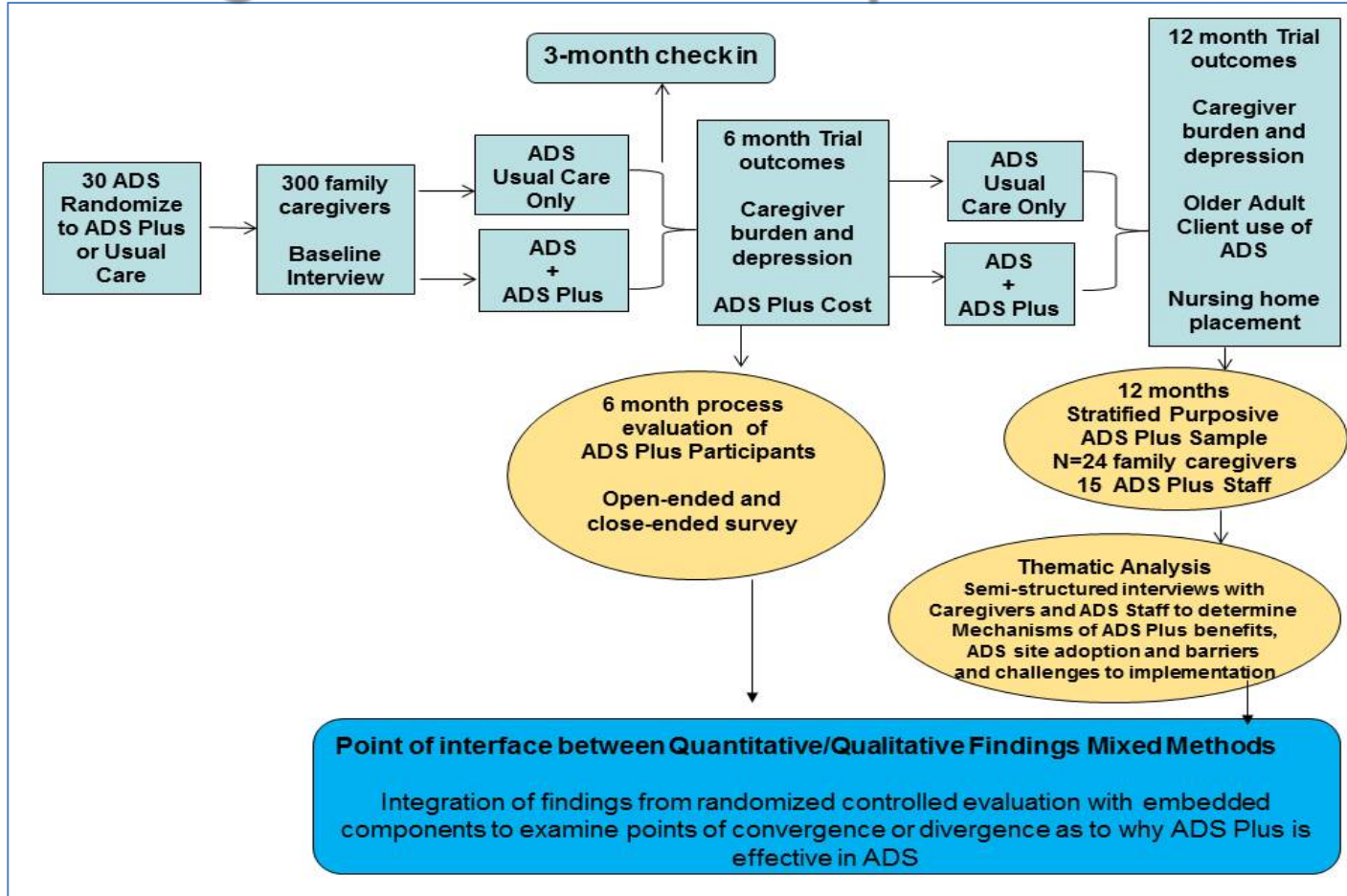
# What is the Adult Day Plus Intervention?

- Provision of on-going caregiver support to families using adult day services using a protocol tested in previous and ongoing pilot work
- Five intervention components:
  - Assessment of care needs
  - Referral and linkage
  - Education about disease, behavioral symptoms, caregiving, resources
  - Skills training in problem solving, managing behaviors,
  - Taking care of self
- Novelty of approach:
  - Standard yet tailored to unique needs
  - Caregiver-centered - caregivers identify top 3 challenges they want to address
  - Program integrated into ADS work follow as much as possible
  - Use of indigenous staff to deliver intervention
  - Minimal staff training
  - Families participate at times convenient to them upon pick up, drop off or another time to minimize burden

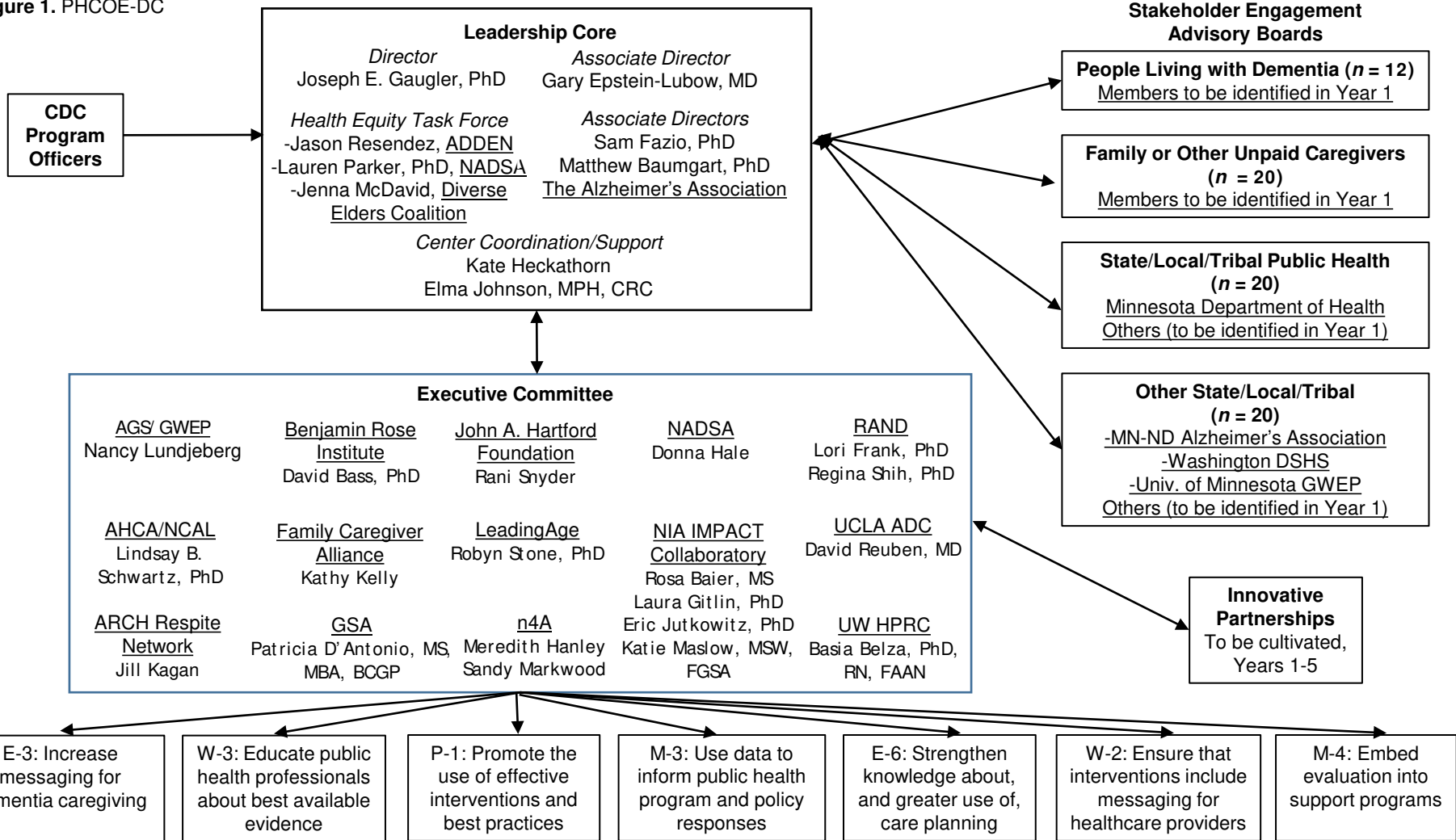
## Two Primary Study Aims

- Evaluate effectiveness of ADS Plus to improve caregiver well-being and reduce depressive symptoms compared to routine ADS use at 6 months
- Evaluate long-term maintenance effects of ADS Plus at 12 months on caregiver well-being and depressive symptoms

# Hybrid Design Effectiveness-Implementation



**Figure 1. PHCOE-DC**





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