

Roundtable on Quality Care for People with Serious Illness: Supporting Family Caregivers

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Challenges to Structural Support of Family Caregivers

1. Misaligned reimbursement: lack of compensation for provider time and effort to support family
2. Prevailing orientation toward patient autonomy and privacy: missed opportunities for effective clinician-family partnerships
3. Patient-oriented information systems: absence of structured fields to document information about identity and characteristics of involved family members/friends

Effective Interventions Exist

Most effective interventions are:

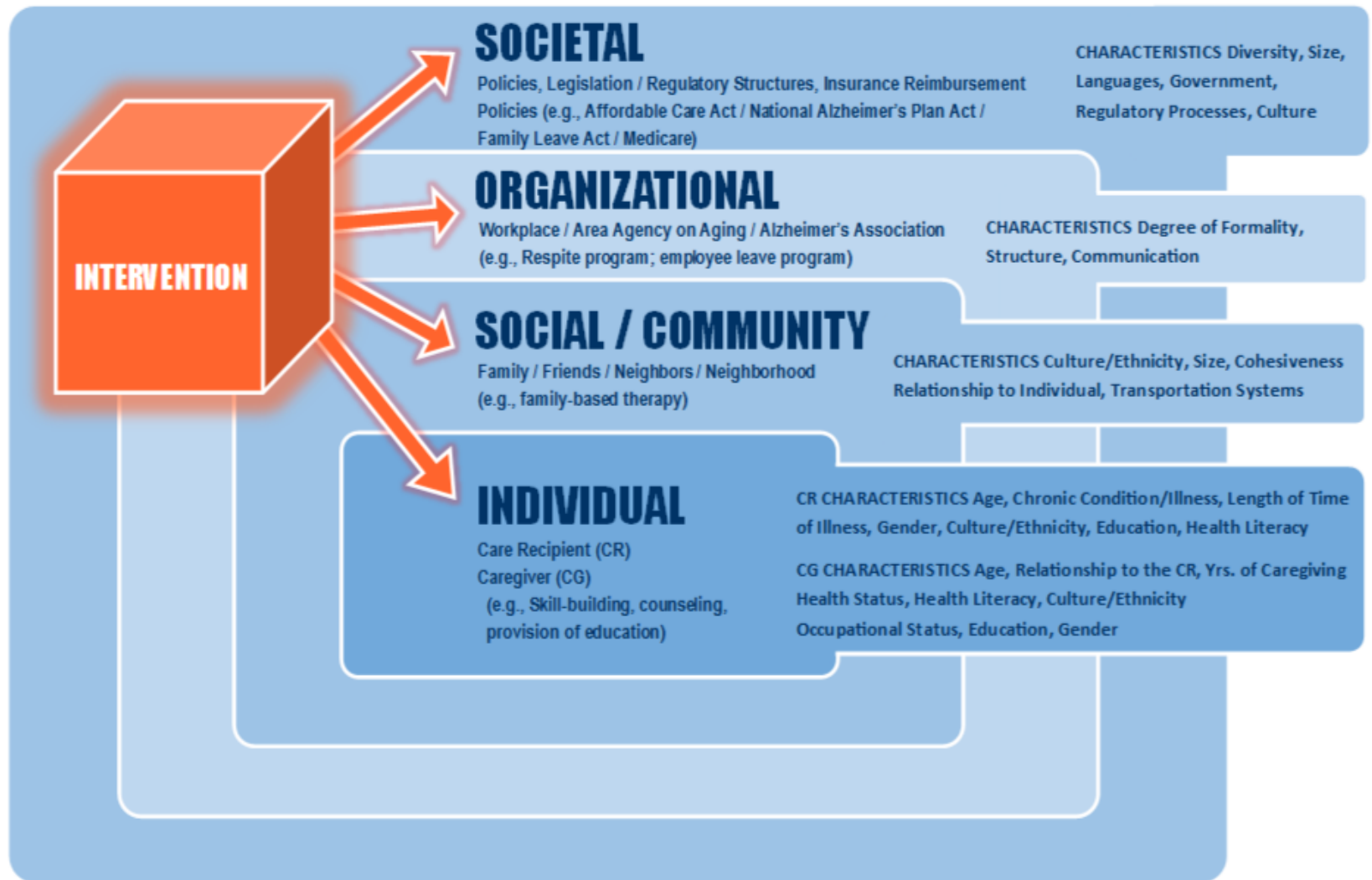
- Tailored: to individual caregiver risks, needs, preferences, and care context (by type of diagnosis, trajectory, stage of illness). Thus, **assessment is essential** to guide education, training, & support.
- Multidimensional: encompass varied support such as education, skills training, counseling, self-care, relaxation, respite. Typically engage caregivers in learning new skills

Few caregivers now benefit from evidence-based models

- Implementation science bottleneck

Need to do research in new ways: Shift toward “embedded” trials to learn what works and facilitate diffusion

Framework for Caregiver Interventions



Socio-ecological framework for caregiver interventions,
From Chapter 5 of NASEM Report: Families Caring for an Aging America

Encouraging Developments

State Policy

- Paid family leave: CA, DC, NJ, NY, RI, WA
- CARE Act to support families through hospital discharge
- State innovation to connect support through Medicaid and ACL programs

Delivery & Payment Reform

- New Medicare billing codes (transitional & chronic care management, advance care planning; dementia care planning) and Conditions of Participation (e.g, in home health, hospital discharge)
- Medicaid expectation of family caregiver assessment when care plan depends on them (1915(i) HCBS state plan option)
- Bundled payment models (e.g., Accountable Care Organizations; Managed Long-Term Services and Supports) that emphasize value and quality

A National Strategy

Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (S. 1028/H.R. 3759)

- Signed into law January 22, 2018
- Requires Secretary of HHS to develop, maintain, & update a strategy to recognize and support family caregivers
- HHS to convene Family Caregiving Advisory Council to develop initial strategy within 18 months, with public input & broad stakeholder involvement
- Biennial reporting & termination of Council after 5 years

Moving toward a National Strategy

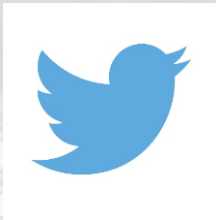
Elements in Care Delivery

- **Identification:** Annual Wellness Visit, Structured fields in the electronic health record, Clinical assessments of patients (e.g., the home health assessment instrument, the OASIS), Shared access to patient's portal accounts
- **Engagement:** Incorporate family perspective & insight in care processes (e.g, experience of care measures)
- **Inter-professional care:** Clarify & legitimize role; Assess & respect capacity; Availability of tailored **supports**; Ensure competencies of professional workforce

Toward a coherent strategy: Deliberative & integrated approach across care settings (LTSS & health care), programs (Medicare, Medicaid, ACL, States, Employers) with surveillance to assess and monitor effects

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Thanks!



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