

CREATING GREATER FAMILY RESILIENCE FOR BETTER PATIENT OUTCOMES



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TODAY'S TALK



- Why family matters to population health
- Research from two movements
- Steps toward patient and family resilience
- Barriers to integrating family caregivers into healthcare
- An approach to dyadic care: Concord Hospital's Frail Elderly House Call Program















Why Family Matters (More Than Ever) in Healthcare

- Despite traditionally patient-centric American healthcare system, myriad factors -> emphasis on families
- Rapidly aging population (20% over 65 by 2030)
- Rising incidence of chronic illnesses, functional limitations
- Decreased hospital lengths of stay and emphasis on preventing bounce-backs
- **Families seen as one key to implementing outpatient treatment plans, decreasing hospital utilization and lowering costs**

Two Movements



- **1) Family Systems Medicine**--bringing insights of family systems theory and family therapy to physical healthcare, research on families + health
- Don Bloch, MD: founder of journal (now Families, Systems & Health) in 1983; co-founder of CFHA
- *Family-Oriented Primary Care* (McDaniel et al, 1990, 2004)
- Medical family therapy (McDaniel, Hepworth, Doherty, 1992; Rolland, 1994; Wright et al, 1996)



- **2) Family caregiving**—multi-disciplinary **research** and practice over past 30 years, originally focused on dementia--e.g., Aneshensel et al, 1995, Gaugler & Kane, 2015
- Healthcare and legislative policy/consumer advocacy—e.g., Caregiver Action Network, **Mintz**, 1993; National Alliance for Caregiving, 1996, United Hospital Fund of New York’s Families and Health project, **Levine**, “Next Step in Care”

Family Caregiving in America

- 43 M Americans engage in some form of caregiving activity in a year (NAC/AARP, 2015)
- Numbers increasing because of demographics, medical advances



US Caregiving (cont.)

- Heterogeneous group—e.g., ¼ Millennials
- Roth et al (2009): Results of epidemiological survey of 43,000 respondents:
 - 33% of caregivers reported no strain; 49% some strain; 18% a lot of strain
- **“Strains and gains”**



Research on Caregiving's Negative Effects

- Dementia caregiving linked with 63% increased mortality (Schulz & Beach, JAMA, 1999)
- Schulz & Martire, 2004:
- Insomnia
- Depression and anxiety
- Musculoskeletal problems (e.g., back pain)
- Decreased use of preventative medical services

Potential Positive Effects of Caregiving



- Roth et al (2013) studied over 3500 caregivers and found that, rather than suffering increased mortality, they had “18% reduced rate of death compared to non-caregivers”
- Others caregivers report that they grow personally and spiritually as a result of caregiving

Family Caregivers' Healthcare Roles (Wolff, Jacobs, 2015)

- Attendant
- Administrator
- Companion
- Driver
- Navigator
- Technical Interpreter
- Patient Ombudsman
- Coach
- Advocate
- Case Manager
- Healthcare Provider

Research on Impact of Family Functioning on Patients' Outcomes

Examples:

- Research on Expressed Emotion on psychotic symptoms (Hooley, 2007)
- Improved treatment retention adherence among HIV youth (Wiener, 2007)
- Family presence improves quality of medical visits (Wolff, 2008, 2011)
- Family involvement can improve patients' knowledge about diabetes (Kang, 2010)

Research (cont.)

- Notable example: Mary Mittelman's NYU Caregiver Intervention—increases caregiver well-being, forestalls nursing home placement of Alzheimer's patients for nearly 2 years (2006)



Elements of Family-Centered Integrated Care

- Acknowledgement
- Communication
- Decision-Making Power
- Money
- Assessment
- Care management/coordination
- Training & Support
- Technology

Acknowledgement



- Identification of family caregiver in patient's chart (Mintz)
- Recognition of dyadic nature of care:
- ***“We, the family Mintz, need clinicians and payers to view us as a single unit of care.”***
- Provide case management when caregiver is sick, even when patient isn't

Communication

- Access to patients' medical records through EMR portals
- Ability to share observations, ask questions
- Ability to review healthcare team's notes and correct them (Whiting)

Foot & Ankle Institute

Home Forms to Fill About Us Contact Us Help Logout

Welcome Jason Keele

My Message

Message	Date	View
No Messages Available.		

Show All Compose Message New Message

My Lab

Doctor	Lab	View
No Labs Available.		

Show All Order Result

My Prescription

Date	Category	Drug	SIG	Doctor
Jun 24, 2012		Gbenfloro		Andrew Powell
Jun 24, 2012		METformi		Andrew Powell
Feb 28, 2011	Antibiot	ZYVOX 60	Take 1 t	COPE COPE
Mar 15, 2011	Fungus	LAMISIL	1 PO qd	Andrew Powell

Show All Drug Education

My Document

Date	Description	Visit	View
No Documents Available.			

Show All View Document Not Exist

My Future Appointment

Doctor/Room	Date	Time	Procedure
U S Kent Burton	Nov 04, 2014	08:15 AM	
U S Kent Burton	Nov 10, 2015	07:30 AM	

10:48 PM 9/9/2013

Decision-Making Power



- Include patient and family goals in care plans
- Consider family caregivers as lay members of healthcare team
- “Shared decision-making”
- “Empowerment” (Feinberg)

Money



- ***“Develop payment incentives for healthcare providers to support family caregivers’ involvement”*** (Levine)
- Should produce measurable change, including appropriate healthcare utilization, improved quality of life, etc.

Assessment

- ***“Assessing and addressing both the individual’s and the family caregivers’ information, care, and support needs and their experience of care”***
(Feinberg)
- Willing and able to perform care tasks?



Care Management/Coordination

- Family caregivers are acknowledged for the care management and coordination roles they already fulfill
- But caregivers may need additional help from care managers, especially during patients' transitions from one care setting to another
- E.g, Coleman, Naylor

Training & Support

- Better preparation for family caregivers for performing complex medical tasks at home
- More support groups
- More online support services
- For pros: Retraining in HIPAA (Whiting)



Technology

- Not just EMR portals
- Enhanced portals (e.g., VA Blue Button) with easy access, medication support systems, etc. (Whiting)
- Mobile technology (e.g., VA Family Caregiver Pilot)



**Blue Button
Download
My Data**

Objections to Family Involvement

- ***“Caregiver involvement undermines patient autonomy and confidentiality”***
- ***“It alters the quality of the patient-professional relationship”***
- ***“Working with families takes additional time”***



Objections (cont.)

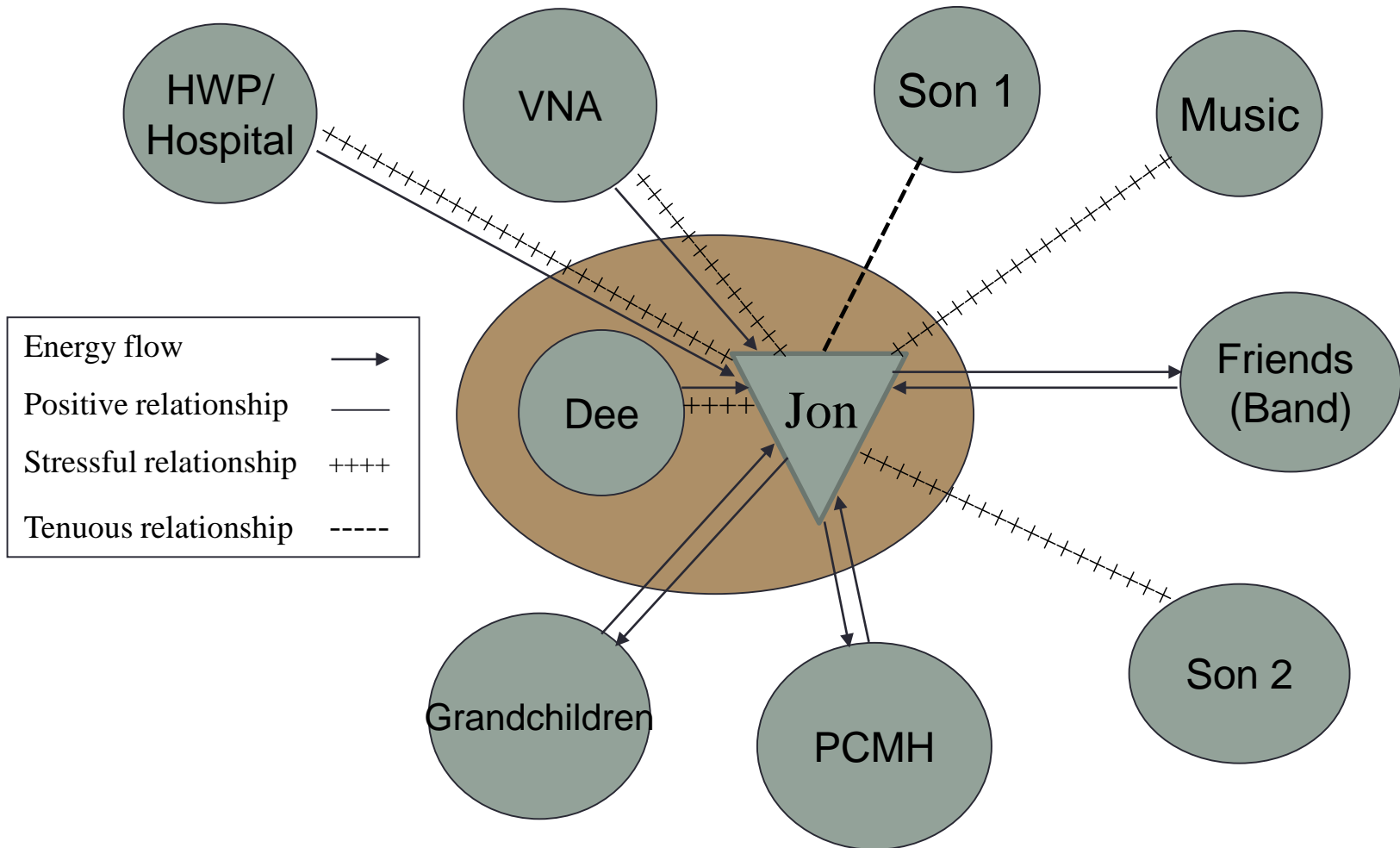


- ***“I don’t want to get in the middle of conflict between the patient and family member. I don’t want any conflict with the family member.”***
- ***“The time I spend with patients’ family members is unreimbursed.”***

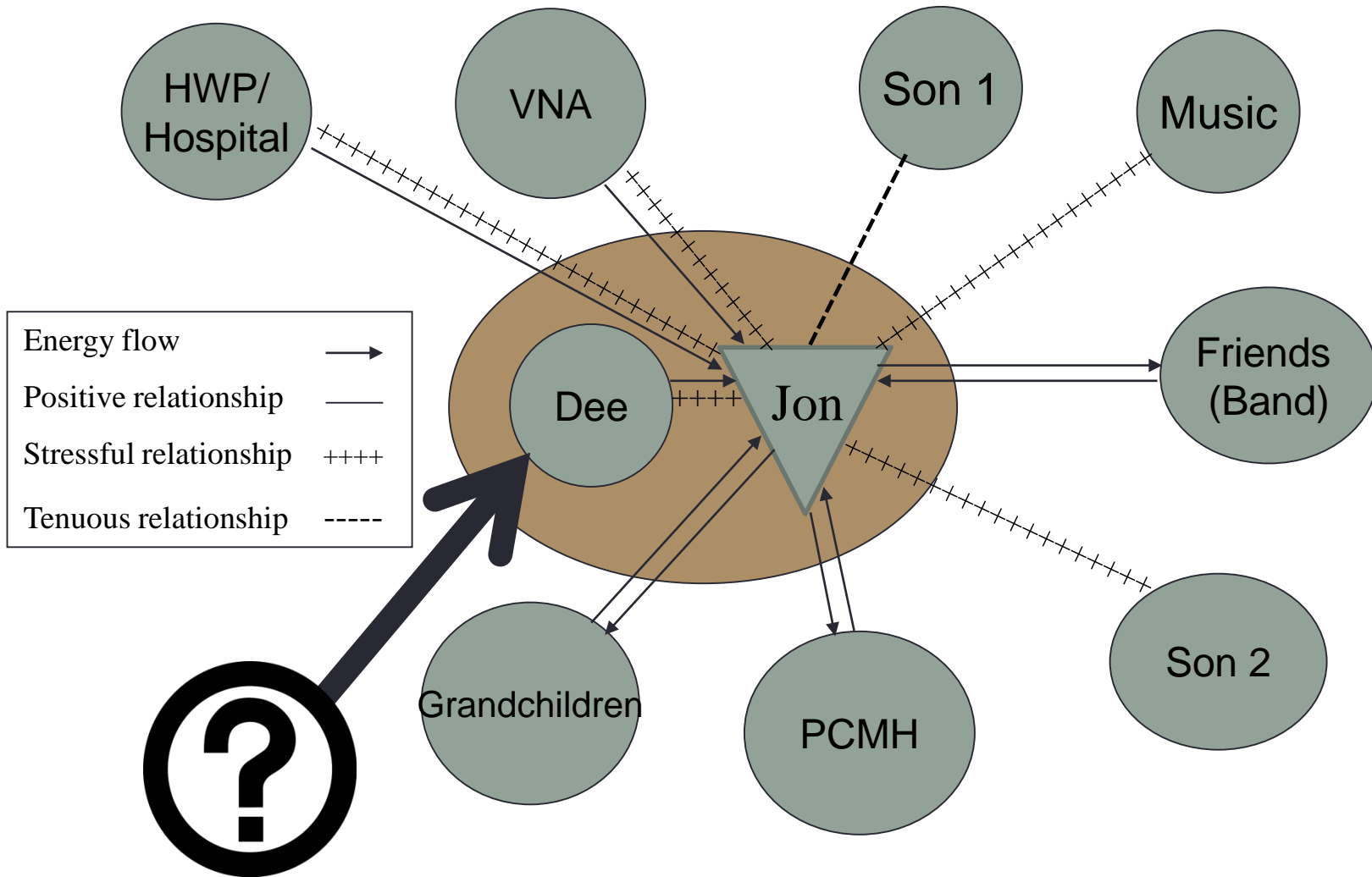
Broadening the PCMH lens to include the health of family caregivers



Jon's Ecomap



What about Dee?



Dee

68 year old Female
Family Caregiver for Patient

Medicare Patient

7+ Chronic Health
Conditions, including:

- ✓ COPD on Home
O2
- ✓ CAD
- ✓ DM
- ✓ Anxiety
- ✓ Depression

10+ daily medications

Dee

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From 3/2015-3/2016,

2 Hospital Admissions

- ✓ COPD
- ✓ Pneumonia

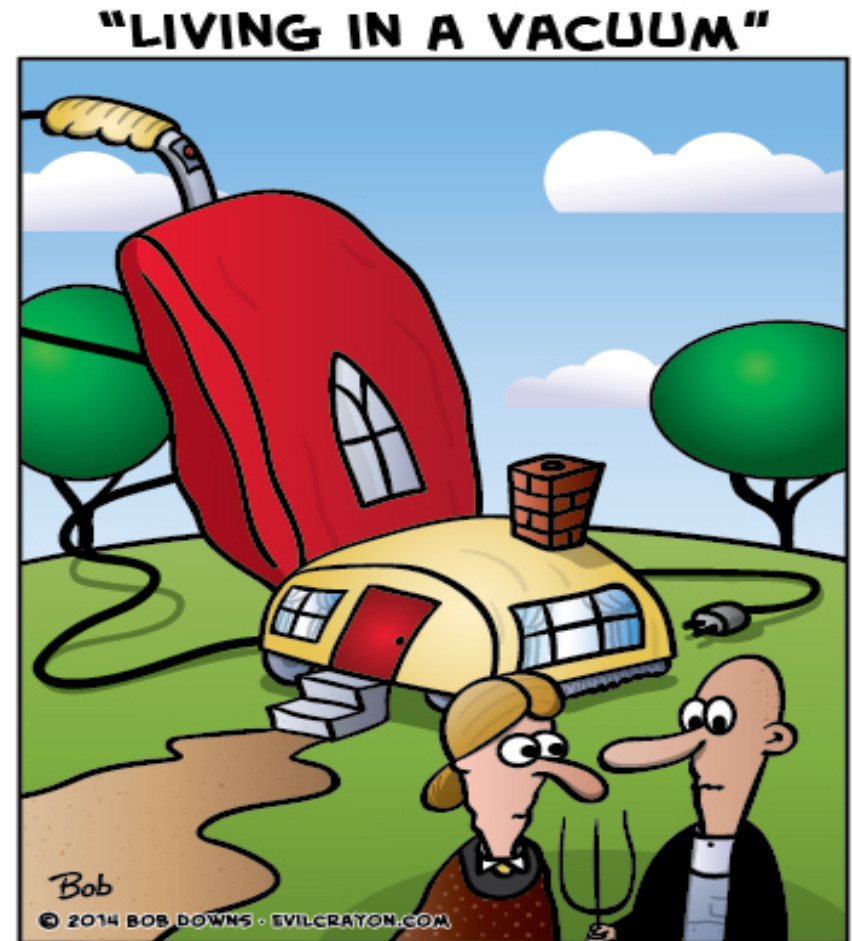
20% appointments
missed with PCP

100% appointments
missed with specialists

We're working in a vacuum

“Every system is perfectly designed to get the results it gets”

- *Paul Batalden MD, Senior Fellow at the Institute for Healthcare Improvement*



“Quadruple Aim”



This is an improvement from the triple aim... but are we still missing one?

“Quadruple Aim”



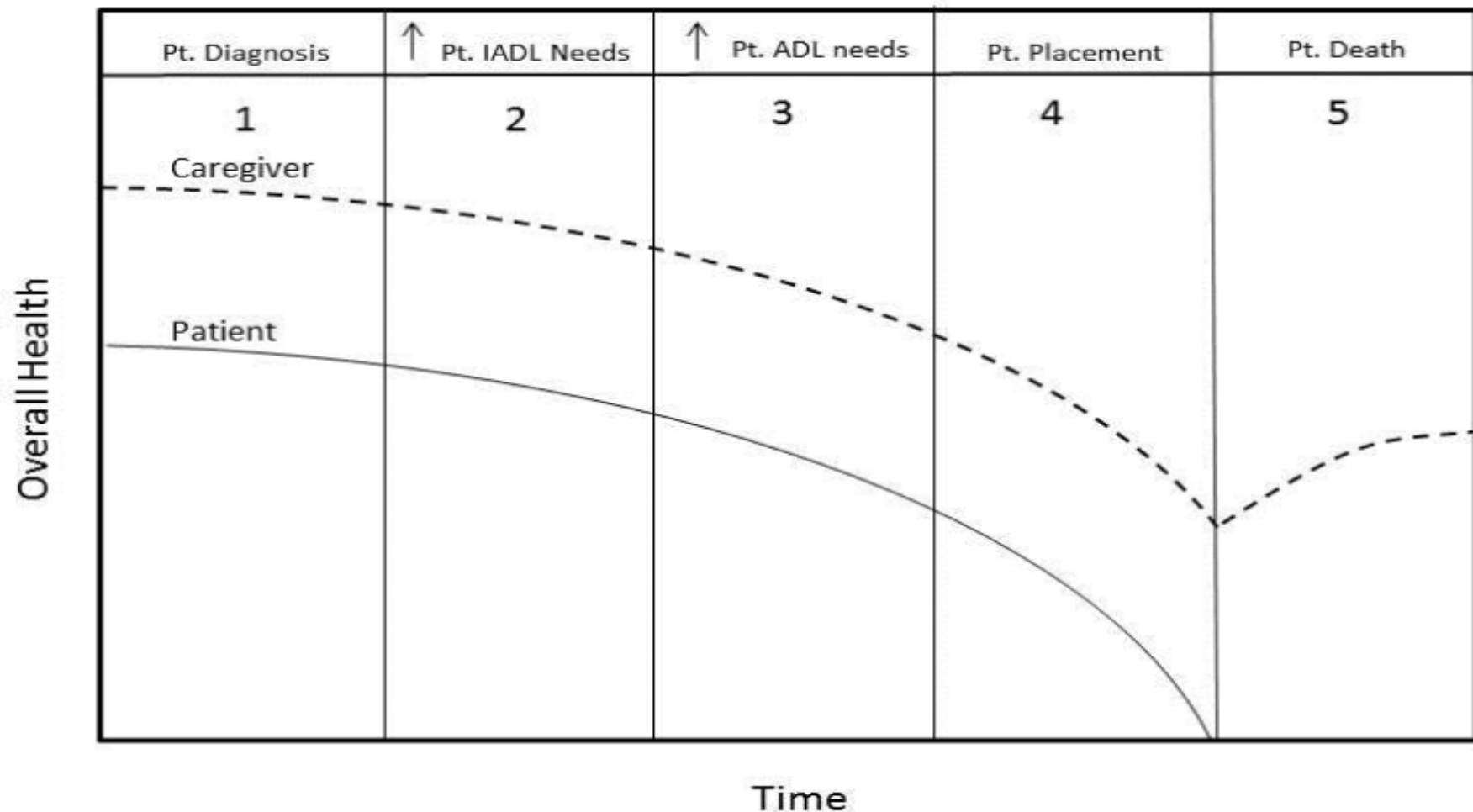
This is an improvement from the triple aim... but are we still missing one?

“Quintuple Aim”



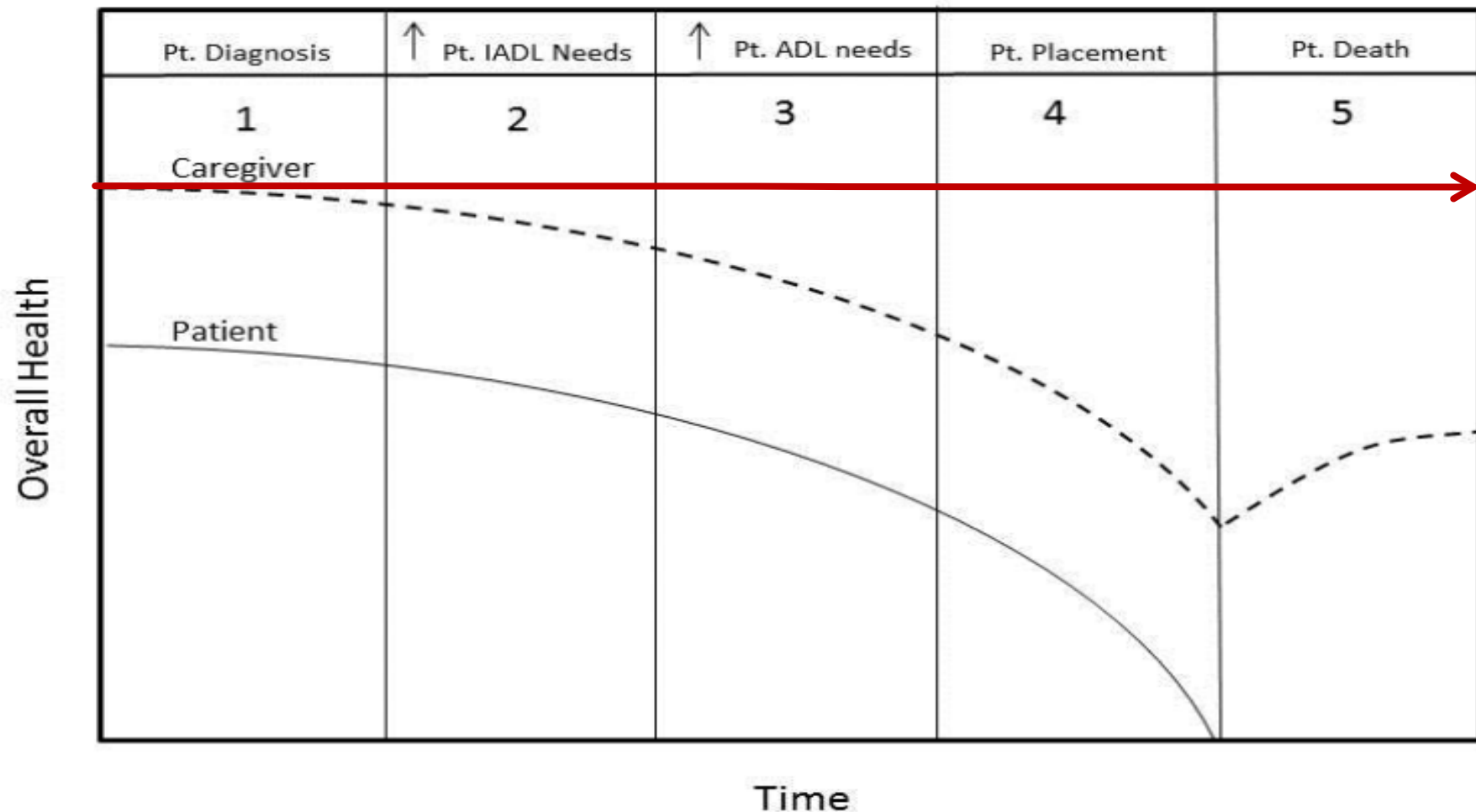
I propose that we add the family caregiver experience!

Health of the patient-caregiver dyad



Hong 2016. Agile, trajectory-based population health framework for supporting caregivers©
(Adapted from work by Dr. Richard Schulz 2012)

Building caregiver resiliency



Hong 2016. Agile, trajectory-based population health framework for supporting caregivers©
(Adapted from work by Dr. Richard Schulz 2012)

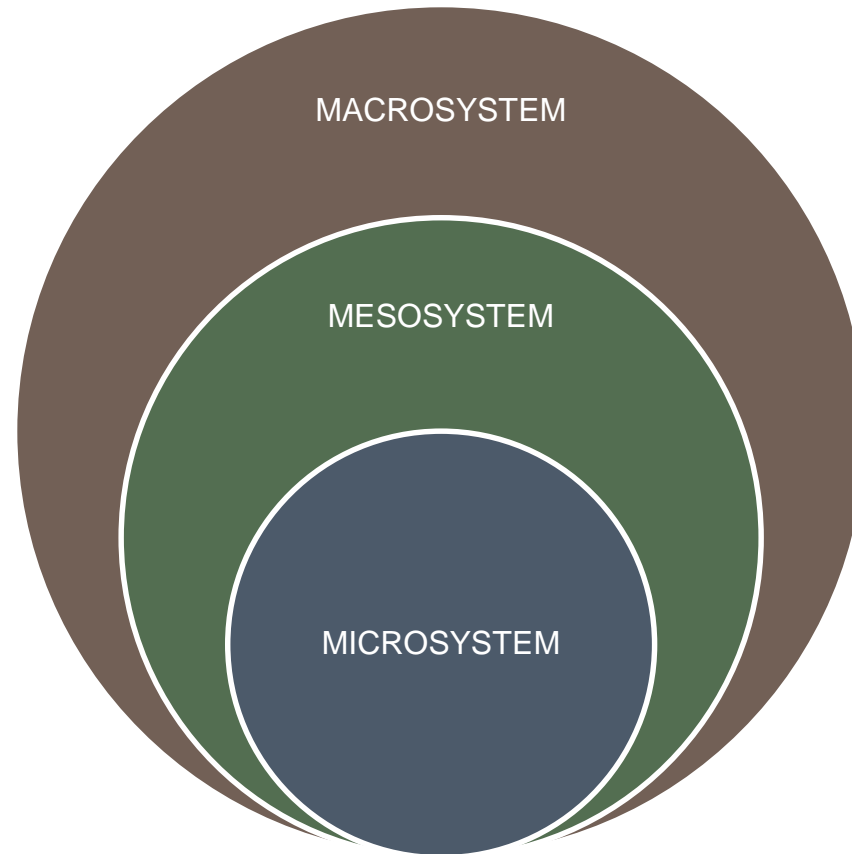
Frail Elder Housecall Program

Purpose:

Our system exists to provide home-based primary care to frail elders in the community, and teach geriatrics to family medicine residents.

**Integrated Behavioral Health & Primary Care
Home Visit Team**

Systems Approach



Mission: We partner with patients, families, and community-based organizations in building caregiver resilience.

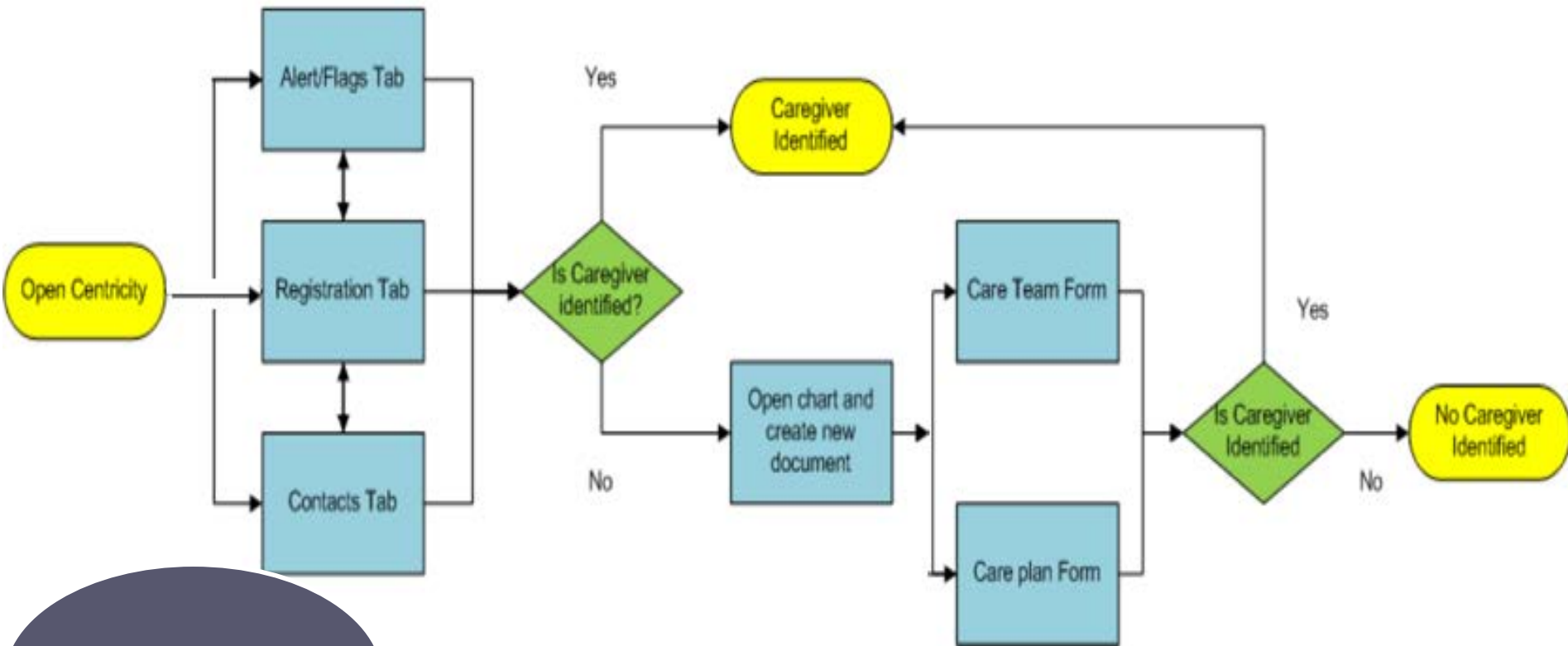
1. Who is the family caregiver?

“Family caregivers are like undocumented aliens- they have no official status and there is no official record of their existence.”

- *Suzanne Mintz (Co-Founder, National Family Caregiver Association)*

Who is the Caregiver?

"As Is" Process Map of Identifying Informal Caregiver on CHMG Centricity EMR



MICROSYSTEM

Caregiver Entry Field

Dependency screen

Are you independent with all IADL functions?

i

Yes, independent

No, dependent

(These activities include shopping, transportation, laundry, light housework, light meal preparation, telephone, taking meds")

Social Support

Who could help you in case of emergency?

Phone number:

Caregiver name:

Caregiver phone number:

Advance Directive

Include Directive in Note

Counseled regarding importance of Advance Directive Planning

Last review of Advance Directive

Directives PAIN MANAGEMENT CONTRACT

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MICROSYSTEM

Listen, Learn, Leverage

Caregiver Teams

- ✓ Routine feedback
- ✓ Sets priorities
- ✓ Approves strategies



First priority identified by Caregiver Team:

“We need help planning so we do not burn out.”

2. How do we build bridges with community organizations?

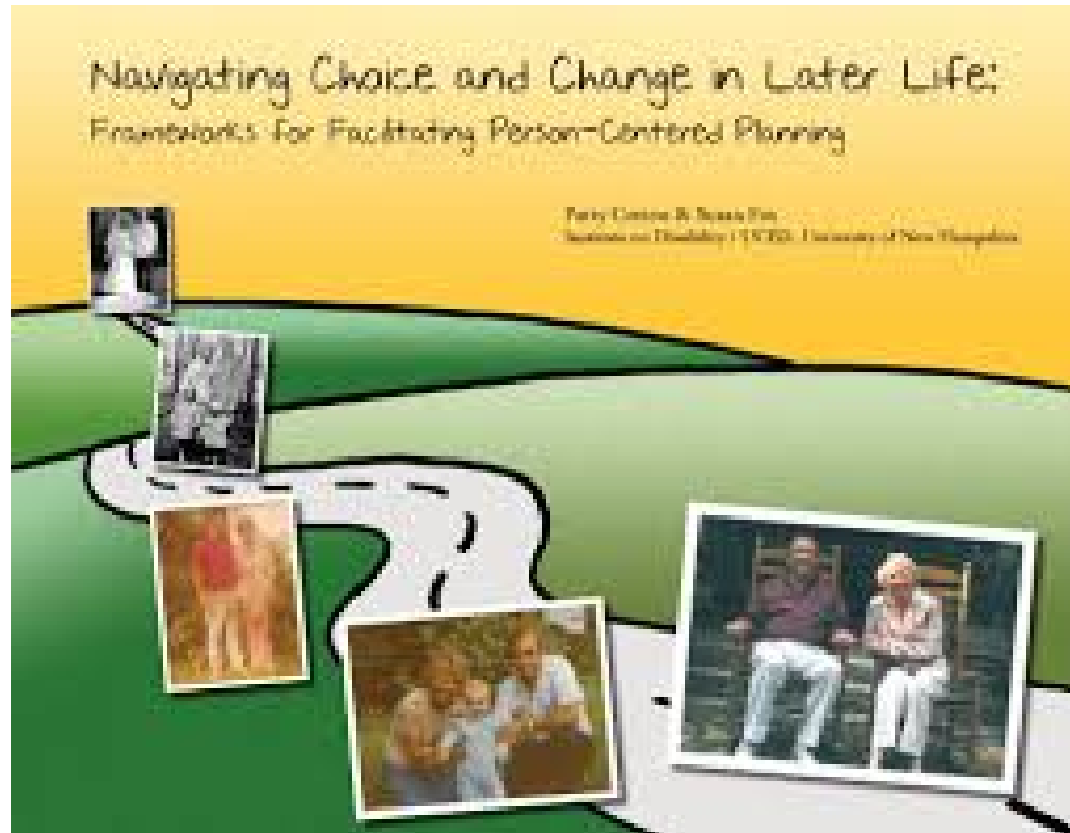


CENTER ON AGING AND
COMMUNITY LIVING



MESOSYSTEM

Integrate person-centered tools into the medical setting



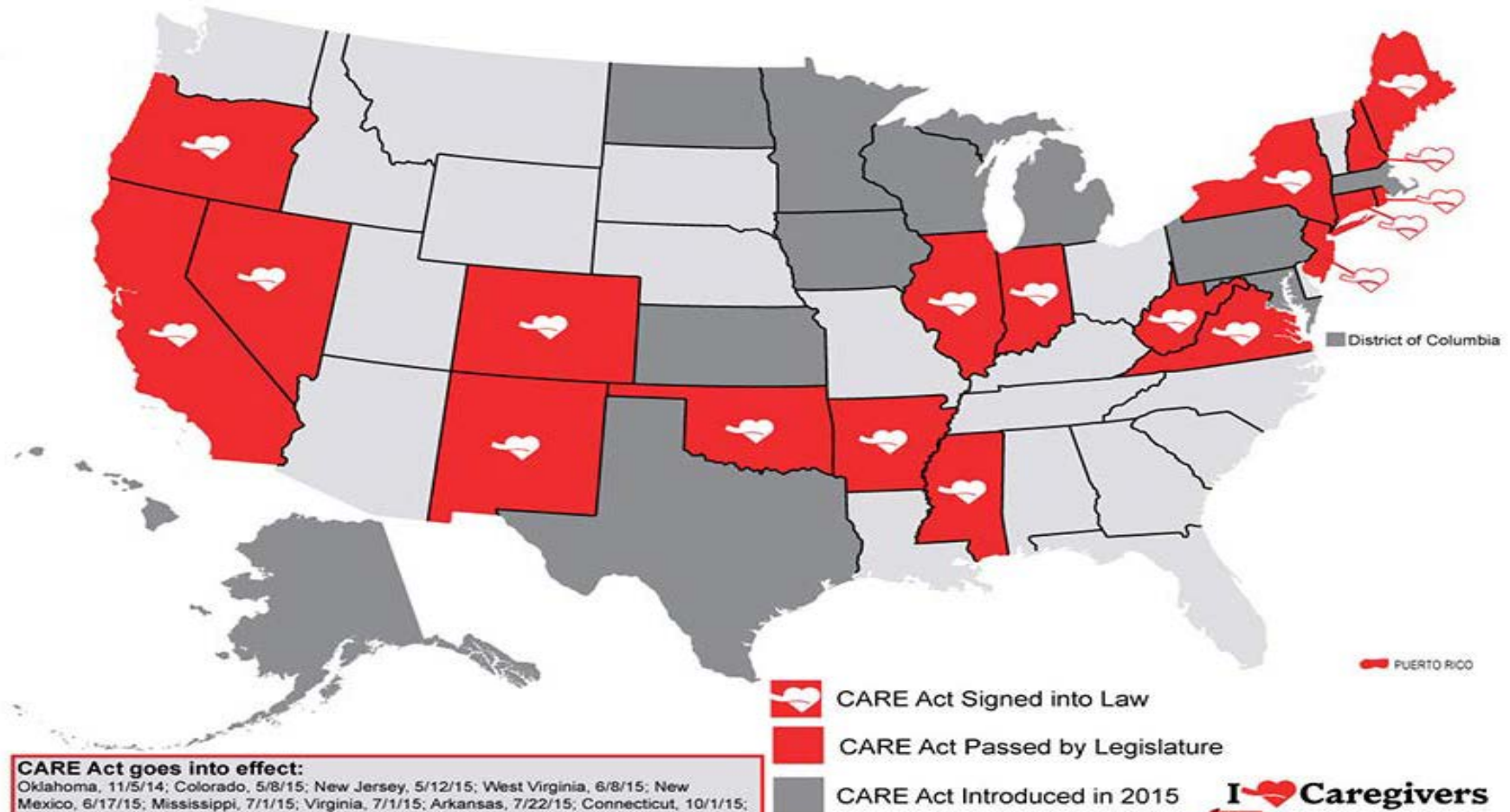
MESOSYSTEM

Patty Cotton & Sue Fox (2011)

3. How can we advocate for family caregivers?

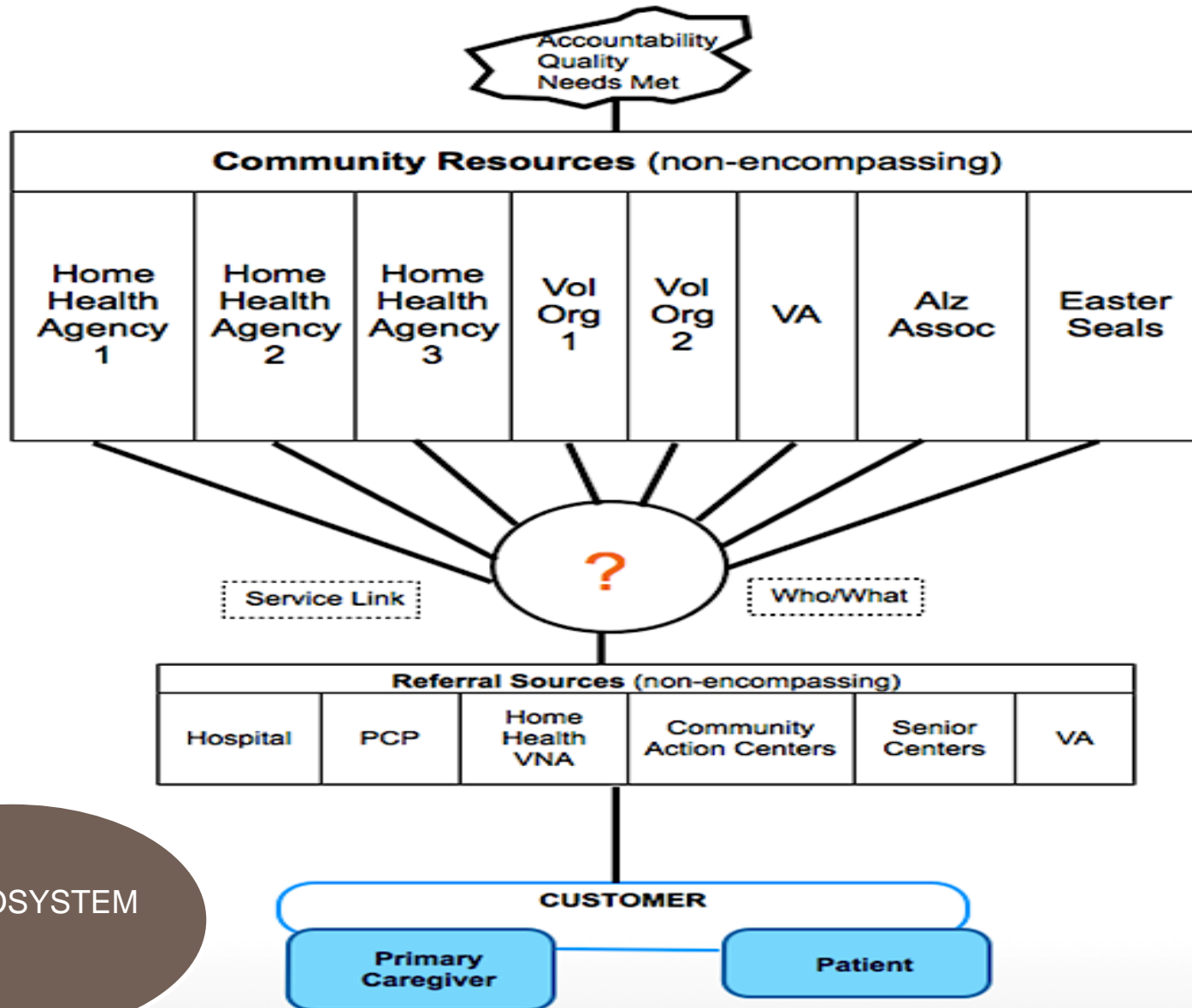
The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.



**Updated on 11/16/2015

Mobilize Seniors and Family Caregivers



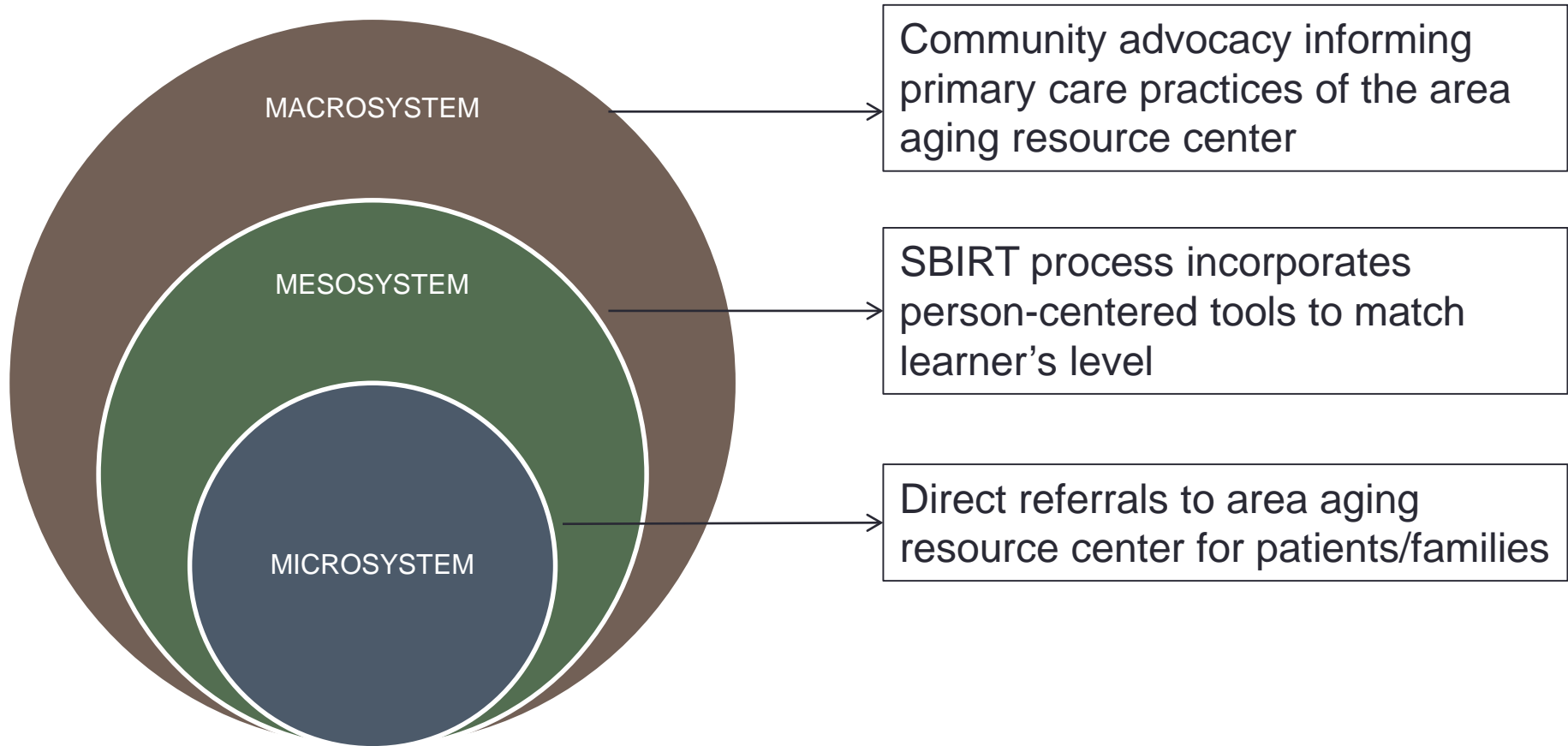
MACROSYSTEM

How does this all come together?

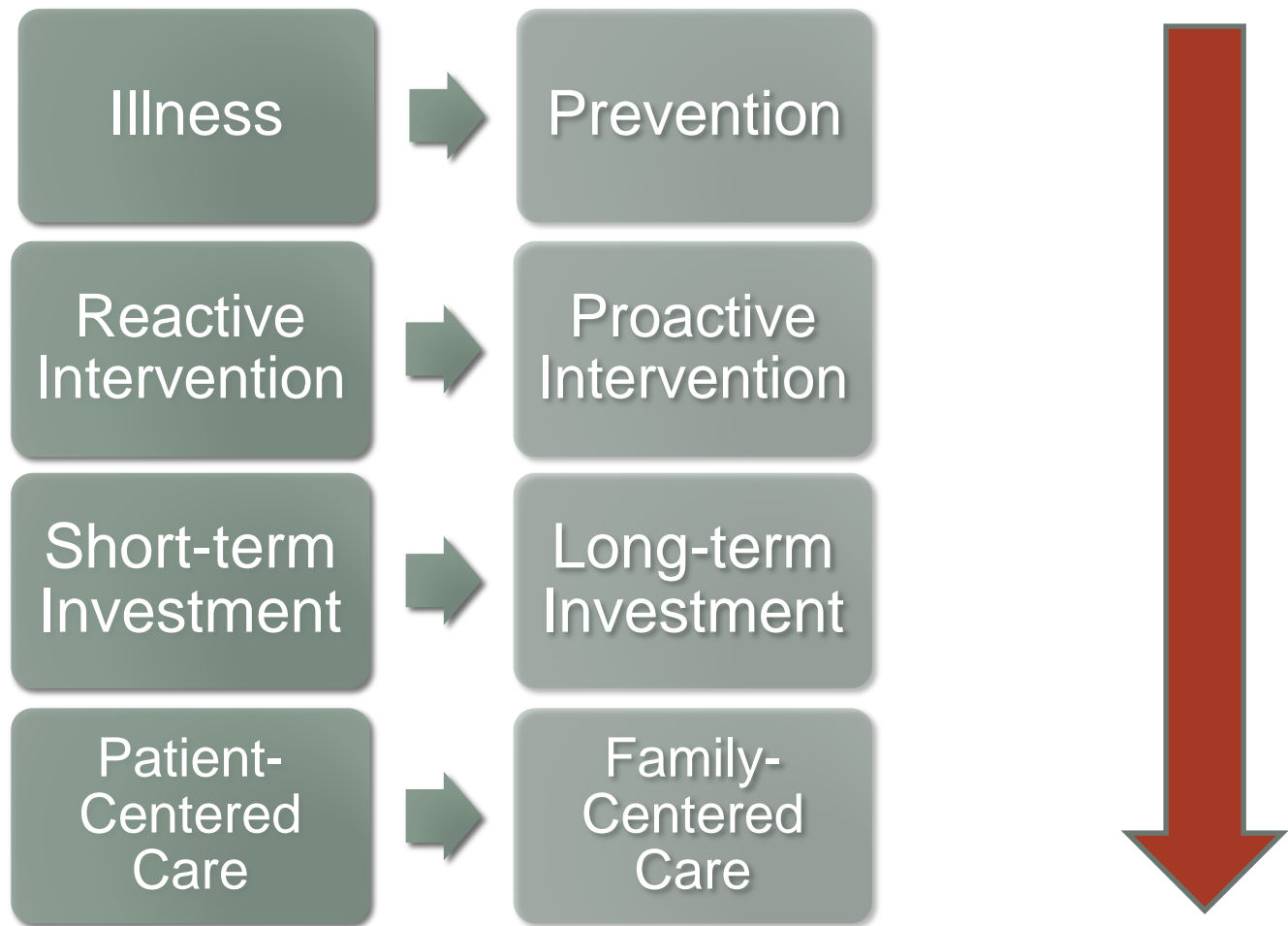


Caregiver Advisors identified the priority.
We listened.
We learned.

Action: “We need help planning for the future, so we do not burn out.”



Family-centered care is Population Health!



Timing is everything!



"I skate to where the **puck** is going to be, not where it has been."

- *Wayne Gretsky*

Summary

- Identify the family caregiver
- Listen, Learn, Leverage
- Embrace as collaborator
- Get involved in family caregiver advocacy



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