



## The Lived Experience & Long-Term Planning of 'Sandwiched' Caregiver Families

Life in households with dependent children, dependent adults with chronic conditions, and a single generation caring for both

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# Introduction | Project Intent

To understand the real-life experiences for a group that frequently interacts with the health care system, often in complex ways: caregivers in **“Sandwiched generation” families.**

These caregivers care for two generations at once:

- older family member(s) with a **chronic condition**
- their own **dependent children**

*Research goals:*

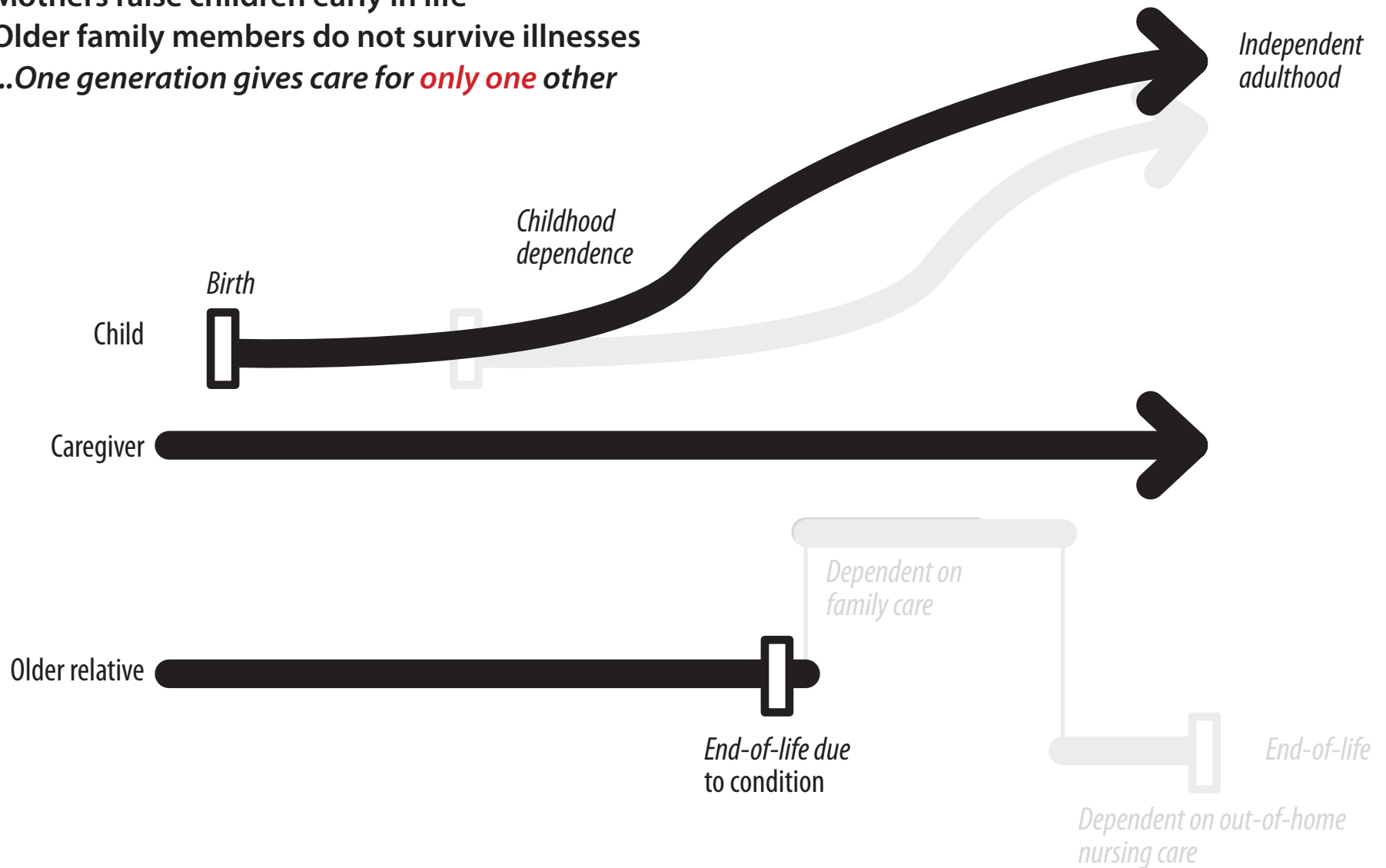
- Understand their everyday, **lived caregiving** experience
- Understand their processes and experiences of making **long-term planning** decisions

From this, we will

- Identify **possibilities for design**: design principles, user needs, and design opportunities

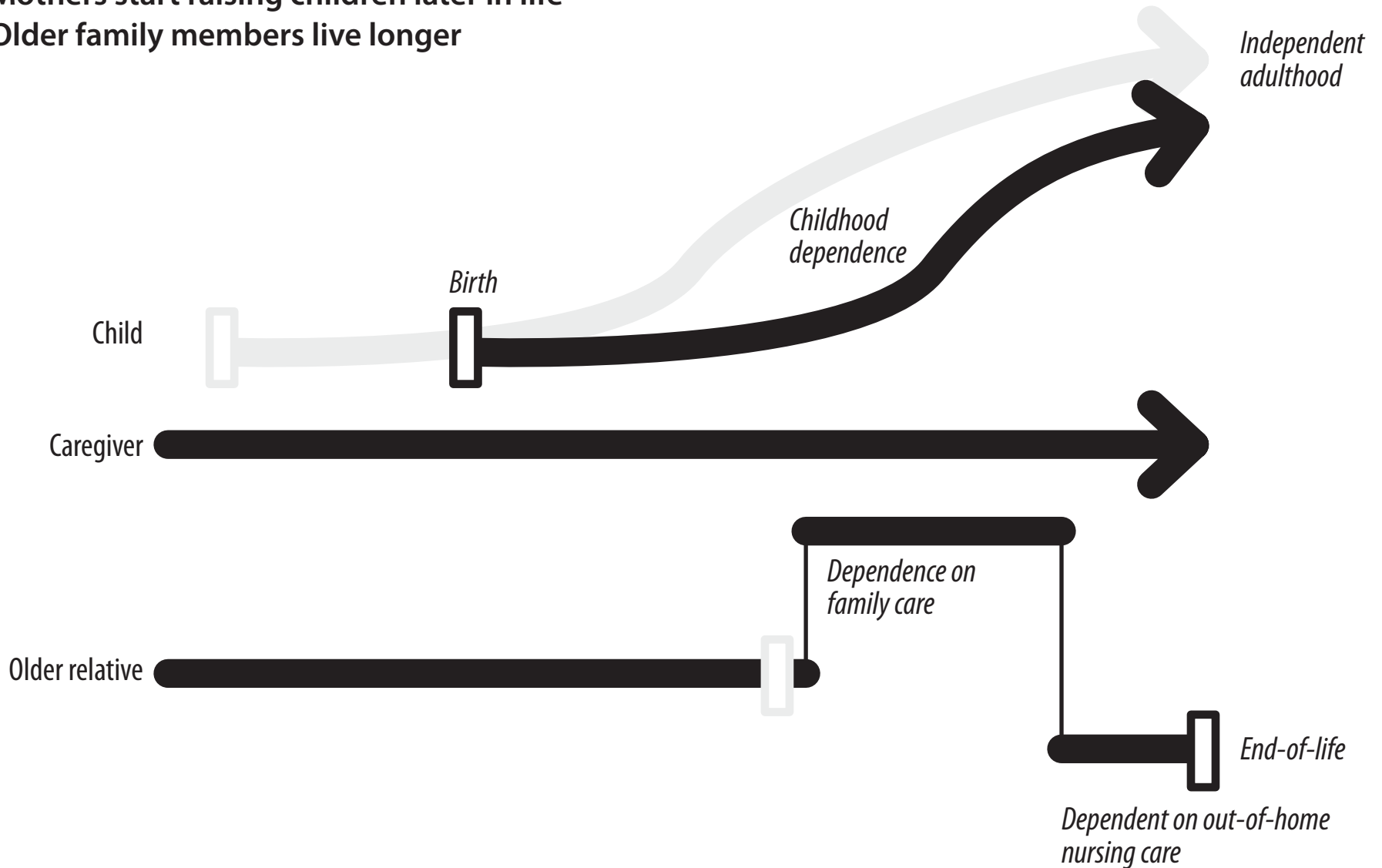
# Introduction | Historic Caregiving Stages

Mothers raise children early in life  
Older family members do not survive illnesses  
...One generation gives care for **only one** other



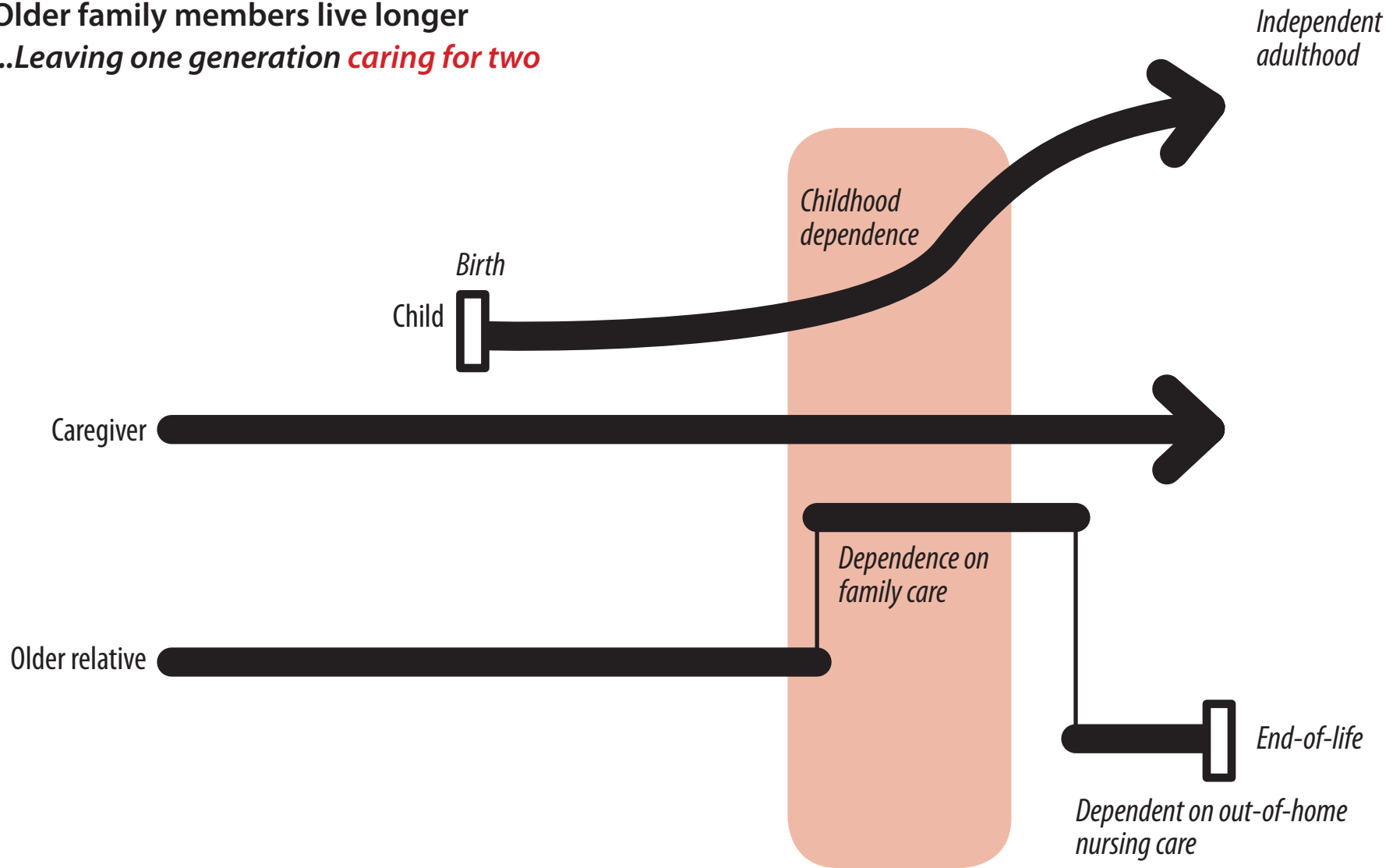
# Introduction | 'Sandwiched' Caregiving Families

Mothers start raising children later in life  
Older family members live longer



# Introduction | 'Sandwiched' Caregiving Families

Mothers start raising children later in life  
Older family members live longer  
...Leaving one generation *caring for two*



# Introduction | Research Protocols

## Lived caregiving experience in depth

*(One sandwiched caregiver)*

- Day-in-the-life in-home observation
- Contextual interview
- One-week photo diary



# Introduction | Research Protocols

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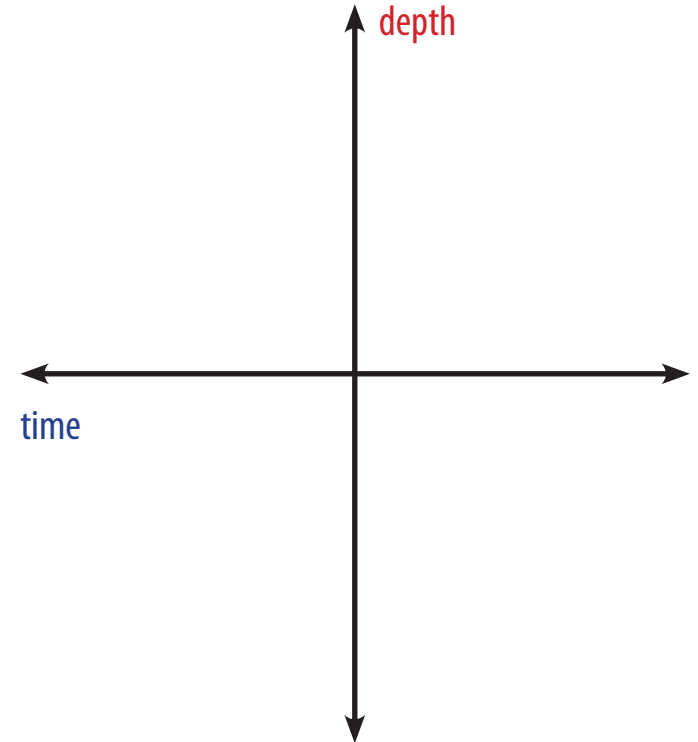
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- Day-in-the-life in-home observation
- Contextual interview
- One-week photo diary

## Decision-making over time

*(Three former & current caregivers in half-day reflective workshop)*

- Decision-making styles
- Personal roadmap
- Rating helpfulness of health care system personas
- “Gift”-making for new caregivers



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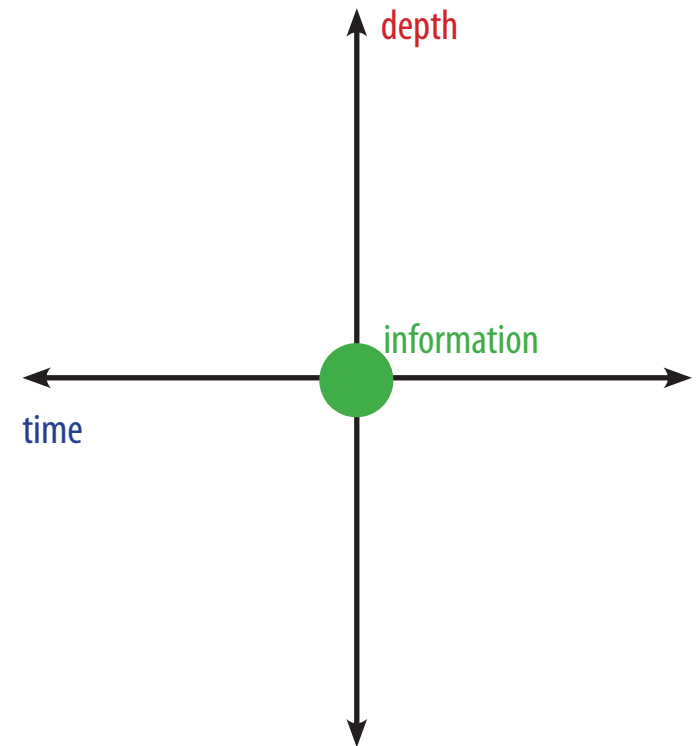
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## Information sources within caregiving

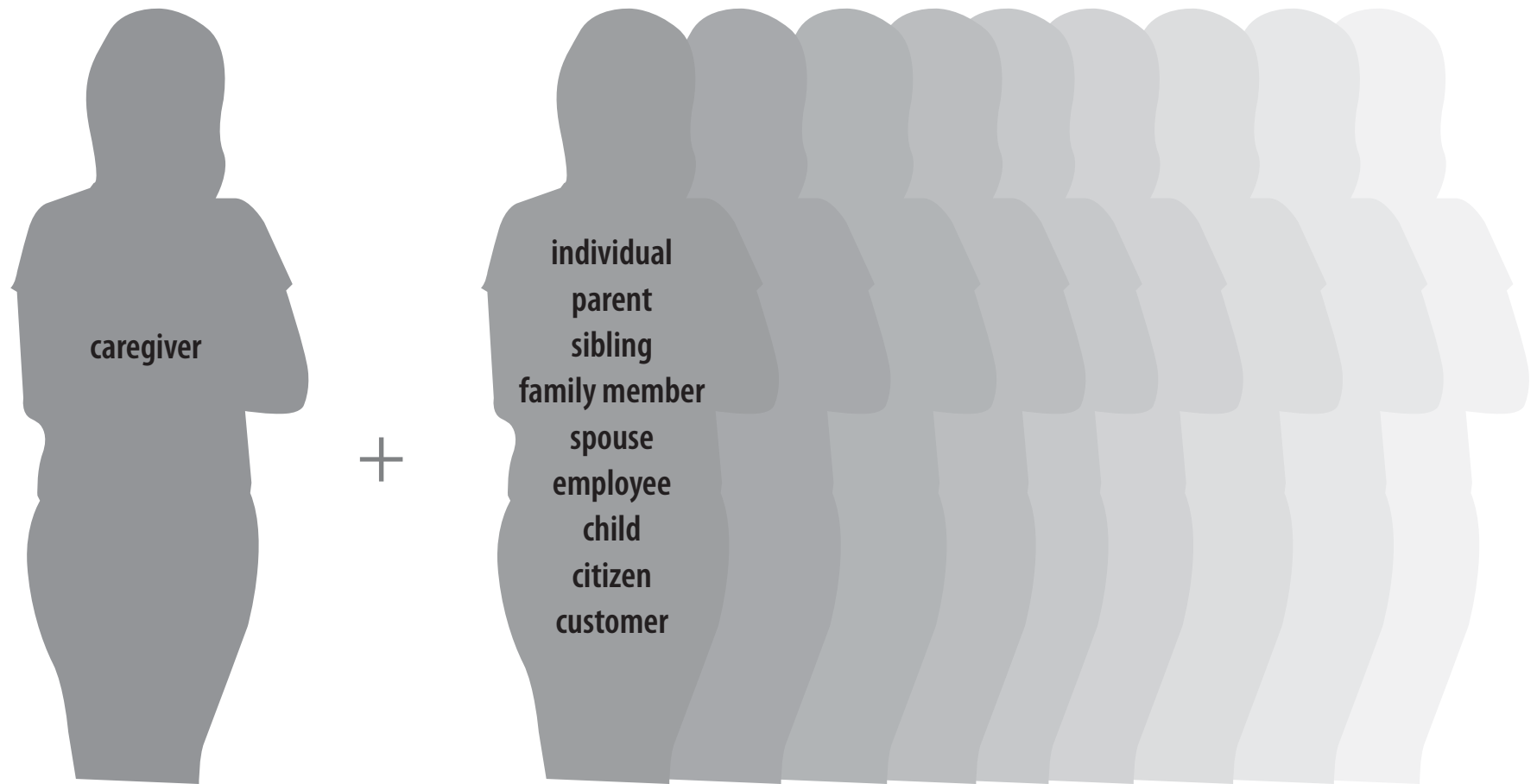
*(All four research participants)*

- Information trust-relevance map

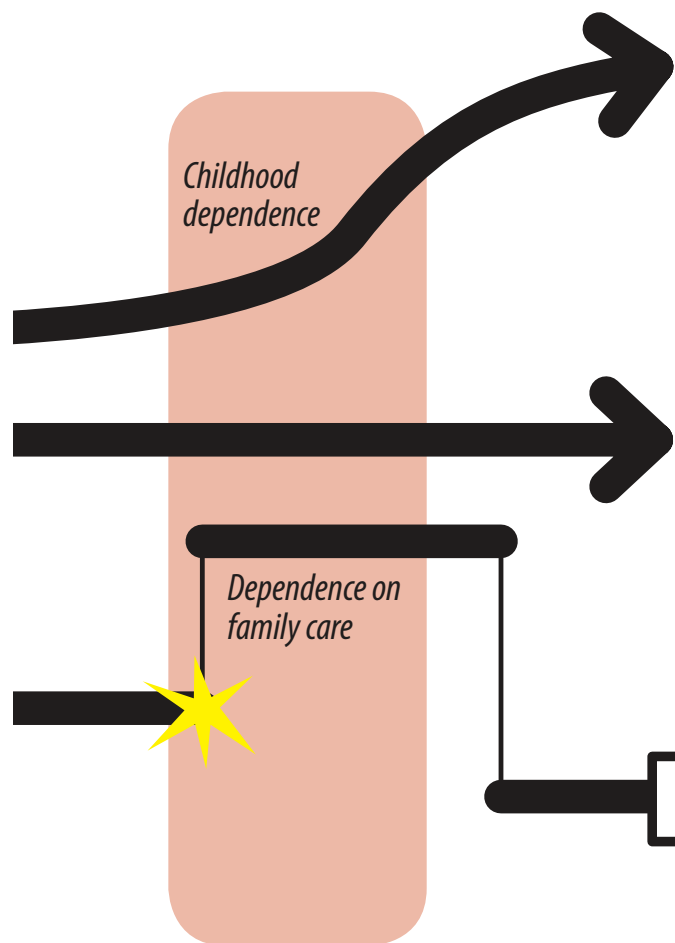


# The Work of Caregiving

Everyone navigates multiple roles as they go through life.  
Caregivers gain a new role that will change all their other roles.



# The Work of Caregiving | Spontaneous Beginning



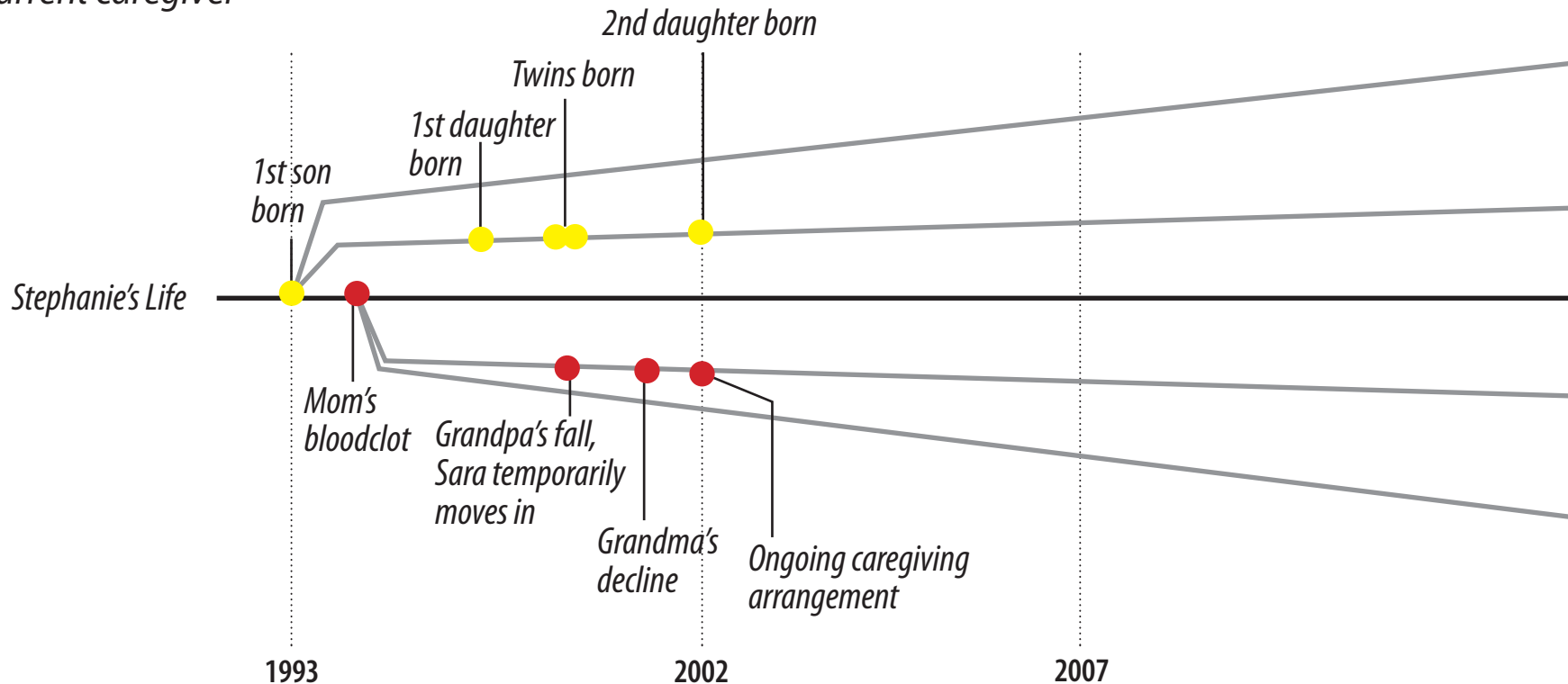
## Instant responsibility

- Can start abruptly and with an emergency, even at a young age
- Family or cultural values (filial piety) influence or determine who the job of caregiving falls to
- A caregiver gets **no instruction manual** and must learn the role of caregiving through experience
- Decline can be so gradual that it takes an emergency to make caregiving need apparent

# The Work of Caregiving | With Ambiguous Future

**“You have to bring your time horizon way in.”**

- Peter, current caregiver



- Caregiving may start as a temporary arrangement, but a worsening condition may make it indefinite
- Even when plans exist, emergencies may dictate their ultimate timing
- Caregivers are seldom in the position to make plans for the future.

# The Work of Caregiving | Situated in Present

**“Even to have a glass of wine, you don’t know if something’s gonna happen and you might have to race out in the middle of the night.”**

*- Stephanie, current caregiver*

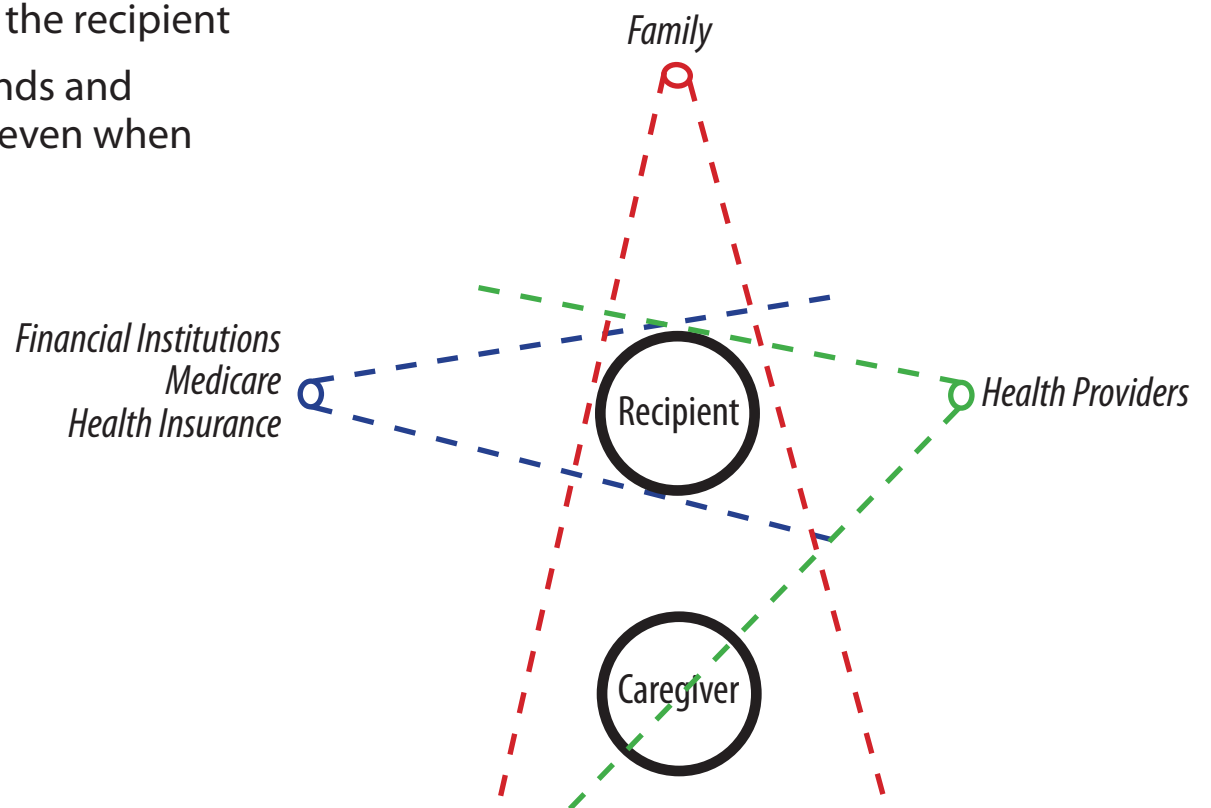
## **A state of constant improvisation**

- Caregivers continuously respond to events outside their control
- Sandwiched caregivers, in particular, must be ready for anything at anytime
- This **constant vigilance** makes planning for the future hard to think about
- Daily life requires honed improvisational skills

# The Work of Caregiving | Peripheral

## The perennial afterthought

- Caregiver's primary interactions are on behalf of another, not themselves
- The healthcare system's focus is on the recipient
- Caregivers can lose touch with friends and acquaintances, becoming isolated even when surrounded by family



# Sandwiched Caregiving | Two Puzzles

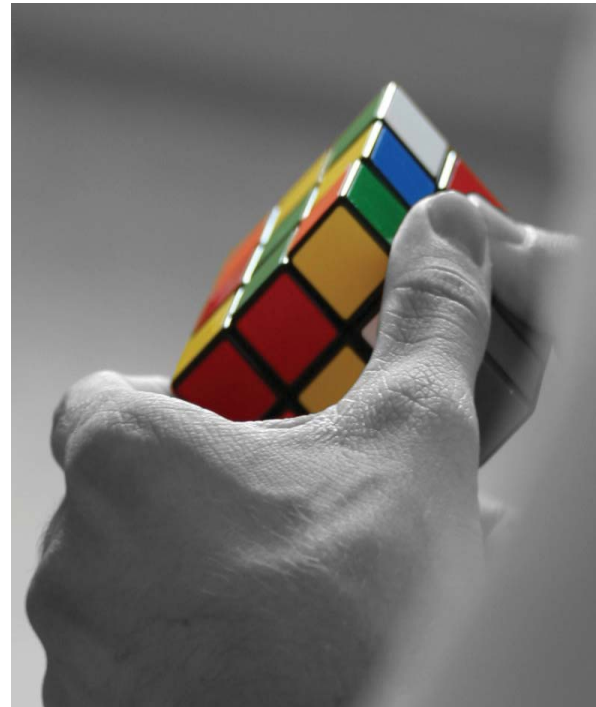
Caregivers are constantly maneuvering through and figuring out two difficult arenas — the dynamics within their **families** and the systems of **officialdom**.

For them, these realms are puzzles to be solved.

Family



Officialdom



# Sandwiched Caregiving | Family Puzzle

**“We don’t believe a word from my father-in-law.”**

*- Peter*

**“...they want to quote-unquote ‘protect’ you.”**

*- Monica, former caregiver*

**Surprisingly, caregivers don’t always trust what their loved ones are saying**

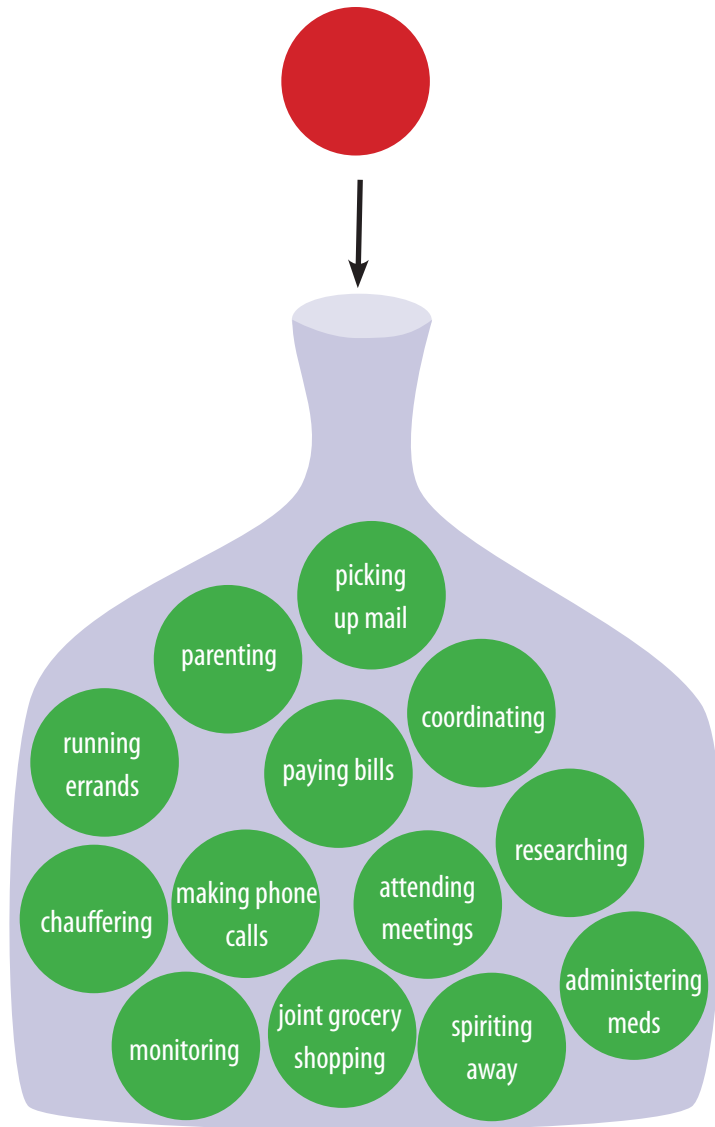
This is because some recipients may be:

- shielding family from discomfiting issues
- hiding the severity of their condition for fear of losing their independence
- exaggerating a problem to gain attention and companionship
- too cognitively impaired to be accurate

*Observed caregiver tactics:*

- Validating facts with another family member
- Independently consulting a medical professional

# Sandwiched Caregiving | Family Puzzle



Caregiving shuffles the family relationship deck, amplifying existing dynamics or creating new ones

- Tension can develop between those who participate and those who don't
- Non-participants may frustrate caregivers with suggestions not based in reality of the situation
- Care recipients may accept assistance from favorite family members, while refusing it from others
- Supportive relationships can be strengthened

*Observed tactics:*

- Creating paths for indirect assistance for reluctant recipient
- Learning everyone's patterns of assistance, and requesting specific help based on specific strengths

# Sandwiched Caregiving | Family Puzzle



**Sandwiched caregivers worry about not giving their children enough attention**

- Several subjects were the children of sandwiched caregivers themselves
- Feel guilty about missing children's events due to caregiving emergencies
- Concerned about not burdening children with the same situation later in life

*Observed tactics:*

- Protecting children from experiences beyond their maturity to handle
- Planning for their own future so children won't have to be caregivers to them

# Sandwiched Caregiving | Bureaucracy Puzzle

## Bureaucrats:

*Medicare*

*Health insurance*

*Pension Funds*

*Local & state Government Programs*

*Financial Institutions*

## Proof Required of Observees:

Are you below the maximum **threshold** for assistance?

Do you actually **represent** the recipient?

Do you have **access** to the material you're discussing, and can you describe it in **exact detail**?

Do you have **Power of Attorney**?

Can you bring the recipient here, **in person**?

## Officialdom requires proof

- When interacting with large organizations, caregivers share a common experience — jumping through hoops
- Because caregivers sometimes operate outside the flow of record-keeping, they must constantly prove things

## Observed Tactics:

- Keeping essential insurance & prescription information in binder accessible to all adults in family

# Sandwiched Caregiving | Bureaucracy Puzzle

*In your caregiving experience, what does government provide?*

*“Broad, scary statistics”*

*“ponderous, impermeable requirements”*

*“black & white requirements”*

*- various, workshop*

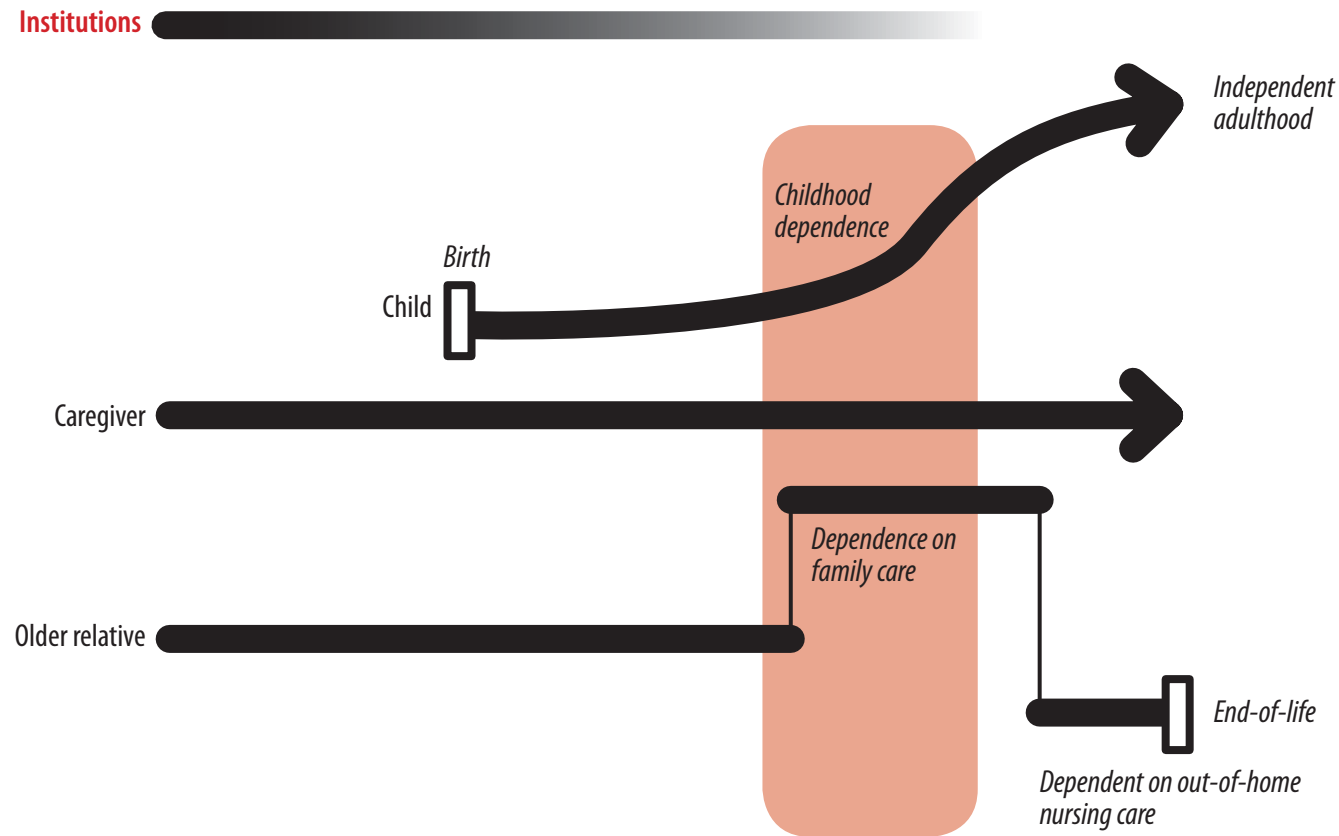
## The blunt instrument of government policy

- Even well-intentioned policy changes can generate **unanticipated consequences**
- Such consequences often hit Caregivers, because they are **peripheral to focus** many new policies

The Health Information Portability and Accountability Act (HIPAA) is such a policy. HIPAA includes provisions on patient privacy and the use of patient information, intended to protect patients from unwanted use of their medical information.

- HIPAA has raised the **thresholds of proof** for our subjects to gather information
- HIPAA has dramatically increased the **information barred** to any caregiver without power of attorney
- HIPAA has made it harder to **access** the proofs needed by the other elements of officialdom

# Sandwiched Caregiving | Institutional Fading



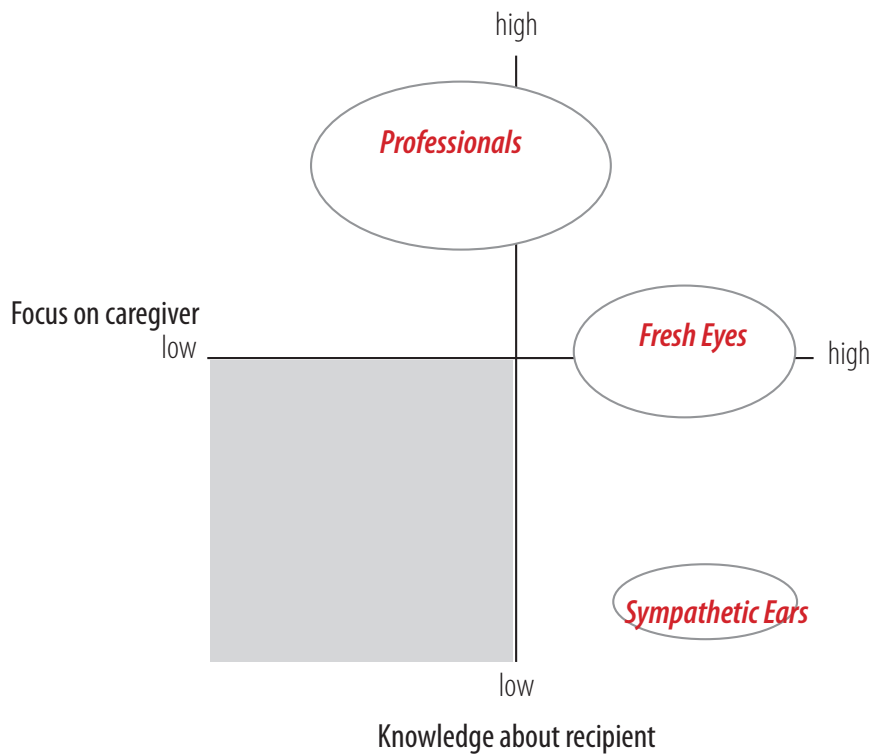
**“My dad had awesome insurance.”**

- *Monica*

- Current caregivers resign themselves to the benefits available

- Demographic mobility and economic changes work against multi-decade customer relationships
- For our observees, church-based support is decreasing

# Possibilities for Design | Insights



Caregivers do not face their struggles alone.  
Our subjects found trusted allies in several roles.

**Professionals:** Family GP, Geriatric Specialist, Therapist

- Health providers with specific medical **expertise**
- Directly serve the recipient
- Can provide the caregiver direct, **specific** information and advice **relevant** to their caregiving work

**Fresh Eyes:** Friends, Kids, Support staff (e.g. Nurse's aide)

- See the recipient less frequently or infrequently
- Have trusted relationship to the caregiver
- Can see effects of **gradual change** in recipient that caregiver might miss

**Sympathetic Ears:** Support groups, Domain Experts

- No direct interaction with recipient
- Interact with caregiver
- Can provide emotional or information **support** to caregiving work

# Possibilities for Design | Design Principles

**Extend tactics from improvisation to strategy.**

**Recognize the caregiver as their own person.**

**Bring the periphery into the light; treat caregivers as prime actors and key decision makers.**

**Provide foresight to forestall or mitigate crises.**

**Leverage the trusted points of contact; attention is an expensive resource.**

# Possibilities for Design | User Needs

## *The work of Caregiving*

- Means to add longer-term strategizing to short-term improvisation
- Information about future possibilities: what might happen before it happens, and what could be done
- Pathways to increased social connection

## *The family puzzle*

- Aid and support in making confident decisions
- Foresight into the implications of a decision
- Support in working through issues with the family before crises force decisions
- Help in juggling
- Easier ways for Caregiver to have family members help in productive, useful ways

## *The bureaucratic puzzle*

- Help figuring out the system and what it wants
- Simplified or standardized proofing processes for officialdom

**The unsung Caregiver needs some recognition and support.**

# Possibilities for Design | Opportunities

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## *The bureaucratic puzzle*

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- Create tools for strategizing difficult personal matters
- Use “what if” scenario planning for long-term planning
- Proactively identify and reach out to Caregivers, without prompting
- Provide unbiased sounding boards
- Assist with simple, yet time-consuming tasks
- Occupy chauffering time with podcast series
- Explain the system in simple, digestible overviews and actionable tasks
- Preassemble document and form packages

Thank you.