



Universal Family Care

Designing State-Based Social Insurance Programs
for Long-Term Services and Supports, Paid Family and Medical Leave and
Early Child Care and Education

Study Panel of the National Academy of Social Insurance

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Caring Across Generations

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- 02 Flexibility
- 03 Variety
- 04 Confidence

About the Study Panel

Overview

- **Timeline:** December, 2017-March 2019
- **Funding:** the Ford Foundation and Caring Across Generations
- **Task:** Design Policy Options for *State-Based Social Insurance* Programs for Long-term Services and Supports (LTSS), Paid Family and Medical Leave (PFML), and Early Child Care and Education (ECCE)
- **Panel Co-Chairs:** Marc Cohen and Heidi Hartmann
- **Project Staff:** Benjamin Veghte (Director) and Alexandra Bradley
- **Panel Members:** 30 experts in three working groups
 - **LTSS Working Group:** Chaired by Marc Cohen
 - **ECCE and PFML Working Group:** Chaired by Heidi Hartmann
 - **UFC Working Group:** Benjamin Veghte and Alexandra Bradley

LTSS Working Group Members (1/2)

- **Marc Cohen**, Working Group Chair; Co-Chair, Professor, McCormack Graduate School of Policy and Global Studies, University of Massachusetts, Boston; Co-Director, LeadingAge LTSS Center @UMass Boston; Research Director, Center for Consumer Engagement in Health Innovation, Community Catalyst
- **Eddie Armentrout**, Consulting Actuary, Actuarial Research Corporation
- **Brian Burwell**, Vice President, Health Policy and Data Analytics, IBM Watson Health
- **Henry Claypool**, Policy Director, Community Living Policy Center, University of California, San Francisco
- **Robert Espinoza**, Vice President of Policy, PHI (Paraprofessional Healthcare Institute)
- **Judith Feder**, Professor of Public Policy, McCourt School of Public Policy, Georgetown University
- **Howard Gleckman**, Senior Fellow, The Urban Institute
- **David Grabowski**, Professor of Health Care Policy, Harvard Medical School

LTSS Working Group Members (2/2)

- **Michael Miller**, Director, Strategic Policy, Community Catalyst
- **Rebecca Owen**, Consulting Actuary, HealthCare Analytical Solutions, Inc.
- **Patrick Reeder**, Senior Vice President, Government & Industry Relations, Genworth Financial
- **Heinz Rothgang**, Professor of Health Economics, SOCIUM Research Center on Inequality and Social Policy, University of Bremen
- **Allen Schmitz**, Principal and Consulting Actuary, Milliman, Inc.
- **Mary Sowers**, Director of Special Projects, National Association of State Directors of Developmental Disabilities Services (NASDDDS)
- **David Stevenson**, Associate Professor, Health Policy, Vanderbilt Univ. School of Medicine
- **Eileen Tell**, Principal and CEO, ET Consulting, LLC
- **Anne Tumlinson**, CEO, Anne Tumlinson Innovations LLC

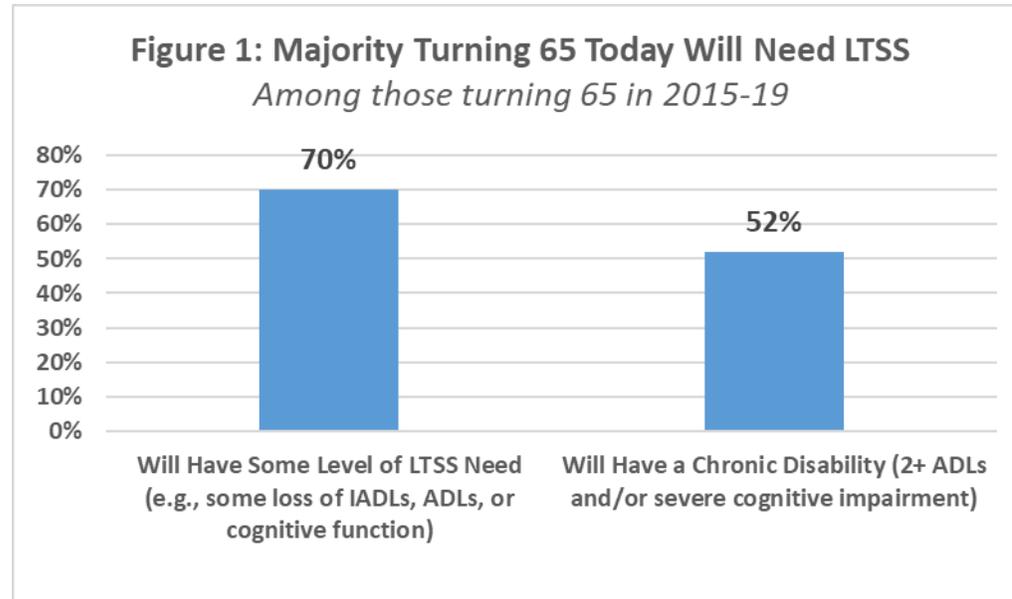
UFC Working Group Members

- **Benjamin Veghte**, Project Director, Academy Study Panel on Caregiving
- **Alexandra Bradley**, Lead Policy Analyst, Academy Study Panel on Caregiving
- **Marc Cohen**, Professor, UMass/Boston; Co-Director, LeadingAge LTSS Center @UMass Boston; Research Director, Center for Consumer Engagement in Health Innovation, Community Catalyst
- **Heidi Hartmann**, President and CEO, Institute for Women's Policy Research; Research Professor, The George Washington University; MacArthur Fellow
- **Eddie Armentrout**, Consulting Actuary, Actuarial Research Corporation
- **Henry Claypool**, Policy Director, Community Living Policy Center, Univ. of California, San Francisco
- **Michael Miller**, Director, Strategic Policy, Community Catalyst
- **Indivar Dutta-Gupta**, Co-Executive Director, Georgetown Center on Poverty and Inequality
- **Joan Entmacher**, Senior Fellow, National Academy of Social Insurance
- **Mary Sowers**, Director of Special Projects, NASDDDS
- **Rebecca Owen**, Consulting Actuary, HealthCare Analytical Solutions, Inc.

LTSS Decision Points

The Case for Action (1/2)

- **LTSS needs are growing as families are becoming less able to meet them**

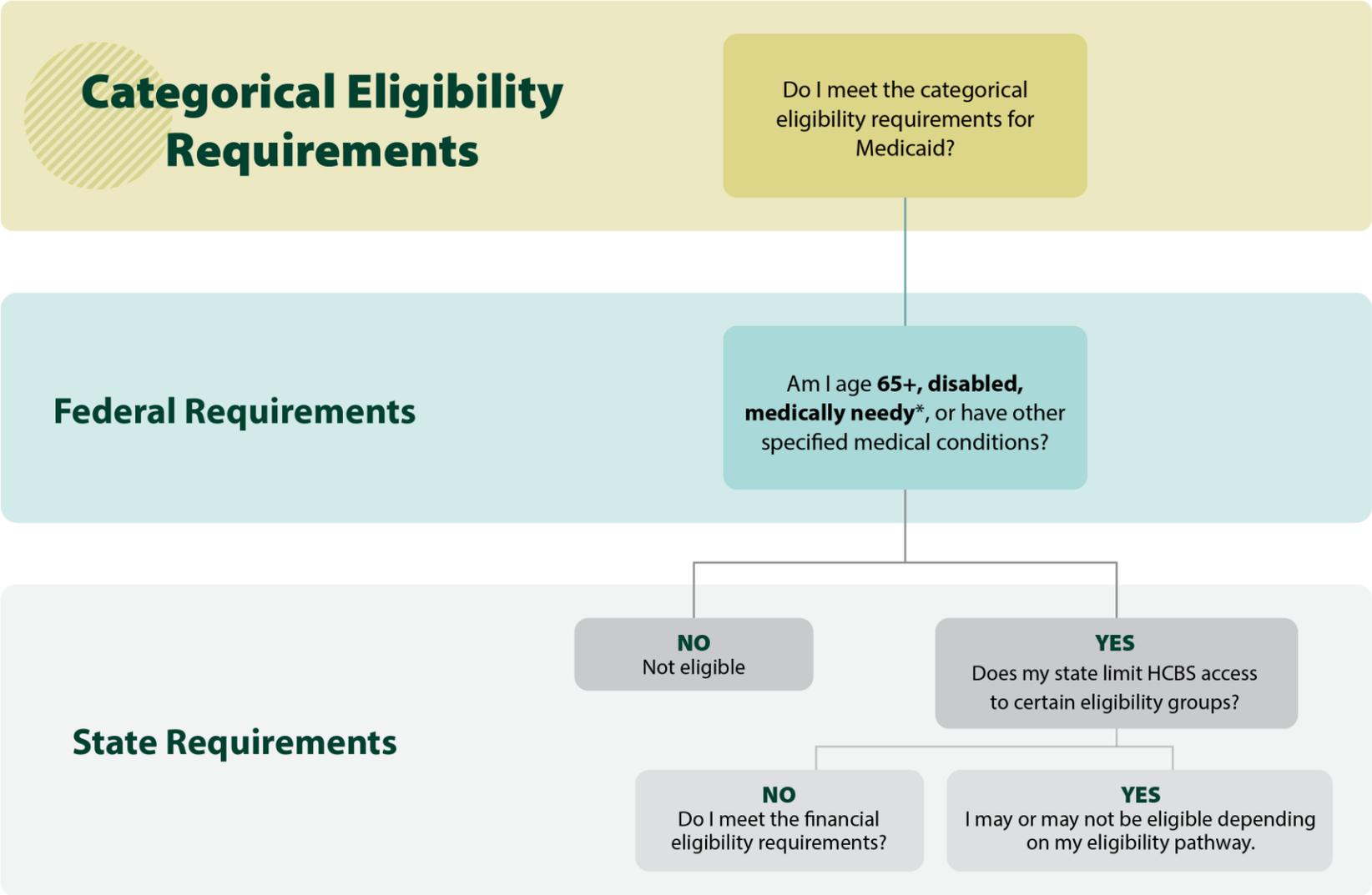


- **LTSS needs can exist at any age**
 - 40% of those needing LTSS today are working-age
 - Intellectual/developmental, mental-health, or physical disabilities; often lifelong
- **Caregiver support ratio declining**
 - Ratio of people 45-64 to 80+ projected to decline from 7:1 in 2015 to 3:1 in 2050

The Case for Action (2/2)

- **LTSS can be costly**
 - Average cost of LTSS for the 52% of Americans with significant need: \$266,000
 - In addition to lost earnings and career growth for family caregivers
- **Individual Savings insufficient to finance LTC needs for most Americans**
 - Half of working-age households projected to be unable to maintain living standards
 - Typical household approaching retirement has \$10,000 in 401(k)/IRA savings
 - Median balance among 58% of households with some retirement savings: \$108,000
- **Private insurance helpful to some, but not broad-based solution**
 - About 7% of households 50 or older have private LTCI; market shrinking
 - Enactment of social insurance could revitalize market (front-end/wraparound)
- **Problem of lack of insurance mechanism for LTSS is not going away**
 - Cost of inaction is greater than the cost of action

Figure 5: Barriers to Access to Home and Community-Based Services (HCBS) under Medicaid



Functional Eligibility Requirements

Do I meet the functional eligibility requirements for Medicaid?

Federal Requirements

Do I meet the level of care requirements (e.g. ADLs)?

State Requirements

NO
Not eligible, unless my state has a buy-in option

YES

Does my state cover optional HCBS benefits (e.g., personal care)?

Are the services that I need covered under my state's 1915(c) waiver (or, in rare cases, 1115 waiver) for HCBS?

NO
Not eligible

YES
I am entitled to those benefits, which may or may not be sufficient to meet my care needs

NO
Not applicable to my care needs.

YES
Does my state have a wait list for HCBS coverage?

NO
I am likely eligible for HCBS coverage, which may or may not be sufficient to meet my care needs.

YES
Depending on my position on the wait list, I may or may not get Medicaid HCBS coverage.

Why State-Based Social Insurance?

- **Why social insurance?**
 - As strains on Medicaid grow, very risky to rely on future access to Medicaid HCBS
 - Risk-pooling is needed to relieve financial pressure on families when most vulnerable
 - Universal program would enable families to keep loved ones at home, working-age pwd to live in community, seniors to age in place
 - Social insurance could fill enormous coverage gap for broad middle class, guarantee access to HCBS and protect against impoverishment due to LTSS needs
 - Provides peace of mind
- **Why state-based?**
 - Relieve pressure on state's Medicaid budget
 - Support development and quality of state's LTSS providers
 - Stimulate economic growth by increasing LFP and creating quality jobs
 - Most countries have strong local component in LTSS financing/admin/delivery
 - Washington state/Hawaii already moving, others on path

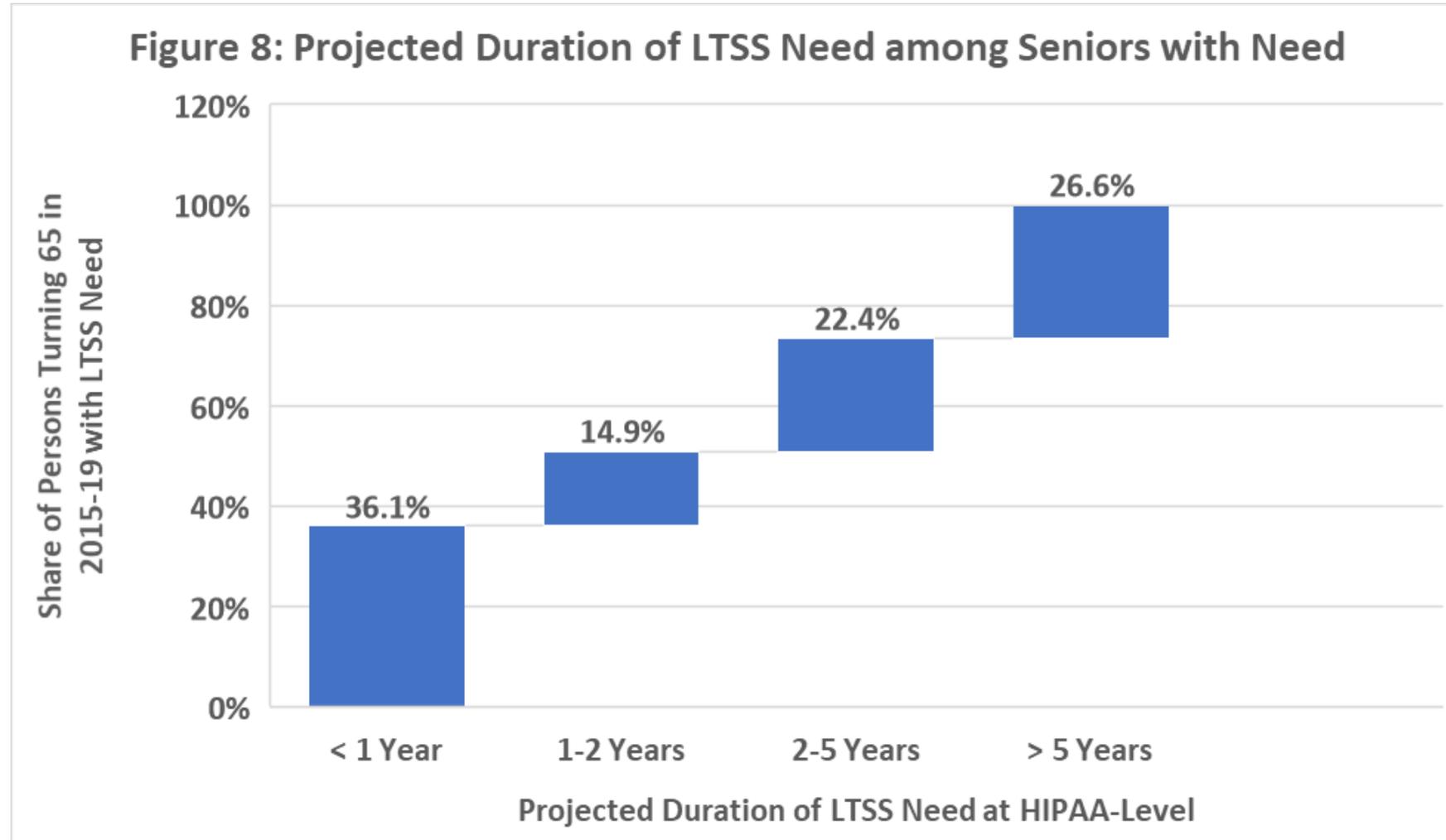
Decision Points for States

- **Program structure**
 - Eligible population
 - Timing and duration of coverage
- **Program financing**
 - Sources of funding
 - PAYGO vs. pre-funded
 - Program Cost
- **Program integration**
 - Coordination with Medicaid and private insurance
 - Integration of LTSS and health care
- **Program implementation**
 - Workforce development, provider credentialing, revenue collection/management, eligibility determination, cash-service reimbursement continuum, care coordination

Program Structure

- **Eligible population**
 - Only those who have paid in and vested vs. everyone
 - Generational transition issues (Current and future disabled vs. only future)
- **Start and duration of coverage**
 - Front-end
 - Back-end (Catastrophic)
 - Comprehensive (unlimited)

Timing and Duration of Coverage



Comparison of Front/Back-end, Comprehensive

	Front-end	Back-end (Catastrophic)	Comprehensive
Who is covered?	Everyone with an LTSS need receives some benefits.	Targets funding to those with the greatest LTSS needs (longest duration).	Everyone with an LTSS need receives benefits.
Program costs	More predictable program costs and more affordable premiums, all else equal.	Costs may be more unpredictable, as life span increases over time or as duration of morbidity increases.	Most expensive (all else being equal) because both front- and back-end needs are covered and duration of needs is unpredictable.
Impact on family caregivers	Helps all families cope with initial period of care need, giving them time to identify appropriate planning and resources for continuing to meet needs (e.g., apply for Medicaid if needed to cover longer term need)	Reduces need for family care during phase when family care resources are “burnt out” or high-level care needs at longer care durations exceed what family can support.	Reduces family care burden throughout entire duration of need.
Private market gap-filling	More difficult for private market to supplement because private market unlikely to cover back-end risk.	Easier for private market to gap-fill with affordable front-end coverage for those who want it.	Private market might gap-fill with a benefit that adds to the daily benefit amount.

Program Financing

- **Potential financing approaches**
 - Social Security tax base
 - Medicare Part A tax base (with higher earners paying higher rate)
 - Medicare Net Investment Income Tax (NIIT) base
 - Combination of Medicare Part A and NIIT tax bases
 - Medicare Parts B and D approach
 - Income tax base
 - Sales surtax
 - Estate tax
 - Provider fees
 - General revenues

Funding Considerations

- **Funding Considerations**
 - Size of tax base
 - Fiscal sustainability
 - Political sustainability
 - Affordability
 - Connection with program benefits
- **PAYGO vs. Prefunding**
 - PAYGO implications
 - Prefunding implications
 - Blended approach (DE)

LTSS Funding in Practice

	Revenue Source	Scope of Coverage	PAYGO or Prefunded
United States			
Medicaid program	General revenues	Means-tested	PAYGO
Washington state proposal*	Payroll tax on all earned income	Universal	PAYGO with limited prefunding
Cohen-Feder proposal**	From age 40 onward: Payroll tax on all earned income (split between employers and employees); Tax on investment income of high earners (above \$200k/\$250k)	Universal (after income-related waiting period)	Prefunded
International			
Germany	Payroll tax on earned income; Pensioners pay full contribution; Childless workers pay supplementary contribution; UI pays con-tributions for unemployed	Universal	PAYGO with limited prefunding
Netherlands	Contributory for institutional care and 24-hour home care (with general revenue funding for other home care and LTSS)	Universal	PAYGO

Tax Rates Required to Fund Some LTSS Programs

75-Year Rates Based on a \$100 Daily Benefit

Tax Base	Washington Front-End	Home Health Program			Cohen-Feder Catastrophic or Back-end
		\$36,500 Benefit Maximum	\$73,000 Benefit Maximum	Unlimited Benefits	
Social Security	0.75%	1.08%	1.73%	4.03%	0.74%
Income Tax	0.58%	0.83%	1.33%	3.12%	0.57%
Medicare Payroll	0.62%	0.89%	1.43%	3.33%	0.61%
Medicare Investment	13.68%	19.67%	31.53%	73.56%	13.43%
Medicare Total	0.59%	0.85%	1.37%	3.19%	0.58%

Existing LTSS Systems Abroad

- **Social Insurance Programs**
 - Germany, Japan, Netherlands, South Korea
 - U.S. proposals: Washington state, Cohen-Feder
- **Universal-Comprehensive Systems**
 - Sweden, Denmark, Finland
- **Residual**
 - England, United States (Medicaid)
- **Hybrid**
 - France
- **Pervasive challenges**
 - Funding, labor-market participation and health of family caregivers, integration of LTSS with health and social services, quality of jobs for LTSS workforce

About the UX Design Project

Process and Insights

- **Process**

- Funding from Pivotal Ventures (Investment and Incubation Company)
- Partnering with IDEO.com, leading practitioners of User Experience (UX) design
- 6-week design sprint mid-November 2018 to first week of January 2019
- Starting point: 15 semi-structured interviews explore needs of sandwich generation caregivers and care workers; 6 interviews with policy experts and practitioners
- We developed narratives around support needs expressed by interview partners
- We developed WebApp grounded in those needs and informed by study panel policy design parameters

- **Insights**

- Goals for policy design look different if conceived in functional vs. relational terms
- Paradigm shift needed
- UX perspective surfaces unexpected support needs
- We highlight these in stylized form using four families



Esmeralda

24-year old mom of a three-year old daughter and full-time caregiver for her epileptic and schizophrenic 54-year old mother.



Theresa

45-year old mom of three adult children, legal guardian of a two-year old granddaughter, and part-time caregiver for her 65-year old mother. Works full time as an executive admin at a university.



Leah

30-year old pregnant mother (expecting in May) of a 2-year old son and part-time caregiver for her 78-year old father. Works full time as a marketing manager.



Sally

53-year old mother of two teenagers and part-time caregiver for her 89-year mother, who has needed 24-hour, live-in professional care for the past 10 years. Works part time as a travel agent.

Less able to pay for care

More able to pay for care







“I need guidance to confidently do care right.”



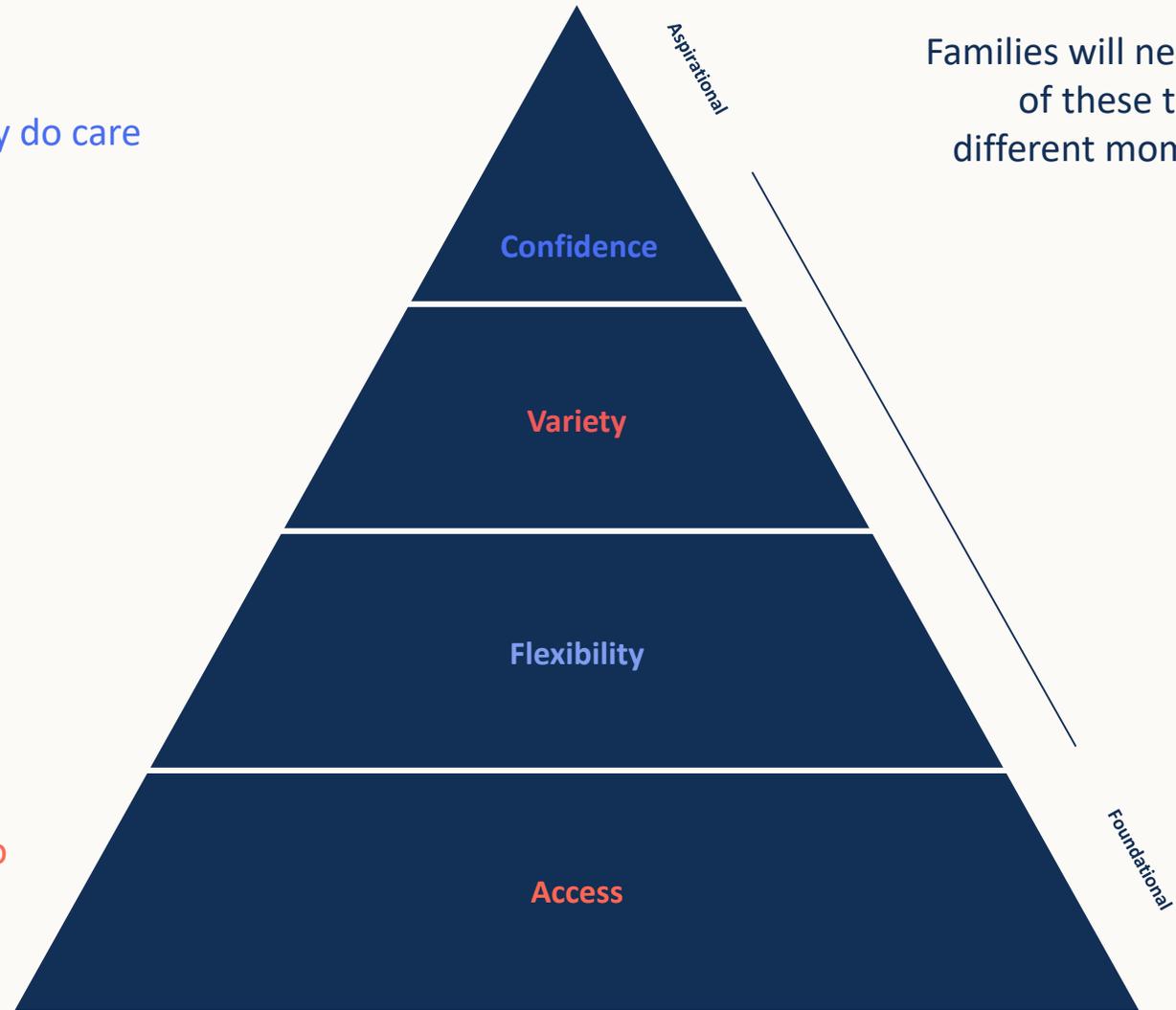
“I need the right variety of support.”



“I need flexible care options.”

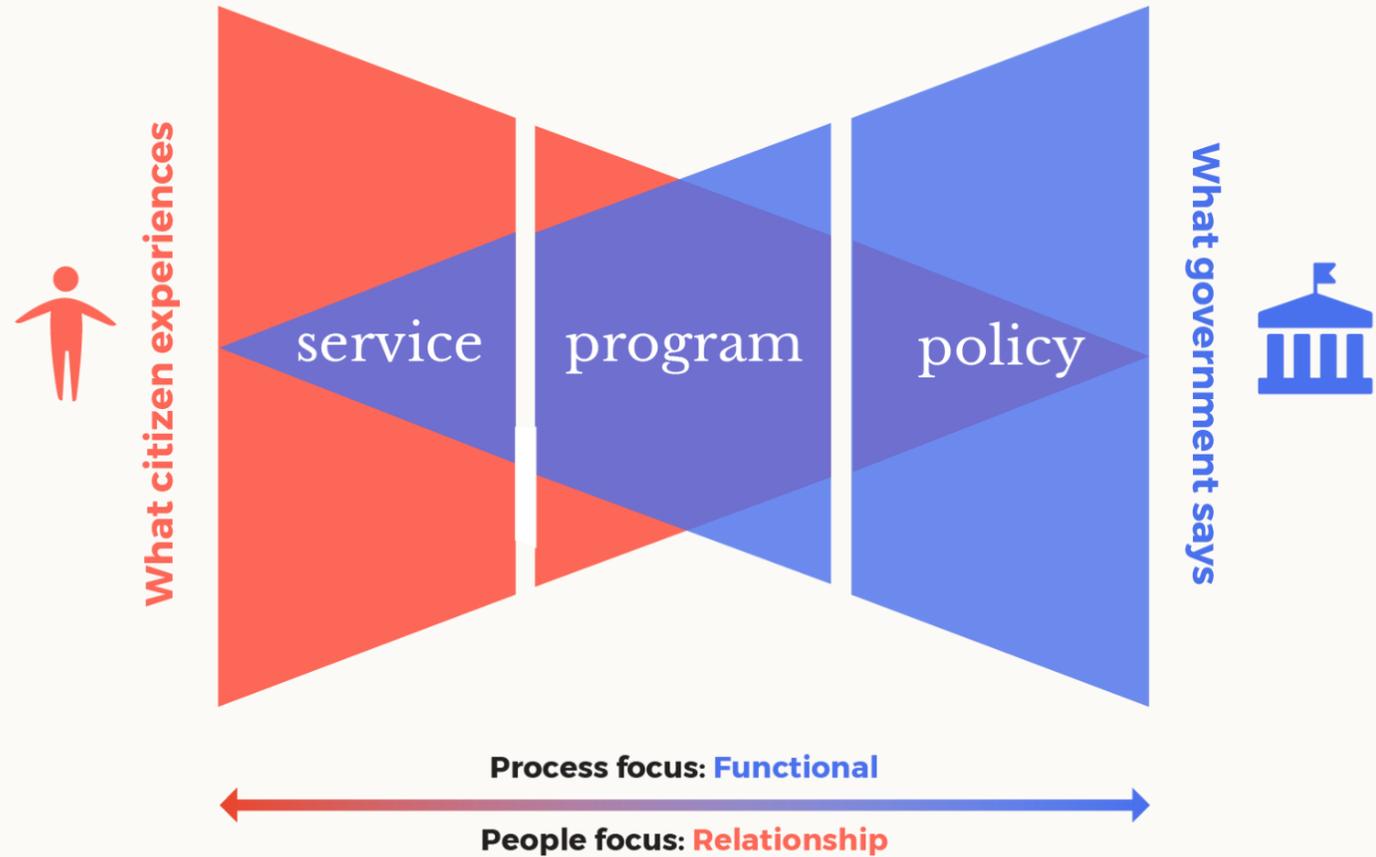


“I need care to be accessible to me.”

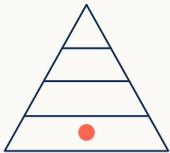


Families will need each of these things at different moments of life.

Human-Centered
Policy Design:
Bringing together
UX & Policy Design

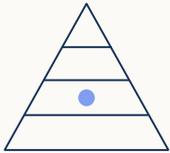


A Universal Family Care program



What if Esmeralda had access to care for her mom and daughter?

In-home care for her mom and day care for her daughter would allow her to go back to school and ultimately work and contribute financially to her family and build a career.



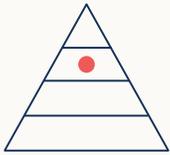
What if Theresa had an affordable daycare with flexible hours for her granddaughter?

Child care subsidy allows her to enroll in daycares that match her work schedule. The reduced reliance on her mom removes stress and prevents her from missing as much time at work.



What if Esmeralda had access to care for her mom?

In-home care for her mom and day care for her daughter would allow her to go back to school and ultimately work and contribute financially to her family and build a career.



What if Leah had a variety of support for her dad?

Service marketplace connects her dad to speciality supports, like walking partners, that help him with his health and socialization. This removes some of her care burden, allowing her more time to focus on her young children and career.



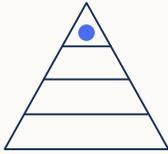
What if Theresa had an affordable daycare with flexible hours for her granddaughter?

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What if Esmeralda had access to care for her mom?

In-home care for her mom and **day care** for her daughter would allow her to go back to school and ultimately work and contribute financially to her family and build a career.



What if Sally had a way to feel financially confident in her mom's care?

In-home care subsidy supports payment for her mom's care, allowing her financial peace of mind and allowing her more time with immediate family and to find work.



What if Leah had a variety of support for her dad?

Service marketplace connects her dad to speciality supports, like walking partners, that help him with his health and socialization. This removes some of her care burden, allowing her more time to focus on her young children and career.



What if Theresa had an affordable daycare with flexible hours for her granddaughter?

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What if Esmeralda had access to care for her mom?

In-home care for her mom and **day care** for her daughter would allow her to go back to school and ultimately work and contribute financially to her family and build a career.

Pillars of a Universal Family Care program

Work is the foundation & funding mechanism.

Everyone pays into it through a payroll deduction, and the program enables people to work.

Combines disparate programs.

Into a connected and easily navigable program

Flexible and portable.

Accessible throughout your lifetime, as your needs change

Elevates care work.

Provides growth paths and careers for caregivers, alongside the regulations surrounding it.

Access to a variety of services.

Including those that are non-medical and might delay the need for intensive care.