



# **Longitudinal Evaluation of State Medicaid Supports for Paid and Informal Caregivers**

**SUMR 2022**

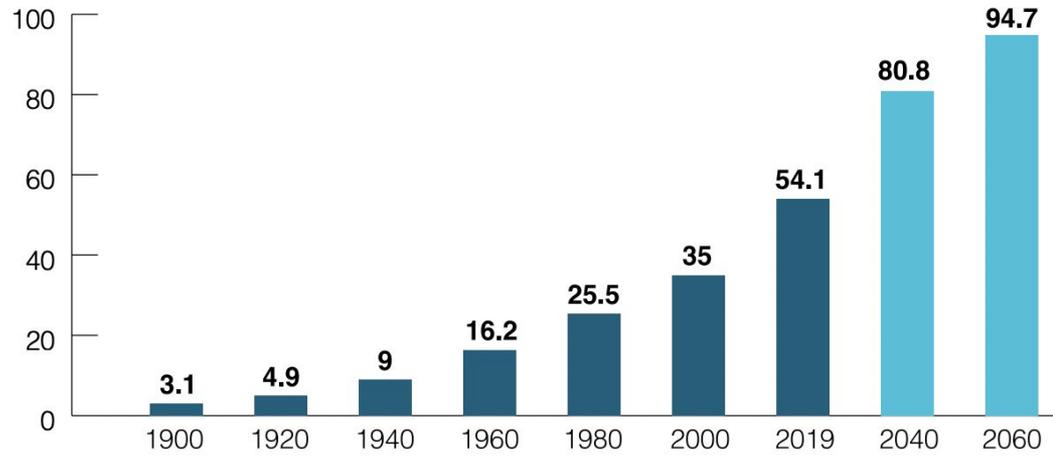
Priyanka Parikh

Mentors: Pilar Gonalons-Pons, PhD; Norma Coe, PhD; Katherine Miller, PhD

# Medicaid Provides At-Home Long-Term Care

- Medicaid is the primary payer of long-term care
- Transition from institutional to home and community-based settings
- The number of older adults is expected to grow by 30 million by 2040, further straining the caregiving workforce (ACL 2022)

Number of Persons Age 65 and Older, 1900 - 2060 (numbers in millions)



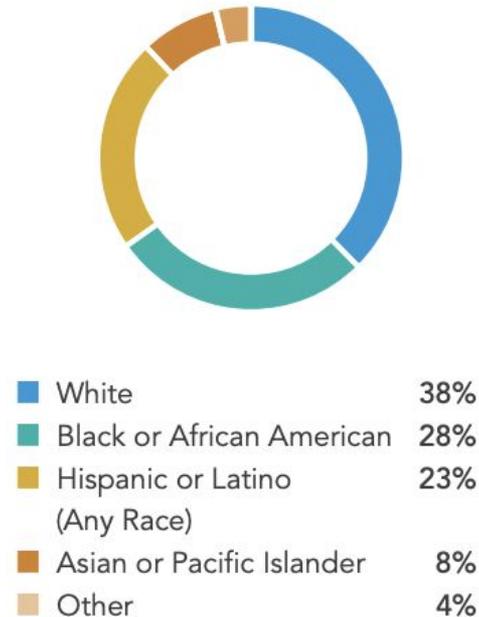
Note: Increments in years are uneven. Lighter bars (2040 and 2060) indicate projections.

Source: U.S. Census Bureau, Population Estimates and Projections

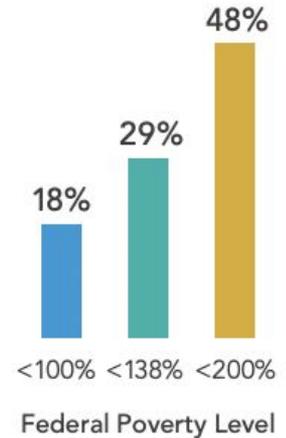
# Paid Caregivers

- **Over 2 million people are home health aides**
  - One of the fastest growing occupations in the US (US BLS 2022)
- **Significant inequities exist within the paid home care workforce**
  - Vast majority are low-income women of color (PHI 2019)
  - Home health aides and personal care assistants were included in the Fair Labor Standards Act and garnered equal rights as workers in 2015 (Iezzoni, Gallopyn, Scales 2019)

RACE AND ETHNICITY, 2017



BY POVERTY LEVEL, 2017



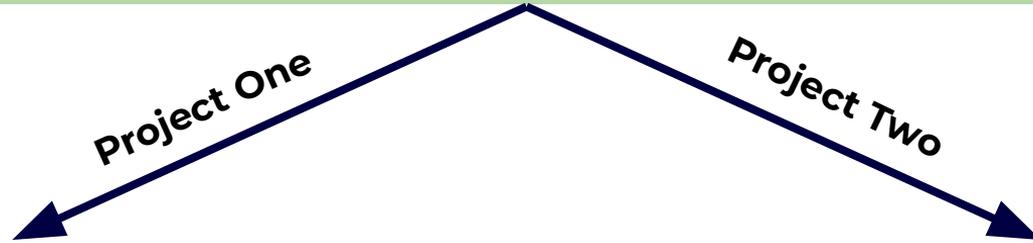
**(PHI 2019)**

# Family Caregivers

- **Relying on unpaid, family caregivers to provide HCBS creates significant harms**
  - Often must leave work partially or entirely to accommodate caregiving duties
  - Women who cared for an older parent lost between \$144k - \$200k across two years
- **Family caregivers provide bulk of at-home care**
  - 1 in 5 adults provide unpaid care (AARP 2020)
- **Access to supports as caregivers is limited & gaps exist in our understanding of how supports are linked to wellbeing**

# Objective

**Create a database of Medicaid policy supports available through 1915(c) waivers**



**Paid Caregiver Supports**

**Family Caregivers for  
People Living with  
Dementia**

# What are 1915(c) waivers?

Home and Community-Based Services

State Plan

Waivers

1915(c)

```
graph TD; A[Home and Community-Based Services] --> B[State Plan]; A --> C[Waivers]; C --> D[1915(c)];
```

The diagram illustrates the structure of Home and Community-Based Services. It is divided into two main categories: State Plan and Waivers. The Waivers category is further subdivided into 1915(c) waivers, which are highlighted in a green box.

# What are 1915(c) waivers?

## Home and Community-Based Services

### State Plan

### Waivers

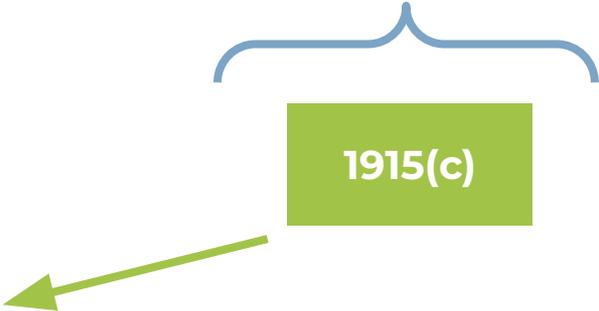
#### Benefits

1. Population-specific supports
2. Cover gaps in state plan

#### Supports

1. Respite care
2. Home health + personal care services
3. Self-direction
4. Case management

1915(c)



# Methods: Compile Active + Expired Waivers

## State Waivers List

Section 1115 demonstrations and waiver authorities in section 1915 of the Social Security Act are vehicles states can use to test new or existing ways to deliver and pay for health care services in Medicaid and the Children's Health Insurance Program (CHIP). All current and concluded state programs authorized under these authorities may be accessed using the below dynamic list. Learn more about the section [1915\(b\)](#), section [1915\(c\)](#), and section [1115 authorities](#).

Search State Waiver List

Showing 1 to 10 of 11 results

SHARE RESULTS

### [PA Adult Autism Waiver \(0593.R03.00\)](#)

State: **Pennsylvania**

Waiver Authority: **1915 (c)**

Status: **Approved**

### [PA AIDS \(0192.R04.00\)](#)

State: **Pennsylvania**

Waiver Authority: **1915 (c)**

#### REFINE YOUR SEARCH:

##### Filter by State

- Alabama
- Alaska
- Arkansas
- California
- Colorado
- Connecticut

##### Filter by Waiver Authority

- 1115
- 1915 (b1)
- 1915 (b2)

- Collect active and expired waiver counts for every state using online CMS database
- Provides a broad overview of states' reliance on 1915c waivers

# Methods: Compile Active + Expired Waivers

## PA HCBW for Individuals Aged 60 & Over (0279.R05.00)

State: **Pennsylvania**

Waiver Authority: **1915 (c)**

Status: **Terminated**

### Waiver Dates

Approval: **07/01/1995**

Effective: **07/01/2018**

Expiration: **06/30/2023**

- Gather approval, effective, expiration dates for each waiver
- Understand longevity of individual waivers

# Methods: Extracting Data from Waiver Applications

Application for 1915(c) HCBS Waiver: GA.0112.R07.02 - Apr 01, 2019 (as of Apr 01, 2019)

Page 1 of 241

## Application for a §1915(c) Home and Community-Based Services Waiver

### PURPOSE OF THE HCBS WAIVER PROGRAM

The Medicaid Home and Community-Based Services (HCBS) waiver program is authorized in §1915(c) of the Social Security Act. The program permits a state to furnish an array of home and community-based services that assist Medicaid beneficiaries to live in the community and avoid institutionalization. The State has broad discretion to design its waiver program to address the needs of the waivers target population. Waiver services complement and/or supplement the services that are available to participants through the Medicaid State plan and other federal, state and local public programs as well as the supports that families and communities provide.

The Centers for Medicare & Medicaid Services (CMS) recognizes that the design and operational features of a waiver program will vary depending on the specific needs of the target population, the resources available to the state, service delivery system structure, state goals and objectives, and other factors. A State has the latitude to design a waiver program that is cost-effective and employs a variety of service delivery approaches, including participant direction of services.

## Request for an Amendment to a §1915(c) Home and Community-Based Services Waiver

### 1. Request Information

A. The **State of Georgia** requests approval for an amendment to the following Medicaid home and community-based services waiver approved under authority of §1915(c) of the Social Security Act.

**B. Program Title:**

Elderly and Disabled Waiver

**C. Waiver Number:GA.0112**

Original Base Waiver Number: GA.0112.90R2

**D. Amendment Number:GA.0112.R07.02**

**E. Proposed Effective Date: (mm/dd/yy)**

04/01/19

Approved Effective Date: 04/01/19

Approved Effective Date of Waiver being Amended: 11/09/17

- Extract data about caregiver supports from 1915c waiver applications that apply to people living with dementia
- Identify policy support provisions that are consistently and easily found across all waiver applications to maintain reproducibility

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Page 1 of 241

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Page 1 of 241

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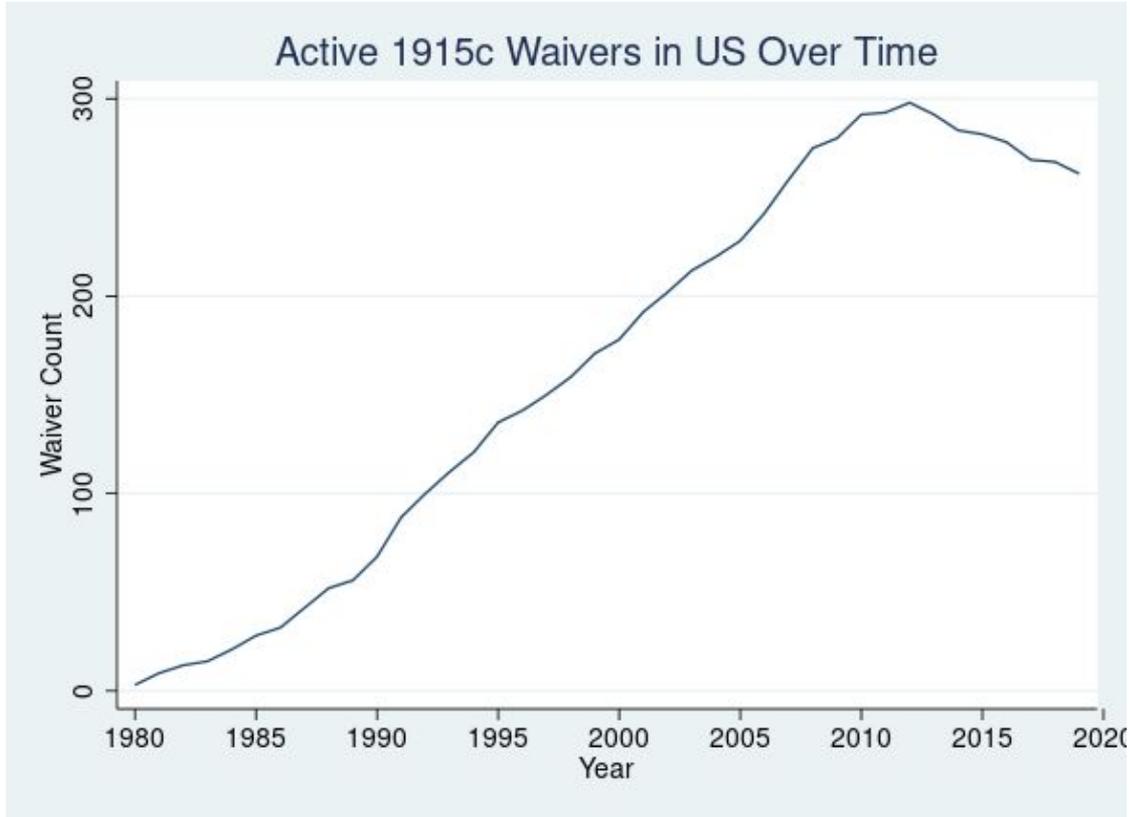
- Process is tedious and manual
- Central and accessible database with 1915c waiver supports data does not currently exist

# Methods: Storing Data in Excel

State	Waiver Name	Waiver Number	Meets age	Applies to dis	Effective during study period	Proceed to data extr	1.F Levels of
Arkansas	AR Community and Employment Support	0188.R05.00	1	1	1	1	
Arkansas	AR Living Choices Assisted Living Waiver	0400.R03.00	1	1	1	1	
California	CA HCBS Waiver for Californians w/ DD	0336.R04.00	1	1	1	1	
California	CA Home and Community Based Alternatives Waiver	0139.R05.00	1	1	1	1	
California	CA Self-Determination Program for Individuals with Develop	1166.R00.00	1	1	1	1	
Colorado	CO Developmental Disabilities	0007.R08.00	1	1	1	1	
Colorado	CO Elderly, Blind and Disabled	0006.R08.00	1	1	1	1	
Colorado	CO HCBS Waiver for Community Mental Health Supports	0268.R05.00	1	1	1	1	

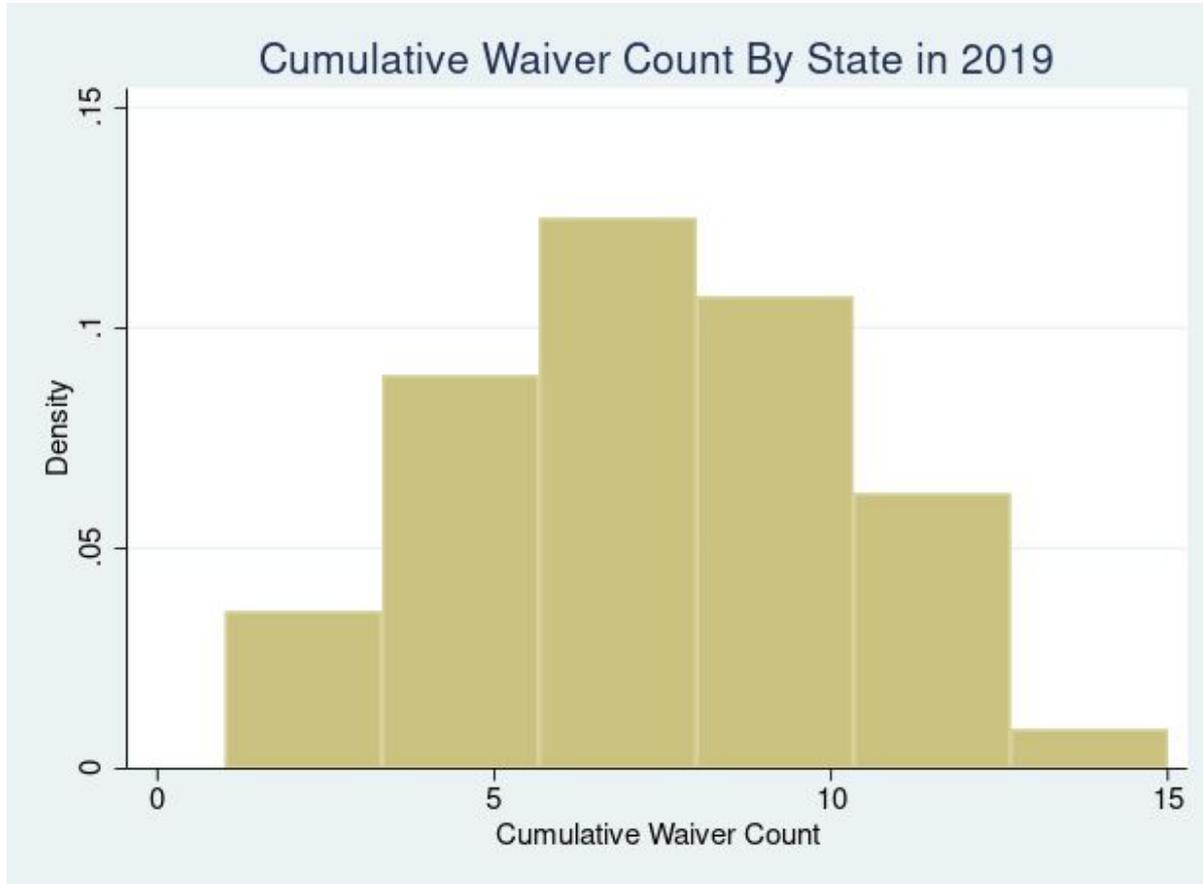
- Compile caregiver support data for each 1915c waiver in Excel
- Meticulously document entire process to ensure reproducibility

# National Increase in 1915c Waiver Use Over Time



- Active 1915c waiver counts have significantly increased since the program's inception in 1980
- Demonstrates increasing national reliance on 1915c waivers to provide HCBS

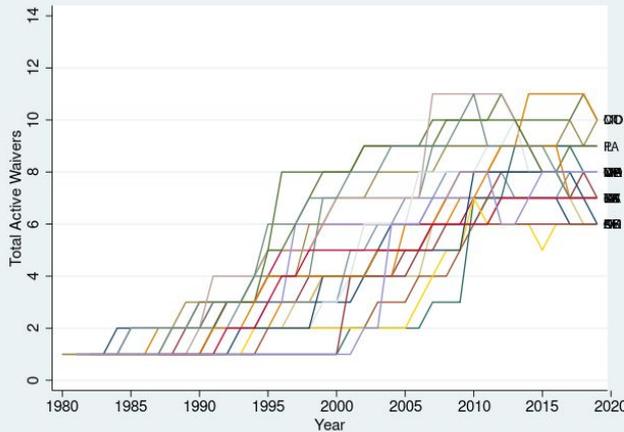
# Most States Have Relied on > 1 Waiver



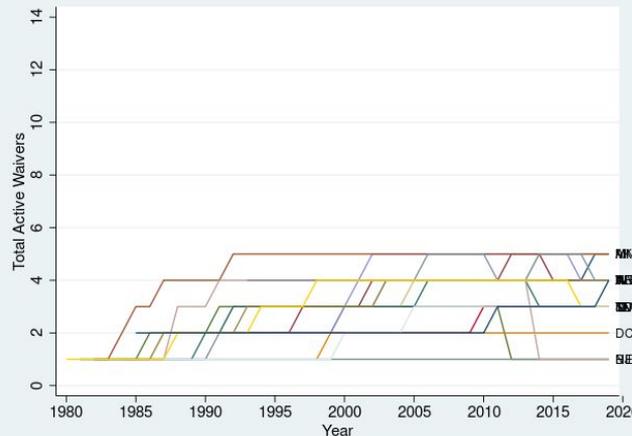
- Increase in 1915c waivers nationally (from previous slide) isn't just driven by more states starting to use 1915c waivers to provide HCBS
- Underscores centrality of 1915c waivers in shaping access to caregiver supports

# Closer Look at States with Increasing/Decreasing/Stable Active 1915c Waiver Counts

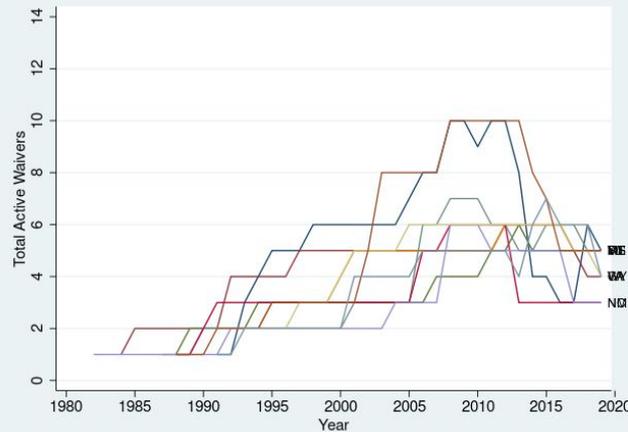
- Unclear what determines if a state's waiver counts increase, decrease, or remain stable over time
- Understanding what drives states' waiver counts can help elucidate how states choose to provide HCBS



**Increasing Counts (n = 22)**



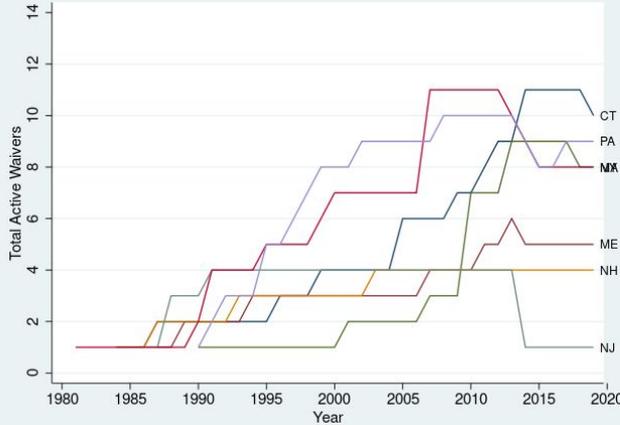
**Stable Counts (n = 16)**



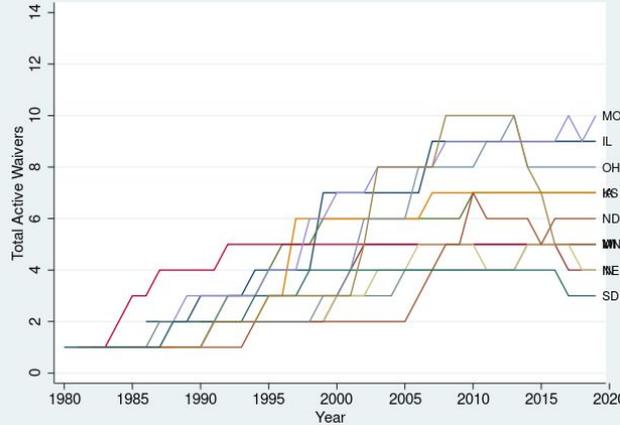
**Decreasing Counts (n = 10)**

# Look into Active Waiver Counts by Geography

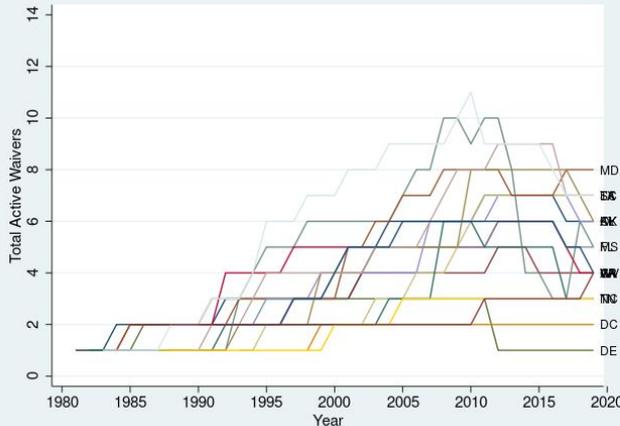
## Northeast



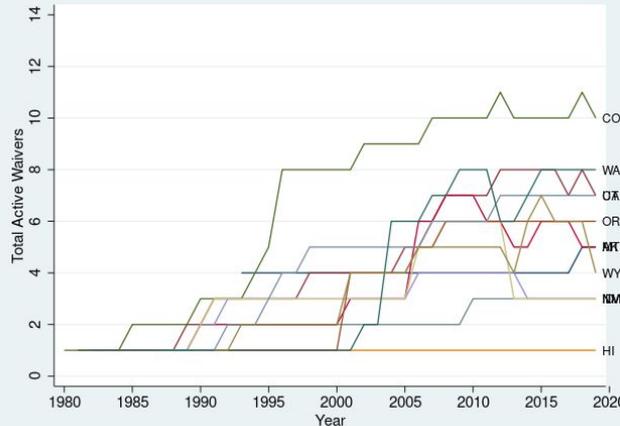
## Midwest



## South

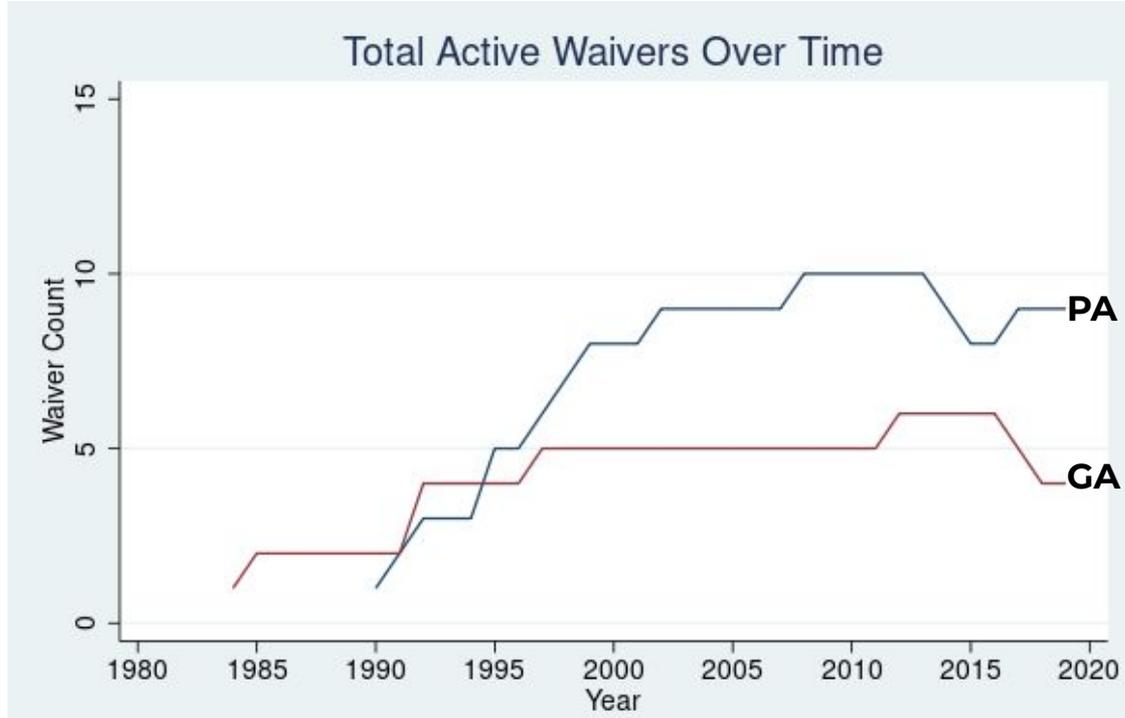


## West



- Significant variability in 1915c waiver counts exist among states
- Geography doesn't explain these differences

# Deep Dive into 1915c Waivers in 2 states: PA and GA



- Extracted and compared specific caregiver supports within 1915c waiver applications for older adults living with dementia in Georgia and Pennsylvania

# Supports for Family Caregivers for People Living with Dementia

	<b>PA</b>	<b>GA</b>
<b>Total Waivers for Older Adults</b>	5	4
<b>Respite - Self Direction</b>	80%	50%
<b>Personal Support - Self Direction</b>	40%	50%
<b>Training/Counseling for Family Caregivers</b>	60%	0%
<b>Payments to Relatives/Legal Guardians</b>	100%	100%

# Future Steps

**Complete database of 1915(c) family caregivers from 2011 - Present**

- 1. Create a metric for caregiver supports and compare across states**
- 2. Examine link between caregiver support metric and family caregiver outcomes + availability**

**Examine how Medicaid reimbursement rates influence workforce characteristics**

# Lessons Learned

1. Research is cross-disciplinary
2. Mentorship

# Acknowledgements

Mentors:

Pilar Gonalons-Pons, PhD

Katherine Miller, PhD

Joanne Levy, MBA

SUMR Team

Medicaid HCBS Workforce Team:

Norma Coe, PhD

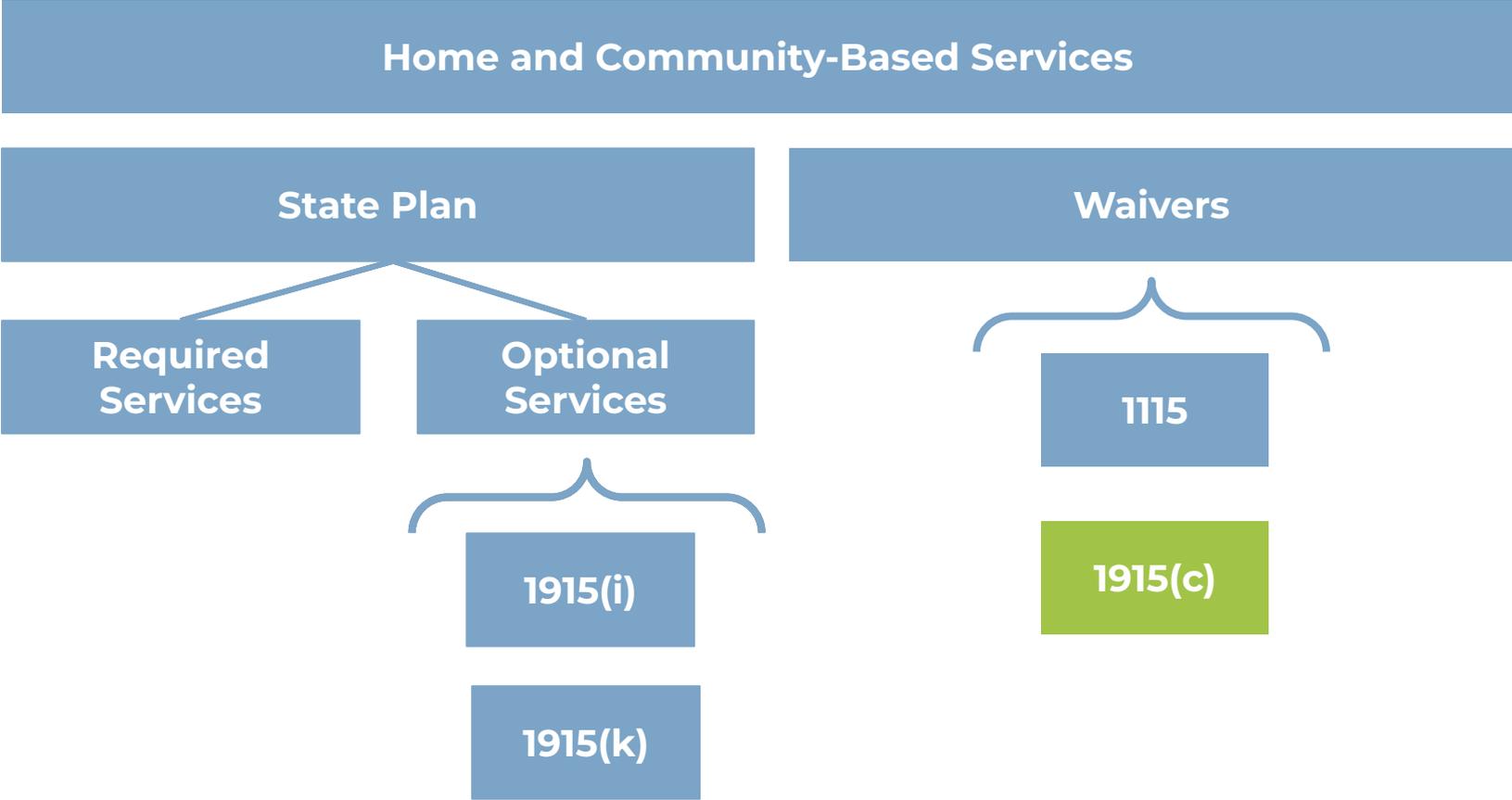
Amanda Krieder, PhD

Allison Hoffman, JD

Katherine Rohde, JD

**Questions?**

# Why 1915(c) waivers?



# Home and Community-Based Services

## State Plan

- Services must be available to all (waitlists are *not* allowed)
- Budget neutrality *not* required

## Required Services

- Home health services
- Must have NH-level needs

## Optional Services

- Optional personal care services (provided by 37 states)

## 1915(i)

- Services match 1915(c)
- NH-level needs *not* required
- Can target specific populations (generally those with mental illness/intellectual disabilities); this is subject to CMS regular re-approval
- Financial eligibility: 150% SSI [states may allow less restrictive eligibility in some cases]
- Provided by 13 states

## Community First Choice Option/1915(k)

- Attendant Care Services (ADLs and IADLs)
- Higher federal matching rate
- Provided by 9 states

## Waivers

- Responsible for providing most HCBS
- Services may be capped (Waitlists *allowed*)
- Budget neutrality required
- Subject to regular CMS re-approval

## 1915(c)

- Includes case r services, homemaker services, home health aide services, personal care services, adult day health care services, habilitation services, and/or respite care services
- NH-level needs *required*
- Financial Eligibility: 300% SSI
- Provided by 46 states + DC

## 1115

- Managed long-term care supports
- Provided by 12 states (3 states provide HCBS exclusively through 1115)

# CMS Definitions

**Personal Support Services:** “PCS are categorized as a range of human assistance provided to persons with disabilities and chronic conditions to enable them to accomplish activities of daily living or instrumental activities of daily living. An independent or agency-based personal care attendant (PCA) may provide these services. Medicaid PCS are different from home health aide services provided through the Medicaid or Medicare home health benefit. However, home health aides may perform PCS”

**Activities of Daily Living:** Activities of daily living are activities related to personal care. They include bathing or showering, dressing, getting in and out of bed or a chair, walking, using the toilet, and eating.

**Instrumental Activities of Daily Living:** related to independent living. They include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone

**Home Health Care:** includes skilled nursing care, as well as other skilled care services, like physical and occupational therapy, speech language therapy, and medical social services