The US Care Infrastructure: From Promise to Reality

Care for Older Adults & People with Disabilities

Shengwei Sun (Moderator), Robyn I. Stone, Mousumi Bose, Fawn Cothran, Bethany Lilly, Jennifer Craft Morgan

The session will begin shortly.
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Speakers:

- Robyn I. Stone, DrPH (LeadingAge LTSS Center @UMass Boston)
- Mousumi Bose, PhD (Montclair State University)
- Fawn Cothran, PhD, RN, GCNS-BC, FGSA (National Alliance for Caregiving)
- Bethany Lilly, JD (The Arc)

Discussant:
Jennifer Craft Morgan, PhD (Georgia State University)

Moderator:
Shengwei Sun, PhD (National Women’s Law Center)
Policies Supporting Long-Term Services and Supports for Older Adults and People Living with Disabilities

Robyn I. Stone, DrPH
(the LeadingAge LTSS Center @UMass Boston)
The U.S. Care Infrastructure: From Promise to Reality

Caregiving in a Diverse America: Beginning to Understand Systemic Challenges Facing Family Caregivers

March 4, 2022

Mousumi Bose, PhD Montclair State University

Fawn Cothran, PhD, RN, GCNS-BC, FGSA
Hunt Research Director
Objectives

• To describe The Diverse Caregivers Report findings

• To discuss implications for the US Care Infrastructure
Methods

• Secondary analysis of Caregiving in the U.S. 2020
  • Data collection from May – July 2019

• Caregiver characteristics
  • Race/ethnicity
  • LGBTQ status
  • Income
  • Geographical location

• Caregiver outcomes
  • Physical, emotional, financial strain
  • Activities of daily living (ADL/IADL)
  • Caregiving intensity
  • Information used

• Multiple logistical regression analyses
## Results

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<tr>
<th>Category</th>
<th>Count</th>
<th>Sample details</th>
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<tbody>
<tr>
<td>All caregivers of an adult age 18+</td>
<td>801</td>
<td>Includes any Non-Hispanic White caregivers found in the online national sample only (part of base sample)</td>
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<tr>
<td>Non-Hispanic White</td>
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<td>Includes any Non-Hispanic White caregivers found in the online national sample only (part of base sample)</td>
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<td>African-American</td>
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<td>Includes any Non-Hispanic African American or Blacks found in the base sample (online national sample + online African American targeted oversample)</td>
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<tr>
<td>Hispanic</td>
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<td>Asian American and Pacific Islander*</td>
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<td>Includes any Asian Americans and Pacific Islanders found in the base sample (online national sample + online Asian American and Pacific Islander targeted oversample) and the phone Asian American and Pacific Islander oversample</td>
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<td>Includes 7 American Indian or Alaska Native, and 61 respondents with two or more races.</td>
</tr>
<tr>
<td>LGBTQ</td>
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<td>Includes any LGBTQ caregivers found in the base study (online national sample + online African American targeted oversample + online Hispanic targeted oversample + online Asian American and Pacific Islander targeted oversample)</td>
</tr>
</tbody>
</table>
Results - Financial Strain:

• Family caregivers spend over $500 billion a year in costs associated with providing care

• Caregivers in the lowest income bracket (<$15K per year) are more likely to assist with:
  • bath/shower
  • grocery shopping
  • meal preparation
  • housework.

• Caregivers in the lower income bracket are more likely to use respite services, use home modification and use the internet caregiving information

• More African-American and Hispanic caregivers are in lower income brackets and have more financial impacts
Results - Mental Health:

- Self reported health of Hispanic/Latinx and AAPI caregivers declined over the last five years;
- Hispanic/Latinx caregivers are often the sole caregiver, reporting lower psychological and physical wellbeing particularly when caring for recipients with dementia;
- Burden of tasks of AAPI caregivers/Majority of AAPI feel that they had no choice in assuming their caregiver role;
- LGBTQ+ caregivers are
  - more often the primary caregiver
  - More likely to feel alone
  - Half as likely to have a partner
  - Twice as likely to live alone
  - Likely do to continued bias and discrimination
  - Less formal familial structures
- Some groups report less emotional strain and finding more meaning in their caregiver experience.
Results – Unique Experiences:

• Compared to 2015, African American and Black caregivers had an increased role in shared decision making for care recipients.

• Despite increased burden of Black, African-American, Hispanic and Latinx caregivers are less likely to experience emotional strain from their caregiving experience.
Implications:

• More research needed: intersectionality

• Culturally tailored, relevant material and resource delivery

• Less restrictive, inclusive eligibility criteria for program access (Ex: broad definitions of family)
Building Back Better

THE AMERICAN FAMILIES PLAN – Calls on Congress to invest $225 billion over a decade to create a national comprehensive paid family and medical leave program.

- Partial wage replacement
- Twelve weeks of paid parental, family, and personal illness/safe leave
  - three days of bereavement leave per year.
  - up to $4,000/month, with a minimum of two-thirds of average weekly wages replaced, rising to 80 percent for the lowest wage workers.

- Pass Healthy Families Act which will require employers to allow workers to accrue seven days paid sick leave per year.

Too early to say what will happen, but the potential is here to support family caregivers, persons living with disabilities, and older adults (ACL FY 2022 Administration Budget)
Thank you!

Questions?

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People with Disabilities and the Care Infrastructure

March 4, 2022
Care and People with Disabilities

People with disabilities are a hugely diverse population. Some require regular access to health care, some rely on heavily on direct care work in some form, others need none of these supports. Needed care is usually provided by:

• Unpaid family caregivers
• Paid caregivers via Medicaid or paid out of pocket, including services for children
• Other social programs
Care and People with Disabilities

This means that the care infrastructure is crucially important for people with disabilities.

- Home and Community Based Services (HCBS) expansions in Medicaid
- Paid leave (for both people with disabilities themselves and family members who provide care)
- Other social programs that provide income, care, or health care support
Home and Community Based Services (HCBS) help people with disabilities with activities of daily living
• This can include help with bathing, toileting, meal preparation, transportation, employment, and other activities
• People with disabilities and older adults often rely on HCBS to continue to live in their homes and communities, rather than in institutional settings
• The umbrella term for care, in either institutional or community settings is Long Term Services and Supports (LTSS)
HCBS

LTSS are primarily funded by Medicaid:

Long-term services and supports (LTSS) spending, by payer, 2018.

Medicaid LTSS Spending = $196.9 billion

Total National LTSS Spending = $379 billion

NOTE: Total LTSS expenditures include spending on residential care facilities, nursing homes, home health services, and home and community-based waiver services. Expenditures also include spending on ambulance providers and some post-acute care. This chart does not include Medicare spending on post-acute care ($83.3 billion in 2018). All home and community-based waiver services are attributed to Medicaid.

Use of HCBS has increased over time:

Medicaid long-term services and supports spending, by institutional vs. community setting.

Annual Medicaid LTSS Spending, in billions:

1995: $57, 18% Institutional, 82% Community
2000: $76, 27% Institutional, 73% Community
2005: $107, 37% Institutional, 63% Community
2010: $139, 48% Institutional, 52% Community
2012: $142, 49% Institutional, 51% Community
2013: $146, 51% Institutional, 49% Community
2014: $152, 53% Institutional, 47% Community
2015: $159, 54% Institutional, 46% Community
2016: $167, 57% Institutional, 43% Community

HCBS

But major issues related to the HCBS system remain:

• Waiting Lists: there are over 800,000 people on waiting lists across the United States. These individuals are usually eligible for institutional care in their state, but want HCBS instead and so are waiting.

• Low wages for the majority women of color Direct Care Workforce: Because wages are set by Medicaid rates, they can be less than minimum wage. This both fails to provide a living wage for workers and creates staffing crises.
Congress is considering several bills that would address long standing HCBS issues:

- The Better Care Better Jobs Act
  - Includes a $150 billion investment in HCBS, with specific focus on raising the wages of direct care workers
- Making the Money Follows the Person program permanent
  - Helps transition people from institutions into the community
HCBS

There are also broader systemic proposals:

• The HCBS Access Act
  • A discussion draft released in 2020
  • Would make HCBS services mandatory in the Medicaid program, ensuring that institutional and HCBS services are available to everyone who wants them

• Medicare Part E for Home Care
  • A discussion draft from the Energy and Commerce Committee
  • Would add a cash HCBS benefit to Medicare
Paid Leave

Paid leave is important both for people with disabilities and for their family members.
• People with disabilities will need time off to care for or bond with a new child and time off to care for loved ones.
• Paid leave also helps people with disabilities have needed time off for medical needs.
• For family caregivers, paid leave helps people maintain jobs and employment.
But the structure of paid leave matters a lot. Important components include:

• Inclusion of part time workers
• Definition of family (including siblings and other caregivers)
• Progressive wage replacement
• Job protection
• Continuation of health insurance
• Intermittent use
• New funding sources
Several pieces of legislation have been introduced in Congress to expand access to paid leave:

• The FAMILY Act (a comprehensive social insurance model)
• The New Parents Act (a parental leave-only proposal to borrow against future Social Security benefits) and the Advancing Support for Working Families Act (a parental leave-only proposal to borrow against the Child Tax credit)
• The Job Protection Act (an FMLA reform bill to cover more low-wage and workers of color)
Other Supports

• Child Care
• Child Tax Credit
• Earned Income Tax Credit
• Supplemental Security Income
• Social Security
• Medicare
• Affordable Care Act coverage
• SNAP
Where are we politically?

• Build Back Better is dead.
• Long live the bill formerly known as Build Back Better.

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Questions?

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