

Working to Move: The Hidden Work of Medicaid Personal Care Assistance (PCA) Services Users Planning and Pursuing Cross-state Moves

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Background

Nearly 3 million people have access to Medicaid-funded home and community-based services, an umbrella set of services and supports that may include personal care assistance (PCA).¹⁻³ PCA is a form of care work provided by people to other people who need assistance or support with activities of daily living (e.g., bathing, toileting), instrumental activities of daily living (e.g., light housework, meal preparation), and other community living tasks (e.g., transportation) in a variety of contexts including home, work, and while navigating public spaces.^{4,5} PCA stands as a significant achievement in the independent living and disability rights movements' struggles for deinstitutionalization and community living options.⁶⁻⁸

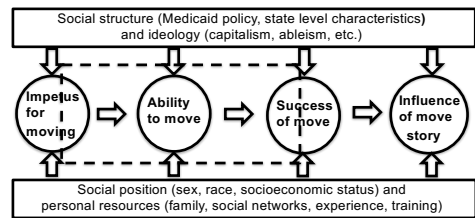
As PCA users plan and pursue cross-state moves, they are reminded that they qualify for services *only in their current state* and must re-establish eligibility in the desired destination state under that state's rules, without assurance of continuity of access.⁹⁻¹³ To pursue cross-state moves, PCA users must engage in this work-intensive process on their own, accessing resources from their networks to navigate the system in the hopes of achieving their goal.^{9,14}

Research Questions

1. How do Medicaid PCA users actively perform "work" as they plan and pursue cross-state moves?
2. What specific types of work are performed by Medicaid PCA users? How can these be identified, described, and understood as overlapping and/or related to one another?

Conceptual Framework

Figure 1. Moves in Context: A Model of Cross-State Movement Dynamics for Medicaid (HCBS) Users



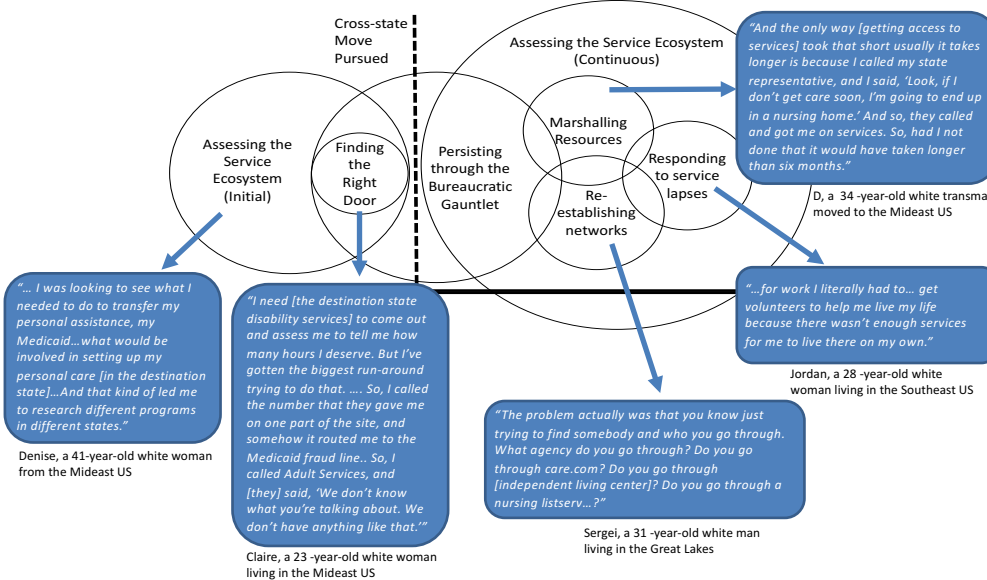
(Grossman, 2018)

Summary

By engaging Feminist and symbolic interactionist concepts of work, this project illustrates how Medicaid PCA users who desire and pursue cross-state moves engage in "beneficiary work," a hidden form of labor^{15,16} to maintain benefits. Medicaid PCA users perform this unpaid work by: 1) assessing service ecosystems, 2) finding the right door, 3) persisting through the bureaucratic gauntlet, 4) advocating for systems cooperation, 5) re-establishing networks of support, and 6) responding to service gaps/lapses.

Beneficiary work:

Hidden labor performed by Medicaid PCA users who desire and pursue cross-state moves



Discussion & Implications

As they plan and pursue cross-state moves, Medicaid PCA users engage in multiple forms of unremunerated, and prior to this analysis, unnamed work. Collectively the six identified forms of work illustrate beneficiary work, a category of invisible labor akin to patient work¹⁸ or the work of women negotiating the welfare system.¹⁹⁻²¹ The term recognizes how PCA users act to maintain their service eligibility in a policy context fraught with obstacles and barriers. Despite more than four decades of disability law and policy aimed at reducing barriers to education, employment, and participation in community and civic life, Medicaid policy continues to envision people with disabilities as immobile, remaining in the states where they currently reside (often where they were born) in perpetuity.⁹⁻¹⁴ Additionally, beneficiary work illustrates how responsibility to ensure access to the "most integrated setting" has devolved from the Centers for Medicare and Medicaid Services (CMS) and state governments (*Olmstead v. L. C.*, 1999) to PCA users.

Claiming and naming this hidden labor performed by people with disabilities contributes to and expands upon Feminist and interactionist conversations about invisible work. By focusing on PCA, the context of the invisible work changes from patients in the hospital to people with disabilities living at home and in the community. Beneficiary work, originating with PCA users but likely generalizable to other users of means-tested programs, indicates a further reason to engage in invisible work: continuity of access, or taken to the extreme, survival.¹⁹⁻²² That is, despite the documented forms of degradation accompanying how one qualifies for and maintains benefits, beneficiary work is necessary for continued community living.¹⁹⁻²³

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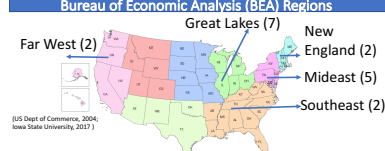
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Participants

18 Medicaid HCBS users with physical disabilities

- 8 moved, 10 considered moving
- Aged 21-64 (average = 33)
- Most white, 2 participants of color
- 9 females, 7 males, 1 genderqueer person, 1 trans man
- 2 identified as queer, 1 as gay
- Highly educated group (all had some college)
- Most lived alone (3 with partners, 3 with parents)

Number of Participants by Bureau of Economic Analysis (BEA) Regions



US Dept of Commerce, 2004
State University, 2017

Methods

Data Collection

- Interviews conducted by phone, video chat, or email
- Interviewer was a Medicaid HCBS user
- 18 month period from 2014-2016

Data Analysis

- Grounded theory methods¹⁷
- Over 180 pages of transcripts
- Codes, memos, theorizing

Acknowledgements

The research protocol was approved by the University of Illinois at Chicago's Office for the Protection of Research Subjects (OPRS, #2014-0486). This work was supported by the Carnus Research Board (CRB) Award from the Office of Vice Chancellor for Research (OVC) at the University of Illinois at Chicago (UIC). I am grateful to the interview participants who trusted us with their stories. For their invaluable research assistance, thank you to graduate students Ashley M. Volion (AMV, data collection, transcription, analysis, and member checks) and Meghann O'Leary (transcription).