

Mobile Citizens: Medicaid HCBS Users Desire and Pursue Cross-state Moves

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Background

As of 2013, approximately 3 million people had access to Medicaid-funded home and community-based services (HCBS), including personal care attendant (PCA) services¹. Due to the shared federal/state funding model of Medicaid, state programs differ in the types of services offered, functional and income eligibility criteria, and mechanisms through which services are made available; known as **interstate variation**^{2,3,4,5}. Service eligibility is neither portable nor transferable across states, making moves across states difficult and/or risky for HCBS users.

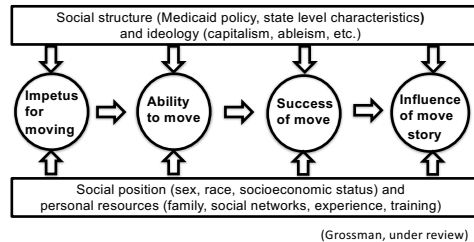
Research investigating cross-state moves by people with disabilities is limited⁶ and almost exclusively focuses on older adults^{7,8,9}, ignoring those who are most likely to pursue cross-state opportunities for work or schooling. Given the legal changes of the past three decades, younger disabled people have "come of age" with consistent knowledge of their rights¹⁰, and are more likely than previous generations to pursue cross-state opportunities.

Research Questions

1. How do Medicaid HCBS users with physical disabilities experience the *desire to move across states*?
2. How do these Medicaid HCBS users' *experiences of opportunity* differ based on whether or not they were able to pursue a desired move?

Conceptual Framework

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



Summary

Findings from this project offer empirical evidence that Medicaid HCBS users with physical disabilities desire and pursue cross-state moves to follow educational, employment, social and cultural opportunities. Participants' move stories offer support for the Moves in Context framework, illustrating how both interpersonal (i.e., family) and structural (i.e., interstate variation in Medicaid HCBS policy) factors influence their trajectories. The patterning of these trajectories demonstrates how, for program users, opportunity may be: dreamed, missed, delayed, or pursued.

Findings: Four Opportunity Arcs



Arc 1: Opportunity Dreamed

Program users described plans to move responding to both pull factors (e.g., job, school) to new states and push factors (e.g., weather, need for autonomy) away from home states.

"[I] definitely would [move to another state] if it were for work"

- Jazzy, a 34-year-old Black woman who considered moving



Arc 3: Opportunity Delayed

Program users outlined plans to pursue opportunities in other states after initial attempts did not result in a move.

"I would call the first two [PCAs] and say, 'Hey, I am ready. I can pay you now.' Either they would say, 'I couldn't wait. I had to find a different job.' or they just wouldn't answer my calls."

- Blaine, a 30-year-old white man who desired a cross-state move

He experienced two unsuccessful attempts to move. One attempt involved taking time off from his graduate studies. He remained hopeful that his planned, third attempt would be successful.



Arc 2: Opportunity Missed

Program users expressed regret about a specific opportunity that they could not pursue expressing immediate and long-term effects of loss.

"It's one of my regrets that I didn't go [to university in that state]... my whole life would've been different"

- Jordan, a 28-year-old cisgender white disabled queer woman

After completing college in one Great Lakes state, she moved to a neighboring state for a job. She was unable to get the new state to cover her personal care attendant services so she returned to her home state to pursue her graduate degree.



Arc 4: Opportunity Pursued

Program users moved to another state. Some self-evaluated their respective moves as successful, others as unsuccessful, and others still, faced uncertainty.

"It was a very, very good experience and it got me self-directing and self-managing [PCA services]." [successful]

- Claire, a 23-year-old, white woman who moved for college

"the bare minimum" [unsuccessful]

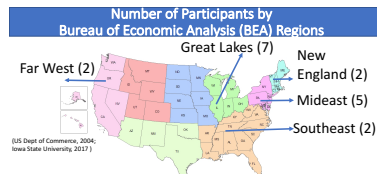
- Mike, a 25-year-old white man

He left the Pacific Northwest for the Midwest to pursue a higher-paying job and to move closer to his girlfriend. Medicaid in his new state would not pay for his PCA due to his income. He initially relied on his girlfriend and later switched to paying for PCA out of pocket, foregoing assistance with physical exercise and meal preparation. He and his girlfriend were moving back to his home state so he could retain his PCA while working.

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)



Discussion & Implications

From a disability policy perspective, **opportunity pursued** is what successful education and employment programs look like for disabled people. Policy needs to address how opportunities may be in other states and that moves to pursue them are possible. Similarly, **opportunity delayed** and **opportunity missed** indicate a need for greater consideration of the effects of interstate variation on Medicaid HCBS users' access to social participation and the pursuit of educational and economic advancement. Lastly, **opportunity dreamed** clarifies that Medicaid HCBS users with physical disabilities think about their futures, considering how potential opportunities will draw them out of state.

Future policy changes should address how users who secure higher-paying jobs in new states are penalized and/or disqualified for the services they currently receive elsewhere. Additionally, policies should better support access to PCA workers during cross-state transition to alleviate delayed (e.g., Blaine) or missed (e.g., Jordan) opportunities. It is necessary to recognize that cross-state opportunities are not *equitably accessible* to Medicaid HCBS users. To address this inequity, national HCBS policy needs to ensure that money follows persons not just out of institutions within states, but also alongside them as they pursue self-determined journeys^{13,14}, including those in other states.

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Acknowledgements

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