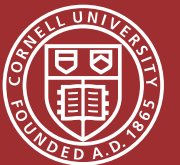


CARING LIKE A STATE:

Publicizing Family Caregiving Through the Medicalization of Disability Care

Yiran Zhang, Cornell ILR School

2024 Health Law Professors Conference



THESIS

- Medicalization of long-term home care as a state legibility project
- Nurses and ADL/IADL task assessment protocols become the state's eyes and spectacles to see the value of home care
- Enhanced visibility: family caregiving
- Limitation of the legibility project: lay narratives of home care's health value other than the task list

METHODOLOGY

- 3954 Fair Hearing decisions about “CDPAP” from New York State’s Office of Temporary and Disability Assistance
 - *Between 2011 and 2022*
- Document research of regulations, court adjudications, guidelines, and government reports related to CDPAP
- Supplementary background interviews with 7 CDPAP users/advocates

NEW YORK'S CDPAP

- Where the care recipient chooses their own care provider, often a family or friend
- Exclusion: spouses and parents of minor children
- Recent expansion in reaction to Managed Care Plans and care worker shortage
- More than half of NY's HCBS
- Under attack for fraud associated with paying family members

HOW THE NURSE ASSESSOR SEES CARE

Activity	Per Day	Per Week	Per Week
Meal Prep Breakfast	1	7	75
Meal Prep Lunch	1	7	100
Meal Prep Dinner	1	7	125
Change Linens	1	1	10
Make Bed	1	6	20
Clean Living Area	1	7	75
Clean Kitchen	1	1	30
Laundry Off-Site	1	1	110
Shopping	1	1	60
Errands/Mail/Bank/Bills	1	1	60
Stairs	4	10	40
Managing Meds	4	28	20
Bathing	1	7	50
Hair Care	1	7	25
Shave/Apply Makeup	1	7	25
Mouth Care	2	14	50
Nail Care	1	1	5
Skin/Lotion	1	7	25
Dressing Upper	2	14	50
Dressing Lower	2	14	25
Toilet Use	6	42	75
Transfer Toilet	6	42	75
Incontinent Care	0	0	0
Catheter Care	0	0	0
Ostomy Care	0	0	0
Bed Mobility	0	0	0
Indoor Locomotion	6	42	75
Escort to Appointments	1	7	0
Feed Breakfast	1	7	75
Feed Lunch	1	7	75
Feed Dinner	1	7	75

Total Hours: 23.42

- How ideology plays out
 - *The rehabilitation orientation*
 - *Guarding against overuse of service for clinical and fiscal reasons*

Grace is an 82-year-old Medicaid recipient who's diagnosed with Alzheimer's disease and arthritis. Under New York law, Medicaid should pay for Personal Assistance service to enable Grace to stay outside the nursing home.

Grace lives with her Daughter who works outside the home from 10 am to 7/8 pm every weekday. Grace hires her Niece as the Personal Assistant. Niece comes every morning when Daughter leaves for work. She helps Grace to get out of bed, prepares meals, encourages her to eat and drink fluids, assists her to take shower, to use bathroom as needed, and does "everything" on demand.

Niece also stays with Grace to make sure that she does not leave the stove on, lock out family members, or wander off. Whenever Grace gets up, Niece walks with her to make sure that she does not trip on the walker. Niece waits until Daughter comes back from work and the two get Grace ready for bed. Daughter responds to Grace's needs at night and takes care of Grace on weekends.

Grace's Grandson brings her to doctor appointments and sometimes stays with her when Niece and Daughter are occupied.

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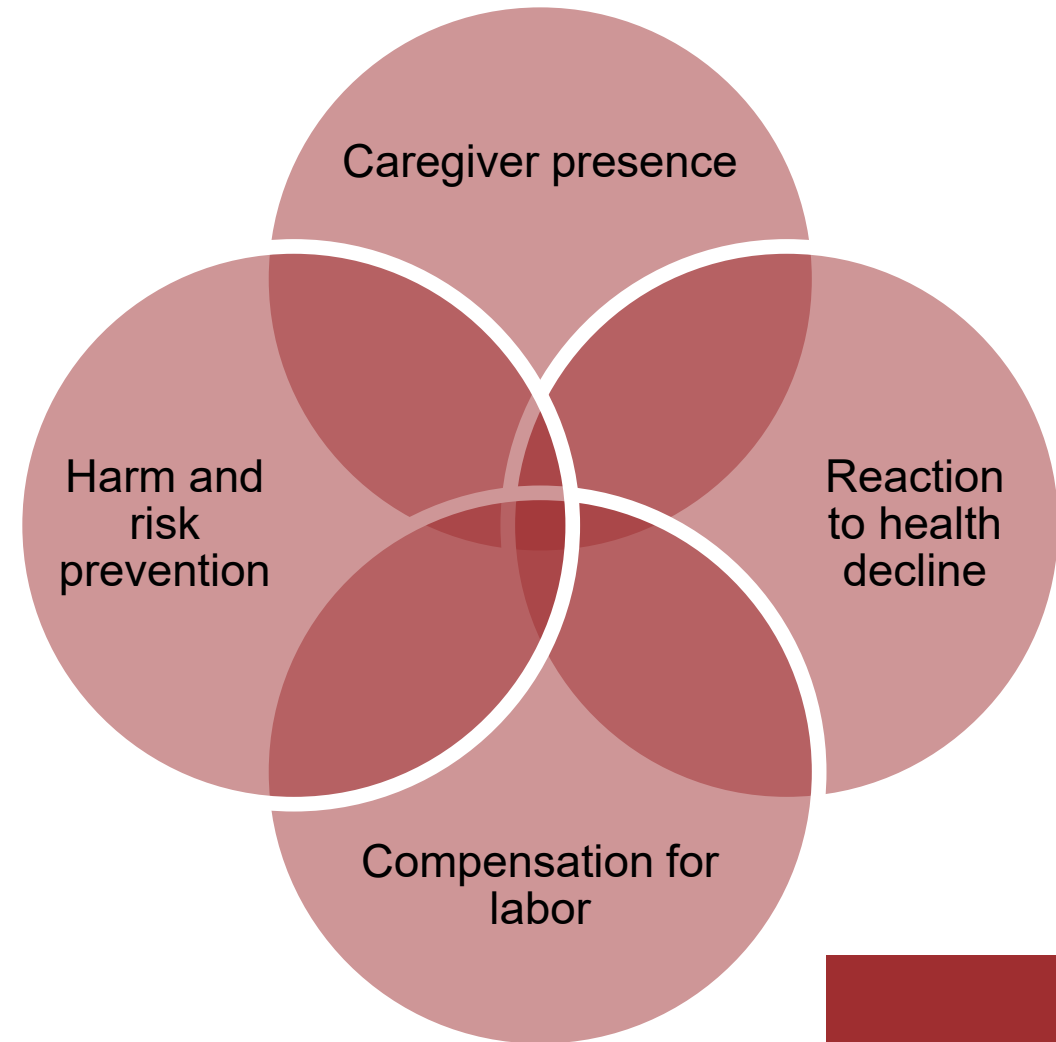
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LAY NARRATIVES ABOUT THE VALUE OF CARE



EXAMPLE I

- The patient: “ she does not want her daughter (the unpaid caregiver) to stay with her on the weekends, because she is worried about the daughter. An ambulance had to be called for the daughter once while she was at the her home due to the daughter needing medical assistance.”(Testimony C-1)
- The daughter also testified that she was disabled herself and “wants these hours for herself, so she can shop, go to her own appointments, get her own medicine, and to cover for her if she does not feel well” and that she “leaves the mother with fear of whether the mother will be okay.” (Testimony C-2)

EXAMPLE II

- Patient F: “due to pain in her legs and tremors in her hands, she sleeps only two to three hours at a time and is then up for several hours...and must use the bathroom several times per night,” Lacking authorization for nighttime care, all these declining health conditions “have resulted in many nighttime falls since the June denial of increased services.”

CONCLUSION

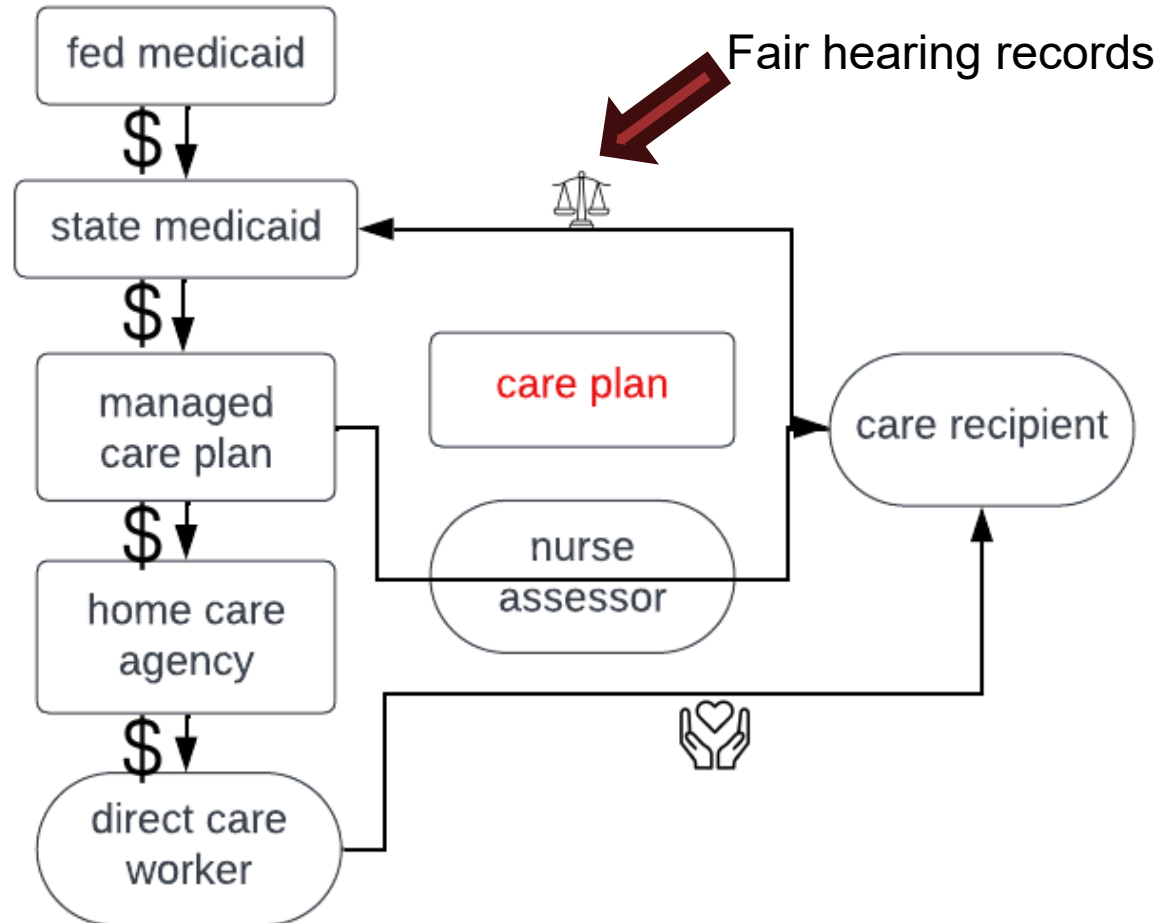
- Contextual legibility of the health value of home care?

QUESTIONS?

Yiran Zhang

yiranzhang@cornell.edu

THE STRUCTURE OF PUBLIC HOME CARE



SOME BASIC INFORMATION

Total: 3954 files

2010	15
2011	30
2012	32
2013	32
2014	26
2015	44
2016	67
2017	190
2018	331
2019	504
2020	1026
2021	998
2022	655

Table 1:
number of
hearing, by
year

representative	1857
reverse	2010

Table 2:
representation and
ALJ decision

daughter	1363
family	1185
mother	685
son	615
spouse	336
friend	265
sister	264
parent	257
husband	247
father	222
wife	197
brother	167
granddaughter	151
uncle	98
sibling	85
grandson	84
niece	72
neighbor	59
grandmother	48
nephew	34
aunt	21
families	18
grandfather	7
grandparent	6
son-in-law	3
family term	2558

Table 3:
family term
counts

F	2443
M	1059
NA	449
Elder	1385
Adult	809
Child	180
NA	1577

Table 4:
recipient
gender and
age