

Politics of Empowerment

Disability Rights and the Cycle of American Policy Reform

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Some not so fun facts...

- About 20% of Americans identify as having a disability.
 - About 13% of those 35-64.
- 20% of nursing home population is under 65.

- Those aged 31-64 are fastest growing group in nursing homes.
- 2/3 of people in nursing homes are funded through Medicaid.

An "Institutional Bias"

• Medicaid is the primary source of funding for home care.

• But, home care isn't an entitlement; nursing home care is.

ADA didn't solve the problem.

• A series of failed attempts at reform over the last 30 years.

Outline

- Disability and the American welfare state.
- What motivated rehabilitation as an alternative to institutionalization.
- The link between vocational rehabilitation and civil rights.
- Implications for groups challenging the Medicaid bias.
- Where are we today? Where is this issue headed?

The (Long) History of Disability Policy

- 1920 Vocational Rehabilitation Act a policy innovation.
 - Disabled people are "deserving" as clients of service provision.
- Policy monopoly (or "iron triangle").
 - RSA/HEW, select congressional committees, and established disability organizations.



Figure 2.5 Norman Rockwell's *The Paycheck*, 1958. *Source:* Goodwill Industries International.

An Alternative to Institutionalization

"Considerations of both humanity and self-interest."

More palatable than cash benefits.

Residential facilities are expensive.

Relied on organizations to connect clients to services.

Civil Rights

Changes endogenous to this policy network.

• 1970s – political entrepreneurship – rights provisions added to Rehabilitation Act.

Backlash and rights retrenchment.

Invited a disability rebellion.

Protesting for Change

Militant Advocacy Group for Disabled Revels in Role of Agitator

Disabled Hold Protest on **Capitol Hill**

Hearing Sought on Bill To Aid Home Care

> By Cheryl W. Thompson Washington Post Staff Writer

More than 350 disabled people from across the country staged a sit-in yesterday at the Rayburn House Office Building, demanding that a hearing date be set for a bill that could mean the difference between the ability to live at home or being forced into an institution or nursing home.

The demonstrators, members of Americans Disabled for Attendant Programs Today, lined the corridors and crammed into the office of Ren



Some of the 350 protesters with the group Americans Disabled for Attendant Programs Today conduct a sit-in in the halls

PROTESTING HOME CARE LAWS





Figure 6.1 A protester being removed by Capitol police, June 2017, from a crowd chanting "No cuts to Medicaid" outside Senate Majority Leader Mitch McConnell's office. Source: Photo by Andrew Desiderio. Reprinted with permission.

Conclusion

Policy reform: A Story of Fits and Starts

Are presidential candidates seeking meaningful institutional reform?

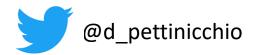
It isn't just the money, it's the administration of a system.

- The carceral state.
 - Continuum of incarceration and the industrial-institutional complex.

Thank you!

Special thanks to Cody Telep and Jacob Young for organizing my visit and talk.

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- For more, please check out:
 - American Prospect The Bipartisan Failure to Address Long-Term Home-Based Care for Disabled Americans.
 - Washington Post Why disabled Americans remain second-class citizens.
- For reviews of the book:
 - Mobilizing Ideas David Pettinicchio's Book Illustrates the Interplay between Activists and Institutional Actors by Joshua Basseches.
 - Social Forces Reviewed by Didem Türkoğlu.