Aiming (and Missing) for Stability in an Ever-Changing Environment

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Those who cannot remember the past are condemned to repeat it

George Santyana

Deinstitutionalization: Influential Factors

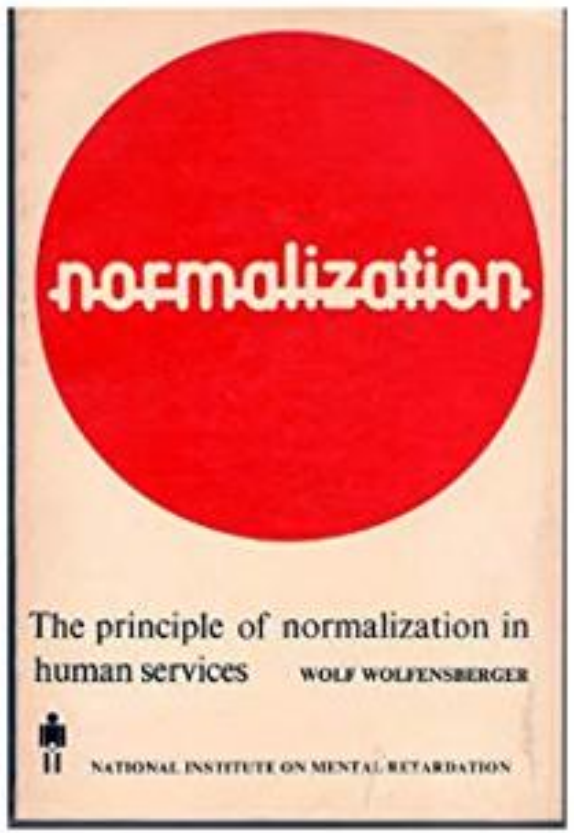


- Driven in large measure by the concept of normalization
- In the 1960s and 1970s, scandals and exposes
- Major lawsuits
- Expansion of federal mandates in the areas of health care and income support
- Power of the civil rights movement

IN 1963, THERE WERE 175,00 PEOPLE WITH IDD IN PUBLIC INSTITUTIONS – BY 2019, THERE WERE 16,200 PEOPLE

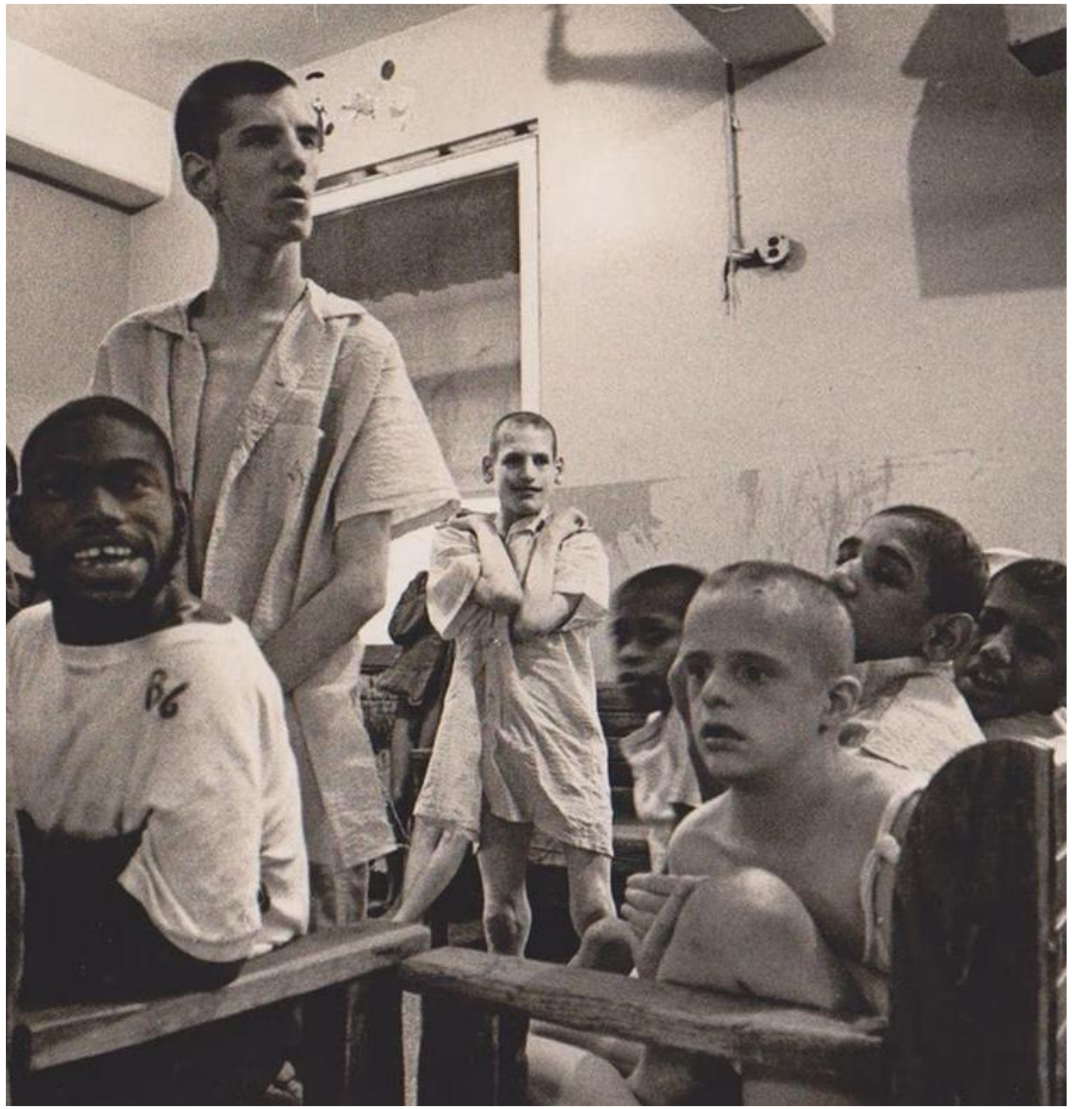
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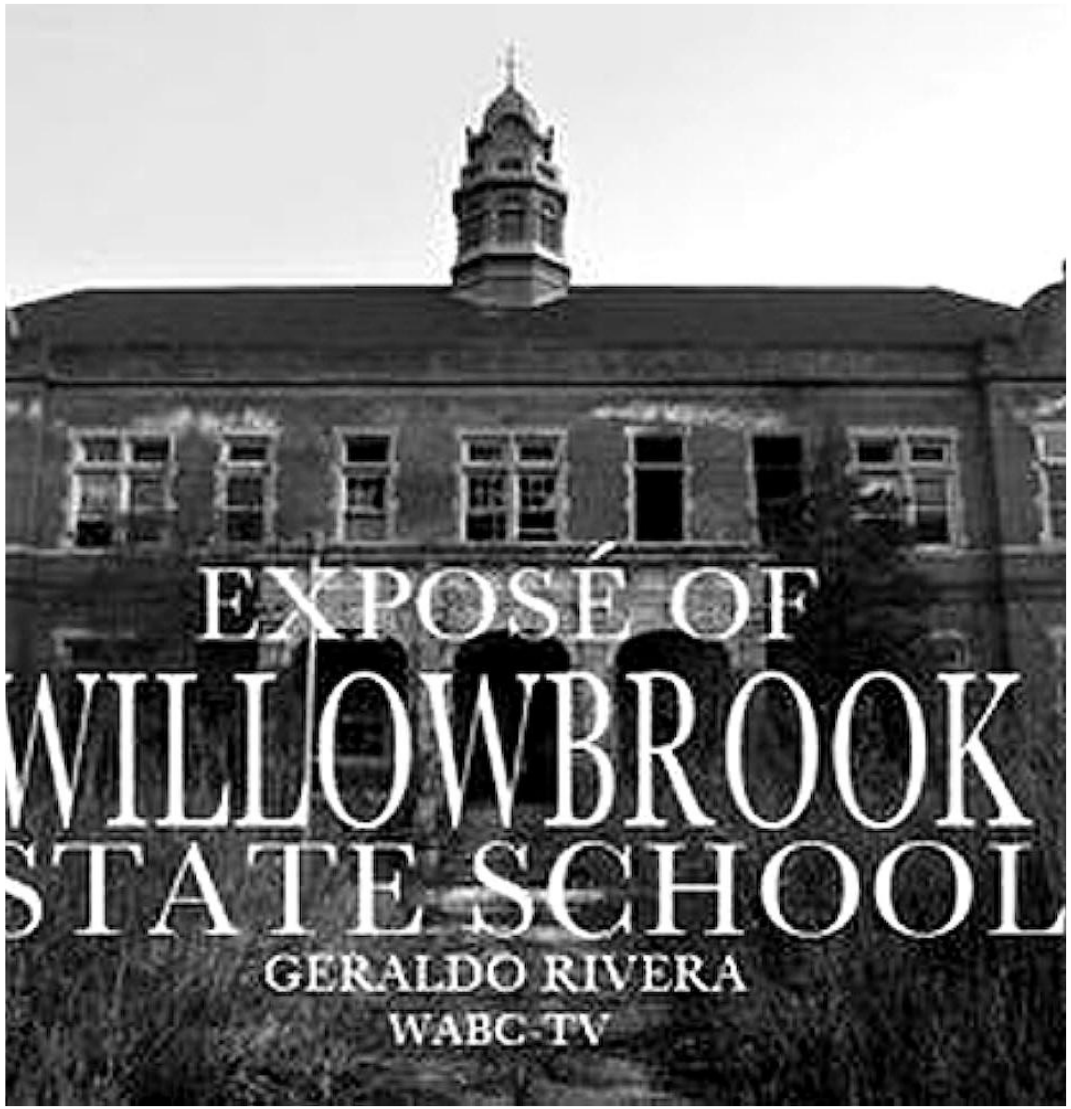
Normalization



- The normalization principle
  - making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society.
- Normalization began in Scandinavia (Bengt Nirje) and was brought to the U.S in a 1970 book by Wolf Wolfensberger

1972





Watch: The Path Forward: Remembering Willowbrook
https://nadsp.org/webinar-the-path-forward-remembering-willowbrook-2/

Major Lawsuits

- PARC v Pennsylvania (1972)
- Wyatt v Stickney (1974) – landmark right to treatment suit
- O’Connor v Donaldson (1974)– mandated placement of individuals who could live in communities
- Halderman v. Pennhurst State School and Hospital (1978) – found that institutions were incapable of providing habilitation guaranteed by the developmental Disabilities Act
- Olmstead v. L.C. – segregation constitutes discrimination and violated the Americans With Disabilities Act





Influential Federal Initiatives

- Establishment of the Medicare and Medicaid programs; Home and Community Based Waivers in 1965
- Passage of Supplemental Security Income in 1974
- Title XX of the Social Security Act in 1975
- President Nixon's goal in 1971 to reduce institutional populations by one third
- Creation of the President's Committee on Mental Retardation (Now President's Committee on People with Intellectual Disabilities) in 1970
- Civil Rights of Institutionalized Persons Act 1980

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National Movements that Influenced Deinstitutionalization

Civil Rights movement

Independent Living Movement

Family Support Movement

Self Advocacy Movement

What I Didn’t Know Then That I Know Now….

The Legacy of Institutionalization

- Recent research from Stancliffe et. al using NCI data shows that relative to those who had never lived in institutions, those who had were:
  - More likely to live in larger group settings today
  - Less likely to report making choices about their services today
  - More likely to report they often feel lonely today
  - More likely to participate in the community with staff or housemates as companions today, as opposed to family or more organic social networks

https://onlinelibrary.wiley.com/doi/full/10.1111/jar.13103

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Lack of Emphasis on Competitive Employment

- Instead of moving people into community jobs, we created sheltered workshops with sub-minimum wages (made possible by Section 14 (c) of the Fair Labor Standards Act)
- Sheltered jobs involved repetitive tasks and reinforced the stereotype that people with IDD – especially those previously institutionalized – could not work
- Even today NCI data show that 17% of all respondents have paid community jobs and 45% of people who don’t have a job want a jobs and



Individual Plans that Ignored the Goals and Preferences of the Individual

- Individual habilitation planning sessions were heavily clinical and mimicked the professional sessions in institutions
- Plans tended to focus on skills development whether those skills were relevant or not (e.g., climbing a 3-foot ladder)
- The person and/or their family were not necessarily present nor in charge of the session



Heavy Reliance on Medications

- Community physicians not familiar with the needs of people with IDD
- Providers concerned about having the capacity to support people with significant disabilities
- Even more recently, people leaving facilities in GA are on more medications in the community than they were taking in the institution
- 32% of NCI-IDD sample take 1 or more medications for mood, anxiety, and/or psychotic disorders and 17% take 1 or more medications for behavior challenges



Impact on DSPs

- We persuaded policy makers that deinstitutionalization would be cheaper
- Initial HCBS waivers were only approved if the alternative to institutions were less expensive
- In many states, workers in institutions were unionized and had decent wages and benefits
- Community providers paid less
- Wages disparities contributed to the current crisis



We Didn’t Value the Importance of Friendship



- People who lived in institutions had friendships over many years
- In moving people, we didn’t take those friendships into account
- Many people had strong connections with their staff and the severing of these relationships may have been traumatic for many



Creation of Mini Institutions

In many states, deinstitutionalization was premised on the assumption that community programs would provide the same or better care

Lead to a desire to replicate “good” institution like residences

Assumed that people would move from more restrictive to less restrictive settings as they acquired skills

Things to prioritize so as not to make the same mistakes again…..

- Value DSPs and pay them commensurate with their value to the well-being of people with IDD
- Recognize the importance of employment in people's lives
- Commit to person-centered principles and practices
- Embrace the importance of friendship in the lives of people with IDD
- Make sure the medications aren't used to subdue and control people
- Create supports embedded in communities and ensure that people are included in civic life
- Continue to ask people receiving services about their lives and how supports can make their lives better
- Make use of advances in technology (e.g., location devices)

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More Recent Factors that Accelerated Deinstitutionalization

- Home and Community Based Waivers in 1983
- The promulgation of the ICF/MR regulation in 1988
- Americans with Disabilities Act in 1990
- Recent litigation Olmstead v Georgia (1995) -- Comprehensive plan for moving individuals out of institutions and accommodating those on the waiting list
- Money Follows the Person in 2005
- **HCBS Settings Rule in 2014**



2014 Medicaid HCBS Settings Rule: What is it?

Main question: *Someone might be living in a community-based setting but does the person's HCBS setting actually support community living?*

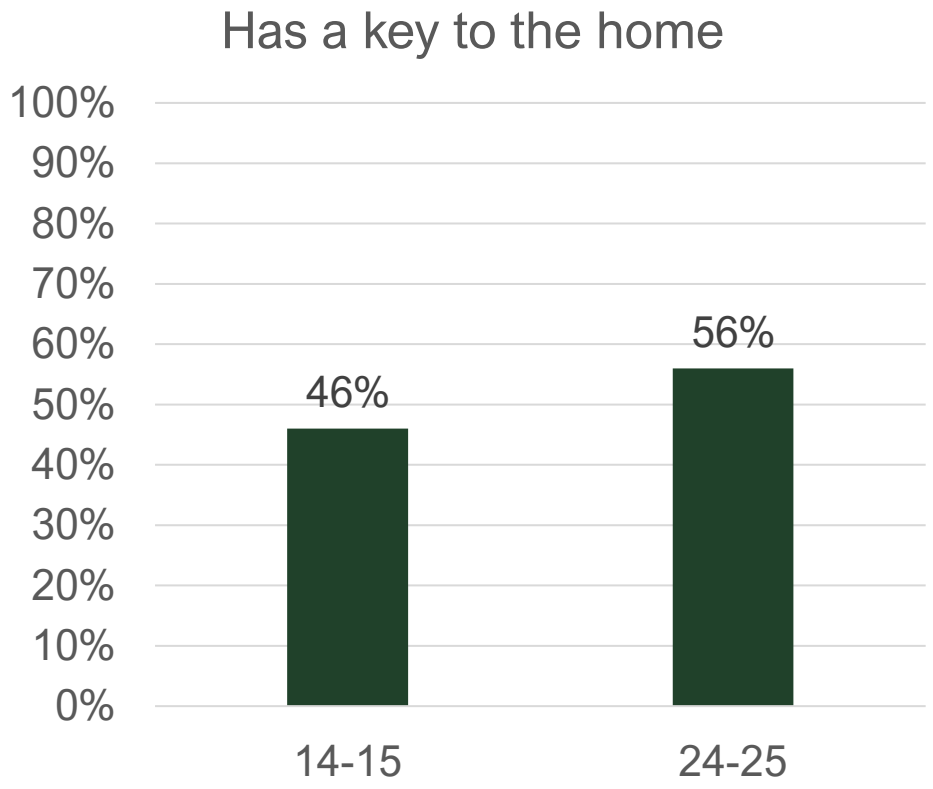
- The 2014 Medicaid HCBS Settings Rule says that people who get Medicaid home and community-based services should have choices about where and how they live their lives.

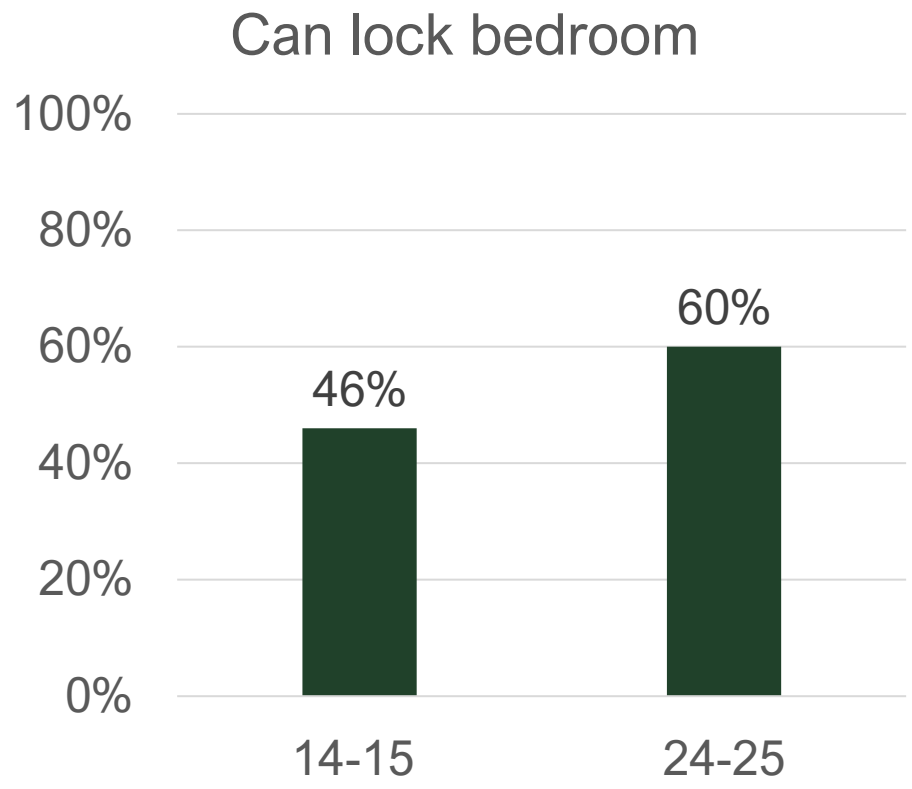
This means people should be able to:

- **Choose where they live.**
- **Choose who they live with.**
- **Spend time with people in their community.**
- **Make choices about their daily lives.**
- **Have privacy and respect.**
- **Have the same rights as other people.**
- **Get the support they need to be part of their community.**

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Have we seen progress? Some measures more than others….





Have we seen progress?

	Has a place to be alone at home	There are rules about having friends or visitors at the home	People read their mail without permission
14-15	96%	34%	13%
24-25	97%	29%	11%

	Chose or had some input in choosing where they live (if not living in the family home)	Chooses or helps decide their daily schedule	Decides or has help deciding how to spend free time
14-15	57%	92%	92%
24-25	57%	93%	93%

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However, . . .

It is never wise to assume that progress is a constant unless there is an abiding commitment to make it happen. . . .

Things to watch…

BREAKING: 9/24/26 A TX district judge approved an agreement to remove references to “most integrated setting” in a 2024 update to HHS’ regulations related to Section 504 of the Rehabilitation Act.

- Growing “campus” and farmstand movement
- Almost half of people receiving services have a guardian
- Private equity is entering the IDD market and providers are consolidating
- Managed Care
- Ever shrinking workforce
- DOJ opinion on Olmstead and threats to 504
- The narrative that paid caregiving and self direction are fraudulent
- Workforce threats (immigration)

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