

The disability “blind spot” in health care reform

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Faces of disability: Mariam Pare



The fundamental reality and dilemma

- In its human reality, disability is a multi-dimensional and continuous set of functional limitations that interact with the real-world environment.
 - Is my myopia a disability?
 - How about a graduate of University of Chicago Law School who uses a wheelchair?
 - Is a coal minor with mild depression and back pain disabled?
 - Same coal minor with an Oxycodone problem?
 - Same coal minor. He can actually work, but the only available work is minimum wage.
- Importance of Medicaid expansion for people with disabilities.

ACA as a missed opportunity on many fronts

- Preexisting conditions, Medicaid expansion, and other gains
- Failed CLASS Act.
- Disability community rather peripheral to original ACA fight, with distinctive political interests not universally shared in ACA coalition
 - Played central role in defending ACA and Medicaid, earned seat at the table
- But...disability policy as costly and complicated as the rest of health policy combined.
 - Looming LTC issue
 - What to do with fifty years of Medicaid wiring
 - A lot more.

Disability community defending ACA



U.S. Capitol Police remove a protester from in front of the office of Senate Majority Leader Mitch McConnell on Thursday.

Waiting lists for services

- 707,000 people on HCBS waiver waiting lists in 40 states as of 2017.
 - 281,000 in Texas, 66,000 in Louisiana, 68,000 in Ohio
 - 19,354 in Illinois, 0 in Massachusetts.
 - People living with intellectual and developmental disabilities (I/DD) comprise about two-thirds of waiting list enrollment.
 - One-quarter are seniors and adults with physical disabilities.
- Wait lists have been growing about 8% per year.

Emerging consensus (among Democrats)

- SSI countable asset limit
 - Last raised in 1989
 - Adjusted for inflation, about $\frac{1}{4}$ of its value in 1975.
 - Buttigieg, Warren, and Sanders seek to raise it.
 - Others across the political spectrum agree—but this is costly.
- Eliminate Medicare waiting period for those qualifying for SSDI
- ABLE accounts
- Other challenges
 - Presumptive eligibility for Medicaid HCBS for individuals who cross state lines.
 - National Medicaid buy-in for all who satisfy disability criteria.
 - LTSS through Medicaid expansion.

IDD reflects quiet successes of American disability policy

- Social acceptance and support
- Changes in popular culture and social norms.
 - The line at ORD security
- Legal protections
 - *Olmstead*, ADA, IDEA
- Entitlement security, expenditure growth
- So much more.

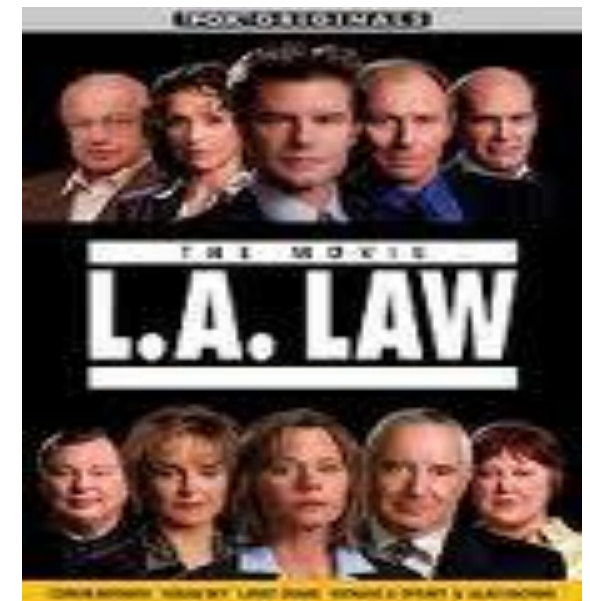
It's good to consider where we were not so long ago

- Consider America in 1945 or 1960, let alone 1930.
- I/DD was considered a private tragedy not a public policy challenge.
 - 1944, Eric and Joan Erickson had a child diagnosed with Down's Syndrome. They concealed the child from their other children, saying that he had died at birth.
- Limited schooling and care supports
- Institutional care often the only supports
- Community-based services essentially did not exist.
- Limited lifespan and significant medical challenges facing individuals with I/DD

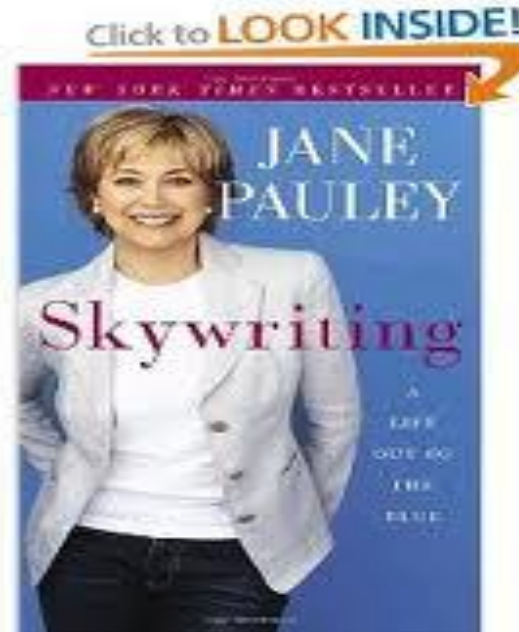
It's also good to consider what individuals and families confront with other conditions and disorders

- Social and family stigma much more intense for severe mental illnesses than with severe mental illness.
- Popular culture and public supports also much more generous in the case of IDD than SMI.
- Implications of such patterns for policy proposals such as Medicaid block grants.

Images of IDD in popular culture

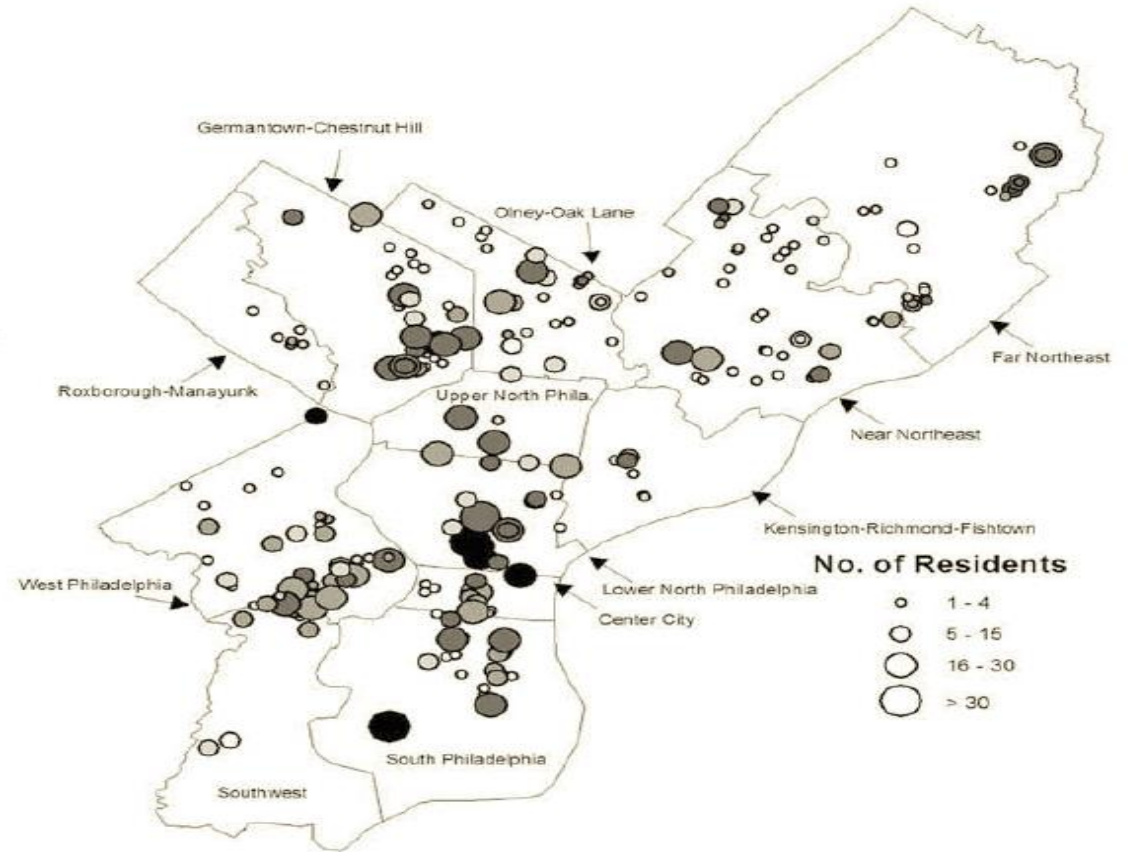
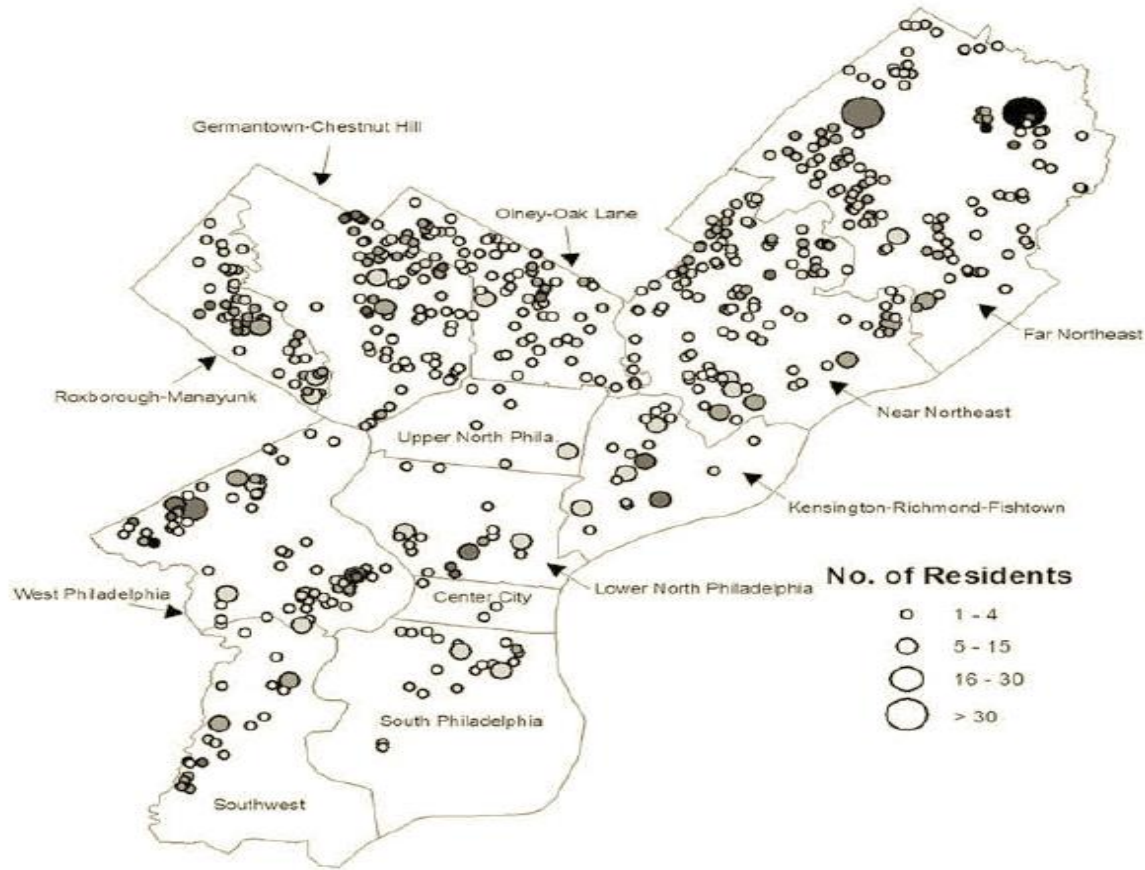


Pop culture representations of SMI



Distribution of supportive housing for persons w/psychiatric and developmental disabilities

(Wong and Stanhope 2009)



Residents with Developmental Disabilities

0.01 - 2	2.01 - 5	5.01 - 10	10.01 - 50	> 50
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Residents with Psychiatric Disabilities

0.01 - 2	2.01 - 5	5.01 - 10	10.01 - 50	> 50
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That (selective) social
acceptance has historical roots

The modern story begins roughly 1946

- WWII conscientious objectors sent to state institutions, and wrote about what they saw:
 - Channing Richardson “100,000 Defectives” *Christian Century* 1946
 - Inhumane conditions reminiscent of other places...
 - Burnout and cruelty committed by overburdened, undertrained staff.
 - Presence of people with normal-range IQ’s wrongly institutionalized, and more.
- Women caregivers began to write about their experiences.

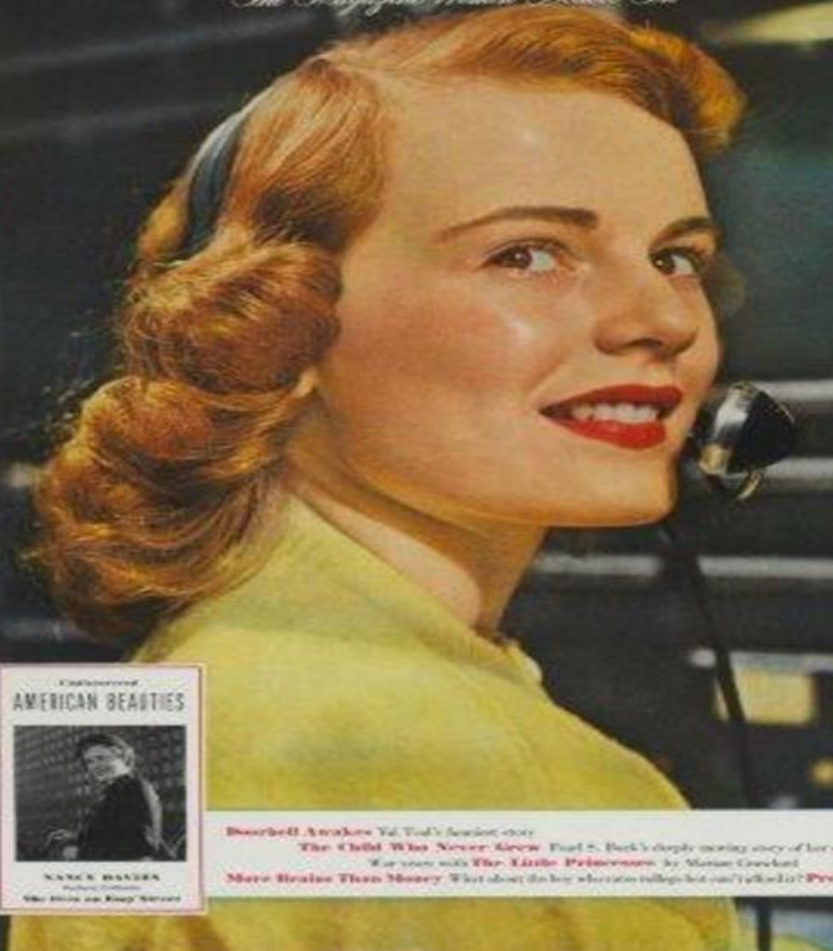
The
CHILD
Who Never
Grew

PEARL
S.
BUCK

Foreword By
JAMES A.
MICHENER

JOURNAL

The Magazine Women Believe In



Illustrated
AMERICAN BEAUTIES

NANCY SANDRA
Public Opinion
Who Shines on King Street

Describe! Analyze! You'll find out why
The Child Who Never Grew Pearl S. Buck's deeply moving story of her
war years with **The Little Princesses** by Marian Crawford
More Brains Than Money What about the boy who rates colleges but can't talk? **Pro**

THE CHILD WHO NEVER GREW

BY PEARL S. BUCK

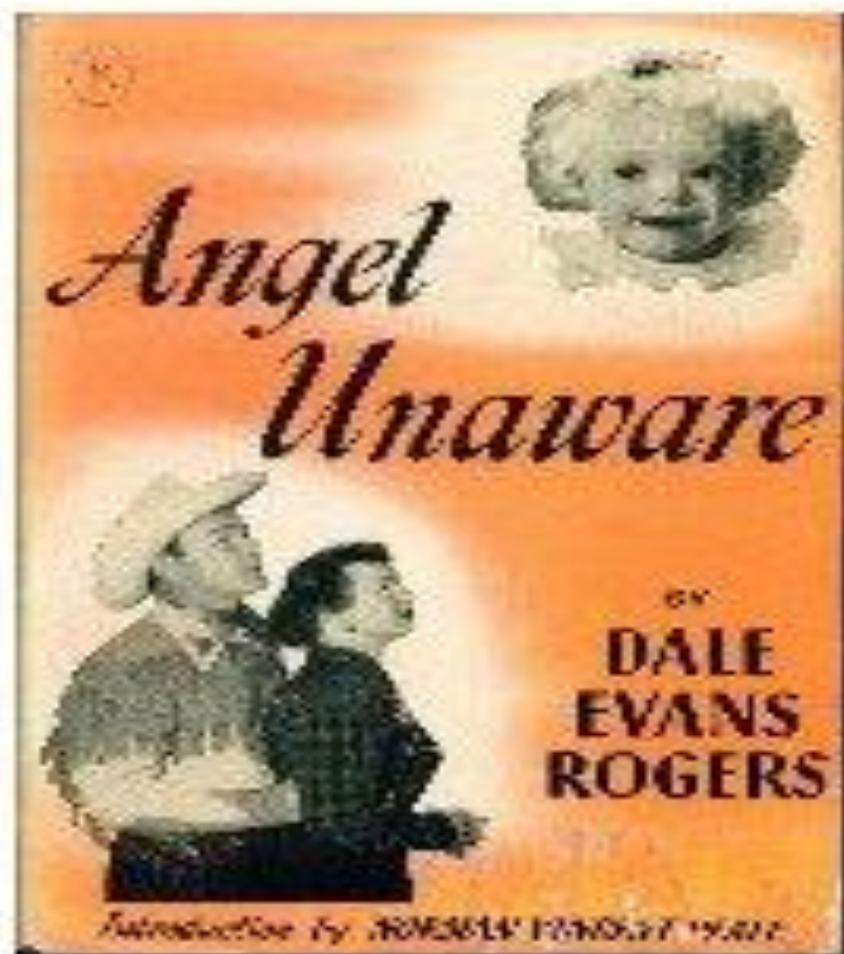
I HAVE been a long time in making up my mind to write this story. It is a true one, and that makes it hard to tell. Several reasons have helped me to reach the point this morning, after an hour or so of walking through the winter woods, when I have finally resolved that the time has come for the story to be told. Some of the reasons are those which I have received

The first cry from my heart, when I knew that she would never be anything but a child, was the age-old cry that we all make before inevitable sorrow: "Why must this happen to me?" To this there could be no answer and there was none. When I knew at last that there could never be an answer, my own resolve shaped into the determination to make meaning out of the meaningless, and so pro-

of use to human beings. In one way, if not the other, her life must count. To know that it was not wasted might assuage what could not be prevented or cured.
This resolve did not come to me immediately. I grew toward it, but once I had reached it I have held to it through all the years of her life. I have let it work in quiet ways, dreading the cold eyes of the curious. Now, today, I will forget those whom I dread, who, after all, I will remember the many who

“For of Gods many children
these are the most
innocent”





*Angel
Unaware*

BY
**DALE
EVANS
ROGERS**

Introduction by ROSEMARY HINDSLEY 1981

The pioneering generation of caregiver community organizers

- In 1946, Laura Blossfeld placed an ad in a Bergen County newspaper.
- Her pitch might have been drawn from a political science textbook or a social media mobilization campaign:
 - **“Each parent can ultimately help his own child by doing something to help all children similarly affected. . . . Therefore I suggest an organization for all parents of mentally retarded children, [one that] may well prove to be the first chapter in a nationwide organization.”**
- In 1949, a New York City housewife placed a similar newspaper advertisement:
 - **“Surely there must be other children like [her son], other parents like myself. Where are you? Let’s band together and do something for our children!”**

The pioneering generation of caregivers

- Middle-class women who began to find each other, founded and spread NARC some of the greatest community organizers in American history.
- Impossible to imagine recent history we're familiar with (ADA, Olmstead litigation, etc.) without that grassroots mobilization.
- Alliance of policy expertise with evidence-based political advocacy to affect change.

Thank you