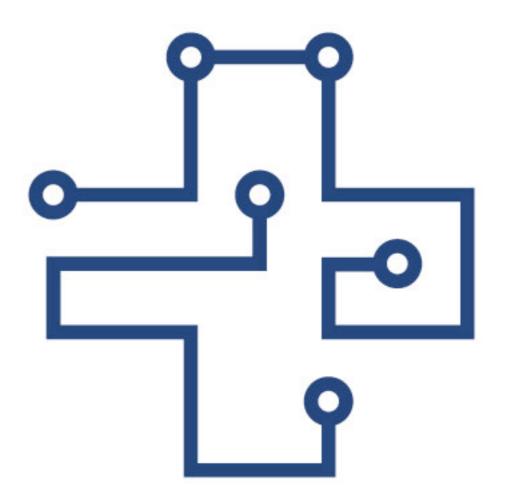
The Safety Net-Work

Vulnerability + Accountability in a Data-Driven World

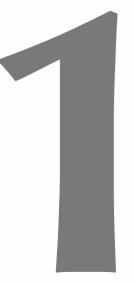


Rhea W Boyd, MD, MPH, FAAP

@RheaBoydMD

National Interoperability Collaborative 2018 Symposium

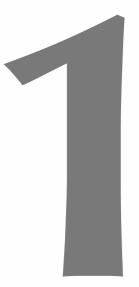
Image Credit: Johns Hopkins Medicine Technology Innovation Center



Social + Health

The Data Logic

Accountability

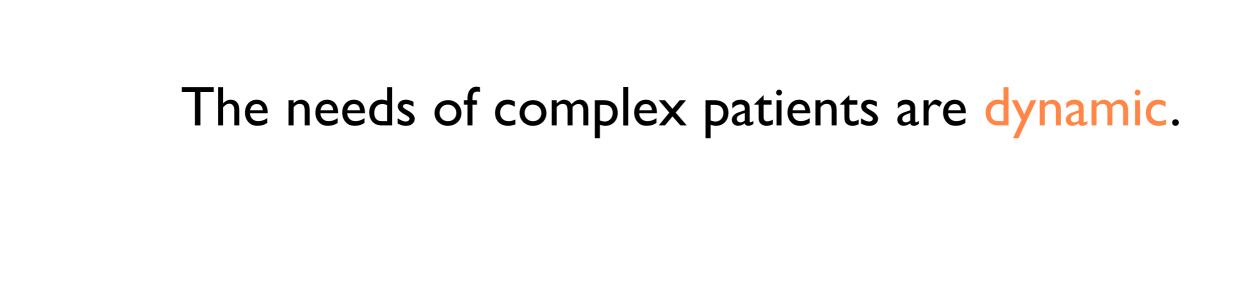




Social + Health

The Data Logic

Accountability



The needs of complex patients are dynamic.

Health care built models that are static.

The needs of complex patients are dynamic.

Health care built models that are static.

We built a box.

The needs of complex patients are dynamic.

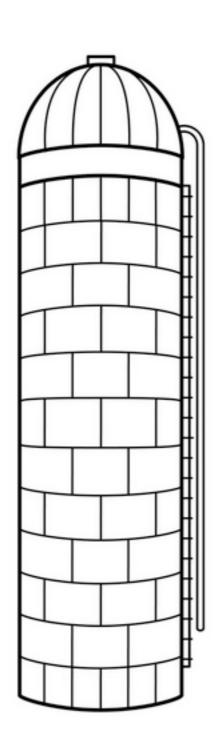
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We built a box.



The Box Represents

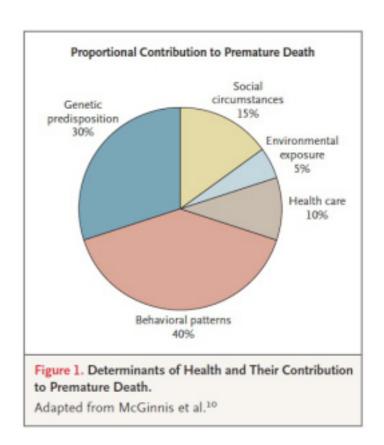
The Structure of Health Care



The Box Represents

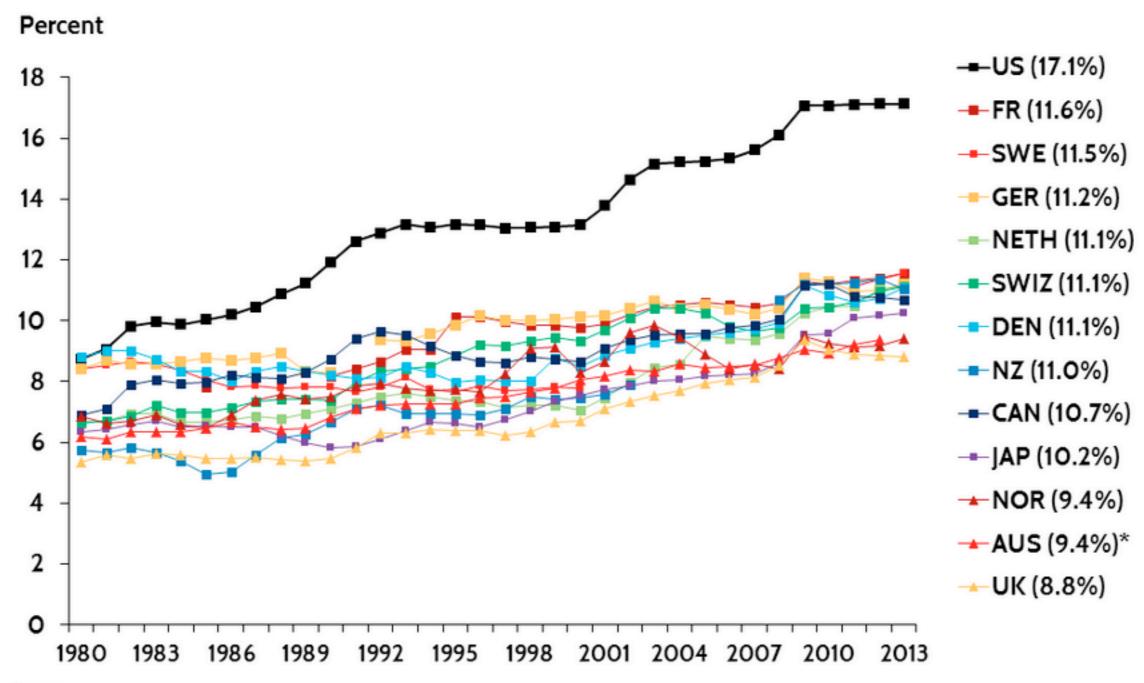
Constraints to what the vital components of health care systems could and should be.





Schroeder S, We Can Do Better - Improving the Health of the American People. N Engl J Med 2007; 357:1221-1228.

Exhibit 1. Health Care Spending as a Percentage of GDP, 1980-2013



* 2012.

Notes: GDP refers to gross domestic product. Dutch and Swiss data are for current spending only, and exclude spending on capital formation of health care providers.

Source: OECD Health Data 2015.

Exhibit 9. Select Population Health Outcomes and Risk Factors

	Life exp. at birth, 2013 ^a	Infant mortality, per 1,000 live births, 2013 ^a	Percent of pop. age 65+ with two or more chronic conditions, 2014 ^b	Obesity rate (BMI>30), 2013 ^{a,c}	Percent of pop. (age 15+) who are daily smokers, 2013 ^a	Percent of pop. age 65+
Australia	82.2	3.6	54	28.3e	12.8	14.4
Canada	81.5e	4.8e	56	25.8	14.9	15.2
Denmark	80.4	3.5	-	14.2	17.0	17.8
France	82.3	3.6	43	14.5d	24.1 ^d	17.7
Germany	80.9	3.3	49	23.6	20.9	21.1
Japan	83.4	2.1	-	3.7	19.3	25.1
Netherlands	81.4	3.8	46	11.8	18.5	16.8
New Zealand	81.4	5.2e	37	30.6	15.5	14.2
Norway	81.8	2.4	43	10.0d	15.0	15.6
Sweden	82.0	2.7	42	11.7	10.7	19.0
Switzerland	82.9	3.9	44	10.3 ^d	20.4 ^d	17.3
United Kingdom	81.1	3.8	33	24.9	20.0 ^d	17.1
United States	78.8	6.1e	68	35.3 ^d	13.7	14.1
OECD median	81.2	3.5	-	28.3	18.9	17.0

a Source: OECD Health Data 2015.

b Includes: hypertension or high blood pressure, heart disease, diabetes, lung problems, mental health problems, cancer, and joint pain/arthritis. Source: Commonwealth Fund International Health Policy Survey of Older Adults, 2014.

[°] DEN, FR, NETH, NOR, SWE, and SWIZ based on self-reported data; all other countries based on measured data.

d 2012. e 2011.

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Netherlands	81.4	3.8	46	11.8	18.5	16.8
New Zealand	81.4	5.2e	37	30.6	15.5	14.2
Norway	81.8	2.4	43	10.0d	15.0	15.6
Sweden	82.0	2.7	42	11.7	10.7	19.0
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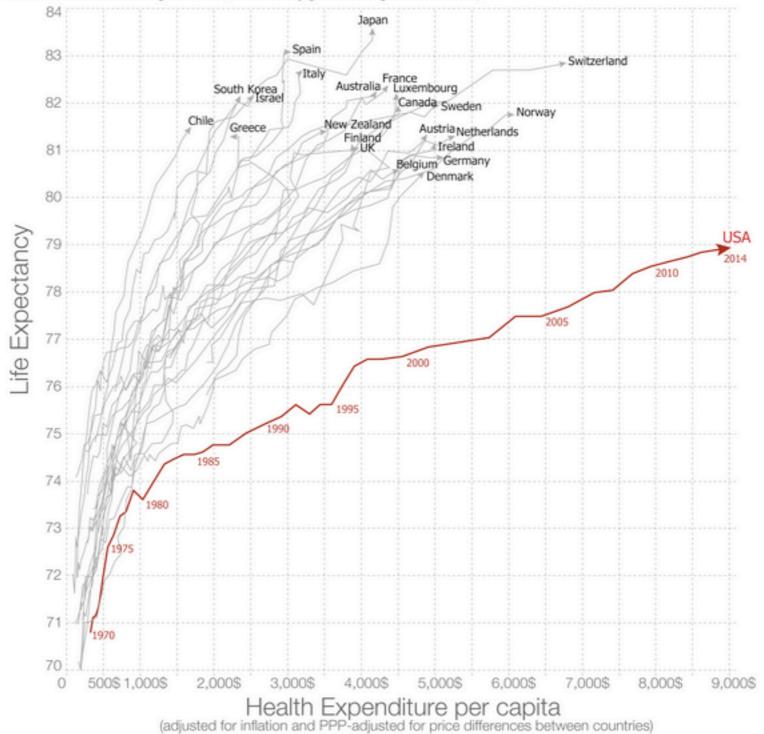
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Life expectancy vs. health expenditure over time (1970-2014) Our World



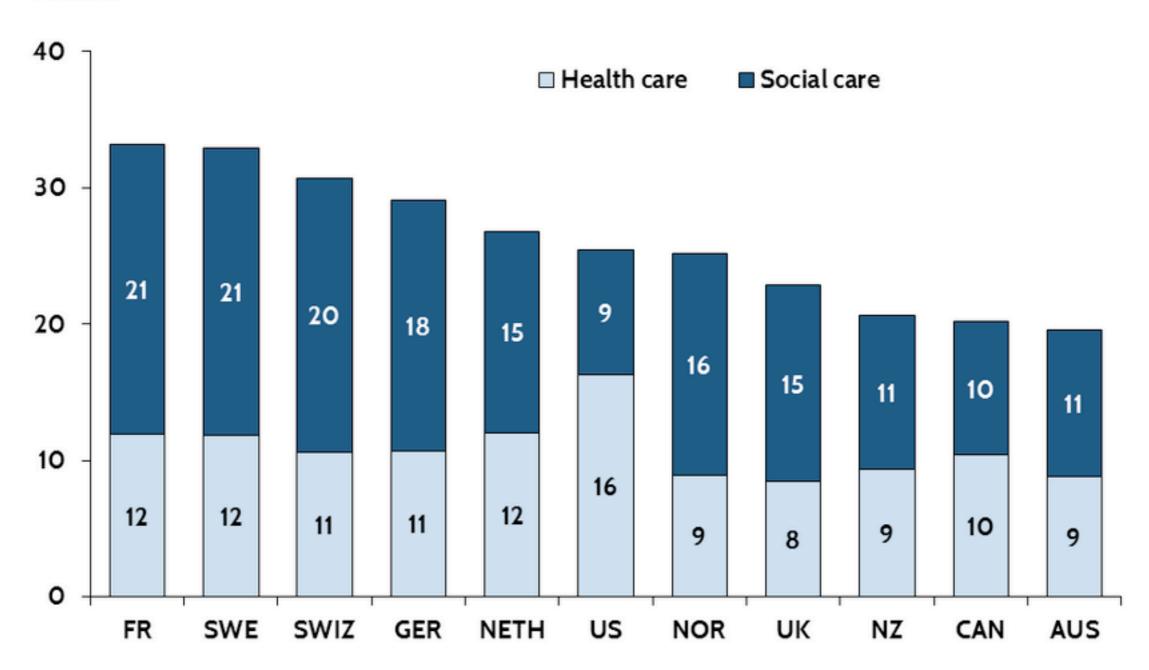
Health spending measures the consumption of health care goods and services, including personal health care (curative care, rehabilitative care, long-term care, ancillary services and medical goods) and collective services (prevention and public health services as well as health administration), but excluding spending on investments. Shown is total health expenditure (financed by public and private sources).



Data source: Health expenditure from the OECD; Life expectancy from the World Bank Licensed under CC-BY-SA by the author Max Roser. The data visualization is available at OurWorldinData.org and there you find more research and visualizations on this topic.

Exhibit 8. Health and Social Care Spending as a Percentage of GDP

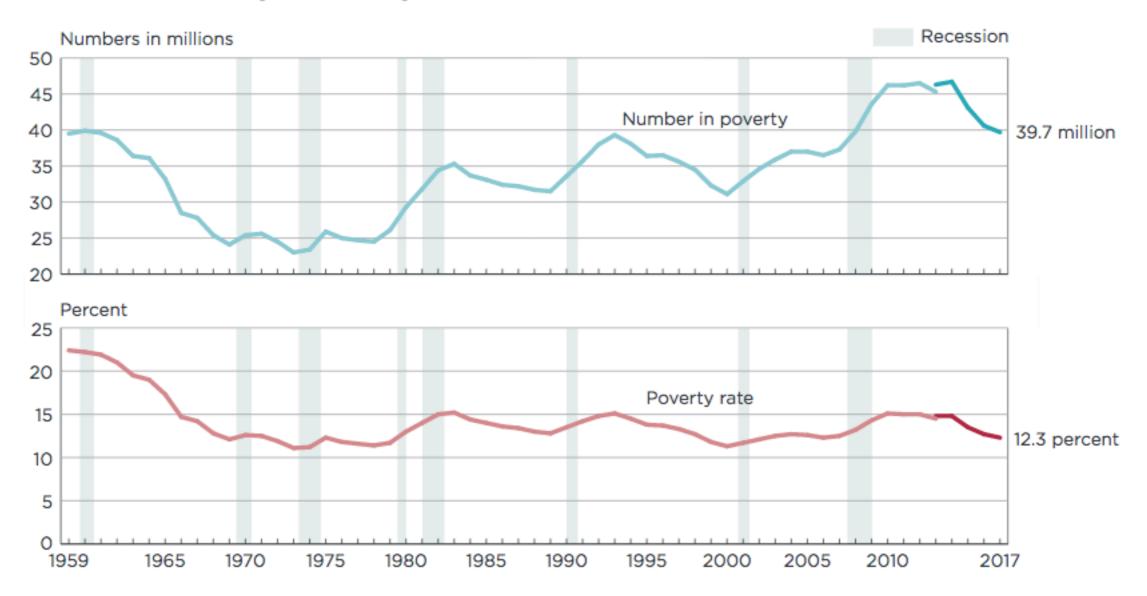




Notes: GDP refers to gross domestic product.

Source: E. H. Bradley and L. A. Taylor, The American Health Care Paradox: Why Spending More Is Getting Us Less, Public Affairs, 2013.

Number in Poverty and Poverty Rate: 1959 to 2017

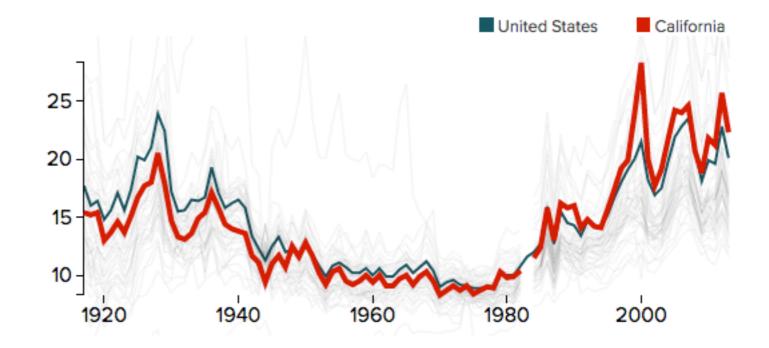


US Census Bureau. Current Population Survey. 1960 to 2018 Annual Social & Economic Supplements.

Inequality is growing.

Share of income captured by the top 1%, 1917–2013

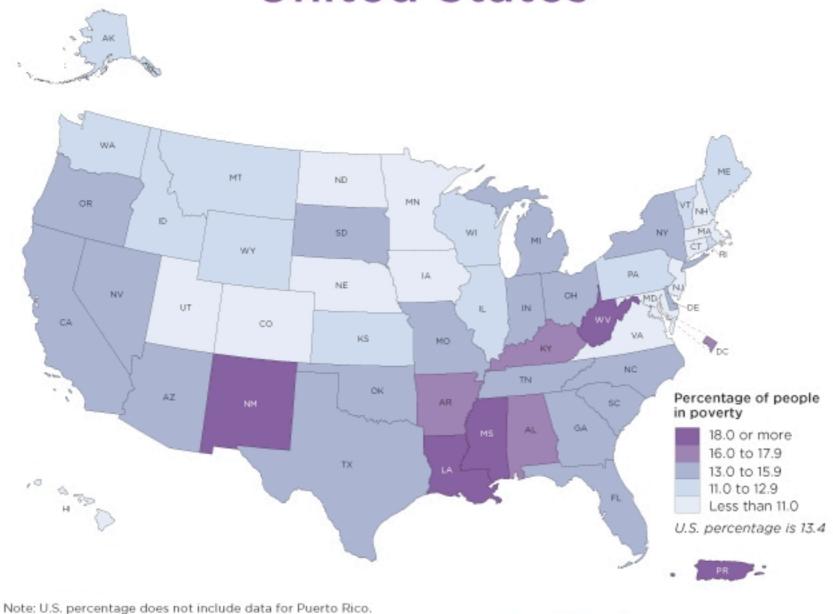
The share of all income held by the top 1% in recent years has approached or surpassed historical highs.



Economic Policy Institute. The Unequal States of America: Income Inequality in California. June 2016.

Place matters.

2017 Poverty Rate in the **United States**



US Census Bureau. 2017 American Community Survey & 2017 Puerto Rican Community Survey.

Poverty defies social categorization.

L	2016				2017					Change in poverty (2017		
Characteristic	L		Below po	overty		L		Below			less 20	16)2."
	Total	Number	Margin of error ¹ (+/-)	Percent	Margin of error ¹ (+/-)	Total	Number	Margin of error ¹ (+/-)	Percent	Margin of error ¹ (+/-)		Percent
PEOPLE												
Total	319,911	40,616	739	12.7	0.2	322,549	39,698	915	12.3	0.3	-918	*-0.4
Race ³ and Hispanic Origin												
White	245,985	27,113	547	11.0	0.2	247,272	26,436	714	10.7	0.3	-677	*-0.3
White, not Hispanic	195,221	17,263	493	8.8	0.3	195,256	16,993	571	8.7	0.3	-270	-0.1
Black	41,962	9,234	388	22.0	0.9	42,474	8,993	373	21.2	0.9	-241	-0.8
Asian	18,879	1,908	175	10.1	0.9	19,475	1,953	190	10.0	1.0	45	-0.1
Hispanic (any race)	57,556	11,137	399	19.4	0.7	59,053	10,790	423	18.3	0.7	-348	*-1.1
Sex												
Male	156,677	17,685	395	11.3	0.3	158,116	17,365	483	11.0	0.3	-321	-0.3
Female	163,234	22,931	460	14.0	0.3	164,433	22,333	525	13.6	0.3	-598	*-0.5
Age												
Under age 18	73,586	13,253	370	18.0	0.5	73,356	12,808	425	17.5			-0.6
Aged 18 to 64	197,051	22,795	473	11.6	0.2	198,113	22,209	564	11.2	0.3	-586	*-0.4
Aged 65 and older	49,274	4,568	198	9.3	0.4	51,080	4,681	190	9.2	0.4	114	-0.1
Nativity												
Native born	276,089	33,999	670	12.3	0.2	277,158	33,095	850	11.9	0.3	-904	*-0.4
Foreign born	43,822	6,617	268	15.1	0.6	45,391	6,603	295	14.5	0.6	-14	-0.6
Naturalized citizen	20,409	2,045	143	10.0	0.7	21,851	2,213	146	10.1	0.6	168	0.1
Not a citizen	23,413	4,572	222	19.5	0.9	23,540	4,390	238	18.6	0.9	-182	-0.9
Region												
Northeast	55,470	5,969	350	10.8	0.6	55,972	6,373	339	11.4	0.6	404	0.6
Midwest	66,897	7,809	355	11.7	0.5	67,345	7,647	397	11.4	0.6	-162	-0.3
South	121,166	17,028	524	14.1	0.4	122,250	16,609	587	13.6	0.5	-420	-0.5
West	76,377	9,810	373	12.8	0.5	76,982	9,069	400	11.8	0.5	*-740	*1.1
Residence ⁴												
Inside metropolitan statistical areas	276,296	33,718	835	12.2	0.3	279,537	33,322	857	11.9			-0.3
Inside principal cities	103,252	16,495	643	16.0	0.5	103,860	16,218	634	15.6			-0.4
Outside principal cities	173,044	17,223	577	10.0	0.3	175,677	17,105	577	9.7	0.3		-0.2
Outside metropolitan statistical areas	43,614	6,898	600	15.8	0.8	43,012	6,376	523	14.8	0.7	*-522	*-1.0
Work Experience												
Total, aged 18 to 64	197,051	22,795	473	11.6	0.2	198,113	22,209	564	11.2			*-0.4
All workers	150,904	8,743	254	5.8	0.2	152,199	8,135		5.3			*-0.4
Worked full-time, year-round	107,781	2,416	131	2.2	0.1	109,700	2,422	128	2.2			Z
Less than full-time, year-round	43,123 46,148	6,327 14,052	223 381	14.7 30.5	0.5	42,499 45,914	5,714 14,073	224 440	13.4 30.7			*-1.2 0.2
	.3,0	,		20.0			,			5.1		J.2
Disability Status ⁵	40000											
Total, aged 18 to 64	197,051	22,795	473	11.6	0.2	198,113	22,209	564	11.2			*-0.4
With a disability	15,405 180,783	4,123 18,629	191 409	26.8 10.3	1.1 0.2	15,116 182,042	3,764 18,412	170 504	24.9 10.1			*-1.9 -0.2
Educational Attainment							_,			3.0		
Total, aged 25 and older	216,921	22,636	425	10.4	0.2	219,830	22,163	516	10.1	0.2	-473	*-0.4
No high school diploma	22,541	5,599	214	24.8	0.8	22,411	5,485		24.5			-0.4
									12.7			*-0.6
High school, no college	62,512	8,309	250	13.3	0.4	62,685	7,942					
Some college, no degree	57,765	5,430	202	9.4	0.3	57,810	5,075		8.8			*-0.6
Bachelor's degree or higher	74,103	3,299	167	4.5	0.2	76,924	3,661	181	4.8	0.2	*363	*0.3

US Census Bureau. Poverty by Selected Characteristics. 2016 & 2017.

Only half of children will earn more than their parents.

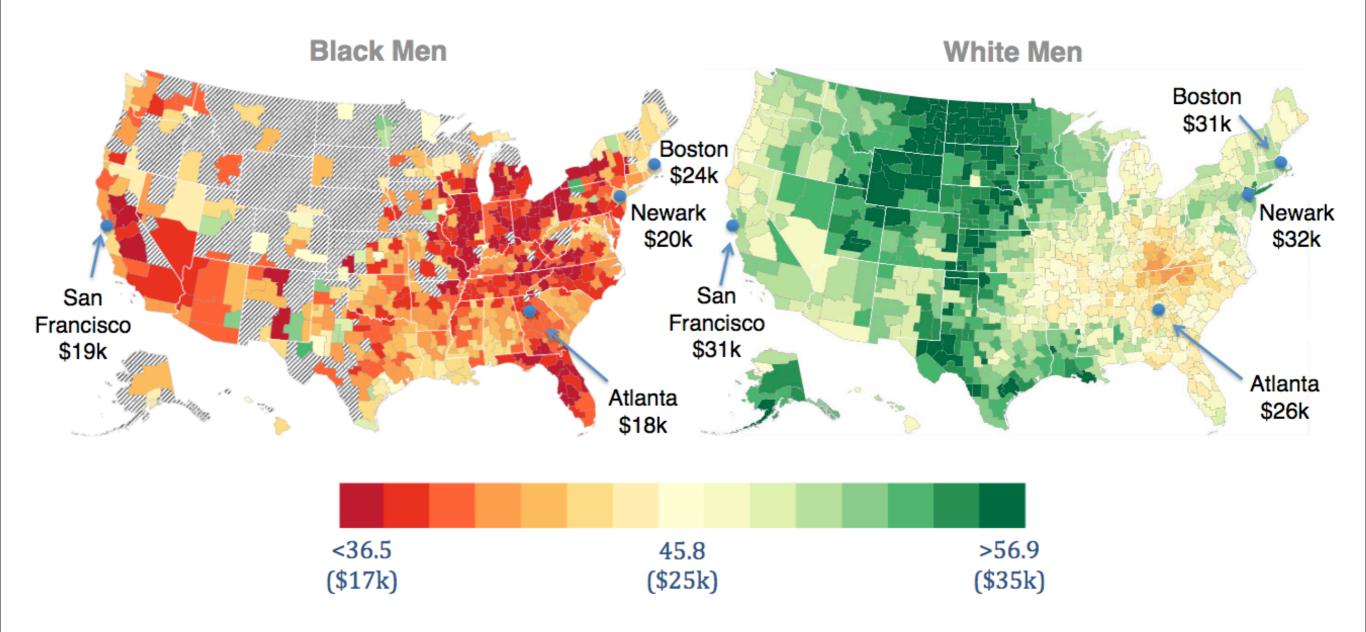
Percent of Children Earning More than Their Parents, by Year of Birth



Chetty, R. The Fading American Dream: Trends in Absolute Income Mobility Since 1940. Science. 356(6336): 398-406. 2017.

Two Americas: The Geography of Upward Mobility by Race

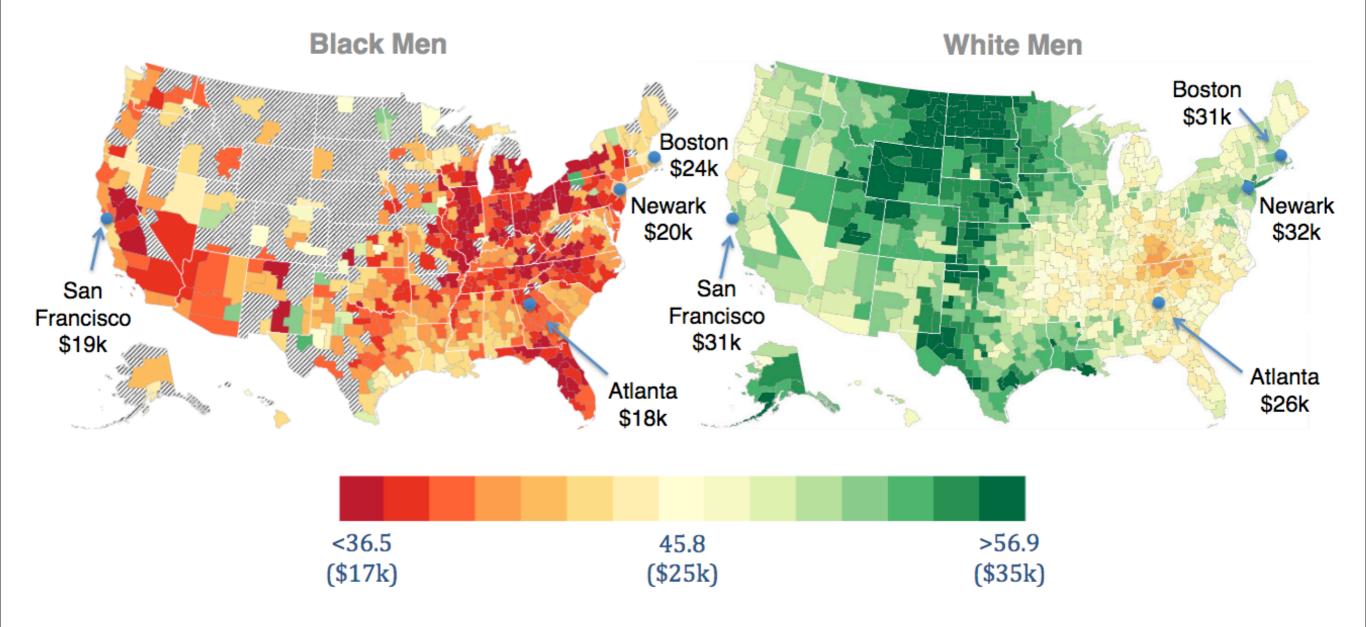
Average Individual Income for Boys with Parents Earning \$25,000 (25th percentile)



Chetty, R. et al. Race and Economic Opportunity in the United States: An intergenerational perspective. Opportunity Insights. 2018.

Two Americas: The Geography of Upward Mobility by Race

Average Individual Income for Boys with Parents Earning \$25,000 (25th percentile)



In 99% of neighborhoods in the US, black boys earn less in adulthood than white boys who grow up in families with comparable income.

Black and white children fare very differently in America,

even if they grow up with two-parents, comparable incomes, education, and wealth, live on the same city block and attend the same school.



Chetty, R. et al. Race and Economic Opportunity in the United States: An intergenerational perspective. Opportunity Insights. 2018.

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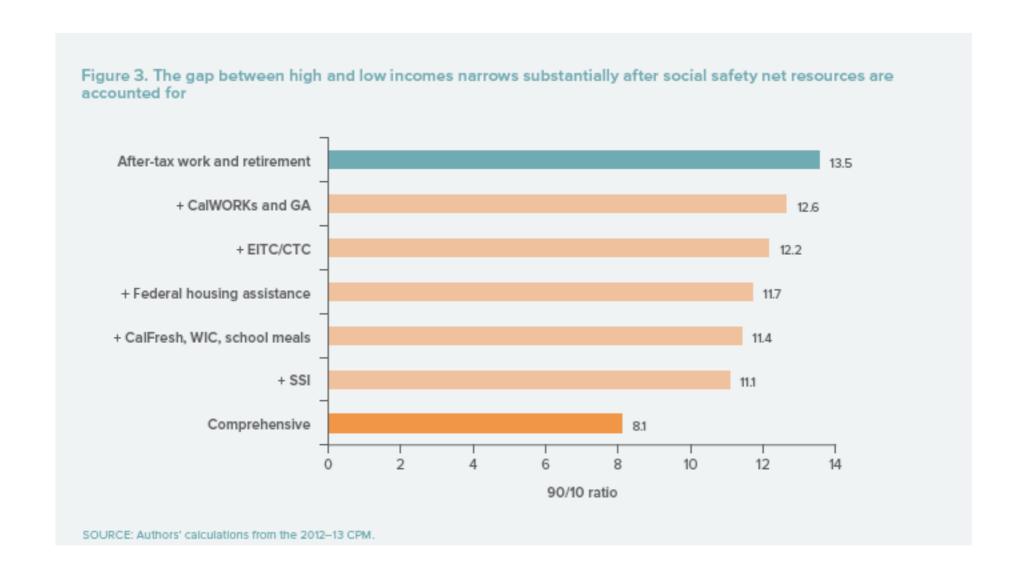
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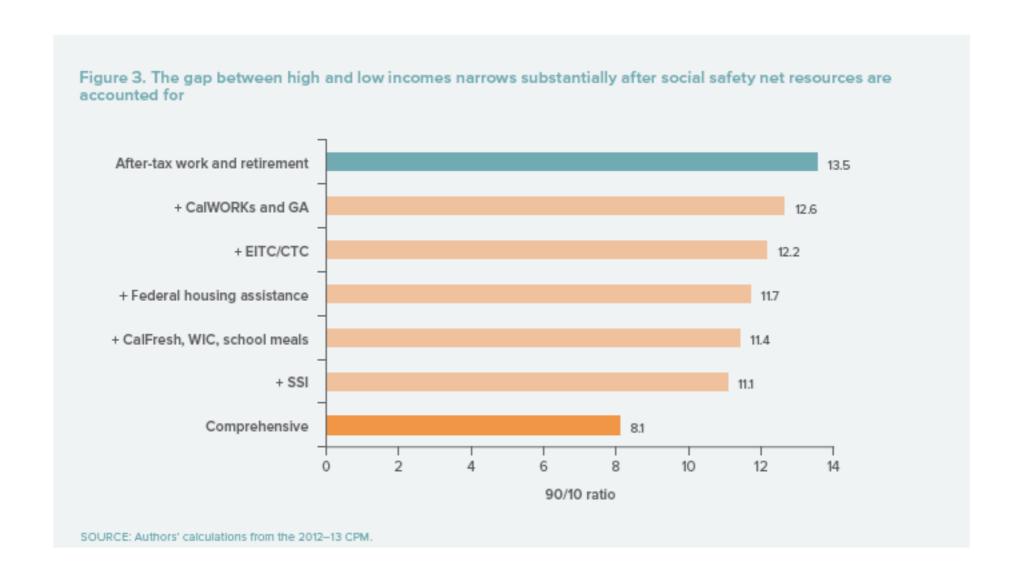
These gaps are <u>smallest</u> in areas with **low racial bias** among whites and high father presence in black neighborhoods.

Chetty, R. et al. Race and Economic Opportunity in the United States: An intergenerational perspective. Opportunity Insights. 2018.

Safety net programs exponentially decrease inequality.



Safety net programs exponentially decrease inequality.



Through re-distributive processes.

Families are the safety in the net.

Table 4. On average, most family resources come from work

	L	ow	Middle		
	1st decile	2nd decile	3rd decile	4th decile	5th decile
After-tax Income work and retirement	65.8%	73.2%	81.3%	90.8%	96.1%
CalFresh, WIC, and school meals	17.5	6.6	4.6	2.6	1.0
SSI	7.2	7.1	3.8	1.9	1.3
CalWORKs, GA	3.3	2.5	1.6	0.9	0.4
EITC/Child tax credit	3.2	4.8	4.9	2.9	1.2
Rental housing assistance	3.0	5.7	3.8	0.9	0.1

SOURCE: Authors' calculations from the 2012-13 CPM.

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Social + Health

The Data Logic

Accountability



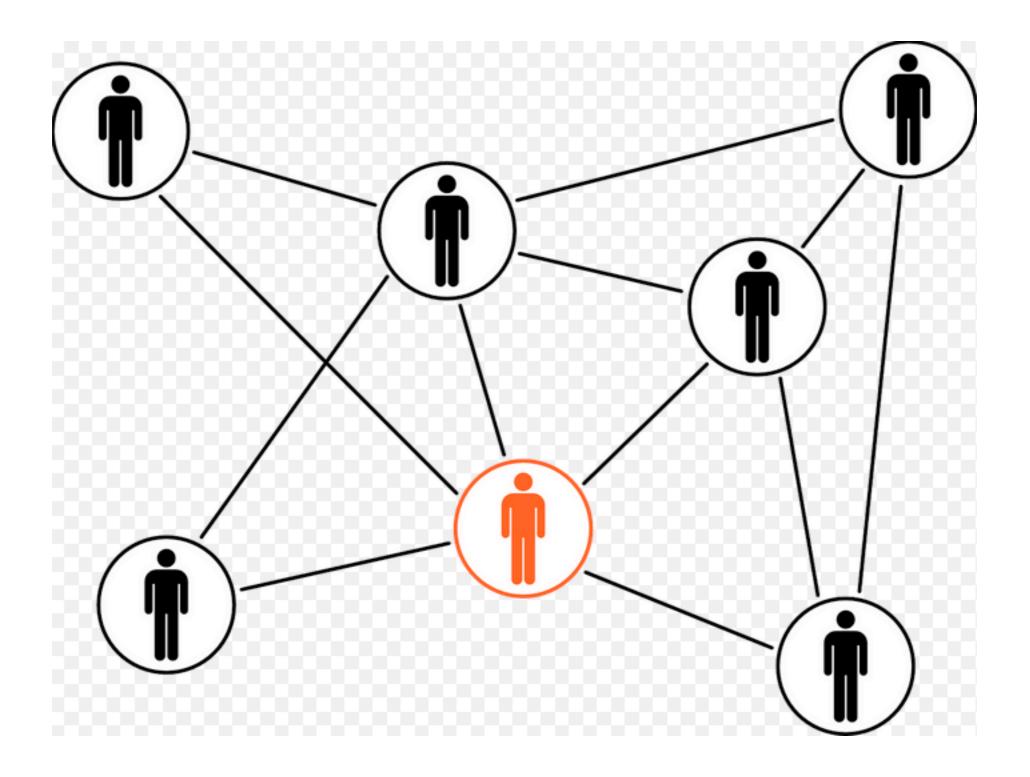


The social safety net is becoming...



...the social safety net-work.

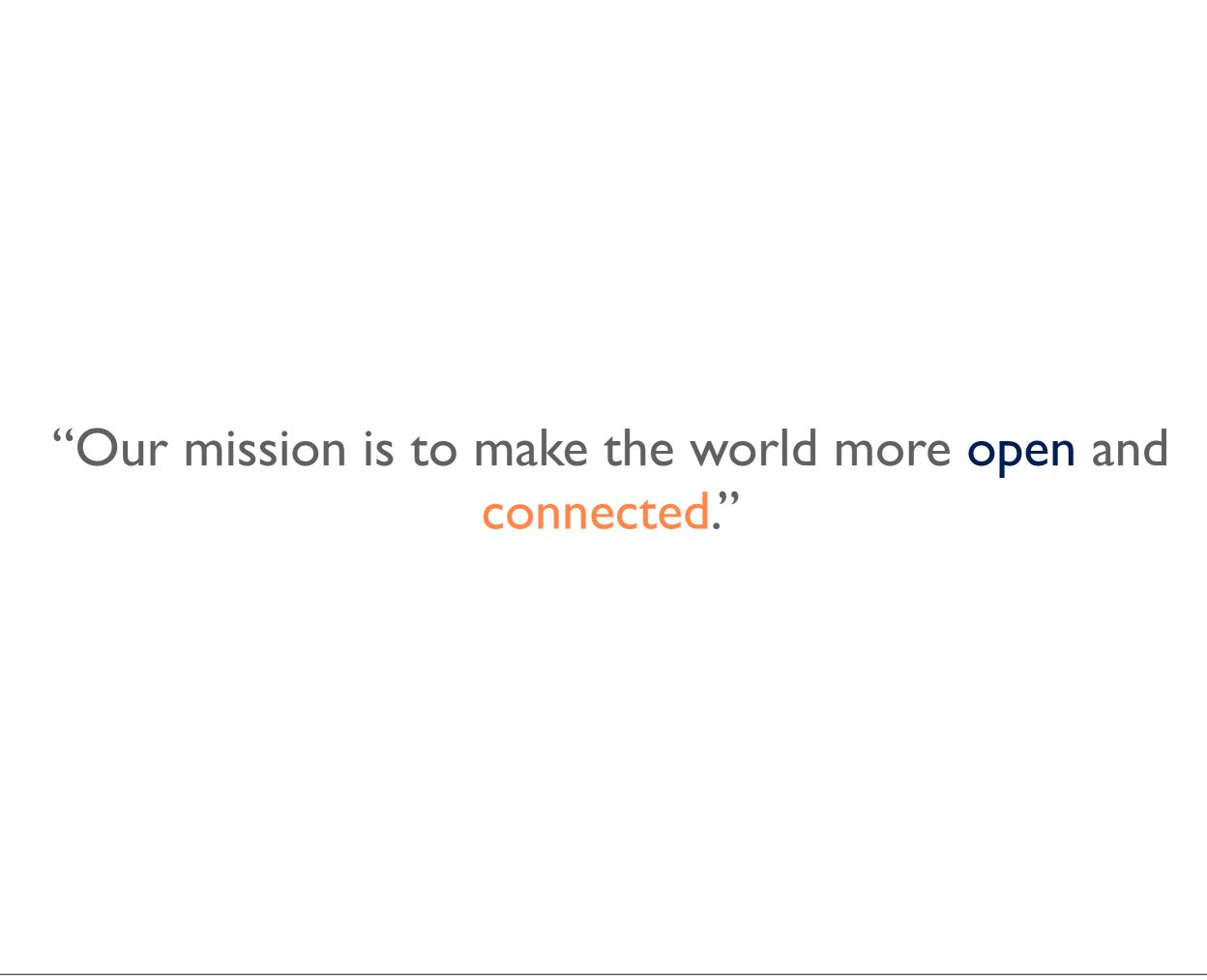
Connection



Vulnerability

People are valuable.

Data is valuable.





"Our mission is to make the world more open and connected."

Privacy



"Our mission is to make the world more open and connected."

Privacy Informed Consent



"Our mission is to make the world more open and connected."

Privacy

Informed Consent

Democracy



"Our mission is to make the world more open and connected."

When data becomes gravity...



We have to ask what grounds us.

Data is valuable.

Financial Capital

Build Resources + Control Access to Information

This is a critical time to lead the industry in human-centered ethical standards that drive data collection, utilization, and sharing.

People are valuable.

Social Capital

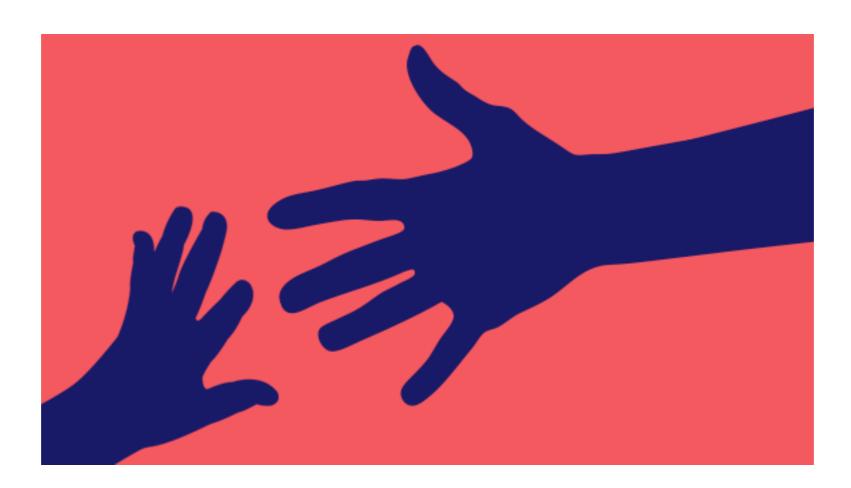
Re-distribute Resources + Share Access to Information

Ethical standards that enable the public sector to anticipate and combat ways social service utilization can be tracked to surveil, profile, and police vulnerable populations.

Child abuse prediction models that solely rely on data collected from families using public assistance are a form of poverty profiling.

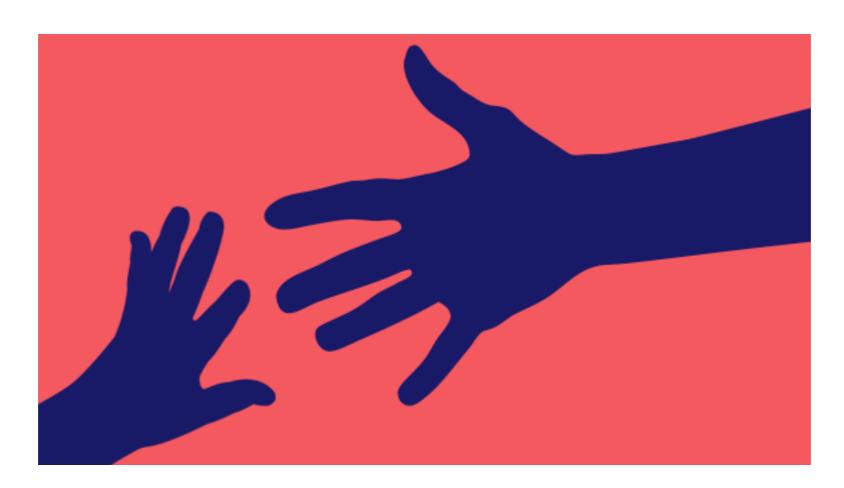


Child abuse prediction models that solely rely on data collected from families using public assistance are a form of poverty profiling.



Efforts to understand community-level risks may oversample the poor.

Child abuse prediction models that solely rely on data collected from families using public assistance are a form of poverty profiling.

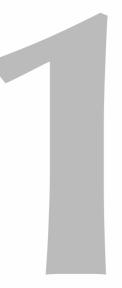


This conflates "parenting while poor with poor parenting."

"We manage the individual poor to escape our shared responsibility for eradicating poverty."

"We manage the individual poor to escape our shared responsibility for eradicating poverty."

What is the relationship between the technology we are building and growing inequality in America?



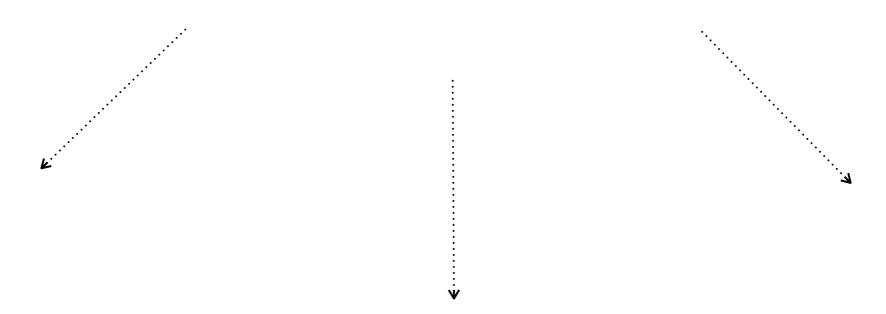


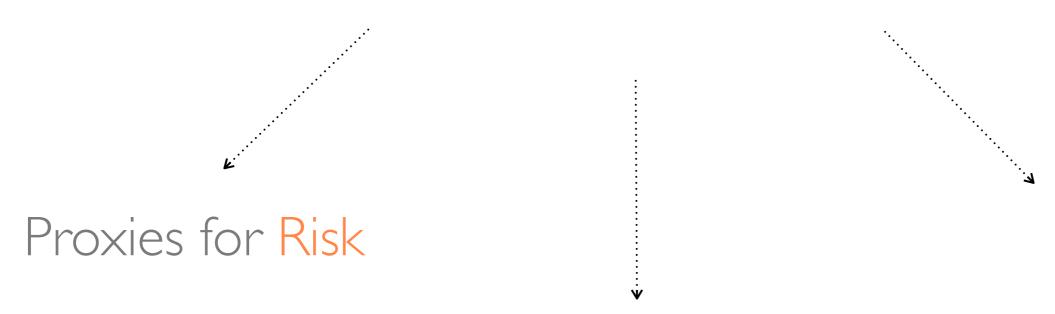
Social + Health

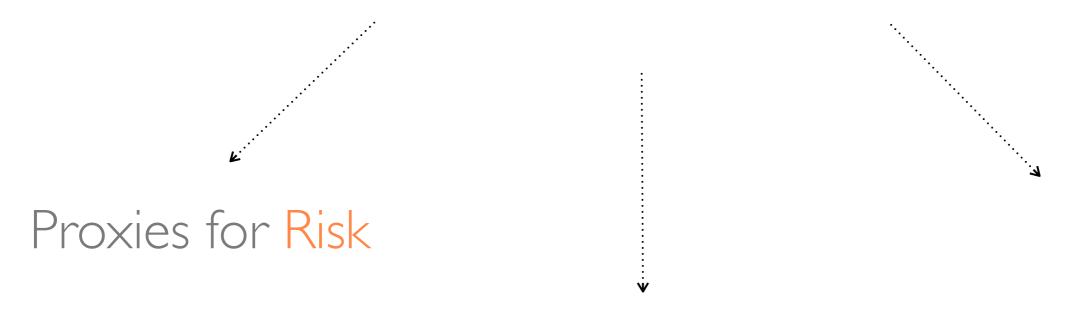
The Data Logic

Accountability

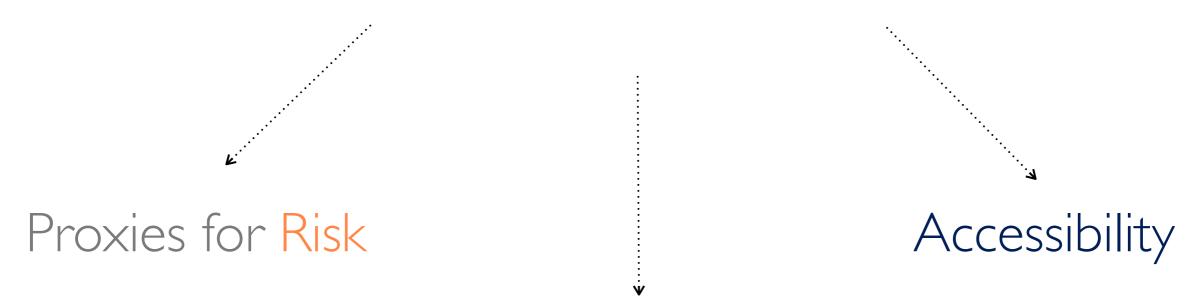
The endeavor to digitalize processes and centralize data that assess risk and grant access to vital community resources is inherently a negotiation in power, ownership, and social control.







Drivers of Acquisition + Accountability



Drivers of Acquisition + Accountability

'Welfare Queen' Becomes Issue in Reagan Campaign

The Washington Star

Presidential primary.

as part of his "citizens' press down on the specifics because conference" format.

cago," the Republican candidate local audiences. said recently to an audience in Gilford, N.H., during his free- The following items were swinging attack on welfare taken from a reporter's noteabuses. "She has 80 names, 30 book after attending 18 citizens' addresses, 12 Social Security press conferences on Jan. 15, cards and is collecting veterans' 16 and 17, all of them in small benefits on four nonexisting towns in southern New Hampdeceased husbands." He added: shire:

"And she's collecting Social welfare under each of her serted at several stops. names. Her tax-free cash income alone is over \$150,000 " According to a spokesman for

WASHINGTON, Feb. 14-Few odds with the facts. The former people realize it, but Linda Tay- California Governor fairly lor, a 47-year-old Chicago wel- bristles with what he calls facts, fare recipient, has become a figures and statistics demonmajor campaign issue in the strating what he thinks is New Hampshire Republican wrong with welfare, Big Government and the United States.

Former Gov. Ronald Reagan The national press entourage of California has referred to her following Mr. Reagan usually at nearly every stop, using her is prevented from pinning him his citizens' press conferences "There's a woman in Chi. are reserved for questions for

Items in Notebook

6Mr. Reagan usually praises Security on her cards. She's his welfare refrom program in got Medicaid, getting food California, "We lopped 400,000 stamps and she is collecting off the welfare rolls," he as-

'Welfare Queen' Becomes Issue in Reagan Campaign

The Washington Ster

Presidential primary.

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According to a spokesman for



Perspective

A New Threat to Immigrants' Health — The Public-Charge Rule

Krista M. Perreira, Ph.D., Hirokazu Yoshikawa, Ph.D., and Jonathan Oberlander, Ph.D.

Old Rule

Immigrants dependent on government for more than 50% of income

Excluded non-cash, health, housing, and nutrition benefits.

Proposed Rule

Immigrants who use or receive "one or more public benefits."

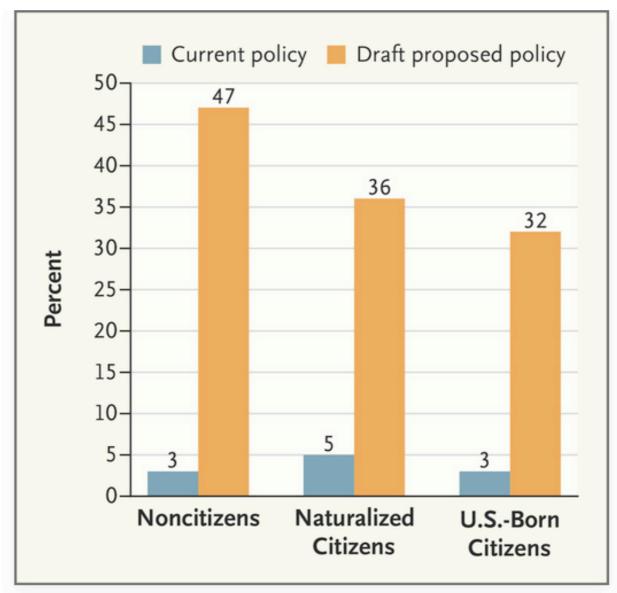
Includes Medicaid, CHIP, WIC, SNAP, Section 8, EITC, Low Income Home Energy Assistance.

Perrerira, KM et al. A New Threat To Immigrants' Health - The Public-Charge Rule. NEJM. 2018.

Perspective

A New Threat to Immigrants' Health — The Public-Charge Rule

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Unilateral Power

Private Ownership

Social Control

Unilateral Power + Informed Consent

Private Ownership

Social Control

Unilateral Power +
Informed Consent

Private Ownership Public Utility

Social Control

Unilateral Power + Informed Consent

Private Ownership Public Utility

Social Cohesion

Social Control

+

Autonomy

Co-designing + Co-building

Co-designing + Co-building

Bi-directional Accountability

Co-designing + Co-building

Bi-directional Accountability

Shared Public Financing + Ownership + Profits

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Anti-racist Design

Families are the safety in the net.

Table 4. On average, most family resources come from work

	Low			Middle	
	1st decile	2nd decile	3rd decile	4th decile	5th decile
After-tax Income work and retirement	65.8%	73.2%	81.3%	90.8%	96.1%
CalFresh, WIC, and school meals	17.5	6.6	4.6	2.6	1.0
SSI	7.2	7.1	3.8	1.9	1.3
CalWORKs, GA	3.3	2.5	1.6	0.9	0.4
EITC/Child tax credit	3.2	4.8	4.9	2.9	1.2
Rental housing assistance	3.0	5.7	3.8	0.9	0.1

Bohn and Danlelson. Public Policy Institute of California. Income Inequality and the Safety Net in California. May 2016.



People don't simply deserve equity.

They deserve justice.

Equity + Justice aren't in the wallpaper.



They are in the wall.

Ultimately, we are the sector that can build tools to shift resources and transform delivery structures to respond to the devastating intersection of racism, poverty, and poor health outcomes.

