Recognizing and Challenging Bias in HCBS & Disability Policy

Jen Sieminski & Lila Starr

December 8, 2021

Jennifer Sieminski, MSW, LSW
Clinical Implementation Manager

IDD/MH & Background 20 + yrs.

What I do:
Clinical implementation & alignment
Contract consultation
New business dev. (RFP/Proposal work)

Fun Facts:

- I am based in PA (Northeast)
- Maximus employee since 2008
- I have two wild boys (Elias, 11 & Ben, 9)

Lila P.M. Starr
PASRR Program Manager
Older Adult Mental Health Specialist
IA Department of Human Services
Division of Mental Health and Disability
Services

37 years as a Social Worker with
Iowa DHS

What I do:
Proactive management of PASRR
contract for State of Iowa

Iowa's Designee and Secretary of
NASMHPD Older Persons Division

National Association of PASRR
Professionals, Board of Directors,
Secretary

Fun Facts:

- Parent of two Twice Exceptional adult sons (Antonio, 27 & Wesley, 24)
- Third Degree Black Belt in Tae Kwon Do
- Massive Elvis Presley Fan
- Elected November of 2021 to my local School Board!

Objectives

1 ▸ Define othering and name at least 3 types.

2 ▸ Recognize examples of ageism and ableism

3 ▸ Examine CQL study of disability prejudice and HCBS spending

4 ▸ Consider the impact of Medicaid's institutional bias

5 ▸ Identify ways to challenge bias and othering in Medicaid/HCBS

Othering

In human geography, the practice of "othering" means to exclude and displace a person from the social group to the margins of society.

Practices and attitudes that devalue and limit the potential of people across all social dimensions and characteristics in which some individuals or groups are defined and labeled as not fitting in within the norms of a social group.

Ageism

Stereotyping and/or discrimination based on a person's age

Robert Neil Butler
Prejudicial attitudes
towards older people,
advanced age, and
the aging process

Dismissive contemptuous
attitudes

Ashton Applewhite

Prejudice against our
future selves

The last "acceptable"
form of prejudice

Ableism

- Beliefs or practices that devalue, discriminate and/or limit the potential of persons with disabilities through assignment of an inferior status or assumption that they need to be "fixed", or something is wrong with them- catering toward individuals without disabilities as the "normative standard."

- A system of superiority and discrimination that provides or denies resources, agency, and dignity based on one's abilities (mental/intellectual, emotional, and/or physical.)

Ageism   Racism   Ableism

Colonialism   **ISMs**   Heterosexism

Classism   Antisemitism

Lookism & Sizeism   Sexism

Othering

Types of Othering

- Internalized
- Interpersonal
- Institutional
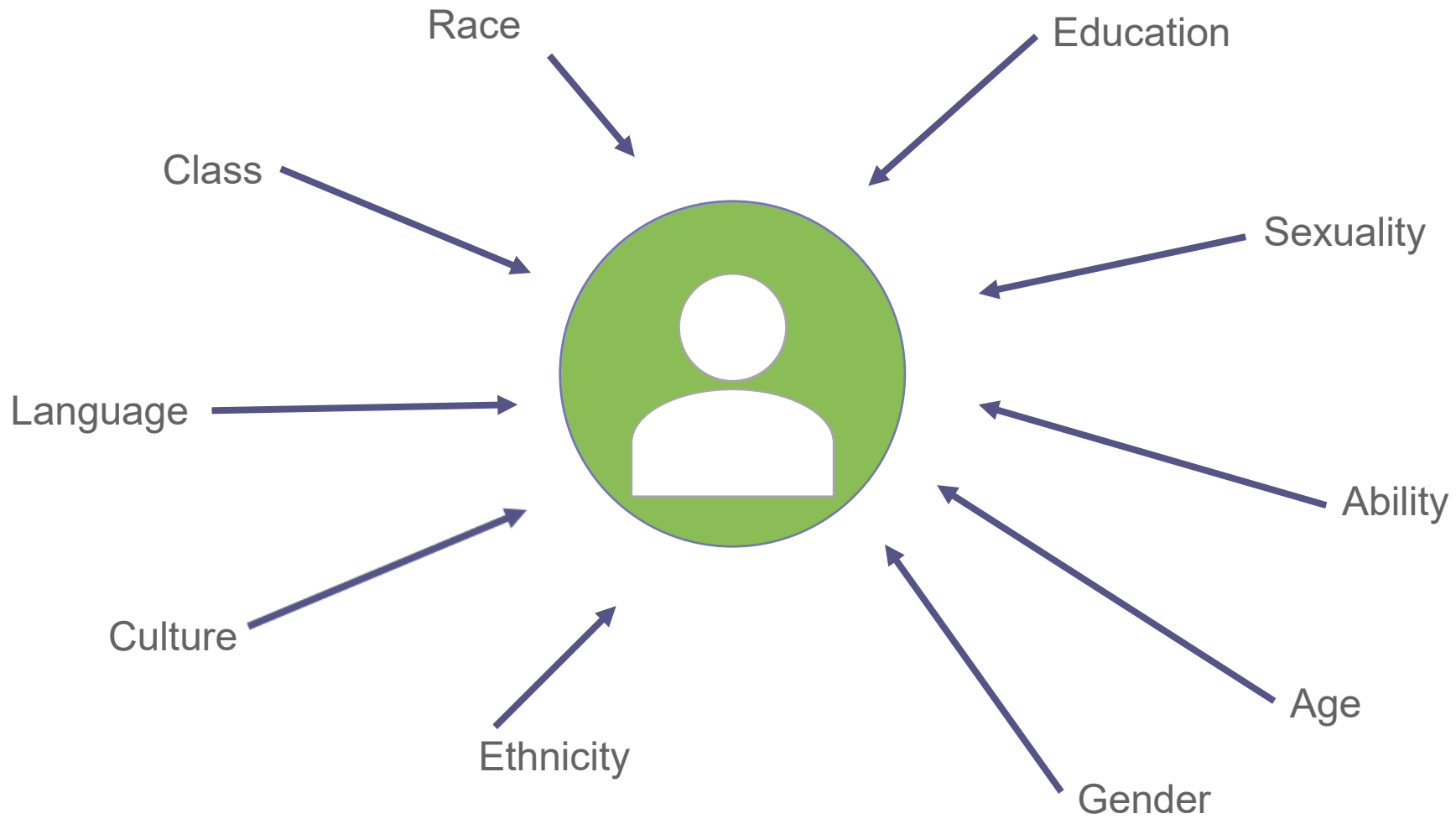- Systemic/Structural

Suppression Strategies

- Invisibility
- Stereotyping
- Assumption of inferiority
- Patronizing
- Tokenizing/Exceptionalizing
- Contempt/Physical revulsion
- Naming segregation as natural
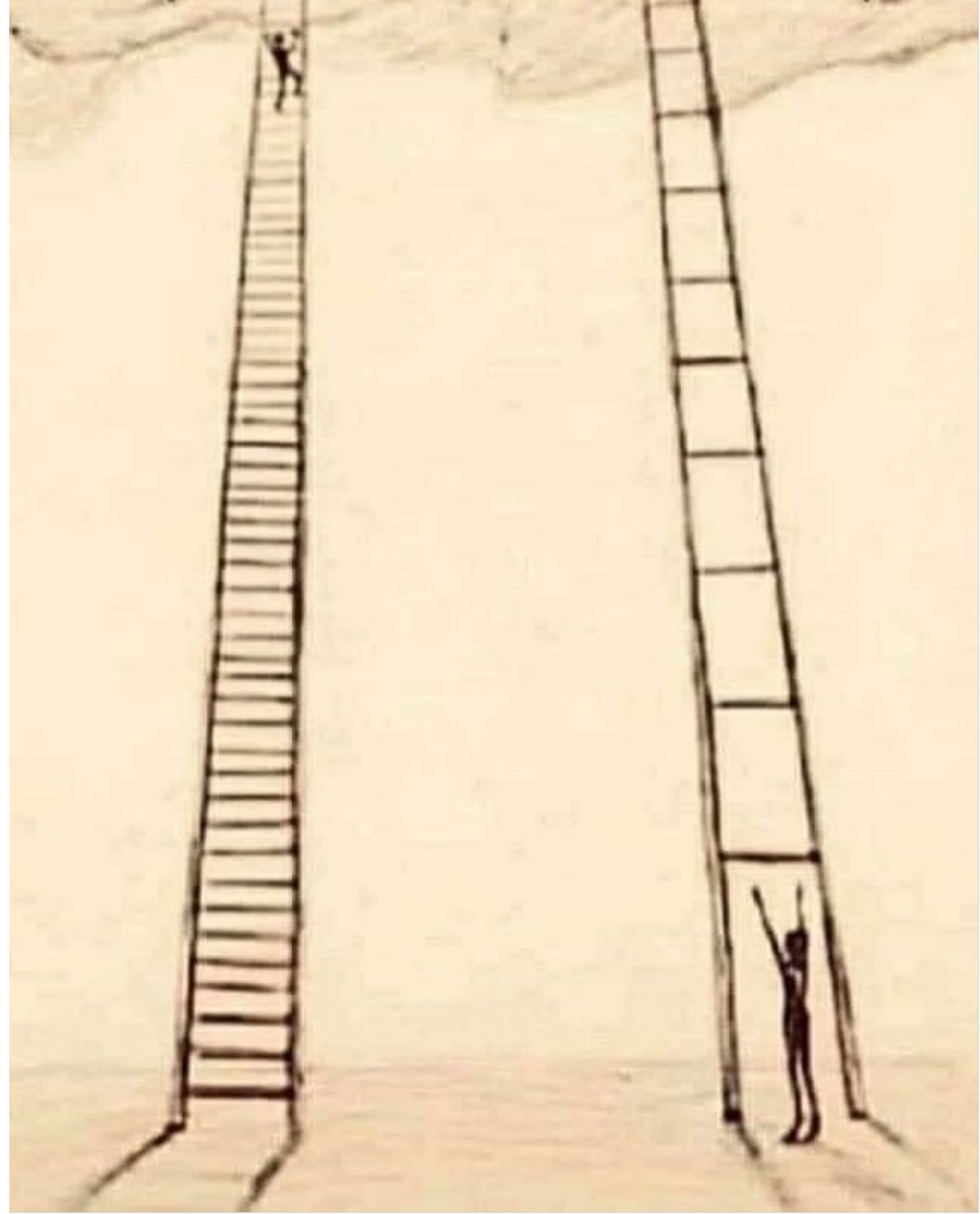- Assuming you'd rather be someone else

Learned Responses

- Passing/Hiding
- Accepting tokenism
- Internalizing attitudes
- Self-segregation/Avoidance
- Criticizing other groups or one's own
- Code switching

Status Quo Sustainers

Intersectionality

Race

Education

Class

Sexuality

Language

Ability

Culture

Age

Ethnicity
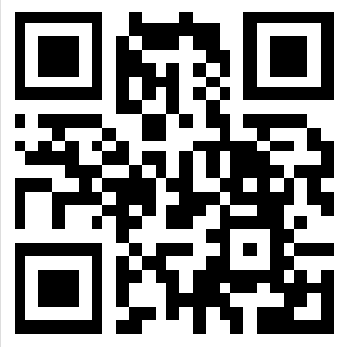
Gender

Reducing Disparities & Advancing Equity

The Relationship Between Disability Prejudice and Medicaid Home and Community Based Spending

Carli Friedman, PhD (The Council on Quality and Leadership) & Laura VanPuymbrouck, PhD (Rush University)

Disability and Health Journal (2019) Jul 12(3); 359-365

Does Disability Prejudice Impact State HCBS Spending?

- **Project Implicit:** Disability Attitudes Implicit Association Test (DA-IAT)
- **FY 2015 LTSS expenditures**
- Statistical Package for the Social Sciences (23) **SPSS®**
- < 325,000 people (**Avg. 6,400 per state**)

- The higher the state's disability prejudice, the less LTSS spending was directed to HCBS (regardless of state size or wealth)

- Bias and prejudice in disability policy decision-making are obstacles to equality and full participation in society.
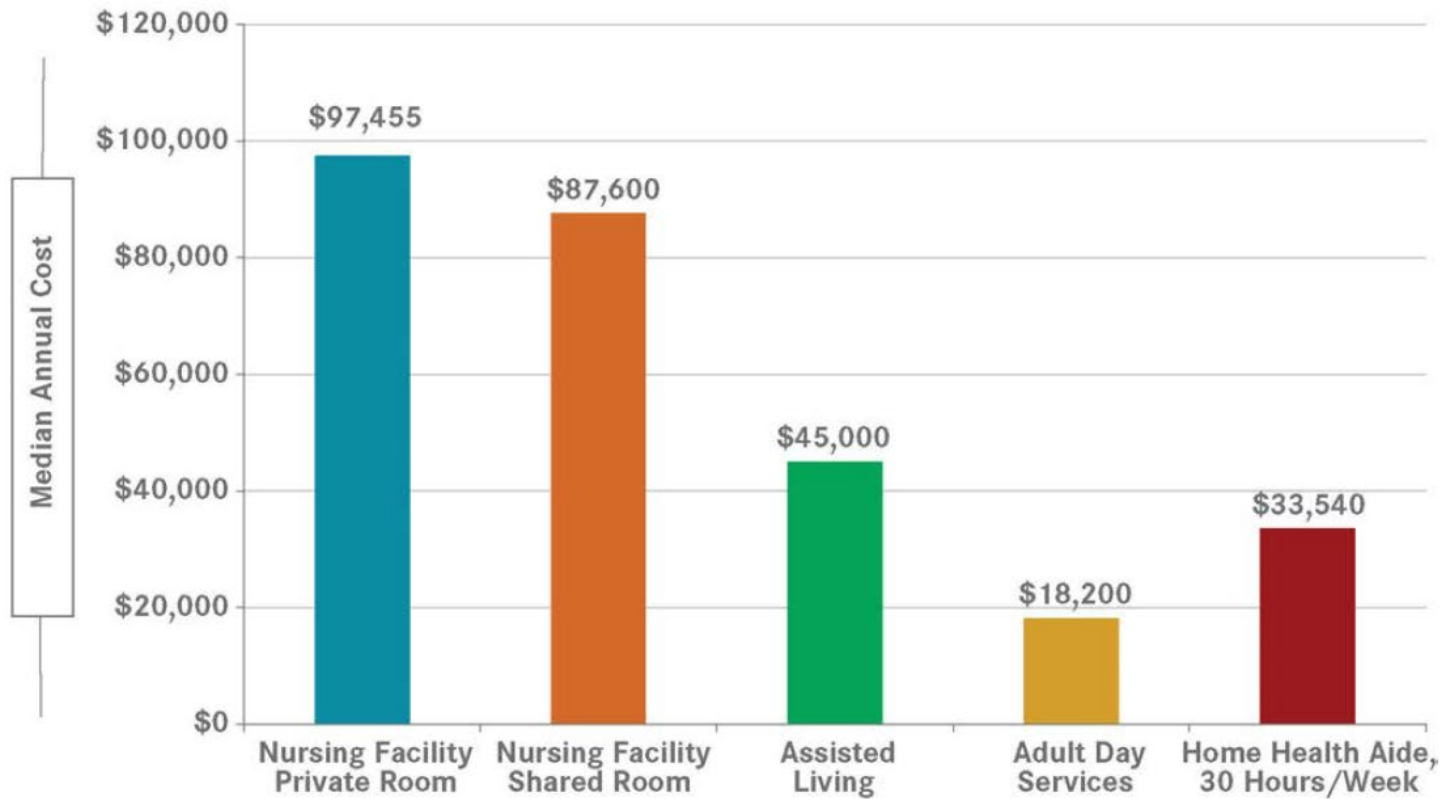
Study Conclusion

Medicaid's Institutional Bias

Deinstitutionalization

Transinstitutionalization

AARP: Cost Comparison

Annualized Private Pay Cost, United States, 2017
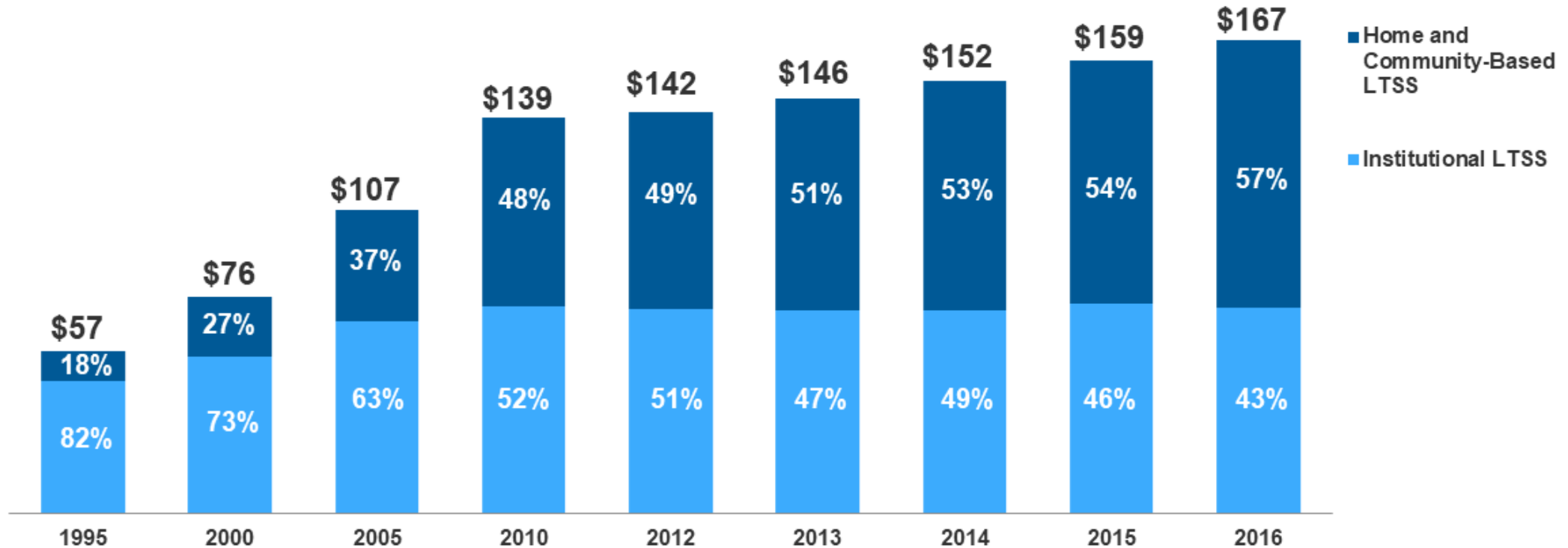
Median Annual Cost

- Nursing Facility Private Room: $97,455
- Nursing Facility Shared Room: $87,600
- Assisted Living: $45,000
- Adult Day Services: $18,200
- Home Health Aide, 30 Hours/Week: $33,540

Who can afford LTSS?

Medicaid long-term services and supports spending, by institutional vs. community setting.

Annual Medicaid LTSS Spending, in billions:

Legend:
- Home and Community-Based LTSS (dark blue)
- Institutional LTSS (light blue)

Year	Total	Home and Community-Based LTSS	Institutional LTSS
1995	$57	18%	82%
2000	$76	27%	73%
2005	$107	37%	63%
2010	$139	48%	52%
2012	$142	49%	51%
2013	$146	51%	47%
2014	$152	53%	49%
2015	$159	54%	46%
2016	$167	57%	43%

SOURCE: Steve Eiken, Kate Sredl, Brian Burwell, and Angie Amos, Medicaid Expenditures for Long-Term Services and Supports in FY 2016 (IBM Watson Health, May, 2018), https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpenditures2016.pdf.

KFF
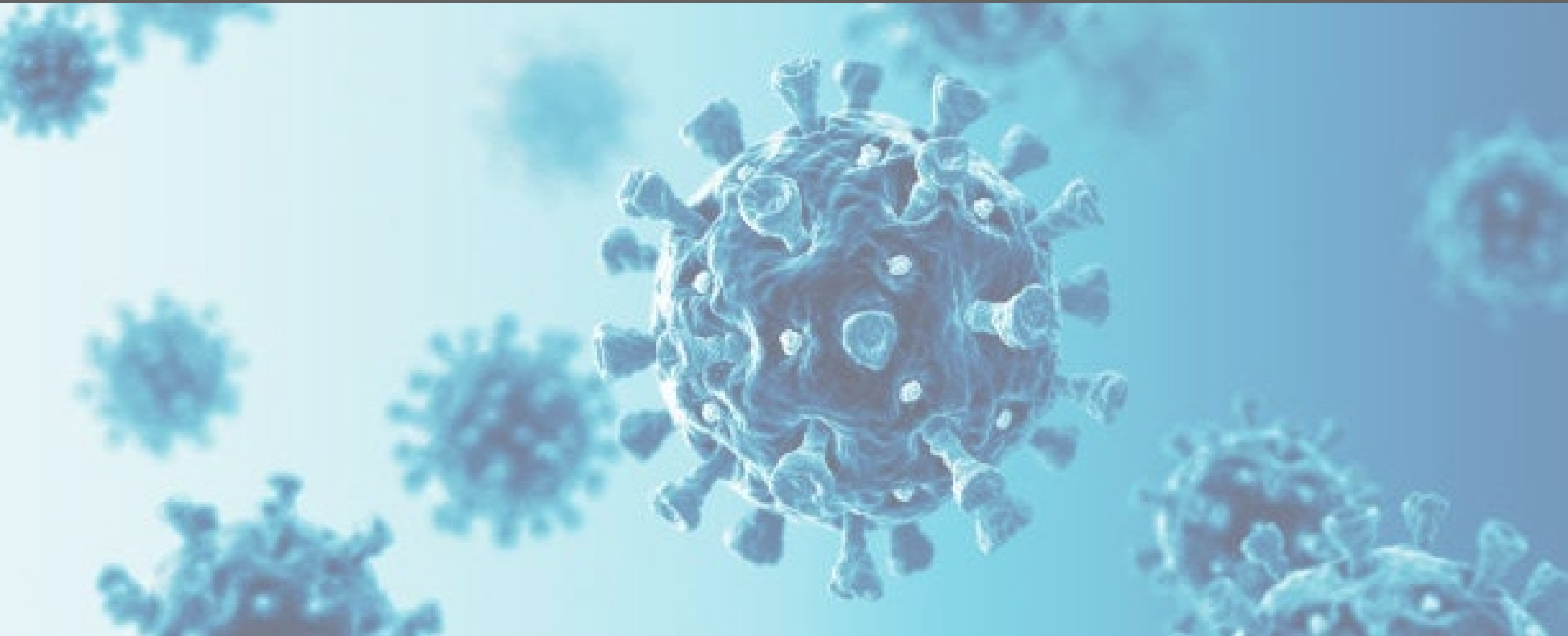HENRY J KAISER FAMILY FOUNDATION

HCBS Challenges

- Funding/infrastructure

- Available and/or qualified caregivers (burnout/turnover)

- Rural/Remote access

- Lack of portability

- Eligibility varies (financial/functional)

- Service options vary

- Spending limits-capping/waitlists
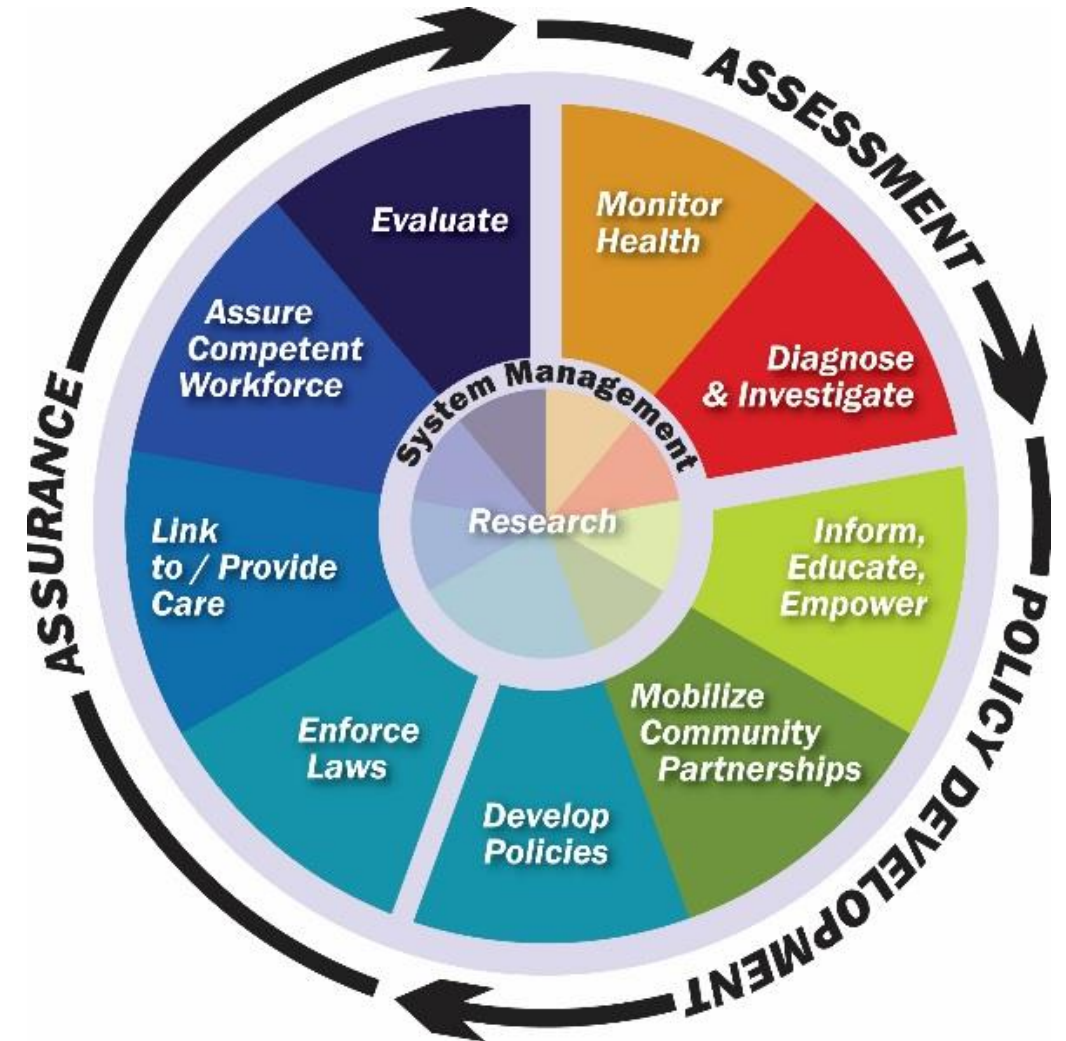
- Institutional LTSS is easier to access

COVID

How do we effect system change?

Address Social Determinants of Health (SDOH)

CQL Study Recommendations

- Increase funding toward HCBS/ Enhance HCBS (+ expand coverage)

- Eliminate states obligations to pay for institutional care

- Proactive deinstitutionalization efforts (vs reactive to Olmstead litigation)

- Include people with disabilities/other marginalized groups into leadership roles which oversee and contribute to policy and system decisions.

- Reduce disability prejudice in the general population

Center for Health Care Strategies (CHCS)

Develop
LTSS System Infrastructure to Promote Greater Access to HCBS

Invest
in programs and Services that Help Nursing Facility Residents Return to their Communities

Expand
access to HCBS for "Pre-Medicaid" Individuals to Prevent or Delay Nursing Facility Utilization

Improved
HCBS reporting

Stabilized
Nursing Facility (NF) Spending

Sustained
growth in Section 1915 (c) waivers and new HCBS programs

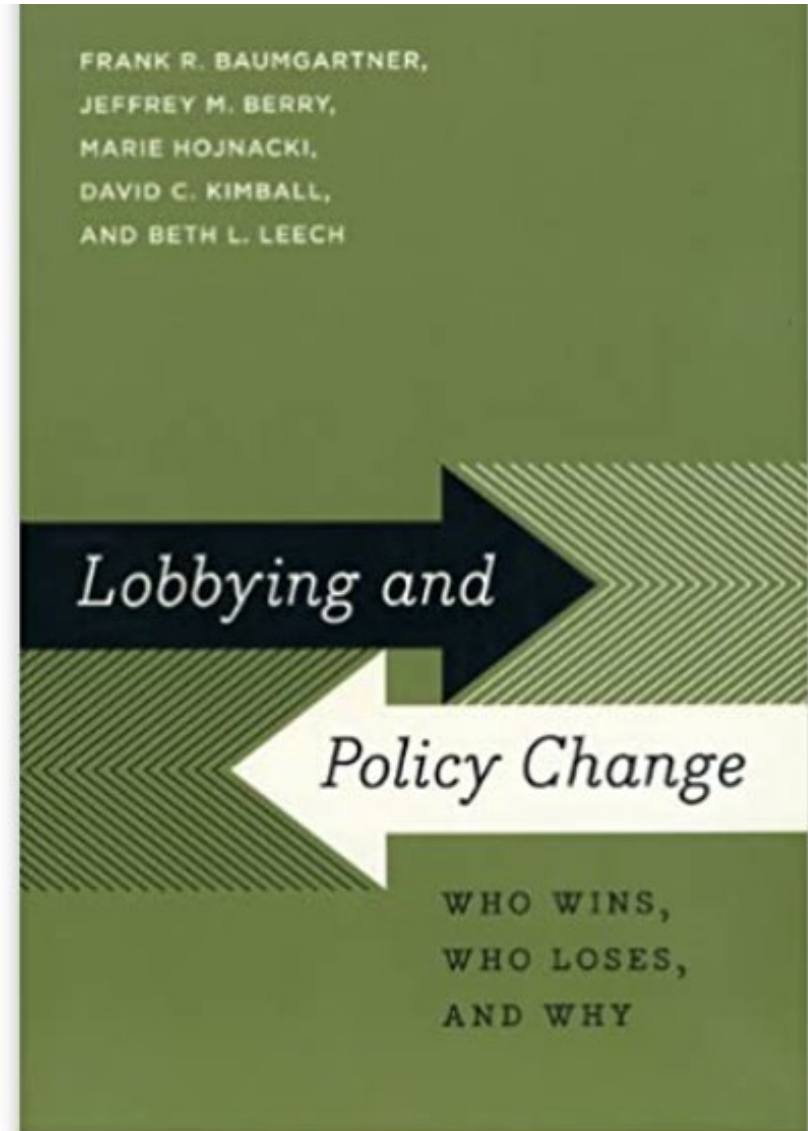# Examining LTSS Rebalancing (MACPAC + CHCS & RTI International)

- Money Follows the Person (MFP) (Permanency)
- Change federal statutes
- Affordable accessible housing
- Examination of PHE flexibilities
- Public awareness and understanding of HCBS options
- Improve communication around care transitions
- Technical Assistance

The Power of PASRR: Furthering Olmstead

The Source of Power? People!

- Resources explain less than 5% of the difference between successful and unsuccessful efforts

- Those with more $ and members (only) won policy changes in Congress about ½ the time.

- Must overcome the bias in favor of the status quo

FRANK R. BAUMGARTNER,
JEFFREY M. BERRY,
MARIE HOJNACKI,
DAVID C. KIMBALL,
AND BETH L. LEECH

Lobbying and Policy Change

WHO WINS,
WHO LOSES,
AND WHY

Advocacy

- Follow advocacy/special interest groups
- Maintain and support professional ethics
- Support institutions of public character
- Contact legislators

Resisting & Creating Change

- Include ageism/ableism in DEI initiatives.
- Allyship
- "Speak up, speak out"
- Recognize and evaluate your own bias
- Make small talk and eye contact
- Words Matter
- Claim your identity and stand out

Real change in society must start from individual initiative

~ Dalai Lama

Resources

- "Othering", *The New Fontana Dictionary of Modern Thought*, Third Edition (1999), p. 620.

- *Mountz, Allison. "The Other". Key Concepts in Human Geography: 328.*

- J. Powell & S. Menendian: Othering & Belonging: Expanding the Circle of Human Concern (Issue 1: Summer 2016): The Problem of Othering: Towards Inclusiveness and Belonging: https://otheringandbelonging.org/the-problem-of-othering/

- Center for Disability Rights: Ableism (L.Smith): https://www.cdrnys.org/blog/uncategorized/ableism/

- US Department of Labor Employment Standards Administrative Office of Federal Contract Compliance; National Conference for Community and Justice: Ableism: https://www.nccj.org/ableism

- Ashton Applewhite: www.ThisChairRocks.com + https://oldschool.info/

- Sally Ann Eck: Metta Center for Nonviolence: Nonviolence Radio: Interrupting Oppression with Strategy and Heart (Podcast: Oct 15, 2019): https://wagingnonviolence.org/metta/podcast/interrupting-oppression-with-strategy-and-heart/ and http://interrupting-oppression.tumblr.com/post/102351553722/list-of-isms

Resources

- https://everydayfeminism.com/2013/07/intentions-dont-really-matter/#:~:text=In%20essence%2C%20the%20%E2%80%9Cintent%E2%80%9D,about%20%E2%80%9Cwhat%20they%20did.%E2%80%9D

- "4 Theories of Discrimination." National Research Council. 2004. *Measuring Racial Discrimination*. Washington, DC: The National Academies Press. doi: 10.17226/10887

- The Old Women's Project: How to Recognize any "Ism" When We See it: http://www.oldwomensproject.org/ism.htm

- Jo Kort PhD (6/25/2019): https://www.psychologytoday.com/us/blog/understanding-the-erotic-code/201906/understanding-intersectional-identities

- Justice in Aging: Strategic Initiatives: Advancing Equity: Framework (2021): https://justiceinaging.org/wp-content/uploads/2021/03/Advancing-Equity-Framework.pdf

- Friedman, C., & VanPuymbrouck, L. (2019). The relationship between disability prejudice and home and community-based services spending. *Disability and Health Journal*, Jul;12(3):359-365: https://www.researchgate.net/publication/331209882_The_Relationship_between_Disability_Prejudice_and_Medicaid_Home_and_Community-Based_Services_Spending

Resources

- A. Houser, W. Fox-Grage, K. Ujvari (April 2018) AARP: Across the States: Profiles of Long-Term Services and Supports: https://www.aarp.org/content/dam/aarp/ppi/2018/08/across-the-states-profiles-of-long-term-services-and-supports-full-report.pdf

- Kaiser Family Foundation (KFF): (8/31/2015): Long Term Care in the US: A Timeline: https://www.kff.org/medicaid/timeline/long-term-care-in-the-united-states-a-timeline/

- MACPAC, RTI & CHCS (April 2021): Examining the Potential for Additional Rebalancing of Long-Term Services and Supports: https://www.macpac.gov/wp-content/uploads/2021/05/Examining-the-Potential-for-Additional-Rebalancing-of-Long-Term-Services-and-Supports.pdf

- Mathematica Policy Research, Inc., Centers for Medicare & Medicaid Services (CMS),& Truven Health Analytics (6/3/2016): Improving the Balance: The Evolution of Medicaid Expenditures for Long-Term Services and Supports (LTSS), FY 1981-2014 https://www.medicaid.gov/sites/default/files/2019-12/evolution-ltss-expenditures.pdf

- Center for Disease Control (CDC):Social Determinants of Health (9/30/2021): https://www.cdc.gov/socialdeterminants/ and https://www.cdc.gov/publichealthgateway/publichealthservices/pdf/ten_essential_services_and_sdoh.pdf

- Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved [date graphic was accessed, from https://health.gov/healthypeople/objectives-and-data/social-determinants-health

Resources

- M. Sowers, H. Claypool , & M. Musumeci (3/11/2016): Streamlining Medicaid Home and Community-Based Services: Key Policy Questions: https://www.kff.org/report-section/streamlining-medicaid-home-and-community-based-services-key-policy-questions-issue-brief/

- Mathematica (Murray, C., Tourtellotte, A., Lipson, D., & Wysocki, A.) 1/7/2021. Medicaid Long Term Services and Supports Annual Expenditures Report. Federal Fiscal Years 2017 and 2018: https://www.mathematica.org/publications/medicaid-ltss-annual-expenditures-report-federal-fiscal-years-2017-and-2018

- Manatt Health Strategies & Center for Health Care Strategies (S. Anthony, A. Traub, S. Lewis, C. Mann, A. Kruse, M. Herman Soper): March 2019: "Strengthening Medicaid Long-Term m Services and Supports in an Evolving Policy Environment: A Toolkit for States: https://www.chcs.org/resource/strengthening-medicaid-long-term-services-supports-evolving-policy-environment-toolkit-states/

- H. Han: When Does Activism Become Powerful: NY Times (12/16/2019): https://www.nytimes.com/2019/12/16/opinion/activism-power-victories.html%20;%20(12/16/19-Hahrie%20Han)

- F.R.Baumgartner, J.M.Berry, M. Hojnacki, D.Kimball & B.L.Leech (2010): Lobbying and Policy Change: Who Wins, Who Loses and Why? Bibliovault OAI Repository, the University of Chicago Press 10.7208/Chicago/9780226039466.001.0001