Recognizing and Challenging Bias in HCBS & Disability Policy

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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

Ashton Applewhite
Prejudice against our future selves

The last “acceptable” form of prejudice

Dismissive contemptuous attitudes
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  Heterosexism

Classism  Antisemitism

Lookism & Sizeism  Sexism

Othering
Types of Othering

- Internalized
- Interpersonal
- Institutional
- Systemic/Structural
Status Quo Sustainers

**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
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.
Medicaid’s Institutional Bias
Deinstitutionalization

Transinstitutionalization
AARP: Cost Comparison

Annualized Private Pay Cost, United States, 2017

Who can afford LTSS?
Medicaid long-term services and supports spending, by institutional vs. community setting.

Annual Medicaid LTSS Spending, in billions:

<table>
<thead>
<tr>
<th>Year</th>
<th>Home and Community-Based LTSS</th>
<th>Institutional LTSS</th>
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</thead>
<tbody>
<tr>
<td>1995</td>
<td>$57 (18%)</td>
<td>$75 (82%)</td>
</tr>
<tr>
<td>2000</td>
<td>$76 (27%)</td>
<td>$73 (73%)</td>
</tr>
<tr>
<td>2005</td>
<td>$107 (37%)</td>
<td>$63 (63%)</td>
</tr>
<tr>
<td>2010</td>
<td>$139 (48%)</td>
<td>$52 (52%)</td>
</tr>
<tr>
<td>2012</td>
<td>$142 (49%)</td>
<td>$51 (51%)</td>
</tr>
<tr>
<td>2013</td>
<td>$146 (51%)</td>
<td>$47 (49%)</td>
</tr>
<tr>
<td>2014</td>
<td>$152 (53%)</td>
<td>$49 (47%)</td>
</tr>
<tr>
<td>2015</td>
<td>$159 (54%)</td>
<td>$46 (46%)</td>
</tr>
<tr>
<td>2016</td>
<td>$167 (57%)</td>
<td>$43 (43%)</td>
</tr>
</tbody>
</table>

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.
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

- Center for Disability Rights: Ableism (L. Smith): [https://www.cdrnys.org/blog/uncategorized/ableism/](https://www.cdrnys.org/blog/uncategorized/ableism/)
- Ashton Applewhite: [www.ThisChairRocks.com](http://www.ThisChairRocks.com) + [https://oldschool.info/](https://oldschool.info/)
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


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


Resources


