SHAME & BLAME

How Stigma Impacts Parents Seeking Help for Young Children with Mental, Behavioral and Developmental Challenges

Mai Le, MPH
Definitions

Mental, behavioral and developmental disorders (MBDD)

Conditions impacting a child’s physical, mental, or social-emotional development, including anxiety, depression, ADHD, Tourette syndrome, autism spectrum disorder, learning disability, intellectual disability, developmental delay, or speech issues.

Stigma

A mark of disgrace that links a person with an undesirable trait; a means to maintain social, economic or political power over members of a social group (Link & Phelan, 2001)

“Shaming is one of the deepest tools of imperialist, white supremacist, capitalist patriarchy because shame produces trauma and trauma often produces paralysis.”

bell hooks
**Purpose**

- Describe how stigma impacts parents of children with MBDD
- Clarify stigma as a public health and social justice issue
- Inform how family-serving institutions can better address stigma

17% children ages 2-8 have at least one MBDD

(2016 National Survey of Children’s Health)

Less than 13% children with identified mental health challenges receive treatment

(Weitzman & Wegner, 2015)
What's the harm in waiting?

Impaired learning and growth
Challenges in school
Higher healthcare costs
Increased likelihood of involvement in criminal justice system
Heightened parent stress and mental health risk

(Glascoe, 2015)

INCREASED RISK

Low income  Adverse childhood experiences  Lack of social support  Poor parent health

(Cree et al., 2018; Weitzman & Wegner, 2015)
### Seeing Stigma

**In Children's Mental Health**

#### Contexts ("Who")
- Public | Institutional | Self

#### Dimensions ("What")
- Stereotypes | Devaluation | Discrimination

#### Targets ("To whom")
- Child | Family | Service

(Mukolo et al., 2010)

### Examples

**Stigma in Action**

**Public Discrimination of Services**
- Local petition to block a mental health clinic from being built nearby

**Institutional Devaluation of Child**
- Preschool teacher views children with MBDD as disruptive and problematic

**Family Self-Stigma**
- Mother of child with MBDD sees herself as a failure
IMPACT

Parents experience internalized stigma
Can take the form of self-blame ("I caused these problems") or bad parent belief ("I should be able to fix this")
(Eaton et al., 2019)

Public stigma towards parents and children is real
Parents AND children more likely to be blamed for mental illnesses compared to physical illnesses.
(Mukolo & Heflinger, 2011)

Institutional stigma towards parents persists
Resources and training for MBDDs are limited. Physician interactions with parents can be disempowering.
(Butler et al., 2015)

IMPACT

Stigma impacts parental help-seeking behavior
Lower levels of internalized stigma increase likelihood of seeking support
(Dempster et al., 2013)

Stigma impacts parent-child relationships
Higher internalized stigma associated with parents acting more negatively towards child
(Mikami et al., 2015)

Stigma experiences differ based on social power
Moms receive more public stigma than dads. Black and Latino parents worry more about stigma than white parents.
(Dempster et al., 2013; Chavira et al., 2017; Francis, 2012)
A new public health approach

TRADITIONAL PUBLIC HEALTH
Educating patients about diseases and disease management; raising public awareness to increase social acceptance

+ 

SOCIAL JUSTICE LENS
Increasing political power of most marginalized; addressing structural discrimination, recognizing intersectionality

Strategies for family-serving institutions

AIMED AT THE PUBLIC

• Depict parents as active champions for their children

• Promote accurate and appropriate media coverage of MBDDs, and hold news media accountable for journalistic practices

• Educate the public on social determinants of health and how communities can support positive child development through policy change (e.g. universal preschool, affordable housing)
Strategies for family-serving institutions

AIMED AT INSTITUTIONS

- Implement routine, universal mental, behavioral, and developmental screening in primary care settings
- Support workforce opportunities for parents (e.g., family navigators, peer educators) to elevate their voices within institutions
- Require continuing education for providers on childhood MBDDs to reduce the knowledge and confidence gap

AIMED AT PARENTS

- Validate parental concerns and challenges related to stigma
- Frame discussions about child psychosocial risks within a social context and offer assistance with basic needs
- Facilitate connections between parents and create opportunities to foster a proud, visible group identity (e.g., special needs play group or parent advisory council)
Conclusion

Stigma is not inevitable

Parents of children with MBDDs experience stigma in multiple ways, from multiple sources

Stigma in harmful to parents and children

Stigma is a public health AND a social justice issue

Family-serving institutions have a key role in eliminating stigma

Acknowledgements

Dr. Marty Martinson & Dr. Juliana van Olphen
SFSU FACULTY ADVISORS

Narges Dillon, Myra Cruz & colleagues at First 5 San Mateo County
SUBJECT MATTER EXPERTS
First 5 San Mateo Commission Meeting
July 22, 2019

2019-2020 State Budget
Overview of 2019-20 State Budget

- 2019-20 Budget: $214 billion
- CA Rainy Day Fund: $16.5 billion
- “California For All” budget
- Governor promoted a “Parent’s Agenda”

New funding across Family Resiliency, Comprehensive Health and Development, and Quality Early Learning

Family Resiliency

Context: How to help families that face affordability challenges daily?

- CA Earned Income Tax Credit (CalEITC) more than doubled – will provide one million more economically distressed household with financial support ($1 B)
- CalWORKs Grant Increases ($331 M)
- Child Saving Accounts ($50 M)
- Paid Family Leave (increase from 6 to 8 weeks)
- Home Visiting Expansion:
  - CalWORKs Home Visiting Initiative (increase to 18,500 cases)
  - CA Home Visiting Program ($45 M)
  - Black Infant Health ($11.9 M)
Comprehensive Health & Development

- **Developmental Screening**: $53.9 M to increase reimbursement for Medi-Cal beneficiaries (part of the Value-Based payments reimbursements)
- **Trauma Screening**: $40.8 M for trauma screening of Medi-Cal beneficiaries to help inform how providers can provide optimal care for patients
- **Trauma Training**: $60 M over 3 years around training to provide trauma-informed care.

Awaiting details from DHCS around reimbursement rates, trauma screening tools, trauma training content. We believe implementation for reimbursement rates will be January 1, 2020.

Role for Help Me Grow in implementation, training, and connections to services.

Quality Early Learning

**Access:**
- Down Payment towards Universal PreK: 10,000 CSPP spaces, staring April 1, 2020 (ongoing $124 M). Expanded eligibility
- Child Care Expansion: 9,400 Alternative Payment vouchers ($80 M from Prop 64); 3,000 General Child Care spaces ($50 M). Dedicates 75% of ongoing Prop 64 cannabis revenues to child care.

**Facilities**
- Full-day Kindergarten facilities ($300 M)
- Early Learning and Care Infrastructure Grant Program ($245 M)
- Child Care Facilities Revolving Loan Fund ($18 M, implementation of AB 452, Mullin).
Quality Early Learning -- Continued

**Workforce**
- Professional development and education supports for child care providers (one-time $195 M over 4 years)

**Master Plan on Early Care & Education**
Report due by October 1, 2020. Budget dedicates $5 million to study the following goals:
1. A fiscal framework to expand early learning and care in the state;
2. Early learning and care facility needs statewide;
3. Needs for services by families eligible for subsidies;
4. A quality improvement plan to support all types of providers; and
5. Steps necessary to provide Universal Preschool for all three and four years old in CA.

Dr. Alinea Stevens, First 5 Placer Commissioner, Medical Director at Chapa de Indian Health Clinic serving Placer and Nevada Counties
May 28, 2019

California State Assembly Member and Budget Chair Phil Ting
455 Golden Gate Avenue, Suite 14600
San Francisco, CA 94102

California State Senator and Budget Chair Holly Mitchell
Wallis Annenberg Building
700 State Drive, Suite 113
Los Angeles, CA 90037

Re: Early Childhood Investments in FY 19/20 State Budget

Dear Assembly Member Ting and Senator Mitchell,

On behalf of the San Mateo County Board of Supervisors, First 5 San Mateo County and the San Mateo County Office of Education, we are writing to express our strong support for the proposed FY 2019/20 May Revise Budget. In particular, we applaud the bold and comprehensive package of early childhood investments that incorporates strategies from the End Child Poverty Plan created by California’s Lifting Children and Families Out of Poverty Task Force. We fully support the portfolio of research-based, whole-child, two-generation budget proposals that will provide significant and immediate relief for our state’s most vulnerable children and families, while simultaneously advancing policies and systems changes that will

Thank You!

Margot Grant Gould,
Policy Director
First 5 Association of CA
margot@first5association.org
Why do we care about the Census?
Survey Content

- Willingness to perform Census outreach and education activities
- Barriers and concerns
- Resources that would be helpful
- Compelling arguments for participating in the Census
- Respondent characteristics
  - Service sector
  - Role in organization
  - Service setting
  - Types of clients

Survey Respondents

<table>
<thead>
<tr>
<th>Service Sector</th>
<th>N</th>
<th>%</th>
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<tbody>
<tr>
<td>Family Support</td>
<td>39</td>
<td>36%</td>
</tr>
<tr>
<td>Early Learning</td>
<td>49</td>
<td>46%</td>
</tr>
<tr>
<td>Health</td>
<td>13</td>
<td>12%</td>
</tr>
<tr>
<td>Policy &amp; Advocacy</td>
<td>6</td>
<td>6%</td>
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<table>
<thead>
<tr>
<th>Role in Organization</th>
<th>N</th>
<th>%</th>
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<tbody>
<tr>
<td>Executive Management</td>
<td>22</td>
<td>21%</td>
</tr>
<tr>
<td>Program Manager/Supervisor</td>
<td>34</td>
<td>32%</td>
</tr>
<tr>
<td>Line Staff</td>
<td>45</td>
<td>42%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>6%</td>
</tr>
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Overall Results

Generalized Findings

• Overall average willingness to participate is 68 on a scale of 0-100
• More willingness to provide passive education, rather than active outreach
• Most commonly cited barriers/concerns
  ▪ Lack of knowledge
  ▪ Not enough time/resources
• Resources identified as most helpful
  ▪ Legal advice from experts
  ▪ Information, resources, and funding
• Most compelling reasons to participate
  ▪ Funding implications
  ▪ Loss of representation in Congress
• High Variability
## Resources Supporting Outreach & Education

<table>
<thead>
<tr>
<th>Service</th>
<th>Not helpful</th>
<th>A little bit helpful</th>
<th>Fairly helpful</th>
<th>Very helpful</th>
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<tbody>
<tr>
<td>Legal advice from experts</td>
<td>4%</td>
<td>17%</td>
<td>33%</td>
<td>46%</td>
</tr>
<tr>
<td>Access to information/resources</td>
<td>3%</td>
<td>19%</td>
<td>36%</td>
<td>43%</td>
</tr>
<tr>
<td>Additional funding</td>
<td>11%</td>
<td>12%</td>
<td>23%</td>
<td>54%</td>
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<tr>
<td>Factual training</td>
<td>8%</td>
<td>22%</td>
<td>32%</td>
<td>39%</td>
</tr>
<tr>
<td>Regular updates</td>
<td>13%</td>
<td>22%</td>
<td>34%</td>
<td>32%</td>
</tr>
<tr>
<td>Communications training</td>
<td>15%</td>
<td>25%</td>
<td>28%</td>
<td>32%</td>
</tr>
<tr>
<td>Ongoing technical assistance</td>
<td>19%</td>
<td>31%</td>
<td>29%</td>
<td>22%</td>
</tr>
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</table>

## Arguments in Favor of Completing the Census

<table>
<thead>
<tr>
<th>Argument</th>
<th>Not at all compelling</th>
<th>A little bit compelling</th>
<th>Fairly compelling</th>
<th>Very compelling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of funding</td>
<td>4%</td>
<td>21%</td>
<td>73%</td>
<td></td>
</tr>
<tr>
<td>Loss of congressional representation</td>
<td>3%</td>
<td>13%</td>
<td>25%</td>
<td>59%</td>
</tr>
<tr>
<td>All people matter</td>
<td>3%</td>
<td>17%</td>
<td>29%</td>
<td>51%</td>
</tr>
<tr>
<td>Secure and confidential</td>
<td>4%</td>
<td>24%</td>
<td>25%</td>
<td>47%</td>
</tr>
<tr>
<td>Civic Duty</td>
<td>13%</td>
<td>28%</td>
<td>35%</td>
<td>25%</td>
</tr>
<tr>
<td>Avoid in-person contact by enumerator</td>
<td>25%</td>
<td>21%</td>
<td>34%</td>
<td>20%</td>
</tr>
<tr>
<td>Required by law; fines/jail time</td>
<td>51%</td>
<td>21%</td>
<td>15%</td>
<td>13%</td>
</tr>
</tbody>
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Findings by Sector

Average Willingness to Participate

- Early Learning (n=47): Min: 6, Max: 100
- Family Support (n=35): Min: 23, Max: 100
- Health (n=13): Min: 6, Max: 87
Barriers and Concerns

Findings by Role
Average Willingness by Role

Management vs. Line Staff
Key Takeaways

- High variability by sector, role in organization, and type of outreach activity
- Desire for legal advice, factual information & resources, funding
- Health Sector significantly less willing to engage
- Greater hesitation among line staff, particularly around more active outreach
- Substantial concern about damaging relationships with clients and putting clients at risk

Questions, Comments, and Next Steps