Transgender Care and Transitioning:
Implications of New Health Insurance Coverage Guidelines and Research Findings

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Introductions

• Health Management Associates (HMA)

• HMA Community Strategies

• Presenters
  – John O’Connor
  – Marci Eads, PhD
  – Heidi Robbins Brown, JD
  – Karen Brodsky, MS
Agenda

• Background and Context
• Proposed Rule 1557
• Research on Experiences of Transgender Individuals with Care and Coverage
• Compliance, Enforcement and Implications for Health Plans
• Q&A
Background and Context

– A history of discrimination spanning issues of violence and personal safety, employment, housing, public accommodation broadly and, yes, health care and more

– Growing awareness of and social equality for transgender people

– A strengthening advocacy community

– A post-ACA environment
Current Landscape

Shifting legal and business landscape:

• State level action
• Medicare exclusion lifted
• EEOC vs. Deluxe Financial Services
• Introduction of proposed HHS Rule to implement section 1557 of the ACA
• Trend in larger employer-sponsored health plans
What Does 1557 Do?

- Prohibits discrimination based on race, color, national origin, age, disability and sex
- Explains consumer rights and provides clarity to covered entities about their obligations
- Coordinates existing laws, policies and regulations in support of policy enforcement
- Extends the definition of sex discrimination to include the basis of gender identity
- Enhances language assistance for people with limited English proficiency
- Requires effective communication for people with disabilities
The rule will affect...

- any provider or insurer receiving federal financial assistance from HHS (including Medicare, Medicaid, federal and state market places)
- any health program administered by HHS
- all ACA marketplace participants
- **AND all plans offered by issuers who participate in those marketplaces**

Therefore, the rule will affect...
most health insurers, hospitals, nursing homes, physicians
HHS Examples of Prohibited Discriminatory Policies and Practices

• Individuals cannot be denied health care or health coverage based on their sex, including their gender identity.

• Individuals must be treated consistent with their gender identity, including in access to facilities.
HHS Examples (continued)

- Sex-specific health care cannot be denied or limited just because the person seeking such services identifies as belonging to another gender.
- Explicit categorical exclusions in coverage for all health care services related to gender transition are facially discriminatory.
- Other exclusions for gender transition care will be evaluated on a case-by-case basis.
Open Questions

• Sexual orientation not specifically addressed

• Requested feedback on:
  – legal sustainability in the face of likely court challenges
  – religious exemption
  – sex-based distinctions
  – individuals’ experiences with discrimination
  – covered entities’ experiences with compliance
Practical Implications

• Clinical guidelines and benefit design
• Determining medical necessity
• Cultural competency - Staff knowledge, resources, and bias
• Provider network adequacy
• Technical capacity for handling gender markers, preferred names, billing codes for gender-specific treatments
• Baseline what is required by law vs. emerging as a leader
• Cost analysis
Do Health Plans Have a Blind Spot?

The new rule lays out policies that are dramatically in conflict with prevalent practices
Unmet Needs: A National Survey

• Background and Purpose

• Partners

• Methodology
Respondent Demographics

- 355 complete responses
- Average age = 35
- Median income = $25,000 - $39,000
- Race/Ethnicity
  - 5% African American
  - 5% Hispanic
  - 10% Multi-racial
  - 73% White/Caucasian
Respondent Demographics

- 42% report some college
- 48% are employed full time
- 54% are single/divorced/separated
- Respondents from all over the country
Respondent Demographics: Gender

Every respondent identified as transgender.

- 30% identify as “female”, “transgender female”, or MTF
- 55% identify as “male”, “transgender male” or FTM
- 15% identify as genderqueer or gender nonconforming

- Over 85% living full-time in gender different from their sex assigned at birth
- Over 50% reported completing their transition
Respondent Insurance Coverage

- Almost half reported having insurance during their entire transition
  - Another 37% had insurance for some of their transition

Despite having insurance, respondents reported facing significant challenges getting services they needed.
High Level Findings

Challenges
– Inadequate coverage
– Inability to find providers
– Prohibitively high out of pocket costs
– Lack of cultural competence about needed services and about being transgender

Outcomes
– Delays in care
– Negative health and other outcomes
Adequacy of Coverage

79% of respondents (n=280) reported their insurance policy did not adequately cover transition-related services
Coverage of Specific Services

“All transition-related care and (currently) any non-transition-related care that my insurer believes to be a consequence of transition [is not covered].”

“My insurance company has paid for nothing other than a physical. All doctor visits, prescriptions, lab tests and surgery have been paid out of pocket.”
Challenges Finding Providers

<table>
<thead>
<tr>
<th>Service/Provider</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgeon “Bottom”</td>
<td>8.31</td>
</tr>
<tr>
<td>Surgeon for “Other”</td>
<td>6.78</td>
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<tr>
<td>Surgeon “Top”</td>
<td>6.35</td>
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<tr>
<td>Endocrinologist</td>
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<tr>
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<tr>
<td>Primary Care Doctor</td>
<td>4.68</td>
</tr>
<tr>
<td>Mental health provider</td>
<td>4.34</td>
</tr>
</tbody>
</table>
Challenges Finding Providers

“If I wanted in vitro fertilization I could get a list of 50 in-network doctors in my state who would provide this service. Not ONE of those would monitor HRT. I have to travel every few months to get my HRT checked.”

“In the conversations that I had with my HR person who was in direct contact with the insurance company it was frustrating because they had no idea of any of the providers for the surgery that I needed. They couldn't comprehend that there were no surgeons in the area.”
Distance Traveled to Provider

Mental Health Providers = 70% less than 25 miles
Primary Care Doctor = 72% less than 25 miles
Electrologist = 61% less than 25 miles
Endocrinologist = 44% less than 25 miles

Surgeon (Top) = 48% over 100 miles
Surgeon (Bottom) = 77% over 100 miles
Surgeon (Other) = 45% over 100 miles
Distance Traveled to Provider

“I had to travel several hundred miles for surgery. Then I had to stay there for over a week. So not only did I have to cover the cost of my surgery out of pocket, I had to find money for travel expenses as well. At the time I was making barely above minimum wage, it caused a lot of anxiety and stress.”
Challenge of “Out of Network” Providers

“Insurance provider has a problem with supplying payments to visit a gender clinic that is “out of network”. They allowed one visit and have attempted to deny future visits.”

“For top surgery, the claim was not submitted because my deductible for out-of-network providers is higher than the cost of surgery.”
Challenge of Costs

Could not access service because of out of pocket costs:

- Surgery: 47%
- Mental Health Services: 23%
- Hormone Therapy: 20%
- Electrolysis: 18%
Challenge of Costs

- $10,000 or more: 38%
- $5,000 - $9,900: 16%
- $1,000 - $4,900: 26%
- Less than $1,000: 20%
Challenge of Costs

“I have had greatly reduced ability to save money for nonmedical expenses, have been unable to contribute as much to my retirement efforts, or build up a greater financial reserve fund in case of other negative outcomes. All of this reduces the safety net that I try to create for myself.”
Years of Delay in Transitioning

0-5 years: 45%
6-10 years: 25%
More than 10 years: 20%
Impact of Delays

- Anxiety and hopelessness
- Thoughts of suicide
- Alcohol and drug use
- Used mental health services
- Dropped out of school
- Lost a job
- Attempted suicide
- Experienced homelessness
Relationship Between Delays and Negative Outcomes?

• The delay in transitioning was a primary reason for the reported negative outcomes = $\frac{1}{3}$
• The delay in transitioning was one of the reasons for the reported negative outcomes = $\frac{1}{3}$
• The delay in transitioning was not a reason = $\frac{1}{3}$
Impact of Delays

I was very depressed because most of my life I never thought I would actually be allowed to or be able to be me.

Multiple suicide attempts with resulting medical and psychiatric hospitalizations. Long periods of depression and feelings of hopelessness.

I suffer from severe chronic depression, anxiety, social phobia due to fearing for my life, body issues, substance abuse, hopelessness, anger, suicidal ideation, insomnia.
Changes Since Transitioning

- Of those who reported being “mostly done” with their transition, $\frac{2}{3}$ said their lives were “much improved”

- Another $\frac{1}{4}$ reported their lives were “somewhat improved”.
Insurers’ Understanding of Transgender Care

Respondents generally reported that insurance personnel they had interacted with “understood very little” about transition-related care.

They also reported that insurance personnel were generally “not very helpful” or “somewhat helpful”.

Insurers’ Understanding of Transgender Care

My current insurance policy has changed to cover transition, but no one seems to know exactly what procedures that covers.

Many insurance employees were uneducated regarding transgender care. Those that were did not consider it anything beyond cosmetic.
Implications

Our research suggests that there are:

• many layers of challenges;
• many opportunities for improved processes and improved care; and
• significant opportunities to move the needle on both care and costs by improving access and reducing some of these barriers
Compliance

• Assurance of compliance must be submitted
• Nondiscrimination policies must be posted
• Grievance procedure and due process requirements
Enforcement

• Title VI
• Age Discrimination Act
• Section 504
• Open questions about enforceability
Compliance

Covered Entities must:

- Keep records
- Submit reports to OCR
- Conduct compliance reviews and complaint investigations
- Provider technical assistance and guidance
- Submit Assurance of Compliance
- Post Nondiscrimination policies
- Implement grievance procedure and due process requirements
Enforcement

- Enforcement actions under Title VI, Title IX, the Age Act or Section 504 apply to any violation of Section 1557
- Federal enforcement tools for violations of civil rights:
  - Suspension of, termination of, or refusal to grant or continue FFA,
  - DOJ referral recommending initiation of enforcement proceedings
- Private right of actions and damages are available
- 92.302 & 92.303 provide procedures for health programs conducted by the marketplace and those administered by HHS
Implications for Insurers and Providers

How to prepare?

– System-wide training at varying levels (awareness and sensitivity, circumstances that change approach to medical necessity reviews, when UM criteria may need reconsideration)
– Administrative and IT preparations
– Coverage design and medical necessity determinations
– Provider Survey to assess network capacity
– Addressing network access challenges
  • EPSDT example
  • Telehealth example
  • Centers of Excellence example
Q & A

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