Eliminating Barriers to care for transgender and gender nonconforming individuals - Establishing and improving health services
PRESENTERS

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• Eowyn Rieke, MD, MPH, Associate Medical Director of Primary Care, Central City Concern, Portland OR
OBJECTIVES

• Identify barriers to medical and non-medical services for transgender and gender non-conforming individuals experiencing homelessness

• Identify promising practices when implementing a targeted program for this population based on existing program models

• Discuss challenges to implementing a targeted program for this population
OVERVIEW

• Background
• Driving forces and trends
• Transgender services in different settings
• Establishing and improving transgender health care
• Discussion session
KEY TERMINOLOGY

- Sex
- Sex assigned at birth
- Gender
- Gender identity
- Gender normativity
- Transgender
- Cisgender
- Gender nonconforming
- TGNC
BACKGROUND (IMPACTS)

- Housing instability
- Suicide attempts or ideations
- Substance use
- Depression and anxiety
- HIV/AIDS
- Involvement with justice system
- Victims of violence
- Survivors of violence
- Lack of or limited access to homeless services
BACKGROUND (HOUSING IMPACTS)

• It is estimated that:
  – 1 in 5 transgender persons are unstably housed or at risk or in need of shelter services
  – 40% of unstably housed youth identify as LGBTQ

• 1.7% of sample were currently homeless
• 40% moved to a less desirable housing
• 19% became homeless due to family rejection
• 11% evicted from housing at some point
• 19% denied housing
• 26% couch surfing
• 12% had sex to secure place to stay
## BACKGROUND (HEALTH IMPACTS)

<table>
<thead>
<tr>
<th>SUICIDE</th>
<th>SUBSTANCE USE</th>
<th>HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>41% reported attempting suicide</td>
<td>26% reported use of alcohol or drugs to cope</td>
<td>2.64% reported having HIV</td>
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<tr>
<td>69% of TGNC who have experienced homelessness reported having attempted suicide</td>
<td>49% of TGNC who have experienced homelessness reported use of substances to cope, 2 times the rate of those who had not had experiences of homelessness than those who have not (7.12% vs 1.97%)</td>
<td>HIV rates higher for TGNC who have had experiences of homelessness than those who have not</td>
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# BACKGROUND (HEALTH IMPACTS)

<table>
<thead>
<tr>
<th>Health Outcome</th>
<th>Est. among samples of transgender individuals</th>
<th>Est. in general US</th>
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<tbody>
<tr>
<td>Depression</td>
<td>Up to 54%</td>
<td>6.7%</td>
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<tr>
<td>Anxiety</td>
<td>Up to 48%</td>
<td>Up to 18%</td>
</tr>
<tr>
<td>Drug use</td>
<td>43%</td>
<td>Up to 21.5%</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>47%</td>
<td>25%</td>
</tr>
<tr>
<td>Suicidal attempt</td>
<td>41%</td>
<td>1.6%</td>
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<tr>
<td>Survivors of sexual violence</td>
<td>10%</td>
<td>5%</td>
</tr>
<tr>
<td>HIV</td>
<td>2.64%</td>
<td>0.6%</td>
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BACKGROUND (ACCESS TO CARE)

EXPERIENCED REFUSAL TO PROVIDE CARE

POSTPONE CARE DUE TO DISCRIMINATION BY PROVIDER

HEALTH CARE IS A HUMAN RIGHT
# BACKGROUND (BARRIERS ACCESS TO CARE)

<table>
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<tr>
<th>Individual</th>
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<tr>
<td>• Reticence to disclose gender identity out of fear of rejection and</td>
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<tr>
<td>compromising safety</td>
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<tr>
<td>• Internalized transphobia</td>
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<tr>
<td>• Perception that providers lack transgender-specific knowledge</td>
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<tr>
<td>• Mistrust of providers</td>
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<tr>
<td>• Limited income/uninsured/underinsured</td>
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<table>
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<tr>
<th>Systematic</th>
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<tr>
<td>• Lack of appropriate accommodations (e.g. welcoming environments, and</td>
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<tr>
<td>gender neutral/fluid restrooms and shelters)</td>
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<tr>
<td>• Limited gender choices on legal documents and service records</td>
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<tr>
<td>• Limited or no access to spousal/partner benefits</td>
</tr>
<tr>
<td>• Insufficient policies protecting their rights and existing policies</td>
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<tr>
<td>going unenforced</td>
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<tr>
<td>• Lack of provider transgender-specific knowledge</td>
</tr>
<tr>
<td>• Lack of cultural sensitivity among providers</td>
</tr>
<tr>
<td>• High cost of primary and transition related health services</td>
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DRIVING FORCES AND TRENDS

• Increased awareness of TGNC issues
• Increase public support for equal rights
• Increased number of health centers delivering culturally affirming care
• Development, passing, and implementation of local and national policies
DRIVING FORCES AND TRENDS

- Affordable Care Act
- Marriage and recognition laws
- Health Insurance Portability and Accountability Act
- US Department of Veteran Affairs Health Administration Directives
- State and local nondiscrimination laws
- Equal Access Rule
- Uniformed Data Systems changes
- Medicare inclusion
- Medicaid inclusion
TRANSGENDER HEALTH CARE IN DIFFERENT SETTINGS

TGNC Workgroup
One-on-one phone interviews
INTERVIEWED SITES

- Outside In (Portland, OR)
- Boston Health Care for the Homeless Program (BHCHP) (Boston, MA)
- Institute for Family Health (IFH) (New York, NY)
- The Ali Forney Center (New York, NY)
WHAT IS TRANSGENDER HEALTH CARE?

• Culturally appropriate care the same for cisgender individuals
  – Primary care based on anatomy
  – Screen for common diseases
  – Diagnose and treat acute and chronic illness

• Unique and critical element for TGNC individuals:
  – Transition related care (HRT and referrals for gender confirming surgery)
  – Referrals and support for behavioral services
  – Referrals and support for social support services
ESTABLISHING AND IMPROVING TRANSGENDER CARE

Community needs
Program structure
Funding sources
Cultural competency of staff
Environment which services will be offered
COMMUNITY NEEDS

• Staying informed of current issues faced by TGNC individuals
• Community needs assessments
• Ongoing feedback from advisory groups and the TGNC community
COMMUNITY NEEDS (SITE EXAMPLES)

• BHCHP: conducted needs assessment of local organizations that served LGBT populations that assessed:
  – Health needs
  – Available social support resources
  – Availability of health services
PROGRAM STRUCTURE (WHERE & WHEN)

• Health Center Program structure:
  – Stand-alone projects
  – Part of larger health center, hospital, or local health department
  – Mobile clinics, shelter-based clinics, and drop-in centers

• Services may be offered specific times days and times of the week or in every day clinic days
PROGRAM STRUCTURE (WHERE & WHEN- SITE EXAMPLES)

• Outside In and BHCHP started by offering services on specific days of the week in the evening hours

• **Challenges:**
  – Limited availability of services offered outside of normal operating hours (e.g. psychiatry and neurology)
  – High turnover of providers
  – Lengthy waitlists
  – Restrictive shelter hours

• As a result, services were scaled up to include transgender health services in every day primary care settings
PROGRAM STRUCTURE (WHERE & WHEN- SITE EXAMPLES)

• IFH transgender health program is unique in that:
• Subcontractor of Care for the Homeless
• Partner with Ali Forney to set up clinic at drop-in center
  – 1 ½ days primary care provider on site
  – 2 days psychiatrist on site
  – Additional services: part time nurses, medical office assistants, and social workers
PROGRAM STRUCTURE (TYPES OF SERVICES)

• Federally funded health centers required to provide:
  – Primary care
  – Preventive health
  – Enabling health
  – Substance abuse; and
  – Additional health services as appropriate and necessary

Either directly or through established written agreements and referrals
PROGRAM STRUCTURE (TYPES OF SERVICES- SITE EXAMPLES)

• Interviewed sites reported providing the following services:
  – Hormone replacement therapy
  – Behavioral health services
  – Specialty care through volunteers
  – Referrals for gender confirming surgery
  – Legal service through volunteer lawyers
  – Identification programs
  – Specialized clinical teams for TGNC persons living with HIV/AIDS
FUNDING TRANSGENDER HEALTH SERVICES

• Federal funds
• Reimbursements from private and public health insurance
• Additional funding can be sought by:
  – Donations
  – Private, local, and national grant opportunities
  – Volunteers providers
  – Collaboration with other organizations
FUNDING TRANSGENDER HEALTH SERVICES (SITE EXAMPLES)

• All health center sites:
  – Diversify funding sources and receive reimbursements from private and public insurance
  – Located in expansion states of Medicaid

• Ali Forney receives funding through:
  – US Department of Housing and Urban Development (HUD), Department of Youth and Child Development (DYCD), Office of Victims of Crime, Substance Abuse and Mental Health Services Administration (SAMHSA), and private donations
  – Maximizes partnership with IFH to get health services at drop-in center
CULTURAL COMPETENCY OF HEALTH CENTER

• Cultural competence- the ability to understand, communicate with, and effectively interact with a diverse population

• Training:
  – Upon hire and periodically throughout employment and in response to emerging issues
  – All staff and volunteers must receive training- frontline to clinicians
  – Use peer providers from within and outside of the organization to deliver training
  – Use TGNC persons from the community
  – Utilize assessment tools
CULTURAL COMPETENCY OF HEALTH CENTER (SITE EXAMPLES)

- All sites provide training that includes
  - Agency operations
  - Nondiscrimination and privacy policies
  - Agency philosophies in serving TGNC persons
  - Using appropriate language and terminology
  - What not to ask (as it pertains to role and client’s needs)
  - Providing not only competent care but affirming care
CULTURAL COMPETENCY OF HEALTH CENTER (SITE EXAMPLES)

• BHCHP faced multiple challenges including:
  – Lack of cultural competency among clients who are cisgender
  – Increased workload of providers who receive more TGNC clients
  – Lack of provider training prior to employment
CREATING A WELCOMING ENVIRONMENT

• Physical environment
  – Use of signs, posters, and relevant and appropriate health fact sheets and brochures
  – Increase visibility of nondiscrimination policies
  – Acknowledgments of relevant days of observations (e.g. National Transgender Day of Remembrance and LGBT Pride Day)
  – Gender neutral bathrooms- clear and prominently marked

• Language use
  – Staff must use appropriate language
  – Use of correct name and pronoun
HEALTH CENTER POLICIES & PROCEDURES

• Nondiscrimination policies
• Privacy policies
• Intake procedures
• Transition-related protocols
NON-DISCRIMINATION POLICIES

• TGNC clients may have a long history of discrimination and refusal of care based on gender identity or expression

• Clear nondiscrimination policies should be:
  – Adopted throughout the health center
  – A part of staff curriculum
  – Visible for all to see

• Policies and procedures for situations if these policies are not adhered to
NON-DISCRIMINATION POLICIES
(SITE EXAMPLE)

• The Ali Forney Center ‘no shade’ policy:
  – Addresses use of derogatory language towards peer by other youth
  – Prominently displayed throughout building
  – Procedures in place to address and resolve and discriminatory actions:
    • Warning paired with education
    • Youth is asked to leave the space and return for additional resolution strategies:
      – One-on-one reflective conversation
PRIVACY PROTECTION POLICIES

• Maintain a high level of confidentiality
• Federal HIPAA laws
• Must protect all information including: diagnosis, medical history, sex assigned at birth, or current anatomy should be protected
• Can be shared only if it is relevant to the patient’s care as well as within your role and responsibilities
INTAKE PROCEDURES

• Using inclusive and affirming language in clinic intake forms
  – Personal names, gender identity, sex assigned at birth

• Where and when to complete intake process
  – Interview by provider (admin or clinician) in private safe space
  – Allow clients to complete forms on their own
  – Clients may reveal themselves in exam room

• Information may not be relevant to clients’ urgent health needs
INTAKE PROCEDURES

• **What is your current gender identity? (Check and/or circle ALL that apply)**
  - ☐ Male
  - ☐ Female
  - ☐ Transgender Male/Transman/FTM
  - ☐ Transgender Female/Transwoman/MTF
  - ☐ Genderqueer
  - ☐ Different identity (please specify): ________________________________
  - ☐ Decline to answer

• **What sex were you assigned at birth? (Check one)**
  - ☐ Male
  - ☐ Female
  - ☐ Other (please specify): ________________________________
  - ☐ Decline to answer

• **What pronouns should we refer to you as?_______________________**
INTAKE PROCEDURES (EHR)

Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group

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2Callen-Lorde Community Health Center, New York, New York, USA
3Transgender Health Care Program, Planned Parenthood Mar Monte, Santa Cruz, California, USA
4Student Health Services, University of Wisconsin-Stout

ABSTRACT
Transgender patients have particular needs with respect to demographic information and health records; specifically, transgender patients may have a chosen name and gender identity that differs from their current legally designated name and sex. Additionally, sex-specific health information, for example, a man with a cervix or a woman with a prostate, requires special attention in electronic health record (EHR) systems. The World Professional Association for Transgender Health (WPATH) is an international multidisciplinary professional organization that establishes guidelines standards for the care of transgender patients. Intake procedures are a critical component of the care of transgender patients. Therefore, in September 2011, the WPATH Executive Committee convened an Electronic Medical Records Working Group, comprised of both expert clinicians and medical information systems experts, to develop recommendations for the use of EHR systems to document the care of transgender patients.
INTAKE PROCEDURES (EHR)

• Electronic Health Records (EHR) systems guide administrative and clinical staff practices and processes
  – EHR developers and vendors have yet to update their systems
  – Most EHRs currently use binary gender fields
  – Most do not have fields for personal names and correct pronouns
INTAKE PROCEDURES (EHR-SITE EXAMPLES)

• What can health centers do to collect this information?
  • Push and advocate for these changes to be made with EHR vendors and developers
  • Find alternative fields to capture information in current EHR

• BHCHCP faced challenges with an EHR that did not allow them to capture TGNC related information
  • Used notes field of EHR to capture gender identity, personal names, and correct pronouns
  • Notes section also provided specialized prompts for clinicians to ask about patient’s history
TRANSITION RELATED PROCEDURES

• When a person begins to live as the gender they identify as rather than sex assigned at birth and includes:
  – Social (e.g. coming out and changing mannerisms)
  – Legal (e.g. name and gender changes on legal documents)
  – Physical changes (e.g. gender confirming surgeries, HRT, gender expression)

• Not all TGNC persons desire to take on any transition related processes

• Health centers should provide a welcoming environment that is accepting and affirming of these changes
GENDER CONFIRMING SURGERY

• Health center capacity
• Health centers can:
  – Become familiar with the process for referrals and letters
  – Provide pre-/post-operative care
  – Become familiar with transition related surgical procedures
  – Become familiar with impact transition related surgical procedure
  – Become familiar with surgeons locally or in neighboring cities or states
  – Advocate on behalf of client with insurance providers and specialists
GENDER CONFIRMING SURGERY
(SITE EXAMPLE)

• BHCHCP’s respite program now provides post-operative care

• Training staff on referral processes and post-operative care. Progress has been made with breast implants but other surgery types are more rigorous.
HORMONE REPLACEMENT THERAPY PROTOCOLS

• HRT- use of sex hormones to achieve physical changes that are congruent with client’s understanding of their own gender identity and body image.

• HRT within capacity of PCPs

• Improves TGNC persons’ mental health and quality of life
HORMONE REPLACEMENT THERAPY PROTOCOLS

• HRT protocols should be based on evidence-based practices
  – WPATH standards of care
  – Evidence-based practices used by other organizations

• Informed consent approach
HORMONE REPLACEMENT THERAPY PROTOCOLS (SITE EXAMPLE)

• All sites used HRT protocols that includes an informed consent approach

• IFH uses clinical HRT protocols adopted from Callen Lorde Community Health Center that includes:
  – Initial medial intake
  – Hormone counseling
  – Education
  – Informed consent
  – Setting realistic expectations
  – Gradual initiation of treatments
  – Ongoing monitoring of lab work and health risks

• Providers received enhanced training on HRT and related issues
HORMONE REPLACEMENT THERAPY PROTOCOLS (SITE EXAMPLE)

• Outside In uses protocols that includes informed consent

• **Challenge:** Client expectations of physical changes and timeline in which HRT will be delivered
  – Meet people where they are
  – Increase transparency of care being provided
  – Use motivational interviewing techniques to setting realistic timelines for transition related health services
  – Be cognizant of competing priorities of TGNC clients who are homeless
  – Set goals with client
TAKEAWAYS

1. Meet clients where they are
2. Lead with a trauma informed perspective
3. Move toward holism
4. Not about us without us
5. Incorporate peers providers
6. Understand the context
7. Evaluate organizational capacity
8. Evaluate organization competencies
9. Maximize collaborative relationships
10. Create welcoming environment
DISCUSSION

HEALTH CARE IS A HUMAN RIGHT
PANELISTS

• Pamela Klein, RN, ACRN, MSN, HIV Nurse Case Manager and Transgender Program Nurse Manager, Boston Health Care for the Homeless Program, Boston MA
• Sara Reid, BA, Health Educator and TransHealth Navigator, BHCHP, Boston MA
• Jazz McGinnis, Lab and Transgender Services Coordinator, Outside In, Portland OR
• Kandi Patterson, CBHS/MHSA, Peer Support Specialist, San Francisco Department of Public Health Transgender Services, San Francisco CA
• Amber Gray, CBHS/MHSA, Peer Support Specialist, SFDPH Transgender Services, San Francisco CA
• Referrals back to main clinic falling short in providing care for this population
• Conflicting laws that cause trauma
• Lack of understanding of providers- resources needed
• Referrals of pts. to larger health facility- how do we scale up TGNC services to larger health center
• Concrete steps to become culturally competent
• How to engage TGNC community in services- safe space
• Fractured care-disconnect between health services
• Supporting pt. and preventing fracture of care
• Retaining TGNC clients without homes
• Hormone blocking drugs during puberty- communicating with family/parents
Audience inquiries and panel feedback

• How can a health center scale up TGNC services to be integrated into larger health centers in everyday primary care setting?
  – Panelist suggested an initial step meeting with decision makers of the health center, particularly with administrators who are responsible for the diversity issues at the health center. Upon meeting with these individuals providing rationale on why health centers need to improve health services for this population will be needed. The LGBT Health Education Center provides excellent rationale behind this issue. In addition, information on the vulnerabilities and driving forces can be found on the National HCH Council resource list that was distributed at this presentation. From there plans of action can be put in place to ensure that staff at main health facilities can provide culturally competent and affirming care.
Audience inquiries and panel feedback

- What are some concrete steps to ensuring that staff are culturally competent in providing care?
  - Panelist suggested the following steps: 1) build partnerships with local LGBT community centers or existing health programs; 2) identify TGNC persons who can help in the process as your health center makes these transitions 3) conduct health center and staff assessments around cultural competency, welcoming environments, and organizational structure and policies; 4) modifying and adopting existing trainings or have partners deliver training; 5) develop and implement appropriate policies and procedures as presented in this workshop; and 6) develop policies and procedures in the event of non-adherence.
Audience inquiries and panel feedback

• How can a health center engage and retain trans* patients in services?
  – Panelists stressed the importance of: 1) making sure that your staff and volunteers receive culturally and affirming care training; 2) creating safe spaces both physically and emotionally for TGNC clients to come for care; 3) meeting clients where they are and using active listening skills to better understand their needs; 4) ensuring TGNC specific resources are readily available; 5) using peer support specialists who also identify as TGNC; and 6) making sure that organizational policies and procedures include gender minority groups.
Audience inquiries and panel feedback

• How can a health center better streamline health services that are often fractured across providers (e.g. between behavioral health and PCPs, or endocrinologists and PCPs)
  – Panelists recommend that health centers can: 1) set up case conferences where all involved providers are present to discuss a particular case; 2) get PCPs training and shadowing opportunities that include hormone replacement therapy procedures so clients do not have to be sent to an endocrinologist; 3) having medical and behavioral health integration is key to having patient-centered care if both services are offered in-house; and 4) all health care providers including behavioral health, case managers, and other specialists should receive appropriate training so as to not have to refer patient to outside providers.
Audience inquiries and panel feedback

• How can health centers deal with family/parents of children receiving or wanting hormone blocking drugs during puberty?
  – Panelists noted that Dr. Norman Spack (may be retired) at Boston’s Children’s Hospital is a leading expert in the field of pediatric transgender care. Check out his TED talk!
  – Note: Puberty blockers are still not covered in the majority of states health insurance regulations. However, they are a needed compromise between children wanting what they want now and parents who may not have seen it coming or need time to be sure of this course of action for their children. Parents and families can become involved and educated as to how transition works and how to support their kids through it. Parents can be informed that: 1) this treatment plan will help relieve their certain mental health issues such as anxiety faced by their child while buying time; 2) it can help prevent the likelihood of the child taking actions into their own hands; and 3) transition related care can be extremely costly of upwards of $100,000 after puberty in adulthood. For many the physical imprint of adult hormones leaves “permanent giveaways.” When it is later decided that the requirements of diagnosis have been met and everyone is onboard it is time to start HRT. Young people who desire to transition may face disappointments, limitations, and heartbreaks of life to pass through but family support is essential to preventing many of the deleterious health and social outcomes associated with identifying as transgender.
WORKING AGREEMENTS

• Respect differences of belief, opinion and values
• Use “I” statements
• Step up/Step back
• Right to pass
• No question is stupid
• Confidentiality
• Take responsibility for what you say and what you don’t say
QUESTIONS?
CONTACT US FOR MORE INFORMATION:

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