Improving the Health of Trans Communities: Findings from the Trans PULSE Project

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Trans Health Advocacy Summit
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London, Ontario, Canada

The Trans PULSE Project: Background and Methods
Community-based mixed-methods study exploring how social exclusion impacts the health of trans people in Ontario.

Trans is defined broadly, and may include those who identify as transgender, transsexual, two-spirit trans, transitioned, bigender, genderqueer, or simply man or woman.

History of Trans PULSE

- Sherbourne Health Centre started LGBT health program in Toronto in 2002. Trans people across Ontario sought these services. Nowhere else to refer people.
- Advocacy Strategy: Collect evidence and make a strong case for creating access to health services.
- In 2004 Sherbourne partnered with community members and received series of small grants to begin work in 2005.
- Project became “Trans PULSE” in 2006 with community soundings and first major grant application.
Our Guiding Principles:

- conduct research that is **respectful**
- **build capacities** for research
- use the **highest quality methods** possible
- ensure maximum **positive impact**
- ensure meaningful **involvement**

Community Control Model

- Community members selected academic partners
- Terms of Reference stipulating trans majority among Investigators
- Trans-majority for all major decision making
- Community-Engagement Team (16 members of trans communities)
- Community Development Coordinator Role
- Research that builds community
Qualitative Phase 1:

- 2006, three “Community Soundings” were held in Guelph, Ottawa and Toronto with over 80 members of the trans community
- Open-ended questions re: experiences with using services, health care, discrimination, etc.
- Findings used to develop theoretical paper on how erasure impacts health care access for trans people
- Findings used to guide the questions asked on the Trans PULSE survey

Quantitative Phase 2:

- In 2009 Trans PULSE launched 87 page survey
- Survey items based heavily on community knowledge
- Quantitative = measurement (how much? how many?)
- Used respondent-driven sampling
Respondent-Driven Sampling (RDS)

- Findings from trans health studies are not always taken seriously by policy makers
- RDS is a method which uses a unique mathematical model to produce results that are harder to dismiss
- Begin with “seeds” (initial participants) who complete the survey and pass it to 3 others, who then also pass it to 3 others, etc.
- Special statistical methods allow for estimating percentages for trans people in Ontario, rather than the percent of participants

Trans PULSE Video
Respondent-driven sample (n=433)

# of Ontario Trans People Known
- = 0-1
- = 2-4
- = 5-9
- = 10-19
- = 20-49
- = 50-99
- = 100+

Who are Trans People in Ontario?
Gender Identity

- 45% Masculine
- 35% Feminine
- 20% Both, Neither or Fluid

Sexual Orientation

- Queer 31%
- Bisexual or Pansexual 30%
- Lesbian 14%
- Gay 11%
- Straight or Heterosexual 30%
- Two Spirit 9%
- Questioning 13%
- Asexual 5%
- Other 8%

Coleman, Bauer, Scanlon et al. Challenging the binary: gender characteristics of trans Ontarians. Trans PULSE e-Bulletin 2011;2(2)

Bauer, Boyce, Coleman et al. Who are trans people in Ontario? Trans PULSE e-Bulletin 2010;1(1)
Region of Residence

- 32% Metropolitan Toronto
- 15% Eastern Ontario
- 17% Central Ontario
- 27% Western Ontario
- 8% Northern Ontario

Age First Aware that Gender did not Match Body

- 59% Under Age 10
- 21% Age 10-14
- 13% Age 15-19
- 7% Age 20-29
- 1% Age 30 and over
We Are More than Just Trans

- Intersex: 6%
- Racialized: 23%
- Living with Disability or Chronic Illness: 55%
- Parents: 27%
- Aboriginal: 7%
- Born Outside Canada: 19%
- Living with Disability or Chronic Illness: 55%

Intersex

Parents

Aboriginal

Born Outside Canada


• Bauer, Boyce, Coleman et al. Who are trans people in Ontario? Trans PULSE e-Bulletin 2010;1(1).


Discrimination

Trans PULSE
Racism impacts trans people
Some examples:

Have been harassed by police because of race or ethnicity

<table>
<thead>
<tr>
<th></th>
<th>Aboriginal</th>
<th>Non-Abor. White</th>
<th>Non-Abor. Racialized</th>
</tr>
</thead>
<tbody>
<tr>
<td>On average</td>
<td>35</td>
<td>5</td>
<td>20</td>
</tr>
</tbody>
</table>

Partners have paid more attention to your race or ethnicity than to you as a person

<table>
<thead>
<tr>
<th></th>
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<th>Non-Abor. White</th>
<th>Non-Abor. Racialized</th>
</tr>
</thead>
<tbody>
<tr>
<td>On average</td>
<td>30</td>
<td>10</td>
<td>5</td>
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</table>


Racism also occurs within trans communities

- Occurs in trans communities due to non-inclusion of colour/cultural and language diversities

Have been uncomfortable in trans spaces because of race or ethnicity

<table>
<thead>
<tr>
<th></th>
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<th>Non-Abor. White</th>
<th>Non-Abor. Racialized</th>
</tr>
</thead>
<tbody>
<tr>
<td>On average</td>
<td>40</td>
<td>10</td>
<td>20</td>
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</table>

Transphobia

- Nearly all trans people have had some trans-specific negative experiences from family, service providers, police or others in the broader community
- Horizontal hostility (which may be related to internalized transphobia) causes a lack of unity within trans communities

Racism and transphobia interact to impact the health of racialized trans people

Impact of an increase in transphobia on sexual risk depends on level of racism

Impact of an increase in racism on sexual risk depends on level of transphobia

Barriers to employment: References and transcripts with current name and gender?


Ever experienced employment discrimination because trans?

If transitioned in workplace, how accepting were coworkers?

Access to Medical Care

Non-transition-related care

- Trans people have the same range of medical conditions as cis people, though care within cisnormative gendered systems may be complicated by structural and information barriers.

Transition-related care

- Trans people may or may not require access to medical transition-related care.

Medical Transition (hormones and/or surgeries)

- Completed (by own criteria)
- In process
- Planning, but not begun
- Not planning to
- Concept does not apply
- Not sure

Figure 1. The impact of informational and institutional erasure of trans people within cisnormative systems.

Bauer, Hammond, Travers, et al. "I don’t think this is theoretical; this is our lives": How erasure impacts health care for transgender people. JAMA 2009;20(5):348-361.
Emergency care

- 21% of trans people reported having avoided the emergency room when they needed it, because they were trans.
- 2/3 of those who used the emergency room while presenting in their felt gender reported having to educate their emergency care provider regarding trans issues.
  - Paper in preparation.

### Unmet need for transition care: large backlog and continued access issues

**Hormones**
- 53% had ever used hormones
- 20% have been denied a hormone prescription

**Other needs**
- Voice therapy
- Relationship and sex therapy
- Hair removal
- Non-OHIP-funded surgeries (e.g. tracheal shave)

<table>
<thead>
<tr>
<th>Surgeries</th>
<th>Need for OHIP-funded sex reassignment surgeries</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Completed all needed surgeries</td>
<td>17.4</td>
</tr>
<tr>
<td>Surgery needed, including vaginoplasty</td>
<td>35.2</td>
</tr>
<tr>
<td>Surgery needed, excluding vaginoplasty</td>
<td>5.8</td>
</tr>
<tr>
<td>Surgery needed, including metoidioplasty</td>
<td>7.1</td>
</tr>
<tr>
<td>Surgery needed, other ^b^</td>
<td>21.6</td>
</tr>
<tr>
<td>Sex surgery received</td>
<td>28.9</td>
</tr>
</tbody>
</table>

^\* 95% confidence interval

^b^ Other surgeries needed include chest binding, hypermasculinization, nipple-tomastoid, arthroplasty, free nipple graft, labia reduction, labia majora reduction, labia majora transposition

Bauer, for Trans PULSE. Unmet need for OHIP-funded sex reassignment surgeries: A report prepared for the MOHLTC of Ontario. 16 August, 2013
Why is access important?

Medical Transition Status and Past-year Suicidality

<table>
<thead>
<tr>
<th>Status</th>
<th>Attempted Suicide</th>
<th>Seriously Considered Suicide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not planning or N/A</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Planning but not begun</td>
<td>20</td>
<td>27</td>
</tr>
<tr>
<td>In process</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>Completed*</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

*Completing a medical transition was self-defined, and involved different combinations of hormones and/or surgery for different people

Coping and working for access

- “Do-it-Yourself” transitions
  - 14% of Ontario trans people have used non-prescribed hormones
  - 5 of 433 participants had self-performed surgeries, or attempted to, during the 10-year period in which SRS was delisted
- Trans people were instrumental in getting SRS re-listed through OHIP in 2008, and in continued work to improve access
- On an individual level, trans people educate doctors, and build informal referral networks for “good” doctors
Some things providers can do: A start

Table 3. Recommendations for Inclusion of Trans People in Institutional Contexts

- Development of intake forms that allow for trans patients or clients to self-identify
- Assumption by providers that any patient may be trans
- Assurance that all providers and staff use pronouns and names appropriate for a patient's gender identity, asking the patient if in doubt
- Indication of trans-friendly environments through posters or other visible signals
- Development of protocols for testing or treatment that are not sex-specific or that do not assume all members of a sex are cisgender
- Assurance that there is a comfortable place for trans patients within sex-segregated systems such as hospital wards or elimination of sex segregation where possible
- Development of resources for referral to trans-friendly providers, where needed
- Assurance that billing systems are set up to accommodate scheduling and billing “women’s” services to men, and “men’s” services to women
- Removal of sex designations from identifying documentation unless necessary


Sexual Health and Behaviours
Some key findings

- High proportion of trans people (25% FTM, 50% MTF) did not have partner sex within the last year
- 46% had never been tested for HIV
- 15% of both FTM & MTF had done sex work


HIV-related sexual risk, by gender spectrum

If we further break down the FTM guys by sexual orientation...

FTM – GB-MSM

FTM – Straight

Types of partners (current and past partners): FTM spectrum


Types of partners (current and past partners): MTF spectrum

Demographics: types of partners (current and past)

Sexual behaviours, past year: FTM spectrum

Sexual behaviours, past year: MTF spectrum
Demographics:
Sexual behaviours, past year


FTM spectrum:
Fluid-exposed sexual behaviours, past yr

MTF spectrum: Fluid-exposed sexual behaviours, past yr

HIV testing

Ever tested for HIV?

Aboriginal trans people were significantly more likely to have ever been tested than either non-Aboriginal group.

Among non-Aboriginal groups, racialized trans people were significantly less likely to have ever been tested than white trans people.

Needle sharing and HIV risk

- Despite reports from the U.S. of high prevalences of needle sharing for hormones, we found no such evidence for Ontario.
- This is likely do to the legality and funding of needle exchanges, pharmacy purchases of needles, and no-fee doctors visits.
Mental Health

Trans youth and suicide, past year


Transphobic harassment/violence and suicide, past year

Depression

- Depression was measured using a standard 20-question scale called the Center for Epidemiologic Studies Depression Scale (CES-D)
- Being “depressed” on the CES-D means having significant levels of depressive symptoms, not necessary being clinically depressed

Rates of reporting depressive symptoms

- MTFs - 61%
- FTM - 66%

Persons on the MTF spectrum were less likely to be depressed if...

**Compared to all MTFs**
- Employed full-time (vs. unemployed)
- Living in Toronto
- Having more social support
- Experiencing less transphobia
- Having postsecondary degree

**Compared to MTFs who were similar on other factors**
- Employed full-time (vs. unemployed)
- Living in Toronto
- Having more support for identity
- Not reporting childhood abuse
- Little involvement with community organizations (any community)
- Not always (or almost always) passing


Persons on the FTM spectrum were less likely to be depressed if...

**Compared to all FTMs**
- Experiencing less transphobia
- Having greater sexual satisfaction
- Not in the “planning but not begun” transition status group
- No reported major mental health diagnoses
- Having more social support
- Having more support for identity
- Currently using hormones
- Had any trans surgery

**Compared to FTMs who were similar on other factors**
- Experiencing less transphobia
- Having greater sexual satisfaction
- Not in the “planning but not begun” transition status group

Impact of parental support, trans youth age 16-24

Very supportive parent(s)  Somewhat supportive parent(s)  Unsupportive parent(s)

- Satisfied with life
- VG/Excellent physical health
- VG/Excellent mental health

Impact of parental support, trans youth age 16-24

Very supportive parent(s)  Somewhat supportive parent(s)  Unsupportive parent(s)

- Depressive symptoms
- Past-yr suicide attempt
What can be done?

• Workers must be able to respond to specific issues facing trans people:
  • Crisis centre staff
  • Mental health workers
  • Youth-serving agencies and school officials
  • Parents must be aware that their strong support can have positive impacts on their trans children

Moving Forward
Information we are now working on producing or getting out ...

- Racism and transphobia
- Primary care access
- Emergency room access
- "Do it yourself" transitions
- HIV testing
- Suicide prevention
- Violence
- Housing
- Parental support
- Qualitative study: Trans people living with HIV
- Plus:
  - Sharing what we have learned about our methods with other researchers
  - Challenges in moving from community involvement to community ownership and control of research

Strategy: Getting important bits out quicker through E-Bulletins
Strategy: Targeted reports

Estimating Unmet Need for OHIP-funded Sex Reassignment Surgeries
A report prepared for the Ministry of Health and Long-Term Care of Ontario

Gay, Bisexual and MSM Trans Guys: No Assumptions!
A report prepared for the gay men’s Sexual Health Summit, Toronto 2012

Strategy: Academic papers

Depression in Male-to-Female Transgender Ontarians: Results from the TransPULSE Project

Prevalence of and Risk and Protective Factors for Depression in Female-to-Male Transgender Ontarians: TransPULSE Project

“I Don’t Think This Is Theoretical; This Is One’s Lives”: How Exasperation Impacts Health Care for Transgender People
Our part in making it better: Knowledge, policy change and social change

- Undoing erasure through making community experience visible
  - Barriers to health care, transition-related and general care, employment discrimination, social support, identity documents, sexual health and relationships, many other areas
- Direct KTE and advocacy input
  - Policy forum, meetings with (and reports to) MOHLTC, politicians, presentations to organizations
- Indirect KTE and advocacy
  - Website, results e-mail list to over 600 people, Resource List
  - Newly redesigned website: [http://www.transpulseproject.ca](http://www.transpulseproject.ca)

Trans PULSE Project Team
(2004 - present)

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Jake Pyne

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89 Community Soundings
433 Survey

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