



Report on Phase I & Plans for Phases II and III

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What is the Trans PULSE Project?

The Trans PULSE Project is an exciting community-based research (CBR) project that responds to problems identified within Ontario's trans communities regarding access to health and social services. In particular, we are interested in understanding the ways in which social exclusion, cisnormativity (the belief that trans identities or bodies are less authentic or "normal"), and transphobia shape the provision of services for trans people and how these, in turn, may affect health. Some of the things we are studying are income stability, housing discrimination, relationships and family, sexual health, HIV vulnerability, mental health, community connectedness, access to social services, access to health care services, and hormone use.

Initiated in 2004, Trans PULSE is currently funded through 2010. The project will unfold over multiple stages, illustrated on pages 6 and 7 of this report. It involves both qualitative (focus group and interview) and quantitative (survey) components as well as action stages. Together these approaches provide the information necessary to change policies and practices to improve the health of trans people.

Phase I involved building a research team, reviewing the literature on trans health, conducting community soundings in Ontario communities to gather information on what health issues were important, and conducting an online survey of providers who serve trans clients. A brief summary of some of our findings is contained in this report.

As a community-based research project, the central involvement of trans people at all project stages is important as we strive to ensure that the research is meaningful, relevant, and empowering. The central research team – the Investigators Committee – is comprised of three allies and five community members who contribute their unique personal and professional experiences and skills to ensuring the success and relevance of the research and its outputs.

We strive to ensure that the research is meaningful, relevant, and empowering by involving trans people at all project stages.

Trans PULSE is part research project and part activist information network. We strive to undertake high quality research that fosters greater understanding about the health of trans people. Additionally, through synthesizing existing studies and mobilizing the findings of our own research, we hope to engage community members, providers, activists, lobbyists and allies working to improve the health and well-being of trans people in Ontario and beyond. We also aim to develop the capacity and knowledge base of other health researchers so that their work can be more inclusive of and relevant to trans communities.

Why is new research on trans health important?

There is a real lack of information on trans health: information needed by individuals to make informed decisions; information needed by care providers to provide the best care, and; information needed by advocates and policymakers to make decisions that are informed by solid evidence. Our goal is to produce strong and relevant information and to provide it in a variety of forms that can be used by community groups, individuals, doctors and other medical professionals, policymakers, and advocates.

Our aim is that the information we produce should reflect the concerns and issues of trans communities. Not only was this project initiated, incubated and directed from within trans community, we have also sought input from community members beyond those on our study team. Most previous research has

unfortunately been conducted by academics who were not necessarily aware of community views or concerns. We understand health as inclusive of physical, mental, emotional, spiritual and social dimensions, and use a multi-faceted approach to documenting the lived experience of trans people in Ontario.

Our goal is to produce relevant and usable information for community groups, advocates, individuals, doctors and other medical professionals and policymakers.

We'll be producing new information on the degree to which trans people experience exclusion in housing, health care, education and broader social participation (e.g. gyms, religious institutions). For some of these, we'll be able to compare to Ontario population rates, so we can document whether trans people experience social inequality, and in what ways. We will also gather information on people's health so that we can see how inequality impacts health.

Community Soundings: Overview

Phase I of our research involved gathering a wide variety of perspectives on health and health issues from trans people in Ontario. Overall, 89 participants took part in seven soundings held in summer 2006 in Toronto, Guelph, and Ottawa. These were trans-only spaces, facilitated by trans investigators from our research team. The soundings provided insight into the current health priorities of trans community members, the challenges confronted when trying to become or stay healthy, and some frequent barriers to accessing health care and social services.

While these soundings represent an important source of information about Ontario's trans communities, there is no way to be certain how closely this reflects the actual state of affairs for Ontario's broader trans population. Thus, the information collected in the soundings will inform the design of our survey that will take place in Phase II

Our findings echo those drawn from other studies in Ontario (Gapka & Raj 2003; Namaste 2000) as well as studies completed across North America. Taken together, this growing body of work shows how the complex challenges experienced by trans people can compromise physical, mental, emotional and sexual health.

Community Soundings: Key Findings

1. Income Instability

Whether before, during, or after one's transition, stable employment was a consistent challenge for trans people in our soundings. This applied as well to those who were not planning to physically transition. Over 40% of participants were unemployed, unable to work, or self-described their employment status as "underemployed;" 55% of participants had an annual income of less than \$20,000. Transitioning negatively affected one's chances with job successes, often relegating people to low paying jobs, and for some, impacting their ability to pay for the basic necessities in life. People often found themselves having to leave their employment and line of work before transitioning. During and after transition, many experienced challenges obtaining work, and discriminatory hiring practices were often suspected. This, in turn impacted how they felt about themselves and many reported depression or poor self-esteem as a result. Several trans women talked about engaging in sex work. Such work was generally regarded

quite favourably and offered a greater degree of autonomy and a greater level of income than other potential sources of work.

“ Personally, it can be a real self-esteem building sort of thing, I know a lot of people in the community...from not being hired by anybody, they’ve had to resort to prostitution in order to get the money even to just rent and it can be a very empowering sort of experience...”

Adding pressure for many were the financial needs accompanying transition. Sex reassignment surgery and other transition-related surgeries and electrolysis of facial hair were delisted from Ontario’s health care plan in the 1990’s. The costs for many of these procedures are quite significant and can be almost unattainable, particularly given the financial instability accompanying transition. The seeming intractability of this situation for many takes its toll on their mental health, and contemplation and attempt of suicides were mentioned on several occasions.

" I think a lot of us get into a weird holding pattern... [thinking that] surgery would really help me [and] having the psychiatrist say 'Yeah, I think that this surgery would really help you... so come back in 6 years when maybe you have \$17,000 but for now, too bad' – and I think so many of us are stuck in this holding pattern."

2. Barriers to Trans-Inclusive Health Care Services

Trans people report significant barriers to finding sensitive and informed health care providers. Health care providers often held serious misconceptions about trans people, or confused trans and gay identities. Health care professionals appeared uncomfortable providing services and treated them differently once they became aware of their trans identity or history. People also felt vulnerable around the fact that their hormones and care more broadly could be ended abruptly; this in turn affected what they felt comfortable telling their providers. For example, one participant described wanting to ask for help managing their substance use but did not for fear their hormones would be cut off.

Participants also described experiences of being forced to follow a certain path in their transition including pressure to behave in gender normative ways and to live post-transition as a heterosexual.

" I had a hell of a time getting hormones because I don't identify as a heterosexual male and I didn't want to transition to become a heterosexual male. And that was a problem 'cause they were like 'you can't transition to be a faggot.' Why the fuck not? ”

Key Findings from Phase I of the Trans PULSE Project

1. Income instability
2. Barriers to trans-inclusive health care services
3. Lack of relevant & accessible health information
4. Systemic social service barriers
5. Challenges to self-esteem, mental health, and finding help
6. Pervasive and diverse experiences of transphobia

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Trans PULSE: Diagram of Project with ongoing Knowledge Dissemination and Capacity-Building

Knowledge Dissemination & Action for Social Change
Building Capacity

1. PROJECT INITIATION

The idea for what would later become the Trans PULSE Project came out of discussions by the Trans Advisory Committee at Toronto's Sherbourne Health Centre regarding problems with access to health care services for trans people in Ontario.

2. FUNDING FOR PHASE I

Phase I of the project was funded by enabling grants from The Wellesley Institute (Toronto, ON) and The Ontario HIV Treatment Network.

3. BUILDING A RESEARCH TEAM

We developed a talented team balanced with academics, health professionals, social service providers, and business people, the majority of whom are also members of Ontario's trans communities.

4. PHASE I: COMMUNITY SOUNDINGS

In summer 2006 we held community soundings in Guelph, Toronto and Ottawa to: 1) gather some basic information about trans health in Ontario, and; 2) compile an inventory of the issues that shaped health. We used information participants provided to develop a community-driven trans health research agenda.

5. PHASE I: LITERATURE REVIEW

We reviewed research that had already been conducted, both by academics (peer-reviewed publications) and by community groups (grey literature). We critiqued this literature, and identified areas that required additional study.

6. PHASE I: SERVICE PROVIDER SOUNDING

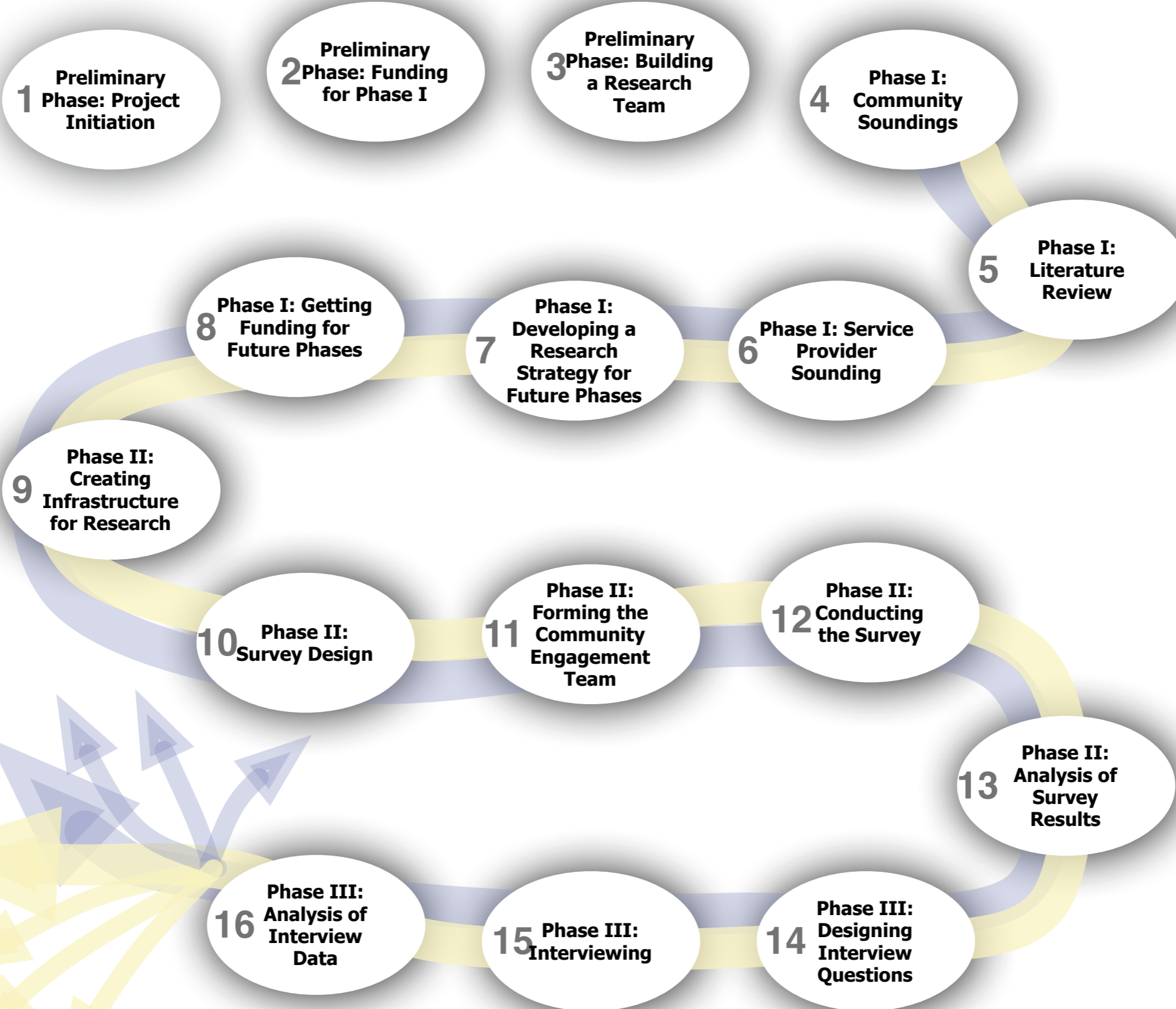
We also conducted a small online sounding for those who provide all types of services to trans community members.

7. PHASE I: DEVELOPING A RESEARCH STRATEGY FOR PHASE II / III

Information from all aspects of Phase I contributed to identification of issues to be addressed in Phase II: social exclusion, employment and housing, relationships and sexual health, social service access, health care access, hormone use, and HIV vulnerability. We decided that Phase II will involve a survey of 1000 trans people in the province of Ontario to document this broad range of issues and the extent to which community members are affected by them.

8. FUNDING FOR PHASE II / III

We spent fall 2006 writing applications for research funding. In spring we learned that we were successful in procuring three years of research funding through the Canadian Institutes of Health Research (CIHR), enabling us to conduct Phase II and Phase III.



9. PHASE II: CREATING INFRASTRUCTURE FOR RESEARCH

We undertook infrastructure development in 2007, involving research ethics approvals, additions to staff, website design, project management, and computer programming.

10. PHASE II: SURVEY DESIGN

Most of fall 2007 will be spent in survey design to ensure that the questions we ask are inclusive of all community members and that the information we generate is respectful, appropriate and useful. This will involve the contributions of not only the Investigators Committee, but also of the CET.

11. PHASE II: FORMING THE COMMUNITY ENGAGEMENT TEAM (CET)

The CET will be formed in December 2007, and be active for the duration of Phase II and III. The CET consists of 15 well-connected members of Ontario's trans communities that reflects the breadth of trans identities, ages, ethnicities and experiences in Ontario. The CET will contribute to the survey design, analysis and interpretation of results, and strategies for ensuring the broadest possible impact of our work.

12. PHASE II: CONDUCTING THE SURVEY

Our survey will be conducted in 2008 and will be a bit different from other surveys. In addition to being generated within the community, it will be multi-mode and involve a special method for recruiting participants through social networks, called respondent-driven sampling.

13. PHASE II: ANALYSIS OF SURVEY RESULTS

Analysis of survey results will be conducted using special statistical methods that are appropriate for the study design.

14. PHASE III: DESIGNING INTERVIEW QUESTIONS

Phase III of the Trans PULSE Project involves 80 follow-up interviews in order to clarify or develop more depth on issues that are brought up in the Phase II survey.

15. PHASE III: INTERVIEWING

Interviews will be conducted by telephone in 2009. We anticipate that all interviewers will be trans staff or CET members.

16. PHASE III: ANALYSIS OF INTERVIEW DATA

Responses from interview participants will be transcribed and analyzed in 2009. The results of interviews will: 1) help us deepen our understanding of findings, 2) explain any unexpected results from our survey, and 3) help provide direction for our work in the future.

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Health care providers also seemed to have little knowledge about how to work with trans clients and trans bodies and participants often had to educate their medical provider.

“ I’ve had more issues with lack of knowledge, having to educate my GP [General Practitioner] and my Gyno[cologist]. The other big issue that I run into is that not only do they not have the knowledge but they have no interest to learn. ”

While many participants had a regular health care practitioner (90%), obtaining such care was often challenging and the limited number of trans-inclusive providers, generally confined to Toronto and Ottawa, was repeatedly cited as a problem limiting the portability of their lives and uprooting them from the social supports in their home communities.

“ Those trans people, those in rural areas ... if they have to go the urban centers to get health care, there's a health implication in that because they are having a family relationship, a social relationship destroyed- being uprooted... ”

3. Lack of Relevant & Accessible Information

Trans people need accurate information to make informed decisions about their health, and this is difficult to find. Despite this, trans people use their resources, their connections and networks, the internet, libraries, and community events to seek out information that will help them make decisions about their health. Many participants conveyed a sense of uncertainty around the lack of medical research for trans people, particularly around long-term hormone use and physical transition, and were concerned about the accuracy of the information they could find.

4. Systemic Social Service Barriers

A number of unique barriers present themselves for trans people. These include institutionalized transphobia where trans people are treated as if they are mentally ill. Service providers in general were ill-informed about trans people and their specific needs, and some even refused care to trans clients. Participants articulated that there is a lack of trans-specific services, including at AIDS service organizations. Others also commented on services intended for ‘everyone’ not being accessible or relevant to trans people and trans bodies.

5. Self-Esteem, Mental Health, and Challenges to Finding Help

The compounding impact of stress in many trans people’s lives can have a cumulative effect on mental health, self-esteem and self-worth. Some struggle with depression and anxiety and may use substances to cope. This in turn can impact trans people’s ability to protect themselves during sexual encounters, heightening their vulnerability to HIV and other sexually transmitted infections.

“ For me, it's a miracle that I am here. I started abusing alcohol and drugs at about age 13 to self medicate. I engaged in very risky sexual behaviour... in an attempt to affirm myself, I think, as female by using sex with men, to get some type of self-legitimization or something, very depressed, wasted, not terribly careful, you know. I tested negative. I don't know why but I attribute all of that self-abuse as relating to low self-esteem. ”

In a context where there is little possibility for significant systemic improvements, many trans people may despair about their futures. Many have extensive informal social support networks through friends, peer support groups and internet groups to enable them to cope, but had difficulty accessing formal mental health services. People talked about the double bind of having their mental health issues dismissed by mental health service providers because they are trans or conversely having their trans related issues dismissed because they also had mental health issues.

6. Pervasive and Diverse Experiences of Transphobia

Transphobia was a frequent experience by many participants. In addition to its implications in the above findings, many participants experienced frequent harassment in their day-to-day lives. Finding housing was challenging and almost 1 in 5 participants were in assisted or unstable housing situations. This was due in part to income instability but also because of cissexist stereotypes held by landlords reluctant to rent to trans people. Others were excluded from loving and respectful relationships because they are trans or when their trans status was discovered by partners. One participant declared, "I didn't have any negative sexual behaviour like that because I felt that as a trans person sex wasn't a realm I was allowed to exist in." Only 35% of participants were married or had a regular sexual partner. Fears were expressed about not having their bodies accepted in sexual relationships, and being assaulted at venues such as bathhouses if their trans identity was discovered.

" I did not see myself as somebody who could be in... what most people considered 'normal' relationships. So I tended to jump into relationships with people who couldn't give anything back or who were abusive or whatever... "

For some, sexual relationships were a way to obtain validation for their gender identity. Many described a significant degree of risk-taking, owing it to low self-esteem and a sense that they couldn't advocate for their health in their relationships.

Community Soundings: Conclusions & Recommendations

Significant Variation in Community Experience & Identity

There is a tendency to see trans people as a relatively homogenous group of people; however this is not the case. The day-to-day experiences and lived identities of trans people vary greatly. Indeed trans people are as diverse as cisgender (non-trans) people, though this is often not apparent to researchers or to care providers.

Social Exclusion

The compounding factors underlying trans people's marginalization serve to erase trans identities, silence trans voices, and exclude many trans people from services and social activities. The pathologization of trans identities and, more broadly, the belief that trans identities are less valid -- and thus less deserving of services, care, and human rights protections -- has very real impacts for trans people in their day-to-day lives. Very often trans people, particularly those who cannot or do not wish to "pass" for cisgender, are at a disadvantage in finding housing and employment and can be pushed to the margins of society because of reigning stereotypes, fears, and prejudices.

Erasure

The processes of erasure of trans identities and experience also sustain popular misconceptions about trans people which help to re-enforce the stigma and discrimination faced. Based on information from the soundings, we saw erasure falling into three broad categories: 1) self-erasure; 2) institutional erasure, and; 3) information erasure. Self-erasure by trans people involves pressure to pass as a cisgendered person and to hide trans histories, identities or anatomies. Institutional erasure of trans people occurs through a lack of health care, education or hiring policies that accommodate trans identities or trans bodies, including the lack of knowledge that such policies are even necessary. Information erasure includes both a lack of knowledge regarding trans people and trans issues, as well as the assumption that such knowledge does not exist, even where it may. Underlying all of these processes of erasure is cisnormativity, the assumption that people will be cisgender and that cis identities and bodies are the most authentic or normal.

These three processes of erasure work together in a mutually reinforcing manner to produce a system where the emergence of a trans person as job applicant, patient or client is seen as an anomaly, and one that is not backed by a visible community of any number or strength. Thus, it too often falls on individual trans people to attempt to remedy systematic deficiencies and policies, and to acquire the knowledge necessary to address their needs.

" [T]he barriers remain within the larger society and even within the larger LGBTQ community, acceptance of who we are as equal and deserving of the same resources, the same attention. And what's the word? Erasure. Which all of [us] are familiar with as a theoretical and practical term. I don't think this is theoretical; this is our lives. "

Needed Changes in Human Rights and Health Care Policy & Practice

Health and human rights policies for trans people are presently inadequate. The lack of explicit human rights protection for trans people is implicated in the frequent reports of active and passive discrimination identified by participants in employment, housing, and other everyday contexts. This shortcoming could be ameliorated by adding "gender identity" as a discrete category in the Ontario Human Rights Code. The denial of OHIP coverage for sex reassignment surgery (delisted in 1998), adds enormous stress to people in transition. The additional burden of needing to save money for SRS can be a significant source of stress, particularly at the same time when one's potential to earn a steady income is precarious. More broadly, systemic change needs to occur within health and social service agencies to ensure that their services are able to be responsive and inclusive of trans experiences, identities, and bodies.

Provider Sounding: Brief Summary

In addition to the community soundings, the Trans PULSE Project also held an online sounding for peer and professional service providers who served trans clients or patients in Ontario. The 63 providers who participated delivered a wide variety of services, including health care, mental health care and counselling, legal services, community development, and formal or informal support services and 59% provided services in the Greater Toronto Area.

Overall, providers felt their formal training was inadequate for the work they do; 43% reported they had no formal training about trans people and their needs, 22% had training that was "not comprehensive," and an additional 21% reported their training was "somewhat comprehensive." In lieu of training, some providers reported that they had learned much from their trans clients directly, and cited the unfair

burden placed on trans patients and clients to research their own health care needs and educate their providers.

Providers did not always have the information they needed to best serve their clients or patients, particularly medical information on transition-related therapies. Even well-informed providers had difficulty finding services their clients needed. Specialized services, such as services for trans youth of colour or disabled trans clients or those with extensive mental health needs were cited as lacking. Referral networks for all types of services outside of Toronto were sparse and not stable.

“ [I don’t know where to send clients] for knowledgeable, non-judgmental, sympathetic medical assistance; the ones I used to recommend are full to capacity and not accepting new patients. ”

A wide range of additional information needs were cited by providers who were looking to provide trans-inclusive care, including information about the long-term health implications of transitioning, and about the impact of being marginalized while not having trans health needs recognized and funded.

What’s Coming Next? Phases II and III

We used the information generously shared with us in Phase I to design Phase II of our work, measuring levels of social exclusion and its impact on the health of trans people in Ontario. Phase II will be the largest survey of trans people ever conducted in Canada. We will follow up our survey with Phase III: interviews with 80 trans community members to make sure we’re interpreting the results correctly and continuing in the right direction.

We’re excited about our survey because to our knowledge no one has ever had the funds available to do a large survey on trans health in Canada. While several prior qualitative studies have provided some good in-depth information on issues affecting the health of trans people, the numbers and statistics to document our health concerns and their importance do not exist. We’ve given a lot of careful consideration to how to do this in a way that will include the most people while using the most rigorous methods (methods that produce the most accurate results, and that doctors and policy makers will consider “legitimate”).

We want as many trans people to participate as possible, so our survey will be available online, as a paper-and-pencil survey, or through a telephone interview. The way in which we recruit participants for our survey will be a bit different and we’ll be using an approach to research called ‘respondent-driven sampling’ (RDS).

The results of a lot of health surveys are not given the consideration they deserve because they are conducted with “convenience” methods. For example, if we approached a handful of trans organizations and surveyed people present at events, the people surveyed would not be considered a “representative sample”. They don’t represent the range of trans community members and certainly not those who are stealth or who can not or would not come out to attend public events. In RDS, participation begins with a number of “seeds,” well-connected trans people around the province selected to represent a range of ages and communities. Seeds then recruit other participants and those recruits in turn bring other participants into the research. Though we don’t know who is who, we track who invited who, and how many potential participants each person knows. This information is used for a new kind of statistical analysis that produces results that are more accurate than those from other types of study designs. It makes for a very strong research study, and we hope the results will have a strong influence on policymakers, providers, organizations, advocates and community members.

Knowledge Dissemination & Action for Social Change

We're committed to making sure that the information that comes out of this study is responsive to community needs and that it has a meaningful and positive impact on the wellbeing of trans people.

We anticipate that our results will be used by people in a wide range of roles: by trans people to better make personal health decisions, by trans activists and cisgendered allies as a tool to advocate for improved services, by medical and professional schools to inform and expand curricula, by researchers to respond to questions and findings raised through our own work, and by policy makers to have strong evidence on which to base policy decisions. Reaching all of these groups of people will require a range of approaches. Some of the ways we plan to make our results available, through print and via download from our website, include:

- 'plain-language' summary reports
- publications in 'free' open-access academic journals
- presentations at trans community events and conferences
- presentations to academic groups (e.g. medical, social work, public health, psychology)
- articles for incorporation into newsletters or circulation via e-mail
- tables or figures that can be used in grant proposals or reports by other groups
- brief series of slides that can be incorporated into presentations

Building Capacity

We aim to build capacity as we go about conducting our research: capacity of trans community members to conduct health research, capacity of cisgendered (non-trans) health researchers and students to understand and address trans health issues, and capacity of providers, advocates and policymakers to effect change to improve the health of trans communities.

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