

Transgender Health Needs in Simcoe Muskoka

RESULTS FROM THE TRANS HEALTH NEEDS
ASSESSMENT: THE HEALTH DATA

Acknowledgement

In March of 2016, the Gilbert Centre was awarded a contract by Orillia Soldiers' Memorial Hospital to examine the health needs of transgender people and families in the Simcoe Muskoka region. This project, funded by the North Simcoe Muskoka LHIN, was to:

- explore the experiences of transgender people accessing health in the region through community consultations and an online survey,
- examine accessibility to health and social services for transgender people through an organization environmental scan,
- review current literature on best practices in the provision of healthcare to people who are transgender.

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The research team thanks the many transgender and gender variant people in Simcoe Muskoka who contributed to the community consultations and the online survey. Your input has been invaluable.

Executive Summary

The following report documents the results of a mixed methods needs assessment study of the health needs and experiences of transgender people in the North Simcoe/Muskoka (NSM) Local Health Integration Network (LHIN). The study was conducted by the Gilbert Centre on behalf of the LGBT Task Force of the Orillia Soldiers' Memorial Hospital and funded by the NSM LHIN.

Design

The trans health needs assessment involved an anonymous online survey and community focus groups across the LHIN. The survey and consultation questions were collaboratively developed by the research team and a committee of trans NSM residents. Results of the assessment were also returned to the committee for feedback in order to validate findings.

Fifty-eight trans-identified individuals completed 75% or more of the online needs assessment survey. Twenty-two trans-identified individuals participated in four community focus groups held in Midland, Orillia, Bracebridge, and Barrie.

For the most part, trans people in the NSM communities had health care needs and experiences that reflect what is known about trans health in most communities, but compounded by their small-town and rural areas, including:

- significant and overwhelming experiences of transphobia in service encounters, and an avoidance of health care services as a result,
- a profound lack of trans health care knowledge on behalf of health care providers, often forced to make the trading-off between knowledge and expertise in exchange for respectful health encounters,
- a cobbling together of siloed services and extensive travel outside of their region for trans health services, and unmet trans health care needs—all resulting in the failure of the health service sector to support both general health monitoring and maintenance unique to their trans and gender identities as well as their transitioning-in-place.

Sample of Findings

- Trans people living in NSM are dealing with multiple health concerns, primarily mental health concerns, but also experiences chronic pain, physical or mobility disability or a chronic illness of some kind.
- Half of the participants made their health services providers aware of their trans or gender identity
- The majority of participants reported having unmet health care needs in the past year, with most avoiding accessing health care when it was needed
- Most participants reported having positive health care encounters, however these experiences are often characterized by a lack of trans health care knowledge. What characterized positive experiences was an identity-affirming experience and respect on behalf of the provider
- A strong majority of participants had never been refused service in NSM, however for the minority, their experiences of refusal are serious cause for concern
- Access to hormone therapy has improved for those who can access specialized services in Barrie, however in general access is still difficult, time-restricted, involves a lot of leg

work, and overall is unnecessarily complicated therefore limiting access and monitoring overall, especially for those not close to Barrie or with limited transportation access

- 81 per cent of the sample said that they had either wanted or needed some form of mental health support in the past 12 months. For almost half of those who wanted or needed it, these services were considered available to them in NSM; for almost 28 per cent though, the mental health supports or services they felt they needed were not available in NSM. However, the results demonstrate that problematic substance use or abuse is not a significant concern for respondents.
- Just over 80 per cent of those surveyed, have experienced suicidal thoughts; with 56 per cent having experienced suicidal thoughts in the past 12 months. Forty-four per cent of the trans community in NSM had attempted suicide. Of those who reported having attempted suicide, most had made multiple attempts.

The health concerns and fears of participants specific to living in NSM conclude the report, and the voices of participants are woven throughout to ground the data in the real lives of trans people in NSM. The entire research team is grateful to all the trans people who contributed to making this report possible. While there are noted limitations to the study methodology, the team hopes this report will meaningfully contribute to addressing trans peoples' needs, health concerns and hopes by providing health service providers and planners insight into peoples' lived knowledge.

Purpose of the Report

In 2016/17, the Gilbert Centre conducted a community-based needs assessment on the health needs and experiences of people who identify as transgender in the North Simcoe/Muskoka (NSM) Local Health Integration Network (LHIN) area. This needs assessment was completed on behalf of the LGBT Task Force of the Orillia Soldiers' Memorial Hospital and funded by the NSM LHIN. The study involved a health best practices literature review, an environmental scan of relevant health services and supports in the NSM area, community consultations with trans-identified residents, and an online health needs and experiences survey of trans residents of NSM. The purpose of the project is to inform and improve health care service delivery and planning in this LHIN based on the experiences and voices of trans residents, but also to advocate for appropriate and excellent care for all trans people living in small, rural, or remote communities.

This report focuses on the health needs and experiences data obtained through the online survey and community consultations. Our representation and interpretation of the data is presented in themes, and is reinforced by direct quotes from the community consultations, therefore the findings of this report are grounded in the voices of the Simcoe Muskoka trans residents who contributed to this study.

Key Terms

For the purposes of this study, the term 'trans' or 'transgender' will be used as a general term to describe those who could be considered as trans on the gender-identity continuum or who self-identify as 'trans'. Participants in the study were asked first if they considered themselves to be included under the trans spectrum, including common terms such as genderqueer, transsexual, non-gender-conforming, gender non-binary, gender-fluid and numerous others. The project team is very aware of the importance of identity terms and the variety of terms commonly chosen by or applied to trans people, and for the sake of clarity, will use "trans" or "transgender" throughout this report. The term "cis" or "cis-gender" is used to denote a person or people whose gender assigned at birth correspond to gender with which they identify.

North Simcoe/Muskoka Trans Health Needs Assessment Study

Data from this project was collected via four community focus groups across the NSM LHIN area and an online health needs and experiences survey completed by 58 respondents. Participants were recruited using peer snowball sampling and also existing networks of the local ASO, the Gilbert Centre, and their reach to the trans community (i.e. their Facebook page). As the study involved a relatively hard-to-reach population of trans-identified residents of a relatively rural and small town region, a sampling frame was not available. It is not known how many trans-identified people live in the NSM LHIN, therefore we cannot determine how representative our sample is of the trans population in similar areas and communities.

Generalizability was not a goal of this research project, but rather to capture local knowledge and experiences to inform local service delivery and planning—however it can be assumed that given the relatively small number of trans people living in remote or rural communities in general, we are confident that our study involved a significant percentage of the local population.

The needs assessment study met the ethical review standards as set out by the Tri-Council Policy on research involving human subjects, and as approved by Laurentian University's ethical review process for research involving human subjects who might be considered vulnerable for

the purposes of research. The small advisory group of trans identified residents of the LHIN were consulted and gave input into the design, topics, and wording of the study's focus group and survey questions. The survey involved 178 questions and ranged from demographic information, to health service use, to health service use experiences, and involving the full continuum of health services from primary and secondary care to community-based health services, from emergency room use to experiences in community mental health settings, walk-in clinics to opticians, from health services that are formal and legitimized to the often informal or un-regulated providers of services, such as internet-based hormone suppliers. Under the direction of the study design focus group, the survey asked questions about experiences of trauma, substance use, and social exclusion. This was requested because: "What if we only have this one chance to get this data about our lives out here?" Because some social determinants were included and because the full spectrum of health services delivery were considered, this study could be considered comprehensive in scope with regard the health needs and experiences of trans people living in this very unique community.

Results from the survey, the focus groups and early findings were verified with the community consultation organizers and the individuals from the community who assisted with the development of the survey tool. Their feedback was incorporated into the final report.

Fifty-eight trans-identified individuals completed 75% or more of the online needs assessment survey. Twenty-two trans-identified individuals participated in four community focus groups held in Midland, Orillia, Bracebridge, and Barrie. The focus group participants represented a full range of ages, were primarily female-identified, primarily Caucasian, and all were English-speaking. One participant identified as Two-Spirited.

North Simcoe/Muskoka LHIN

"The North Simcoe Muskoka (NSM) LHIN has a population of 479,471 (2015), representing 3.5% of Ontario's population. It encompasses the District of Muskoka, most of the County of Simcoe and a portion of Grey County. North Simcoe Muskoka is home to four First Nations. Given its location in and around cottage country, NSM experiences significant seasonal variation in population and demands for related health services" ("About North Simcoe/Muskoka LHIN", 2017, para. 3). The NSM LHIN is responsible for allocating \$880 million in funding to its 70 health service provider organizations, which include: 7 hospitals, 26 long term care facilities, 3 community health centres, 27 community support services, and 7 community mental health organizations ("About North Simcoe/Muskoka LHIN", 2017, para. 8).

The NSM is a primarily rural area comprising approximately 155 villages, small towns, and cities, with a significant seasonal tourist population.

Trans People in North Simcoe/Muskoka

As a hard-to-reach population, and as a relatively small community of identity in rural or remote communities (source), the study's sample (n=58, as it is assumed that all participants of the focus groups also completed the survey), and because the research team did extensive outreach and networking to recruit participants, it is assumed that the data can be interpreted with confidence to broadly represent the health needs and experiences of trans people living in NSM.

Conservative estimates approximate the trans population to be between 0.02% and 0.03 % of the general population, however the Ontario-wide Trans Pulse survey estimates the trans population

to be 0.05% of the general population in Ontario. However, it is more difficult to establish a reasonable estimate for rural or remote areas.

Primarily, most respondents lived in the Barrie area—this is not surprising given it is the largest city in the area and has the most developed social infrastructure. Several respondents lived in Orillia and Midland. The remainder of the respondents lived in the smaller communities and villages comprising the NSM. This means that almost half of the sample lived in smaller towns and villages with little service infrastructure and few other trans peers.

Most of the respondents have called NSM home for a long time. Half of the respondents were long-term residents and reported having lived in NSM for ten or more years. Fifteen of the 58 respondents have lived in NSM area their entire lives. Twenty-one respondents had lived in NSM for up to 10 years, and only 3 respondents were relatively new to the area.

The sample is representative across the lifespan. Respondents ranged in age from youth to seniors, with 8 being under 20 years old and two being in their 80s. Primarily respondents were aged 21-35, then middle-age, and eight were seniors.

Thirty respondents were assigned female at birth, 27 were assigned male, and one respondent was assigned intersex at birth. The survey asked respondents to describe any gender identities they currently identified with using 28 identity terms found in the literatures. The most commonly used identity respondents used was trans/transgender (n=54). Significant was the number of respondents who identified with non-binary identities such as genderfluid, agender, genderless, not exclusively one gender, or androgynous (n=38). It is significant that over half of participants identified under the non-binary umbrella. Gender identity markers that are prioritized in service and social encounters are generally binary. The finding that well over half of trans people in Simcoe County identify under the non-binary umbrella is a relevant finding both in terms of survey tool design capturing the array of gender identities, as well as the experiences of being misgendered that the focus group participants commonly reported as a health care experience.

In terms of identified sexual orientation, 16 respondents identified as straight/heterosexual, 14 as queer, 14 as pansexual, and 16 as bisexual, and one respondent identified as two-spirit. The remaining participants identified as “other” or “not certain”. Worth noting here is that several respondents identified in two or more identities, representing the complexity of gender identity and sexual orientation identity as well as the fluid process of identification. In terms of their health needs and experiences, all but 12-14 respondents could be assumed to have needs and encounters based on the intersectionality of their gender and sexual orientation minority identity and status.

Trans people living in NSM tend to live full-time in their true identity, with less than 5 noting they did so sometimes, and two respondents noting they did not live in their true identity. Just over half of the sample (n=32) have legal names that reflect their current gender identity, however 45% (or n=26) did not have a legal name that reflects their identity. This is significant in terms of identification and gender markers in the health service encounter.

Speaking to matters of representativeness, respondents were primarily non-racialized people. Because the sample is predominantly Caucasian, it is not representative of the general trans population and therefore application to the general population is limited; however, this fits with the predominantly Caucasian or non-racialized composition of rural and small regions in Ontario. Five respondents identified as being Aboriginal. All respondents were Canadian citizens with the exception of one. English was 100 per cent the preferred language for communicating with health providers.

Respondents were representative of the formal education completion spectrum; most had graduated high school (with the exception of the eight youth who completed the survey, most of whom were still in school); a large group were attending community or private colleges at the time of the survey, and seven had graduated university or graduate school. In terms of the overall sample, over half of the sample had partially completed or completed post-secondary education (n=36).

Respondents also represent the full spectrum of employment status: just over half of the sample was employed (20 in full-time work, and 12 in part-time work or seasonal work), 6 were unemployed and looking for work. Thirteen were financially supported by others, and a relatively significant number of the sample was on some form of social assistance. A few were retired, and two supplemented their income with sex work. Given the relatively high level of unemployment associated with people who are in the transition process (for example, the Trans Pulse study found that approximately 20% of trans Ontarians are unemployed or relying on social assistance), it is not surprising to see that approximately 75% of the sample could be considered precariously employed or under-employed, and needing the financial support of others or social assistance. Sixty-five per cent of the respondents identified as having incomes less than \$20,000 per year. Only five respondents identified as having an annual personal gross income over \$50,000.

On a more positive note, 77 per cent of respondents reporting having access to health benefits, primarily through their employment or education affiliation, some through spouse or family coverage, and some through social assistance programs. Of those with extended health coverage, 42 per cent noted that the coverage was adequate in terms of transitioning needs. However, 23% remain without extended health benefits coverage. For those without coverage, only a few (n=3) used the Trillium reimbursement program. It is not known why the majority do not use it—whether it be awareness or eligibility, how to pay or get reimbursed for costly health services should be part of our public health efforts and is relevant to the enormous costs paid out of pocket for life-saving and enhancing health expenses by trans people noted later in these results.

Just under half of the sample considered themselves to be a parent (n=22), with 12 respondents actively parenting at the time of the survey. Interestingly, those who identified as parents or actively parenting were not concerned about getting health or medical services for their child(ren) because of their own trans identity or gender expression. This is a positive note in that respondents do not foresee or are not concerned their own identities effecting the health services their children receive.

Luckily, the majority of trans people in NSM have a dedicated primary health provider, whether it be a general or nurse practitioner. Seventy-seven per cent of those had a dedicated primary care provider in NSM.

To summarize, respondents were primarily Caucasian and living in the more suburban centres of NSM; they represent a broad education status, but are overly represented in precarious work and live in low/lower-income status. Many are parents and most have lived in NSM for a very long time. They primarily choose the trans/transgender identity, but a significant number of respondents do not accept a gender binary or identity marker at all. Many have intersectional gender and sexual orientation identity complexity. Just over half have identification that reflects their true identity, but a large number do not. Most, if they have one at all, have a dedicated primary care provider in NSM.

“When I first told my doctor that I would like to transition, the response I got was rude – He states that I’m just making my life harder.”

Scholarly and professional research have well-established that the trans population is widely under-served in terms of health and medical services and the significant unmet health needs of trans people. Recent Ontario research established that approximately 49% of the trans population in Ontario had experienced a significant unmet health care need in the past 12 months (Giblon & Bauer, 2017, p.283).

Rural communities and small communities pose unique challenges for social support, coping, and health for transgender and gender non-conforming residents. Trans-specific health care and formal supports are typically lacking in such areas, leading to significant stress and mental health-related concerns. Without such supports, trans and gender minority residents of rural areas disproportionately experience poor general health and mental health outcomes than their more urban counterparts (Horvath, Iantaff, Swinburne Romine, & Bockting, 2014; Wienke & Hill, 2013). The academic and professional literature generally agrees that transgender people living in small or rural communities are at increased risk for poor general and trans-specific health and mental health outcomes and have health needs that are challenging to meet in these areas. The professional and scholarly literature have established the urgent need for mental and physical health services to be developed and maintained in rural areas (Horvath et al., 2014).

Trans People’s Health Status in NSM

Sixty-two per cent of the sample reported that their perceived general health was good to excellent (n=36), with “Good” being the most common response (n=21). The second largest category rated their health as neither good nor not good, however just over 15% of the sample (n=9) rated their physical health as not good or poor. More than half of the sample reports living with or being diagnosed with a mental health disorder, most commonly depression however a few cited gender dysphoria. It should be noted here that a diagnosis of gender dysphoria is common among trans people who wish to biologically transition, as it is diagnostic criteria that determines eligibility for public coverage of certain procedures.

It is clear that trans people living in NSM are dealing with multiple health concerns, primarily mental health concerns, but also several experiencing chronic pain, physical or mobility disability or a chronic illness of some kind. Several (n=14) note a learning disability; 6 respondents were visually impaired and 5 respondents were hard of hearing or deaf/Deaf. They also have concerns about their health care in NSM as they age, and likely as these health issues become more complicated: 43 per cent of the sample reported being very concerned or concerned, with less than 20% not being concerned at all.

Trans People’s Health Experiences in NSM

Half of the sample stated that all of their health service providers knew of their trans identity, 27 per cent said some or a few were aware, and 23 per cent said none of their health providers were aware they were trans. Given the important dimensions of health and health care that are influenced by gender and by transition, only 50 per cent having practitioners being fully aware of their identity and status is alarming and serves as an important context for the data that follows.

Fifty-four per cent reported that there was at least one time when they thought they needed health care but did not pursue it; only 32 per cent of the sample responded that they always accessed health care when they thought they needed it. Sixty-four per cent of the sample said that in the past year they had accessed health care in their true gender, while 22% reported

that they did not access health care in their true identities in the past year (the remainder reported that sometimes they did, sometimes they did not).

A third of respondents reported avoiding the local emergency department when they have needed to access one primarily because of concerns about how others would react to their identity as a person who is trans. Over half of the respondents said they did not avoid the emergency department when they have needed it, which is positive, and for the remainder of respondents they have not needed the services of an emergency department.

The majority of survey respondents do not avoid calling 911 emergency response. A small but still significant number (16 per cent) have indeed avoided calling 911 when they have needed to primarily out of concern for how others would react to their trans identity or expression. It was noted that some had had positive experiences with first responders in NSM. For example, a Barrie focus group participant reported:

“I was in a situation with another trans person where they had to go with paramedics, and from the incident that they took over the situation they immediately took asked the preferred name and pronouns and used it the entire time and respected their gender identity the entire way through and supported her the entire time. So, I can say at least the paramedics that were there at the scene and the staff, she went to RVH, at that time, were perfect for the entire situation. Now I know for others that it hasn't been that way, but for her they did a very good job and I was there to witness that.”

Good experiences with health care providers

Most trans residents of NSM have a dedicated primary care practitioner, and 77 per cent of trans residents have one in NSM. Just over half of respondents were comfortable discussing their trans-specific health care needs with their primary healthcare provider.

Many of the focus group participants reported having had good experiences with their local health care providers or services. This theme involves specific dimensions:

- Kindness, compassion, respectful treatment characterizes “positive experiences”, despite that the health service practitioner often had little to no knowledge of trans health care needs or treatments
- A trade-off often has to be made between having knowledgeable/educated providers or willing/supportive providers
- Good experiences were characterized by being properly gendered and the use of the correct name during the service encounter
- Good experiences did not involve interrogation or trans Q&A session
- Good experience appear to have some relationship with a lengthy relationship between client and provider or when the practitioner had some prior experience with trans individuals
- Some experiences involved awkward encounters with providers or in front of general public in the service setting

“I went to ____ for a UTI, and as somebody who hasn't had bottom surgery they did have to know specific parts they're dealing with but it was very awkward because the doctors didn't understand how to approach it in a very good way. So, when I did the general intake I had to tell them what name I generally go by. They wrote that wrong and then they called the name wrong over the system and then I had to correct multiple nurses and doctors. Then when the

doctor who treated me finally came into the room she paused for a second, tried to figure out how to say it then just looked at me and was like “So what kind of trans are you?” It could have been phrased in a much more kind way than how she said it, and I know she didn’t mean it in a rude way, but it was a little awkward.” -*Barrie*

“...most of my alternate healthcare, so my optometrist, my dentists, well my dentist has passed, so the one that I had I’ve had since I was a child. And like most of the people I interact with healthcare wise I’ve known for a long time and they’ve all been very good.” -*Bracebridge*

“I just took on a new physician not long ago and I am her first transgender client and she’s a little nervous about treating me. Okay, it’s kind of a learning experience for both of us. But she’s willing to learn. Recently I went in to get my medical done for my surgery and she would be, I could tell she was nervous. Fortunately, I had a list from Montreal to present to her and that made her that relieved her. But, I’m thinking that she could have had, would have been better for her if she had a little more information to make her feel a little more comfortable.” -*Orillia*

“For the first while I found that I didn’t, it seemed inaccessible because I didn’t know where to go or how to find information of where to go. Now that I’ve found a doctor, he didn’t know, he didn’t come with that experience, but it was easy enough for him to connect with somebody who did, and so we’re working on it together now. And I’m finding less and less that I have to explain myself to doctors, so it seems to be getting better.” -*Orillia*

“I’ve so far been fortunate not to have any negative experiences with the healthcare system. Prior to coming out full-time I did ask another doctor who I get my hormones from about, I was concerned with how I would be received depending on the nature of what I would be at the hospital for and how much information I need to disclose ahead of time. I was unsure whether or not we need to disclose everything every time we go to the hospital. I was assured no, and I felt a bit better after that.” - *Orillia*

“My psychiatrist did find me a doctor out of _____. Going into _____, I’ve had some other experiences with a health centre and, uh, since then it was actually, my life has changed three hundred and sixty degrees, it that’s the correct term, as far as health care goes.. Uh, physiotherapy, uh, psychologists, dieticians, uh, support, the nurses, my family doctor, everybody has been incredibly helpful and willing to learn and wanting information. My family doctor now has gone through all the different phases, whether Sherbourne Health or the Gilbert Centre, to be knowledgeable about trans health, basically, within Simcoe County and how to help not just trans people but lesbian, gay, bisexual all across the spectrum.” -*Midland*

Other positive experiences were noted in the survey results but convey a different message. For example, 13 of the 58 respondents noted that health care providers had allowed them the opportunity to fill out forms in a trans-positive way with regard to gender, and 5 respondents reported that the health care provider did not presume what kind of STI testing they should have. Although the question about STI testing may not apply to the entire sample (for example, to

those not sexually active or who were in monogamous relationships), this low number is hard to interpret. However, in new health encounters or services, forms completion is a routine procedure, and only 22 per cent of the respondents noted that they have had some positive experiences with health care providers about trans-positive form completion in NSM.

When asked about positive experiences with hormone access and health service providers, only 17 per cent of respondents noted that their health care provider knew about hormone contraindications and only 21 per cent said that their health care provider offered hormone access. The informed consent model of hormone access is considered a best practice in trans health care, yet it appears to not be practiced in NSM in a consistent or universal way.

Withheld Services, Service Denial, or Rejection by Providers

The majority of trans residents in NSM have a dedicated primary care provider, and most are within the NSM area. Although approximately half of the sample reported being comfortable discussing their trans-specific health needs with their primary provider, 14 per cent were uncomfortable and most concerning, 10% of the sample do not talk about their trans-specific health care needs with their primary provider at all. Given that the onus and burden of accessing adequate trans health care falls primarily on the trans patient in a patchwork trans health care system, the reality that 10% of trans patients do not discuss their health care needs with their primary care provider out of discomfort is both alarming and has potential consequences for health.

Seventy-six per cent of respondents said they had never been refused health services in NSM as a result of their trans identity or gender expression; however, the experiences of the remaining 24 per cent of the sample are cause for concern. Although we are not able to identify the reasons for why these trans respondents were refused services by their provider, 24 per cent of the respondents had experienced being refused services as a result of their trans identity.

Many participants had experiences of requesting services and being denied care, either directly refused by the provider or by being redirected to a different source. This refusal/redirection may also be attributable to a lack of competence and therefore part of ethical obligation of the practitioner to refuse/refer elsewhere.

“I actually went to a nurse practitioner in Victoria Harbour, uh, again just trying to get on his roster and stuff. And he was, just like you were saying about it; unknowledgeable, unwilling, um. I remember talking to him about getting a referral letter for top surgery and he literally in the exact words that, “I should go home and rethink it”. And like, I had already been on T for three or four months at this point. It's like, you know, it's not something you're just going to rethink. Like, you know, he had no clue about, he was asking me about the surgeries and about, like you know, didn't know what HRT meant, and didn't know ANYTHING [big emphasis on "anything"], like honestly, ANYTHING. And I'm thinking like, this person's got my, at this point my health in their hands and he doesn't even have any idea of what I'm talking about. Like that's terrifying. I know exactly what you mean, like I RAN.” – *Midland*

“I was not even examined, I have physical health problems that are really difficult. I'm grinding my teeth down to nothing in pain and they wouldn't even touch me to examine

me to find out what's going on where and that's horrible and it's a despicable feeling." - *Midland*

"Once you get put in a bad situation, they don't realize either that they're postponing our lives. You know what I mean, like we're the ones that are suffering because of it, like you get pushed out the door and it just, it's not helping anybody. And if anything, we're ending up right back in their doors at the hospitals, at the crisis centres, at you know what I mean, it's just, it's like, exactly. Like if the health care system was better, you know what I mean, you would actually see less people in the psych wards and on medications and yeah." - *Midland*

"I was told by an individual at the Orillia hospital that I would not be treated there." - *Orillia*

"When I first told my doctor that I would like to transition, the response I got was rude. He states, that I'm just making my life harder. And that for me was a very emotional blow. I don't say anything unless I have truly thought it over, truly really mean it, and for a doctor to say that to me about my decision, I don't find that right. Morally or ethically." - *Barrie*

"When I initially came out to my family doctor, she was actually fairly understanding and she tried to get me an appointment with an endocrinologist in Barrie and she found only two, and when she spoke to both of those doctors they said that they would not take me on as a patient because they had no knowledge of trans patients, so they didn't even want to try. I ended up having to go to a doctor in Toronto." - *Barrie*

"I was in all technicality denied access to hormones here, at the time it was it was literally several months before CAMH put out their thing that said GPs have to do hormone therapy..." - *Bracebridge*

"My primary doctor wouldn't prescribe me hormones, he passed me on to the gender doctor and that took me two years before I got an appointment" - *Orillia*

Being mis-gendered and having a lack of response was also noted:

"A person going in to Barrie hospital with a severe heart condition asking for help and uh their question was, "well we don't know if it's a male or a female," and this friend of mine just collapsed on the floor. When they did, um give her assistance for the heart condition, um the name tag on her wrist was totally wrong. Even though all the IDs is female, their past documents were in male and uh the ID bracelet was totally male, totally wrong name, and this person was already in mental distress and had a heart condition and scared." - *Midland*

Experiences Regarding Hormone Access & Support

Forty-two per cent of respondents are currently using hormones. Twelve per cent would like to be on hormones however were not at the time of the survey, whether having access issues or

timing. When asked specifically about puberty blockers, most respondents had not used this treatment primarily because it was not made available to them (n=24), or because they were not interested in accessing them (n=17).

For those who have used hormones in the past year, most receive them from a specialist (just under half of the hormone-using sample) and secondly through their primary health care provider. Worth noting is that although there are several illicit ways to obtain hormones, respondents are not making use of them for the most part: only three respondents noted getting their hormones from friends and one person reported using an internet source.

Access to hormones in NSM has improved with the addition of one day per week trans clinic offered at the Canadian Mental Health Association in Barrie. Just under half (48%) of the sample had access to a practitioner in NSM who prescribe hormones. However, despite this encouraging number, the focus group participants remind us that access means more than availability.

All focus group participants expressed the importance of hormones and access to hormones. There are several dimensions for this topic:

- Access: Access to hormones for the most part takes anywhere from 1-3 months to more than one year once the individual decides to use hormones as part of their transition. Of those who actively use hormones, 33 per cent accessed hormone treatment within 1-3 months, 15 per cent between 3-6 months, 13 per cent between 6-12 months. For 31 per cent of the same it took more than one year between the decision to access hormones and accessing them, with three respondents still waiting to receive their prescriptions. This is usually a reality that forces people to find alternate sources in the interim, especially given the crucial role hormones can play in successful transition, however 90% of respondents noted that they did not try to find other sources while they waited.
- Lengthy wait lists that require a lot of paperwork to complete prior to being put on the wait list, thus making the process longer
- Finding out about services, getting the referral forms and getting them completed often involved complicated and unnecessary hoops
- Respondents didn't seem to have direct access to treatment and several had to access them in other cities or regions
- The process involved considerable legwork to accomplish

Just over one-quarter, or twenty-seven per cent of respondents who use hormones, cite health professionals as their primary source of hormone information. People's knowledge of hormone treatment seems to come from several non-professional or unregulated sources, which poses some concern for harm reduction. Throughout this study, we saw the importance of peers when it comes to trying to piece together trans services; again, 26% of those using hormones cited their trans peers as their primary source of information, and 37 per cent relied primarily on internet sources. Twenty-five percent of the hormone-using sample reported that they did not know, or needed more information, about how to safely inject hormones.

“I don't think there has been a lot of support teaching people how to self-inject hormones. I think most of the guys I know learned either from other guys or from the internet, largely YouTube videos.” – *Orillia*

“Even with a clinic and with a nurse practitioner that wanted to be as helpful as they could, that wanted to get me the hormones that I was looking for, it's still a process that took a year, in my case, about. And that's with people that wanted to help, with people who were doing the readings. And it's just, I mean yes, the clinic was new, yes the person that I was seeing was the head of the clinic, so they had a lot of other duties to also take care of, but like, that was a really, really painful year. Um, and a year, from what I hear from a lot of people, is nothing. Like, a year is almost a good timeline. And that's ridiculous!” – *Midland*

“I saw a temporary doctor, I was just going in to get medical updates for Montreal, and his comment was “Oh, hormone therapy is actually really easy, and I don't know why we aren't just doing it”- *Bracebridge*

“I don't have to go see doctors very often that aren't transition related, and I even avoid trying to see doctors I don't know before-hand. I have my family doctor and then the doctor I see for my hormones and stuff. Because I'm passing as male now my concern is that since I'm legally recognized as female there is going to be some, what is it the trans broken arm syndrome is that what its called? [affirmation from group] So doctors would say, oh you're having this problem because of your hormones or some other trans related thing, its like no my arm is broken [laughs, others laugh too] That's it.” – *Barrie*

“(Participant A): Luckily my family doctor, the one who gave me the bad experience when I first told him, decided that he would help continue the hormone therapy, luckily he was accepting then. So, that has been pretty bad. I was then directed towards CAMH for further transitioning such as surgeries and what not. Strictly speaking hormones, it was a long and rigorous and emotionally draining journey. The contact, the follow-ups, the travel, it was ridiculous it was a nightmare.”

(Participant B): “When I initially came out to my family doctor, she was actually fairly understanding and she tried to get me an appointment with an endocrinologist in Barrie and she found only two, and when she spoke to both of those doctors they said that they would not take me on as a patient because they had no knowledge of trans patients, so they didn't even want to try. I ended up having to go to a doctor in Toronto. I was lucky enough to get an appointment within five days of talking to my doctor, my family doctor. Got that appointment and I went down with all of my paperwork from my therapist, and same day I was able to get my hormones. I was lucky enough to get my hormones and start everything.” - *Barrie*

Avoidance or Delaying Accessing Health Care by Participants

Because of prior negative experiences and/or fears that encounters will involve negative interactions with health service providers in general and specific to NSM, several participants noted that they had delays in accessing health care treatment, or avoided certain health care interactions. Reasons for not accessing needed health care services when required, or not doing so in their true gender were primarily that the needed services were not available in NSM, that they already had a provider in another area that they are satisfied with, and a significant number (n=15) stated that they have tried providers in NSM but found them unable to meet their needs.

Over half of the sample (53 per cent) stated that they access health care services outside of NSM. This is significant not only in terms of burden on the trans individual, but also for health service planning and funding purposes. Over half (54 per cent) stated that they have paid out-of-pocket for these services, with most spending up to \$2500 in general, but some spending over and above \$2500 to more than \$25,000. Most reported that they did not incur debt as a result of this expenditure, however a significant portion (n=11) reported that these expenditures had left them in debt as a result.

“...something that's stopped me...from reaching out for help, and even from people from support groups, from doctors, nurse practitioners, therapists and even that delayed my transition for a while out of fear is, I fall into that category of trans person who, I have a lot of dysphoria, but actually very little genital dysphoria. I'm actually okay being non-op. But based on a lot of the guidelines, especially the old ones, that could get me refused service entirely, if I'm being honest about it. And that's a terrifying thing to admit. I, if I don't fall within that box, I could be refused service.” – *Midland*

“ I don't have to go see doctors very often that aren't transition related, and I even avoid trying to see doctors I don't know before-hand.” – *Barrie*

“They don't treat you the same as they do with you know, normal cis people and it's, it's hard, it's definitely hard. And I can see what you mean about not wanting to reach out or being scared to. And I find we're educating a lot of the people that are taking care [voice rising in volume] of us, and like that's terrifying, because what if something goes wrong?” – *Midland*

But just to go to my family doctor I'd be kind of afraid just for discriminatory reasons. Just growing up here and transphobia and homophobia and all how it is in this town for the most part.” – *Orillia*

This reluctance, although not widely characteristic of all health care encounters, combined with the lack of knowledge reported by respondents of their health care providers reinforces the sense of “being lucky” when they have a good encounter and when they receive adequate care in NSM. Their previous history has developed into a consistent sense of low expectations.

Health Travel/Out-of-community Care & Multiple Providers

Most survey respondents and every community consultation participant travelled out of the NSM to access care, and often to Toronto. Every participant had multiple silo-ed providers, leading to slow and un-coordinated care for health needs or unmet needs due to inability to travel or find a provider in a reasonable proximity. This seemed to be an expectation--participants did not expect to find appropriate care in their small communities. The risks and potential negative health outcomes of unconnected and difficult to access necessary services are significant.

“My family doctor, I have no problem saying that she had no experience with hormones and trans issues and such so she had to send me to Toronto, she just didn't have the education she needed.” – *Barrie*

“They said straight up that they had no idea about any of the services and would not be willing to do particular hormone therapy on their own because it wasn’t within their scope of practice. Since then they have been really good at sending the referrals which I have gotten all of myself, so I find who I need to be referred to and they sign the document and fax it away.” –*Bracebridge*

“When I had finally decided to medically transition I looked for information in around the Simcoe area, and could not find a damn thing. What I did find was next to nothing, it was a website, it was mental health areas, it was strictly going to see counsellors and what not who had next to no experience or no information on where to start. I then had to go outside of Simcoe, St. Catharines to Quest, and from there it was a three-month journey to actually start.” - *Barrie*

“Because we’re seeing all sorts of people all over the place and there’s no real connection. It’s like a whole pile of satellites that’s just floating around out there.” - *Midland*

“Being lucky”

When participants identified that they had had positive experiences with the health care system in NSM, they expressed feeling or being lucky. This seems to imply that they are lucky compared to the situation of peers, rather than access/availability in general. This theme involved a few dimensions:

- Being lucky to find some support for trans health needs
- Being lucky to find secondary providers
- Being lucky to have found a practitioner in their area

“Luckily my family doctor, the one who gave me the bad experience when I first told him, decided that he would help continue the hormone therapy, luckily he was accepting then.” -*Barrie*

“...has said that he had had problems getting onto hormones and I happened to be lucky enough to get it quickly. I don’t know if it was I had specific paperwork, or if I just had a lucky horseshoe up my butt, but I happened to get what I needed but I had to go outside of Barrie to do it.” -*Barrie*

“I just sort of lucked out with finding this group in general and finding doctor resources and that. But just to go to my family doctor I’d be kind of afraid just for discriminatory reasons. Just growing up here and transphobia and homophobia and all how it is in this town for the most part.” - *Orillia*

“Since then I haven’t had a doctor at all. So I know exactly what you mean. I’m in the exact same position right now and, you know, you’re lucky you’ve found somebody. I still haven’t found anybody, you know what I mean, and I know exactly what that’s like.” – *Midland*

Participants also felt lucky to have peers and access to ASOs that provide support and information services to trans people uniquely. The important knowledge transfer and support role peers and ASOs provide to trans residents is significant. A prominent theme in the focus group data was that trans residents obtained most of their local health information from peers and online/in-person support groups.

“... but if it wasn’t for you guys, and you know what I mean, certain places like [local ASO in the NSM], I would have had a lot harder time.” – *Midland*

“I-I considered stealing some of my wife’s birth control as a desperate source. And again, if it wasn’t for the online support that I get from other people who have experience and who know what they’re talking about and who have loved, who have lost people. I probably would have.” – *Midland*

“I don’t think there has been a lot of support teaching people how to self-inject hormones. I think most of the guys I know learned either from other guys or from the internet, largely YouTube videos. I don’t do my own, my general practitioner taught a fiancé to do it for me and I’m not interested in doing it myself. I get her to do it and she offers to do it for other guys who aren’t willing to learn to do it themselves or are going to learn to do it themselves later.” – *Orillia*

“We’re really lucky, like with places like the [local ASO in the NSM] and [community health centre in Midland], that are trying and really trying to change things. Cause a lot of places in town really aren’t.” – *Midland*

Low Expectations

Most participants don’t expect to find both competent AND compassionate/respectful care. Participants did not convey anger necessarily, but disappointment and sadness when discussing these matters.

“Um, just how certain situations esp- like, you can get into situations where you think someone is being helpful and cooperative, like my dental office was really good about offering to change my name even before I had it legally changed. But then I got into a situation where I was on the dentist chair, I had my apertures in my mouth to keep it open, and suddenly the dentist and the assistant start misgendering me while looking at my file. And I have stuff in my mouth, I can't even speak up. And you're stuck there like that for another half hour. And like, it's situations where you think people are being helpful and you - and you let your guard down. And it's when you have your guard down that it hurts most when people screw up.” – *Midland*

Referring to local health care centre, “...everybody has been incredibly helpful and willing to learn and wanting information.” – *Midland*

“...my general practitioner, my family doctor is a doctor in Bracebridge and uh they’ve been pretty good about doing references, so they’ll sign documents to get me the care that I tell them I need, but going into it, they straight up said that they had no idea about any

of the services and would not be willing to do in particular hormone therapy on their own because it wasn't within their scope of practice. Since then, again, they have been really good at sending the referrals which I have gotten all of myself, so I find out who I need to be referred to and they sign the document and fax it away, which is good in some terms..." – *Bracebridge*

"...Umm but not everyone has that experience right, not everybody is confident enough to do that at all, so [clears throat] I think they would seek services, the people I have experience with, would seek services if they knew there was somebody that could provide them with at least some semblance of like knowledge, specific knowledge to trans care. Even if its not that they can do everything, but just that [2 second pause] we don't have to be the doctors and tell them what to do..." – *Bracebridge*

A conversation among three participants:

(Participant A) "I'm still with my old family doctor, he seems sympathetic. I don't feel he treats me any different than he was before. Now, keep in mind that I'm not out full-time, but he knows of my situation and he helps me the best that he can.

(Participant B in response): I've been full-time for just over a year, and I've been with a family doctor now for twenty some odd years. So I'm still with the same doctor, I asked him about his experience with trans gender and I think he had one trans gender patient that I'm aware of probably twenty or thirty years ago. So very very limited experience, but since coming out, the limited dealings I've had with him since, he hasn't really treated me any differently, so that aspect has been good that way.

(Participant C contributes) I'd just like to say about my doctor, she has been excellent with me, despite the fact that she doesn't understand." – *Orillia*

Trans-health Competence of Providers

When trans residents access health care services in NSM, in general they are met with a lack of trans-specific health care competence. This section of the survey data revealed both positive and negative health care experiences, and the complexity of these experiences requires some context that the focus group data are able to provide.

The most common experience reported (n=30) was that their health care provider lacked sufficient practice knowledge about trans health and health care. This is reinforced by the narratives of people who participated in the community consultations as well, with people having to act not only as their own advocates but also as trans health experts in order to receive some level of health care service.

"Doing the legwork"

Most participants, whether they reported having had some positive, mixed, or negative experiences almost universally reported having had to do extensive legwork, often doing the research in advance, educating the providers, finding and providing relevant forms, informing practitioners of the referrals they require and how to complete them, etc. They are the experts in their care out of necessity, not out of health empowerment. This theme involves several dimensions:

- Research is hard to find; often the source of expertise is an individual's peers or generally available internet sources

- Trans people have to be experts in their own care out of necessity, but often feel second-guessed by health care providers
- Some accept having to be experts in their own care because practitioner is willing to provide service but is uninformed
- This can be frightening to take this level of responsibility for complex health care needs
- It is difficult to be in the position of educator or expert when they are in a health crisis, especially psychological

“And I found myself in the past 5 years interviewing healthcare professionals, to see if they are qualified to help me.” – *Bracebridge*

“While he [the health care provider] was trying to be supportive, he didn’t even know when to start, so I had to do all the work, to tell him what I need, and that was difficult.”-*Barrie*

“They want to know that they’re going to go see is going to have some kind of idea of what’s going on, like there’s a lot of fear about being the one that has to teach the lessons, right?”
-*Bracebridge*

“It’s just ridiculous. It was easier to just go find a surgeon and figure that out on my own than it was to actually try and have a place help me that way. I find a lot of people are stuck figuring it out themselves than the actual health care providers are.” –*Orillia*

“...my experience of trying to access trans related healthcare has been that as a trans person it’s the patient who has to do a lot of the leg work for everything. You have to research the doctors, you’re often self-referring, you’re telling your general practitioner what he needs to do.”-*Barrie*

“I was like “do the thing for me”, but again the doctor was willing to give me any kind of referrals to the endocrinologist but I had to find out who that was, who might be taking people, where it was, like all that stuff. It was like, here’s a name send me a referral.”-
Bracebridge

“...it’s hard, it’s definitely hard. And I can see what you mean about not wanting to reach out or being scared to. And I find we’re educating a lot of the people that are taking care of us, and like, that’s terrifying, because what if something goes wrong? Or like anything? Like, we’re telling them what they need to do, like that... that’s scary.” – *Midland*

The second most common health care experience (n=29) was that the health care provider was helpful and supportive, but as the focus group data reveals, this helpfulness and supportiveness often acts in an ameliorative way to the lack of knowledge or expertise to provide adequate health care service. This indicates that basic kindness is a badly needed salve for the trans health experience, often taking the priority over adequate knowledge and expertise – and that trans people are willing to make that trade-off and do the legwork for their own care in exchange for a gender-affirming encounter.

It appears that the experience of accessing trans health services can be characterized as one of fortune (either good or bad), patching together services and mitigating gaps in service by either not receiving adequate care or having to go to great expense and burden to access it in other places (here note that it is not the surgeries – no one expected that to be local) and a lot of waiting. As expected, the community consultation process revealed negative experiences with health care providers in the health care encounter in NSM however this is not the case with the survey respondents as only a few noted overall that they had experienced negative encounters. Of the 58 respondents, 7 noted that their health care provider terminated or refused care once they disclosed being transgender, 12 said that the health care provider used insulting or hurtful language; 10 reported that their health care provider had refused to discuss their trans health concerns specifically, and 10 reported that their provider had belittled or ridiculed either their trans identity or decisions. One dimension was a bit more common: just under 30 per cent of the sample reported that they had a health experience in NSM where the health care provider negated their trans identity in some way, and 12 noted that their health care provider discouraged their gender exploration needs.

Primary Health Care

The majority of trans residents in NSM have a dedicated primary care provider, and most are within the NSM area. Although approximately half of the sample reported being comfortable discussing their trans-specific health needs with their primary provider, 14 per cent were uncomfortable and most concerning, 10 per cent of the sample do not talk about their trans-specific health care needs with their primary provider at all. Given that the onus and burden of accessing adequate trans health care falls primarily on the trans patient in a patchwork trans health care system, the reality that 10% of trans patients do not discuss their health care needs with their primary care provider out of discomfort is both alarming and has potential consequences for poor health outcomes.

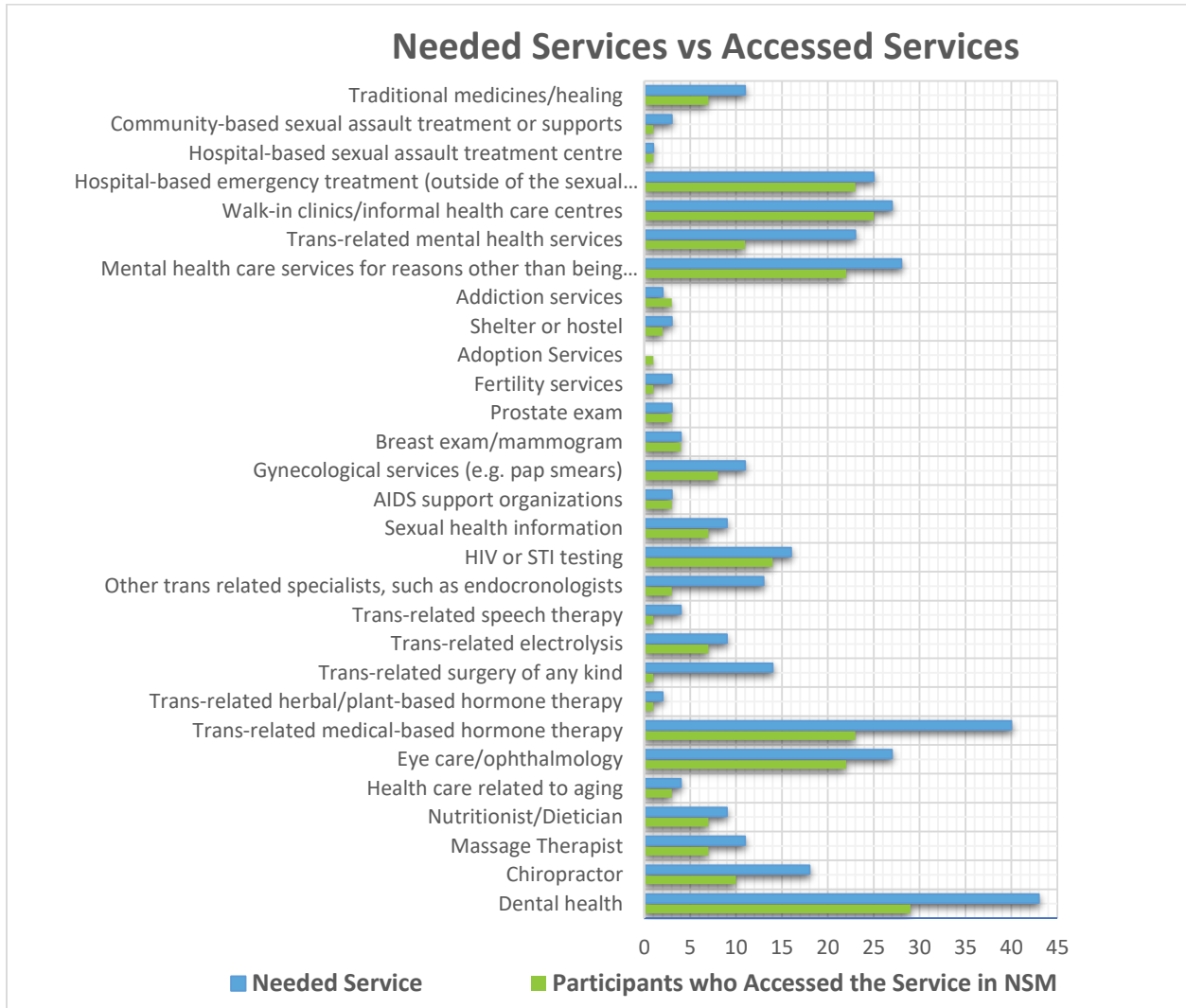
Of those with a dedicated primary care practitioner in the NSM, less than 10 per cent noted that their primary health care provider had knowledge of trans health care needs. Twenty-six percent perceived their primary care provider to be somewhat knowledgeable, however most perceived their provider to have minimal or no knowledge (23 per cent and 12 per cent, respectively). This finding speaks directly to participants' experiences of having to be the expert in their own care, and for doing the "legwork" associated with patching together their health care.

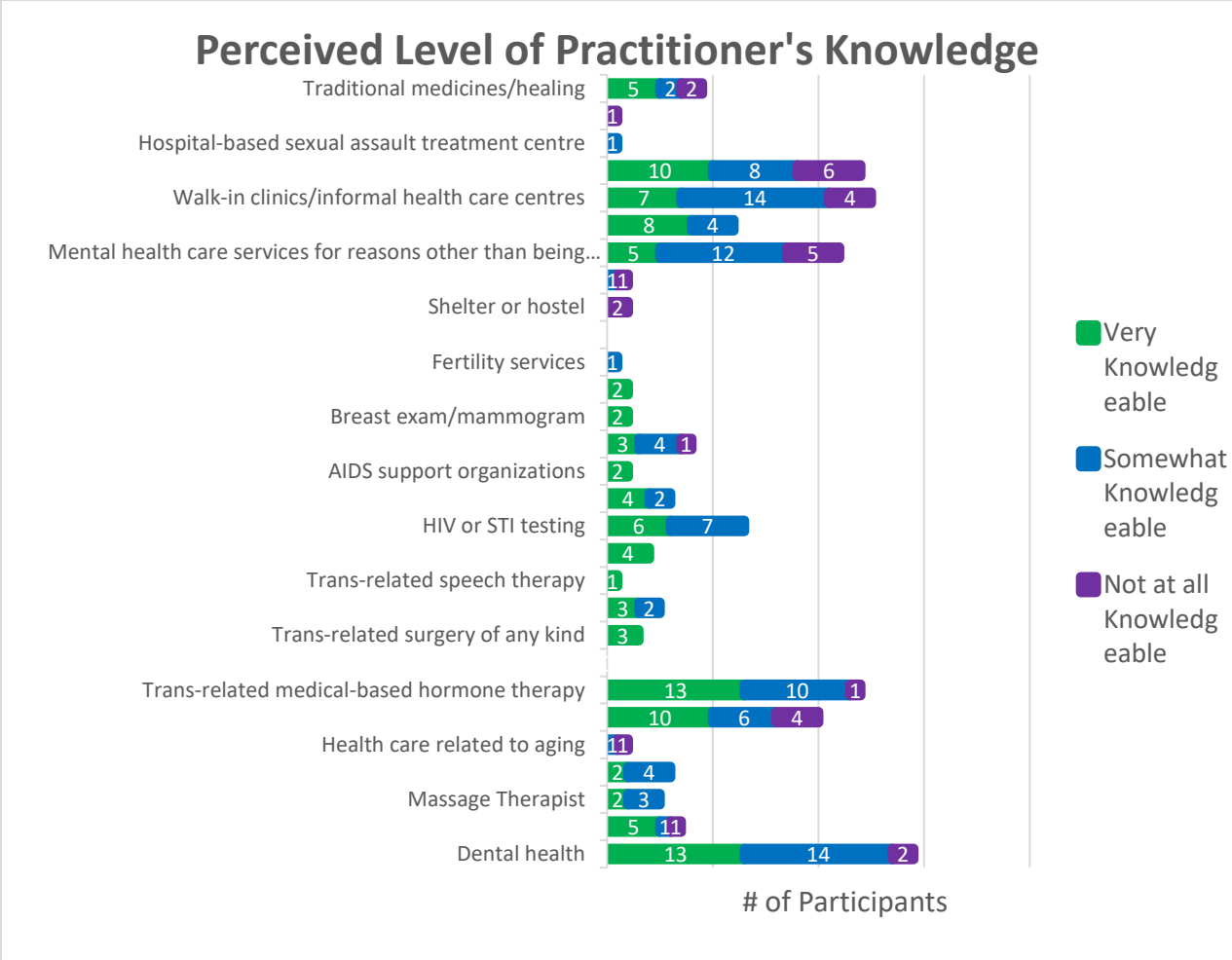
Of those who utilize hormones as part of their trans health care, only 12 per cent were given their initial prescription by their current provider – this speaks to the patching together of services from multiple providers, and perhaps also to an unwillingness to practice with hormones for trans health or the lack of the uptake of the informed consent model of trans health care, as further evidence: only 27 per cent of respondents were having their hormone treatment monitored by their primary health care provider, with 54 per cent being monitored by other practitioners and 15% accessing hormone treatment without a dedicated primary care practitioner at all.

Participants made it very clear that part of what characterized a negative experience was an encounter that negated or refused to validate their true gender. The importance of a gender affirming encounter is therefore a determinant of a positive health service experience. A significant portion of the survey respondents (n=21) noted that they had encounters with health care providers that negated their trans identities in NSM.

Health & Health-related Service Use in NSM

For a better picture of the health-related services that trans residents use or have not used in NSM in the past 12 months and their assessment of each service's competence regarding their specific health needs, the chart below reveals a mixed bag of experiences.





Transitioning

At the time of the survey, many of the participants did not feel as though their bodies reflected their gender identity. Only three felt as though it did completely, and 29 people felt as though it did but only to some degree, while 24 felt as though their body reflected their true gender. Sixteen people felt positive about their overall body image as it relates to their true gender identity, 8 were ambivalent about their body image, and 23 people felt their overall body image as its relates to their true gender identity was negative or terrible. Of note, the 8 people who reported feeling ambivalent about their body image, also identified as gender ambiguous.

Forty-two per cent of respondents are currently using hormones. Twelve per cent would like to be on hormones however were not at the time of the survey; it is not known though whether they were not due to a lack of access issues or a timing matter.

Although it is important to acknowledge that not all transgender people want to biologically or physically transition, or wish to do so by surgical intervention, trans-related surgeries are a significant unmet need for NSM residents. Seventy-two per cent (n=42) respondents reported having had none of the surgeries they hope for regarding transitioning. Only six people have had all of their surgeries, and another six people have had some of the surgeries they want, but not all.

Experience of Transition While Living in NSM

Focus group participants had to travel, do without, find, negotiate and otherwise cobble together some level of adequate ability to transition, versus being offered it. The process of transition was described as slow, fragmented, and frustrating, happening out-of-place and with many fears and risks. The first quote below is indicative of the lengths that people will go to in order to transition, and should be considered in light of the very serious consequences to emotional health that access to transition involves.

“From my own experience, I did actually try to remove my own genitals because I could not get access to proper support. I am currently damaged because of that, but that’s kind of one of the severe things that one might consider when they’re not exactly rational.” – *Orillia*

“I’ve been on testosterone almost three years, it will be three years February 18th, 2017, this year. When I first started this, again three month wait, it was with Quest, -----, it was informed consent, you didn’t have to see the therapist or anything along those lines. It took three months get the prescription, to get that faxed in, start injections, from there I was not told about an endocrinologist, I was told later on by friends who have further transitioned than I have. I started looking around Simcoe, nothing in regards to trans related endocrinologists. I have to go to -----, in Toronto who has a long waitlist, I just got to see him, and I’m talking 8-months waitlist, last December 1st. However, he is very well informed, immediately sent in bloodwork, we need to change your dose, you’re too high. So, I was unmonitored for about two years, actually more than two years.”- *Barrie*

“So overall my experiences here has been acceptable, but it hasn’t been easy. So ya I don’t know if I would still be denied hormone therapy if I were to come in and ask again, and I have thought about that, I have thought about going to my family doctor. I actually went to my family doctor about two years ago and said ok I’ve been on hormone therapy for three years, would you take over? And at that time they again said no. But I haven’t asked again recently...” –*Bracebridge*

“I wasn’t willing to wait and go through CAMH and jump through their hoops and go on a potential multiple year waiting list. So instead I took out a loan to pay out of pocket, and this was before general practitioners or anyone else could refer you. I’m now in massive debt because of it and I can’t really cover that so its kind of messed up my financial situation. I would do it again if I knew it was given the financial situation I’m in, but I really wish that the healthcare referral system had been better so I wouldn’t have felt the need to do that. The choice between going in massive debt or waiting a few years to get the surgery that I needed. - *Orillia*

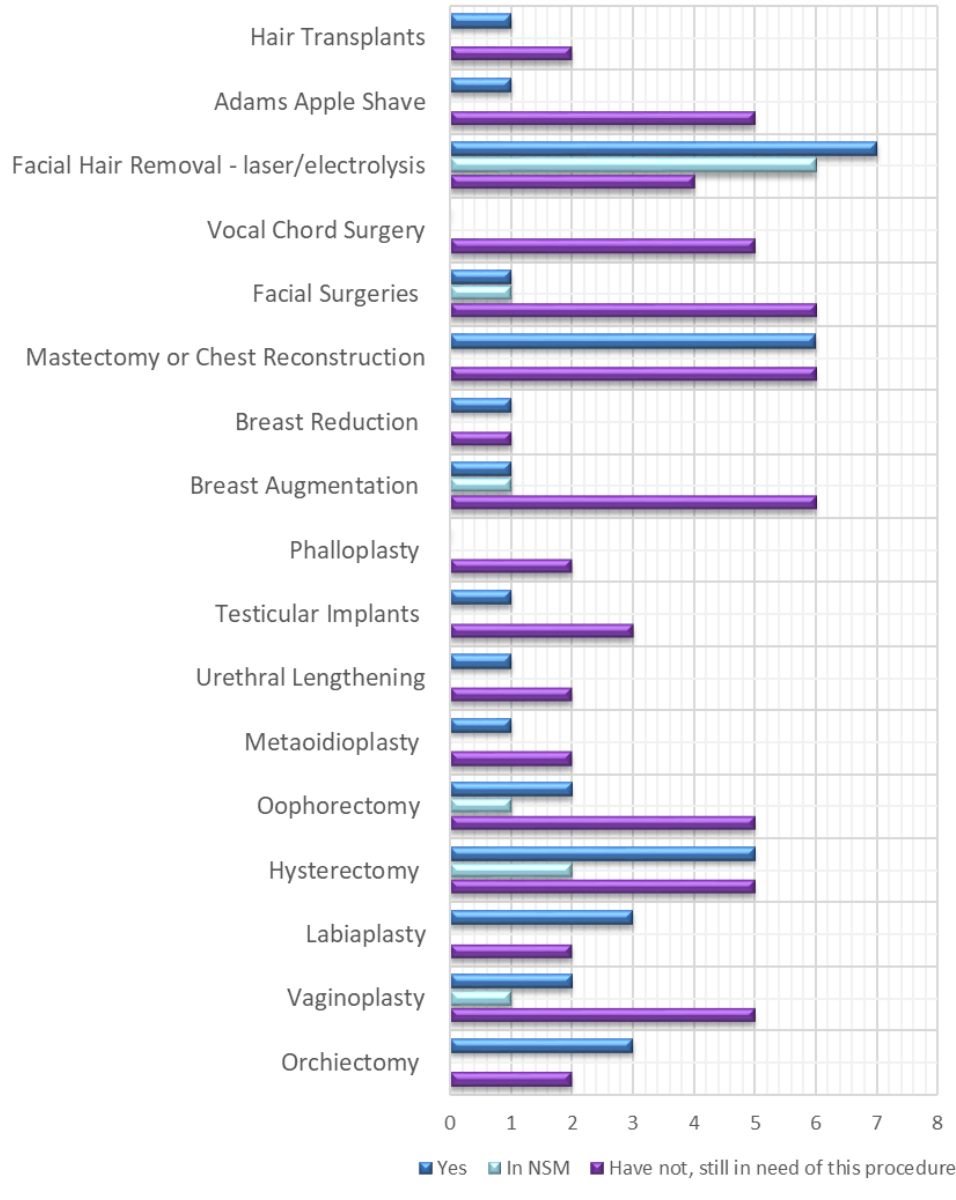
A significant dimension of transitioning or enhancing gender expression is body modification.

Only 26 per cent of the sample had engaged in body modification.

Of the 26 per cent:

Most had not had some of the more common surgeries associated with transition or gender expression. As expected, some people want these procedures, and some do not.

Have undergone the following body modification



The most common modifications done were mastectomy/chest reconstruction and laser hair removal. The most common unmet modification need included vaginoplasty, hysterectomy, oophorectomy, and breast augmentation or reduction. Most in need of follow-up or revision were completed hysterectomies.

In terms of services received or performed in North Simcoe/Muskoka related to modification, one person had vaginoplasty, two had hysterectomies, one had oophorectomy, one had breast augmentation, and one had facial modification surgery done. Laser hair removal was the most common modification done in NSM (as this is considered a cosmetic non-invasive procedure and readily available through local shops and services). The remaining services were

either not performed in NSM or were not needed/wanted (see chart). Four people reported having accessed trans-related body modifications at a NSM tattoo or body mod shop. No one reported ever having self-injected silicone as body modification.

Overall, most of the trans people surveyed did not engage in dieting or exercise behaviours that could be considered detrimental to their health in order to achieve a more congruent body image. However, 26 per cent of participants reported excessive dieting or exercising, and 24 per cent reported engaging in what could be considered risky or distorted behaviour related to body image, including using laxatives, vomiting, and/or regurgitating. Concerning but not unexpected was that most people who engaged in these activities did not discuss them with their health care providers; only 8 per cent of participants noted they had. For the almost 30 per cent of participants who reported they did not disclose this information to their health care providers, 5 per cent noted they withheld that information because they were concerned about their provider's response or discontinued support for their transition

Mental Health Needs and Experiences

In general, transgender and sexual minority residents of rural areas experience elevated rates of mental health concerns and substance abuse than those who live in more urban areas or with access to metropolitan areas (Horvath et al., 2014). Trans people experience extremely high levels of depression and suicide. A recent and representative study in Ontario determined that more than half of trans people in Ontario have levels of depressive symptoms consistent with clinical depression while 43% had a history of attempting suicide, including 10% within the past year (Bauer, Pyne, Francino, & Hammond, 2013).

The self-reported mental health status of the sample was relatively evenly distributed. Thirty-three per cent of the sample self-reported their current mental health as very good or good. Twenty-eight per cent self-reported they were neutral or unsure. Thirty-six percent though reported it was poor or very poor. The majority of the sample reported poor mental health, almost 30%, with an additional four individuals reporting very poor mental health. It is for this reason that there appears to be a high level of mental health services need and usage among trans people in NSM.

Most alarming is that 81 per cent of the sample said that they had either wanted or needed some form of mental health support in the past 12 months. For almost half of those who wanted or needed it, these services were considered available to them in NSM; for almost 28 per cent though, the mental health supports or services they felt they needed were not available in NSM. In general, 56 per cent of the sample had accessed professional support for mental health care in NSM and thirty per cent of the sample had not. Of the 56 per cent of the total sample that had accessed professional mental health supports in NSM, over half were very satisfied or satisfied with the services they received, and just under 20 per cent reported being dissatisfied or very dissatisfied.

A significant number of trans people had accessed institutional mental health/psychiatric crisis services in NSM (26% of the sample). For the most part, when they did access institutional or crisis services, they did not do so in their true gender (only 5 respondents reported having done so in their true identity). Of those who had accessed this level of mental health care, 74 per cent were very satisfied with the level of support they received as trans individuals (only 15 per cent of the sample noted they were not satisfied).

This finding is also reflected in the focus group data, as some had very positive experiences of accessing mental health services; and for those who were not satisfied with what

they received, they reported having some challenging and negative experiences, such as having the experience of trans broken leg syndrome—that their everyday mental health challenges and concerns were seen through the lens of gender dysphoria instead of being taken for value in their own right.

Most concerning though is the high rates of reported suicidal thoughts by trans people in NSM. Forty-five individuals, or just over 80 per cent of those surveyed, have experienced suicidal thoughts; with 56 per cent having experienced suicidal thoughts in the past 12 months. Forty-four per cent of the trans community in NSM had attempted suicide. Of those who reported having attempted to kill themselves, most had made multiple attempts. Most of those who had attempted suicide have either accessed support or treatment at the time of distress or are currently accessing support or treatment. Those who accessed supports or treatment found them at least somewhat helpful but it is not known whether that treatment was in NSM. To put this in perspective, 35.1% of trans Ontarians seriously considered suicide in the past 12 months, and 11.2% had attempted suicide in the last 12 months (Bauer, Schiem, Pyne, Travers, & Hammond, 2015, p.525).

Mental Health Misdiagnosis/Co-occurring Dysphoria

Several participants shared that mental health practitioners were not competent to work with gender dysphoria, or the nuances of dysphoria versus depression symptoms. There were also profound experiences of transphobia intersecting with mental health stigma and oppression, resulting in exacerbated experiences of stigma and discrimination by providers. It is important to note that the profoundly negative experience of transphobic stigma and discrimination contributes to poor mental health outcomes generally for the population, and worsening of mental health outcomes for those who experience mental health disorders (Davidson, 2015). This theme had several dimensions:

- The experience of misdiagnosis
- No providers seemed to be informed or competent in how mental health intersects with trans experience
- Where there was some knowledge of trans mental health need, there appeared to be even less knowledge about the mental health needs of gender fluid or non-binary respondents
- Often involved refusal of service or inability to find service, even through private providers

“A lot of the medical professionals are just brushing us out the door, like we're invalid and it's- it's just insane. And when you add the mental health stuff in the mix, it's just so much worse. Like it's one thing to be okay and going through this to be, you know what I mean. A lot of us, I find, have the mental health problems and stuff and all that's being brushed aside too because of how we identify?! Like it's just really sickening.” –*Midland*

“It's the same story; misdiagnosis, oh they'll come up with, 'you have different things going on, you're anxious so here's a prescription here, you're suffering from depression so here go on this,' when basically it's gender dysphoria.” –*Midland*

“Specifically, in terms of my mental health care, I find it difficult to separate my gender and my gender dysphoria and stuff like that. So, it's hard for me, for someone that's treating me, treating my depression and not understanding that important aspect of it.”- *Barrie*

“ A little more than a year ago I was in crisis. This was a result of the doctor simply not knowing, but I went in in-crisis and the doctor spoke to me about reversal. I was already distraught and that put me into a severe state of distress. While in the hospital when he went away I took every pill I had in a very serious suicide attempt. So the doctors need to be brought up to date. “ – *Orillia*

“I’ve had no trouble with any other part of the hospital when I go in for medical problems. I always, they know me so they already know I’m transgender, but, I’ve never had any problems with the medical part of it and anytime I needed to talk to a crisis worker I always got one in particular and she was excellent. So, I’ve, as far as the experiences in the hospital go that’s fine.” - *Orillia*

Substance Use

The disproportionately higher rates of problematic substance use and substance use disorder among trans people compared to the cisgender population is well-documented in the academic literature (for example, Lick, Durso, & Johnson, 2013). However, the results demonstrate that problematic substance use or abuse is not a significant concern for respondents.

There is very little tobacco use among the trans community in NSM, with only 10 individuals reporting currently smoking. For those 10 tobacco-users, their use is considered frequent or regular, with only three individuals considering their tobacco use to be problematic.

Seventy per cent of respondents reported current alcohol use, and most characterize their use as occasional or rare, and only one individual noted they considered their alcohol use to be heavy and problematic.

Less than half of the sample used marijuana, and citing primarily recreational use. A few non-recreational users have prescription-based use, and 18 per cent of the marijuana-using individuals identified their use as for self-medication purposes. For the most part, respondents do not engage in any other recreational drug use (only 14 per cent identified as using any other drug recreationally) and for the most part did not consider their use of other drugs to be problematic. Only one person in the sample identified as requiring and being in substance use treatment, however a few individuals did note that they would like to access substance use treatment but do not out of concerns regarding their trans identity. Five people have accessed or do access 12-step programs in NSM.

Sexual Health

The results of this section were mixed, demonstrating that for the most part, the NSM trans population was under-served in terms of sexual health information and resources.

- Just over half of those surveyed reported believing they had access to trans-specific sexual health information, with 22 per cent being uncertain; 25 per cent of the sample were certain they did not have access to adequate information.
- Only 35 per cent of the sample perceived they had access to trans-positive STI testing in NSM, and 45 per cent were uncertain

Twenty-one individuals had received testing for HIV/AIDS while living in NSM. For the most part, respondents did not perceive themselves as at risk of infection/reinfection as a result of their sexual activity. Here the survey results can be interpreted in two ways: either by the voices of the respondents alone, in that respondents' self-reporting or self-perception is accurate and they are indeed engaging in safe sex practices for those who are sexually active. However, the scholarly evidence suggests that gender and sexual minority groups are at a disproportionately higher risk of contracting sexually transmitted infections (Davidson, 2015). However, 33 per cent of respondents demonstrate the need for greater access to information and interventions, in that they either believed their sexual activity did present a risk for STI infection/reinfection or were uncertain. Relatedly, less than 15 per cent had accessed an ASO for sexual health information in the last year.

Concerns and Fears about Health/Health Services

Participants were asked specifically about their concerns and fears about their health and health care services in NSM. This is by no means an exhaustive or comprehensive list of the fears and concerns expressed by focus group participants, however it represents some of the larger themes reflected throughout the data.

Most participants, even if they detailed having positive health experiences, had significant fears and concerns. Participants in Midland as well as other focus groups discussed several instances where they were denied services, or were denied parts of services (such as physical examinations).

Being denied service or access

Referring to a nurse practitioner in a neighbouring town: “..uh, just trying to get on his roster and stuff, and he was just like you were saying about it: unknowledgeable, and unwilling. I remember talking to him about getting a referral letter for top surgery and he literally in the exact words that “I should go home and rethink it”. And like, I had already been on testosterone for three or four months at that point. It’s like, you know, it’s not something you’re just going to rethink.” – *Midland*

Wait-lists

As part of a conversation among participants at the community consultations...

First Participant: “I was going through CAMH again waiting list for that and I was on that list for two years before I was finally contacted. So that was an ordinate long time waiting. The procedure went, that was January of this year [2016], by May I had all my referrals done to the clinic for the surgery. Because the recent changes to allow medical practitioners to refer patients directly for surgery, instead of going through CAMH, now that’s created a bottleneck at the clinic. So, I’m presently caught up in that, still waiting for a date, so yeah anyway that’s the best of my experience.”

Second Participant: “This is one of my major fears that this very same thing is coming for me. So it’s going to be very long, that my surgery is going to be delayed quite by several months for the same thing that seems to have occurred with the referral process.”

-Orillia

Stigma & discrimination preventing health and well-being

“Uhhh, again with the experience that I have heard about, in one person in particular trying to access services in Gravenhurst that was just blatantly told we won’t do anything for you, right, get out, get out of town, and they did which is again what generally happens, right, for any and, we were talking about this, if you’re an adult here and experiencing this and you’re not stuck at home you’re probably just going to leave. Because there isn’t services here, or the perception that there isn’t services here. Uhh, overall my experiences here has been acceptable, but it hasn’t been easy. So ya I don’t know if I would still be denied hormone therapy if I were to come in and ask again, and I have thought about that, I have thought about going to my family doctor. I actually went to my family doctor about two years ago and said ok I’ve been on hormone therapy for three years, would you take over? And at that time they again said no.” – *Bracebridge*

Not being able to rely on competent providers

“So, that’s one thing we need, general practitioners to have more education of trans issues so we don’t always have to go out to Toronto or wherever outside of our general community because many of us we don’t have the funds or the transportation to go outside and we have a lifetime of transition to go through. This isn’t just five minutes and we’re done, this is our entire life. If it costs us \$100 to go down to Toronto to see a doctor five minutes then comeback, over the next, you know if you’re 20 years old and you live to be 80 you’ve got 60 years of \$100 a month it’s going to add up to more than someone’s lifetime income so we need to have it in town.” - *Barrie*

Survey respondents were encouraged to use an open-ended dialogue box to add any comments that they felt important after completing the survey. Most reflected what was already noted in this needs assessment: the difficulty in accessing safe and appropriate transition and transition-related care both in general and in NSM, the resulting social and psychological impact of not living their true lives, and the loss felt at years lived in the wrong life. Their comments follow the same themes in recommendations: more access to more services, better training of providers, better accountability in terms of non-judgmental and ethical service provision and a better awareness and service orientation toward not only trans health issues, but gender fluidity and the health needs and concerns of gender fluid individuals as distinct from trans individuals.

“As a gender fluid person, I find that a lot of health professionals have a difficult time with the concept and can’t support me effectively because they get hung up on binary norms. As one professional put it to me “wouldn’t it be easier just to pick one and stick with it?” (survey respondent).

Limitations:

As with any study, there are limitations. As a relatively small community-based assessment, we cannot determine how representative the sample is of trans people and their experiences in NSM, therefore its generalizability is limited. Also, the design involved self-reported data, and therefore is subject to different biases including respondents perhaps presenting information in a positive light to avoid embarrassment or a lack of willingness to reveal details about private information. The sample itself, reflective of the rural/suburban and smaller towns and cities that comprise the NSM, is primarily Caucasian and English-speaking and therefore findings should not be generalized to other communities or populations without acknowledging its homogeneity.

In addition, some of the questions in the survey were distinctly about gender transition or expression as it relates to transitioning. Such questions may have been difficult for participants who have fully transitioned and no longer considered by themselves or others as trans:

“Some of your questions are about acceptance as a transgender individual. They no longer apply to me because I have changed enough with the hormones and other things that I am seen as a woman everywhere and no-one, anywhere, knows I am trans except my health care providers and my family and my support group” (survey respondent).

Recommendations

Education/Training

- There be mandatory education of health service providers, including primary care practitioners. It needs to be noted here that health literacy does not directly translate to reduction in stigma and discrimination, therefore two levels of education and training need to be addressed (Stuart, Arboleda-Florez, & Sartorius, 2012).
- Delivery of on-going trans-specific mental health training for health practitioners and community mental health service providers.
- That there be trans health educators, from the community, training service providers and enhanced opportunities for peer support.
- The development of a respectful and safe trans-health service encounter protocol (for health practitioners, hospitals, community agencies, front line staff) created by trans people who are compensated for their time.
- That there be a recognition of the many non-binary identified people within the trans population, and that education and training be reflective of this fact. Further, that non-binary people are able to access the methods of physical transition that they require.

Service Planning Specific for Suburban/Rural & Under-served Communities

- The creation of a service plan to address lengthy wait lists for surgical interventions.
- The adoption of a holistic health approach (physical, psychological, social).
- Provision of support to navigate trans specific medical, mental health and social services.
- Creation of a comprehensive medical service plan for people in towns and communities not adjacent to larger centres.
- Greater service planning and investment to support “transitioning in place” for those residents who wish to, or are currently in physical transition. Participants travel frequently, often quite a distance, for both procedures and monitoring/maintenance of stages of care or interventions. Participants did not expect that they would not travel for more intensive, specialized procedures however some noted being concerned or even frightened about post-intervention recovery or access to practitioners between appointments. A priority should be placed on providing a continuum of services,

including recovery and after-care for surgical procedures or interventions done far from home.

Creation of a Community-Based Multi-Service Site

- In order to address the considerations of serving rural communities, to manage waitlists, and to enhance/integrate community organizations partnerships, community-based holistic health services should be considered. A multi-discipline, multi-service, multi-dimensional (e.g. mental, emotional, physical and social) centre approach that is widely accessible with regard to geography and cost. Respondents felt that Orillia was uniquely positioned as a possible site for a trans health gateway to serve northern communities.

“I would love us to get to the point where we normalize the trans condition and the normal population, and particularly right across the healthcare profession where healthcare professionals have at least the exposure and some experience about and with trans people.” – *Bracebridge*

“...we have the regional cancer centre, but what we need is, we need to have a transgender centre so that we can have surgeries done here, we can have mental health, hormone therapies, everything covered under one roof so our general practitioners can direct us straight to a place that is local. We don't have to go to twenty different places just to exist we can just be in one central location, basically a one stop shop where we can get everything done.”- *Barrie*

“Ideally, in a perfect world, I'd like to have more access to, now that we have better access to referrals for surgeries, it'd be nice if we had more doctors doing the surgeries so that the wait list isn't so long and people aren't being forced to pay out of pocket because they just can't wait, or get really desperate and do something very desperate. And just more access for hormones and more ways to get the information the doctors need to know. If they won't do it themselves, then they should know directly who to go to get those hormones to instead.”- *Orillia*

“...sensitivity training definitely. And we're not just talking about those health care practitioners directly related to transition, like: nurse practitioners, doctors, therapists. We're also talking about the dentists, the oculists, the – all the other stuff that we also have to see people for and who get access to a certain amount of medical records.” – *Midland*

There are also significant lessons to be learned from previous research, including the Trans Pulse survey (Ontario) and the general academic literature. The evidence base for reducing health disparities and serious consequences to well-being such as suicidal ideation includes:

Social support [both on an individual and community level], reduced transphobia, and having any personal identification documents changed to an appropriate sex designation were associated with large relative and absolute reductions in suicide risk, as was

completing a medical transition through hormones and/or surgeries (when needed).

Interventions to increase social inclusion and access to medical transition, and to reduce transphobia, have the potential to contribute to substantial reductions in the extremely high prevalence of suicide ideation and attempts within trans populations (Bauer, Schiem, Pyne, Travers, & Hammond, 2015, p.525).

Completing a medical transition had beneficial individual and population effects. It was associated with a 62 % relative risk reduction... in ideation. On a trans population level, to facilitate completion of medical transition (when desired) would correspond to preventing 170 cases of ideation per year per 1,000 trans persons, representing 44 % of ideation, and further preventing 240 attempts per 1,000 with ideation...or 69 % of attempts (Bauer, et al., 2015, p.536).

Given the recurring and significant theme of acceptance, rejection, and isolation reflected in this assessment, the following data provides important context that should serve as a foundation for its next steps: follow up, action, and ongoing engagement and participation in their health care as well as their communities.

- Only 4 per cent of respondents reported that they perceived their communities as accepting; 39 per cent were somewhat accepting, and 42 per cent perceived their local communities as unaccepting to some degree

Overall, one survey respondent's comments reflect the main themes of their community as expressed in this needs assessment, speaking to the importance of peers for social connection, the lack of access to needed services, the vulnerability, fears, and real consequences about outing one's self to service providers (such as being denied service) – and of course the resilience and the hope.

“I have lived a very unique and painful experience, including isolation from the outside world for many years. [Name excluded], a trans activist in Barrie found me and saved my life. I just wish I was more like other trans, and shared some of their life experiences, intellect, and social aptitudes so I could connect and have friends. I couldn't get hormones and surgery for most of my life. Just ended up going crazy. But I wasn't even allowed be crazy or they'd lock me up. To genuinely feel sad and empty every single day, and knowing these feelings will never go away, even now after GRS [gender reassignment surgery], it's a hard thing to deal with. Happiness exists, but it's only a distraction from the reality of what is, and what's been lost. I wish I could have had a life, but at least I'm still alive. So will make the best of what's left with the few options available to me. Still hope to one day fix the rest of my body. If I can work hard @ night and save enough money maybe I will. Just hope my addictions don't come back. But I should be ok cuz have a family that loves me now :)”

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