Queer and Trans Experiences of Accessing Mental Health Support in Aotearoa

Summary of findings for participants & community advisors

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If you are reading this report, you have probably helped to make this research happen. This might have involved taking part in an interview, providing guidance and advice around the research process, writing in support of a funding application, funding the project, or giving me a much-needed pep talk! Thank you for your help so far, and I hope you will stay connected as we enter the next stages of the project.

**BACKGROUND**

A substantial body of international research demonstrates that sex, sexuality, and gender diverse people around the world experience high rates of adverse mental health outcomes as a result of stress caused by stigma, violence, and discrimination. Research from Aotearoa – a country well-known for being at the forefront of social change – suggests that mental health disparities within rainbow communities reflect those seen internationally. But are queer and trans people receiving the support they need from Aotearoa’s mental health system?

The aim of this study is to gain an in-depth understanding of the experiences and needs of queer and trans people who access mental health support in New Zealand. My hope is that this will highlight potential areas of improvement in New Zealand’s mental health service provision for queer and trans clients. A second aim of the study is to consider ways in which these findings can inform the development of a resource to guide mental health professionals in their work with rainbow clients. The research questions for this study are as follows:

- What are the experiences of rainbow community members who access mental health support in New Zealand?
- What are the experiences of gender diverse people who undergo mental health assessments for gender-affirming healthcare in New Zealand?
- How can these findings inform the provision of high quality and responsive mental health care for queer and trans people in New Zealand?

**METHOD**

This was a community-based research project informed by queer and transgender theories. Rainbow community organisations (in particular, Gender Minorities Aotearoa and InsideOUT) were involved in decision-making around the research design, interview questions, recruitment, and analysis of findings. Thirty-four rainbow community members aged 16-30 were interviewed for this project. Participants were given the option of taking part in an individual semi-structured interview, or taking part in a focus group. The interviews were carried out between May and September, 2017, and took place at a location of the participant’s choice. Interviews took place at a University campus, university premises, participant’s home, or a bookable room in a community space (e.g. central city library or community organisation). Discussions ranged from 48 minutes to 124 minutes in length, with an average length of 76 minutes. Data were analysed using thematic analysis, a method for identifying, analysing, and reporting patterns of meaning (themes) within a dataset. I identified six themes in relation to accounts of accessing mental health support, and three themes in relation to accounts of accessing gender-affirming healthcare.
**THEME 1**

**Accessing healthcare is like a game of strategy**

In the years leading up to this set of interviews, New Zealand’s public mental health services underwent significant funding cuts. The real-world consequences of these funding cuts were apparent when participants were asked what had made the process of accessing mental health support easy or hard; in response to this question, almost all participants focussed on the structural barriers associated with seeking support. Most participants viewed New Zealand’s mental health system as underfunded and overstretched.

The most commonly cited barrier to accessing mental health support was lengthy waiting times. Participants also reported that they felt they had to be very desperate to get help, and many had previously had referrals rejected. Several participants reported delaying help-seeking as they were aware they may not meet the criteria of ‘moderate to severe mental illness or psychological distress’ for publicly funded mental health treatment. Participants described this process as exhausting, frustrating, and disheartening.

Although the structural barriers participants discussed seem to be a product of an overstretched and underfunded public mental health system, rather than participants’ sexualities or gender identities, it is likely that difficulties in accessing support are exacerbated among queer and trans New Zealanders due to the limited number of explicitly rainbow friendly services. Almost all participants stated that they explicitly seek out services that are queer or trans friendly when accessing mental health support, but noted that it can be difficult to find friendly services.

These findings highlight not only the need for mental health sector reform, but the importance of considering the ways in which system-wide issues may disproportionately impact marginalised groups, such as New Zealand’s rainbow communities.
Although interview questions around stigma and discrimination were specific to experiences within mental health support services, almost all participants discussed fears of, or experiences of, sex, sexuality and/or gender-based discrimination outside of therapy.

The impact of societal stigma and discrimination on participants’ daily lives was most apparent during discussions of the coming out process. Participants typically framed coming out as something to be actively negotiated, with many commenting that there was always a possibility of a negative reaction. Coming out in therapy was described in the same way - as potentially risky.

Together, participants’ talk around coming out in mental health settings suggest that they viewed mental health support settings as a microcosm of the world. Rather than seeing therapy as a safe space, or a context in which their identities would invariably be accepted and validated, participants described mental health settings as places in which they may be exposed to the stigma and discrimination they routinely experience in daily life. Some participants explicitly reflected on the embeddedness of therapy within a homophobic and transphobic society.

The finding that queer and trans clients often see therapy as reflective of the wider social context highlights the need for mental health professionals to actively challenge heterosexism and cissexism, and to communicate this to their clients.
For many participants, the process of coming out in therapy was complicated by the fact that mental health professionals rarely asked about how participants identified their sex, sexuality, or gender, or whether this was something they wanted to discuss. Participants generally reported that mental health professionals had only initiated conversations about identity in cases where clients were presenting for gender-affirming healthcare, or had information about their identity included in their referral.

When participants were asked whether it would be helpful to incorporate questions around sexual orientation and gender identity into standard assessments, there was considerable disagreement, with some saying that this would feel validating and would open up the conversation, and others noting that this could feel confronting and unsafe. A common concern was that asking about sexual orientation and gender identity may put pressure on clients to provide an answer before they were ready.

Participants suggested a range of alternatives to asking direct questions about identity, including asking about pronouns, displaying visual cues, and using gender neutral language.

A number of participants noted that they found visual cues an effective signal that a professional or service was rainbow-friendly. These included posters, flags, stickers, or buttons with rainbow colours and brochures or flyers about sex, sexuality, and gender.

Participants also described changes that mental health services could make at the institutional, rather than individual level. This included having gender neutral bathrooms available at the service, and ensuring that intake forms collected data from people of all genders.
When discussing positive versus negative experiences while accessing mental health support, the single biggest concern participants expressed about their therapy experience was the lack of knowledge they felt mental health professionals had about sex, sexuality, and gender diversity. Participants described knowledge gaps in the use of appropriate language and terminology, understandings of sex, sexuality, and gender, the issues faced by particular groups within the rainbow community, and the nature of the relationship between identity and mental health. Participants commonly reported that they had to educate their mental health professionals about queer and trans issues, and stressed the need for rainbow education and training within the mental health sector.

A number of participants reported that their mental health professionals lacked knowledge of queer and trans terminology, and had asked for definitions of the words clients used in session, including ‘cis,’ ‘LGBT,’ ‘trans,’ ‘dysphoria,’ ‘pansexual,’ and ‘polyamory.’

Although many participants emphasised the importance of language, it is important to note that they did not expect their professionals to always use correct terminology in mental health settings. Rather, participant acknowledged that mistakes can (and do) happen, and focussed instead on professionals’ response to their mistakes. They noted that it was important for mental health professionals to acknowledge their mistake, apologise, and move on, rather than to try and explain away their mistake.

These experiences highlight the potential ramifications of knowledge gaps within mental health services. Although mental health professionals may not harbour queer or transphobic views, a lack of knowledge about sex, sexuality, and gender diversity can compromise their ability to support rainbow clients who are exploring their identity.
While discussions of positive versus negative experiences within mental health settings were primarily centred around professionals’ knowledge of sex, sexuality, and gender diversity, participants emphasised that knowledge of queer and trans issues is not sufficient for supporting rainbow community members; mental health professionals must also draw on their basic clinical skills of reflective listening, empathy, and validation. Participants’ perceptions of their professionals’ clinical skill varied. While some participants had found their mental health professionals respectful and affirming, others felt their professionals had not listened to their needs in therapy. Participants who described negative mental health support experiences commonly felt their mental health professional had focussed on topics in therapy that participants had not presented to discuss, or had crossed professional boundaries.

Participants stressed the importance of mental health professionals checking in with their queer and trans clients about whether they wanted to discuss sex, sexuality, or gender, or how they saw the relationship between their identity and their mental health. This way, professionals can use their client’s responses to guide the conversation.

In conversation around what participants need in mental health support settings, normalising and validating identity were also commonly described as essential for effective therapy.
Though some participants reported that they found their mental health professionals knowledgeable and supportive, conversation was dominated by talk about the difficulties of coming out in mental health support settings, and the ways in which participants feel mental health professionals need to improve their knowledge about queer and trans issues in work with rainbow clients. Despite the challenges that participants had faced in society and in mental health settings, however, participants expressed a deep care for other queer and trans people, and a desire to give back to their communities.

Participants commonly responded that they took part in the hopes of making positive change for the rainbow young people that followed after them.

Several participants reflected that mental health services are only one potential source of support for rainbow community members, and that the rainbow community had been an important source of support when they were struggling with their mental health. As such, taking part in research about queer and trans mental health was a way of giving back to the wider community.

It did seem, however, that this care often came at a cost. Participants who worked in rainbow or activist communities noted that they often found it difficult to care for themselves when they felt a responsibility to care for others. The emotional burnout that participants described (for many, this followed years of advocacy work in their communities) highlights the need for those outside the rainbow community to confront homophobia, biphobia, transphobia, and prejudice against intersex people, to ensure that this responsibility does not fall solely on the shoulders of queer and trans people. While allyship can be complex – as majority members must confront prejudice without speaking on behalf of rainbow community members – it is arguably more important for straight and cis people to support rainbow communities (and potentially make mistakes along the way), than leave this work entirely to the rainbow community.
Participants’ discussion of barriers to accessing gender affirming healthcare closely reflected talk around barriers to accessing general mental health support. Most participants described the process as drawn out and frustrating, due to funding constraints within the public health system. They noted that there is a shortage of mental health professionals and endocrinologists qualified to carry out readiness for treatment assessments, as well as a lack of surgeons who can perform gender affirmation surgeries, leading to lengthy waiting lists to access care.

Participants also reported that, because there is no national medical pathway for accessing gender-affirming healthcare, the availability and accessibility of gender-affirming healthcare is often dependent on the region in which someone is trying to access care. Larger cities were generally described as easier places to access gender-affirming healthcare than smaller cities, towns, or rural areas.

While participants described accessing hormone therapy as difficult, accessing surgery was described as virtually impossible within New Zealand’s public health system. At the time of interviewing, the Ministry of Health stated that to be placed on a waitlist for publicly funded surgery required more than 12 months of continuous hormone treatment, more than two years of successful and continuous real life experience, two psychiatric reports by senior psychiatrists with some experience in the field, as well as a psychologist’s report by a senior psychologist or social worker with experience in the field. Once someone is on the waiting list they could wait up to 52 years. This creates a Catch-22; many gender diverse people are unable to get onto the waitlist (often because doctors do not want to put their patients on such an unethically long list), but the Ministry of Health uses the list to guide funding decisions. As such, the length of the waiting list does not capture the true demand for gender-affirming surgeries, and improving funding for transgender healthcare remains a political non-priority.

**PENNY**

Most people do it privately in [my local DHB] because public’s useless, they admitted they don’t want to know anything about it, they don’t want to deal with it, cause they have no funding for it, and they have virtually no one who’s knowledgeable about it. I know a range of people who’ve just recently done mental health assessments, it cost 500 to a grand, for some of them.

**NYKK**

It was something I was going to do, and then I looked into it and realised there’s no point. The trans surgeries, the average waiting time to get it is 32 years, and I was like what’s the point of me doing anything? I’ll be an old person by the time I get there, what’s the point, I felt like there was just no point (…) you’d be more likely to win lottery basically than be able to get surgery in New Zealand.
At the time of interviewing some healthcare services in Aotearoa were beginning to move away from traditional models of transgender healthcare, which focussed on real-life experience ‘tests’ and diagnosing gender dysphoria. Despite this, participants commonly described assessment experiences that aligned with diagnostic models, in which they felt they had to prove their gender in order to access care.

Many of the assessment questions that participants described seemed to reflect the DSM-V criteria for gender dysphoria, including attempts to establish how long participants had experienced gender dysphoria, or identified as transgender. While some participants noted that questions around gender dysphoria were asked in a respectful and sensitive manner, others reported that their mental health professional’s questioning had felt insensitive. Participants often described a focus on childhood experiences, as well as a focus on their gender expression during assessments for gender-affirming healthcare.

Almost all participants who had accessed gender-affirming healthcare shared that, because assessment questions seemed focussed on establishing they were transgender, they felt there was a particular story they had to tell about their gender in order to access care. Although participants’ perceptions of the trans narrative varied slightly, all agreed that this involved having a binary gender identity, knowing they were trans since a very young age, and wanting a ‘full’ medical transition. Other participants noted that embodying the dominant trans narrative was not only about how they described their gender identity, or gender journey, but about how they expressed their gender in session.

HENRY
The psychologist should take you seriously instead of going out of their way to sort of prove you’re trans (…) They’re always second guessing you and trying to really really really make sure that you’re really trans and really ready to commit when it’s not you haven’t said that 200 times already.

FELIX
In part of my psych assessment to begin testosterone my psychologist had to specify how I dressed (…) When I started dressing as the other gender

WILLOW
You’ve got to present the facade of the 50s housewife if you want to get anywhere. With all the uncomfortableness of that, the connotations of that (…) you have to basically play on a bunch of stereotypes. One of my friends was being the older cynical trans, and she was like yeah just, if you’re going to go to another one of those appointments, the first thing you do is go full high femme, you know, long skirts and high heels and way too much lipstick, et cetera.
In discussions around participants’ views of best practice for providing gender-affirming healthcare, informed consent was typically described as the gold standard. Informed consent has evolved as an alternative to the standard model of care recommended by the World Professional Association for Transgender Health, which emphasises mental health professionals’ role in assessing readiness for gender-affirming healthcare. The informed consent model seeks to acknowledge and support the patient’s right to personal autonomy in choosing care options without the required involvement of a mental health professional.

"I think definitely working towards informed consent and just that approachable, understanding, sort of thing. It's stressful as hell, especially when you've been kind of forced to explain how you're feeling as a requirement to getting medication, which is lots of pressure. So I think if we get as far as possible from that burden of proof, would make things a lot easier, and just a lot more humane" - Lesley

While all participants stressed the importance of having the option to see a mental health professional, most did not think that this should be compulsory in seeking gender-affirming healthcare. Some participants noted that they would have appreciated more information about the physical effects of hormones:

"I didn’t do that much research into the effects of T, like heavy effects and all the random ones that I didn’t know about. When I went and saw the endocrinologist he didn’t seem to go out of his way to mention the risks to me, besides that the infertility one. So it’s kind of like, they spend all this time trying to approve your identity, and they’re not really fully explaining every single risk to you, they just assume you already know. They’re putting all the emphasis on the wrong place" - Henry

Participants’ difficulties accessing gender-affirming healthcare highlights the need to develop a national transgender health standard so that the availability and quality of care is no longer determined by location. Participants’ experiences also emphasise the importance of increasing funding for gender-affirming healthcare, and providing this care in a way that respects and validates patients’ gender identity and expression.
NEXT STEPS

I am currently in the process of writing up the findings from these interviews for my thesis. The next step in this project will be to conduct a survey with rainbow community members across Aotearoa, to find out if their experiences of accessing mental health support reflect those of the 34 people I have already spoken to. This will be an online survey, will be brief (around 10 minutes), and will begin in October 2018. I would be hugely appreciative if you could share this in your networks, so that we can hear from as many people as possible. The link will be sent around via email, and will also be posted to Facebook and Twitter. Keep an eye out!

After the survey the final step in the project will be to create a resource for use by mental health professionals, to guide their work with rainbow clients. This will likely take the form of a short booklet, and I look forward to working with Gender Minorities Aotearoa, InsideOUT, Rainbow Youth, and a range of other community organisations in developing the resource. I will also be looking to gather feedback from the rainbow community through email and focus groups, so please get in touch if you are interested in taking part. We will be developing the resource throughout 2019.

If you have any questions, whakaaro, feedback of any kind, please email me at Gloria.Fraser@vuw.ac.nz.