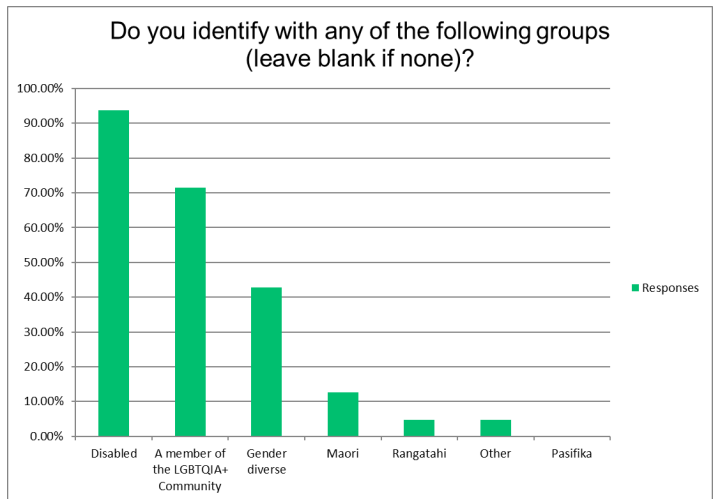


NZCSRH Feedback for Practitioner Training Project:  
Experiences of Disabled Clients Accessing Sexual and Reproductive Healthcare in Aotearoa  
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In November 2021, the New Zealand College of Sexual and Reproductive Health (NZCSRH) wanted to collect feedback from disabled people about their experiences accessing sexual and reproductive healthcare in Aotearoa New Zealand. It was achieved through firstly the use of an online survey, which used social media and community contacts to distribute, then a Hui (Meeting) that took place over zoom and one on one interviews. The survey had good engagement, with 63 participants taking part. In Aotearoa, disabled people make up 24% of the population as reported by the 2013 Disability Survey<sup>1</sup> (The most recent survey available currently).

Our participants mostly came from the main centers of Otago, Wellington, and Auckland with little or no representation from other areas of the country. The age breakdown showed a significant skewing of the survey population to the age bracket 21-30years (71%). In linking our participant age stats back to NZ disability statistics, in the 2013 Disability Survey; the percentage of disabled people can be broken down by age to under 15 was 11%, 15-44 was 16%, 45-64 was 28% and 65+ was 59%. Our survey's demographics section also asked a question asked our participants about intersecting minority groups and the identities that they have.



As seen in figure one, we found that 71% of our participants were LGBTQIA+, 41% were gender diverse and 12% were Maori. Knowing this helps us place our own survey results in the context of Aotearoa's disabled population. Disability is regularly conceptualized using the "Medical Model" and the "Social Model". These are both important in explaining some of the issues faced by disabled clients/patients. Using the Stanford Encyclopedia of Philosophy<sup>2</sup>), the medical model explains disability as the impact of the disability on the body, placing the 'blame' or issues of accessibility onto that of the person rather than society being an inaccessible society for disabled people to live in. "The medical model explains disability disadvantages in terms of pathological states of the body and mind themselves. It regards the limitations faced by people with disabilities as resulting primarily from their bodily differences" in contrast, the social model "explains the characteristic features of disability in terms of a relation between an individual and her social environment: the exclusion of people with certain physical and mental characteristics, or 'impairments' from major domains of public life". In simple terms, these two models of disability are applicable to the experiences of disabled clients in accessing sexual and reproductive healthcare (and healthcare in general) as society is directly shaped and formed by our understanding of disability. The feedback made by participants in this report is presented under two themes, the first is 'Feedback on experiences of care', and the second is; 'Accessing care and resources'. Found within these themes are specific feedback in the form of quotes by project participants and

<sup>1</sup> <https://www.stats.govt.nz/information-releases/disability-survey-2013>

<sup>2</sup> <https://plato.stanford.edu/entries/disability/#:~:text=1.-Models%20of%20Disability.been%20classified%20as%20%E2%80%9Cdisabilities%E2%80%9D.>

statistical data, and recommendations on ways to better support disabled people accessing sexual and reproductive healthcare.

Theme One: Feedback on experiences of care:

Disabled clients accessing mostly negative care:

This section includes:

- Clients feeling uncomfortable during appointments
- Accessing care as a medically complex client
- The essential needs of clients (as rated by participants) in general and in abortion care
- Recommendation: Continuing to centralise the voices of disabled clients in future discussions of the care of disabled clients
- Recommendation: Teaching medical providers about basic sociological theory (such as disability theory, the pros and cons of such theory and feminism theory that underlies the care and treatment of clients)
- Recommendation: The development of an intersectional approach to care (Includes the needs of clients who are Maori, LGBTQIA+ and trauma informed care)

Through our feedback gathering, the major overarching theme is that disabled clients are having negative experiences when accessing sexual and reproductive healthcare in Aotearoa. Negative experiences were the most reported, and indicate the systemic change that is needed to better meet the needs of disabled clients. In the survey, the participants were asked “how would you rate access to sexual and reproductive healthcare in New Zealand?” and “How would you rate the provision of sexual and reproductive healthcare in New Zealand?”. The participants rated these questions both three (rounded up from an average of 2.9) out of five. These ratings can be somewhat explained through the findings of the survey, hui, and interviews.

Firstly, the survey findings state that 58% of the respondents have felt uncomfortable by the practitioners while accessing sexual and reproductive healthcare with experiences including a client being slut-shamed by a nurse during a sexual health check following being sexually assaulted;

*“I was slut-shamed by a practice nurse following my sexual assault when I tried to access a full sexual health check. I was belittled and made to feel like I was at fault for my sexual assault. I left the appointment feeling shame and dirty for being assaulted”*

The survey found that (when accessing sexual and reproductive healthcare), participants were finding difficulties (or were completely unable to) feeling heard by practitioners during appointments (46% of participants) and being able to speak for themselves at those appointments (24% of participants). Of note in this section is the added needs of chronically ill disabled folk or those with complex medical needs. These patients reported in interviews following the survey that they took extra things that they took into consideration when making choices with their healthcare. They all spoke of preferring to use their General Practitioner over more “transactional” forms of sexual healthcare such as through family planning or hospital sexual health clinics. In their words, this is because;

*“I prefer to go to my GP as she knows my entire history and if it ends up turning into a complex thing then she is already involved”*

*“Low cost, good accessibility through online consultation and on campus, good relation(ship) with practitioner”*

*“Accessibility, GP is very caring and kind”*

The reasons that complex medical care clients have said that they choose their GP over other care services seem to overlap with the things that over 85% of our survey participants rated as very important or essential in their appointments with sexual and reproductive healthcare practitioners

- Reliable and Safe Treatment
- High clinical quality and knowledgeable staff
- Confidentiality
- Non-judgemental services
- Sympathetic and kind staff
- Having control over the process, the ability to stop at any stage and take time if needed
- Good advice and information
- Choice in abortion procedures, medical and surgical options, and pain relief options
- Ease of access to clinic/services
- Opportunity for counseling
- Fast access to treatment
- Provision of more effective contraception services as part of an abortion service
- STI Screen and treatment available as part of abortion care

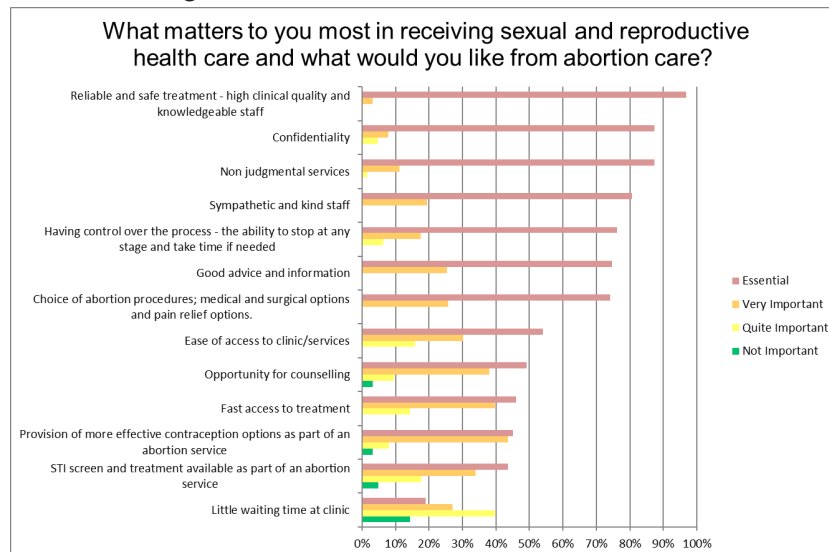
In comparison, the thing that was labeled as of least importance were;

- Little wait time in the clinic. (Where 13% of participants rated it “not important” and 40% of participants rated it “Quite important”)

This participant stated;

*“For me personally, I would be prepared to wait all day for one doctor/nurse that is kind, compassionate, listens and is knowledgeable. My chronic illnesses are complex so I need a professional who is prepared for listening”*

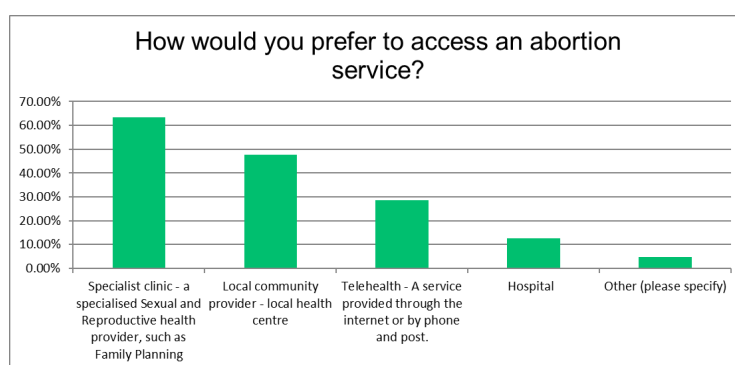
This is also illustrated in these figures below.



This section relates directly to the first recommendation of this report - To centralize the voices and needs of disabled clients in discussions of their care. There is a quote in disability advocacy “nothing about us, without us” and that is a good thing to remember always. The inclusion of disabled voices in the ongoing

training for new and existing healthcare professionals is important. It is worth further investigating how the voices of disabled clients could be intergrated into training programmes in the long term and what would be most viable. Ideas brought up during the hui and interviews included gathering further interviews about experiences (from disabled clients), and simulation training to illustrate to medical professional/providers how to care and not care for disabled clients. This training should also include basic knowledge of disability theory and other sociological theory that underpins the care of clients.

*“I think it is incredibly important to consider the feminist ideals that many of these services were founded on, as their strong stance of free choice (including the right to terminate disabled babies) can conflict against the beliefs of (some) disabled people as all lives being equally important. That being, where a non-disabled person may see a disabled baby as a burden and a reason to terminate, a disabled person may strongly disagree. No comments about choosing to terminate based on ability/disability/possible illness in the baby should be made unless brought up by the pregnant person. Never assume this is a reason for termination!”*



### An Intersectional Approach to care:

I recommend that included in the training being developed now and in the future contains an intersectional approach. Intersectionality is a sociological theory by Kimberle Crenshaw which in simple terms is the “acknowledgement that everyone has their own unique experiences of descrimination and oppression and we must consider everything and anything that can margilise people - gender, race, class, sexual orientation, physical ability etc”<sup>3</sup>. Intersectionality is a concept that is very applicable to the treatment of disabled clients as there is (like all of us) multiple identities, ethnicities and access needs that all intersect and relate to and/or impact each other. The demographic statistics from the survey state that 71% of the participants are young people (aged 21-30), 71% identified as a member of the LGBTQUIA+ Community (Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual/Ace) and 41% identified as gender diverse. Participants spoke of gaps in their care due to being members of the LGBT+ community, and gave feedback including;

*“Accessing sexual and reproductive health care as a trans/nonbinary person is hard because it involves a lot of misgendering. Don't assume people's gender or pronouns.”*

*“Somewhat uncomfortable when I felt I needed to justify my mirena when not using it for contraceptive (due to being gay)”*

<sup>3</sup> Intersectionality definition:

<https://www.womankind.org.uk/intersectionality-101-what-is-it-and-why-is-it-important/#:~:text=Intersectionality%20is%20the%20acknowledgement%20that,orientation%2C%20physical%20ability%2C%20etc>

*“Yes. Trans people, gender diverse people, people of marginalized genders all require different types of services. Gay, queer, bisexual, lesbian people require different types of services. Disabled people have sex, and need reproductive healthcare “*

These comments were made of things LGBT+ clients wanted in their sexual and reproductive healthcare;

*“Sensitivity training around trans health”*

*“Gender diverse - an understanding of the fact that not everyone who has a womb may identify as 'she'”*

The other demographic included in the survey were those are Maori, whom made up 12% of the survey participants (as shown in the introduction). They reported issues such as feeling disconnected from their Tikanga (Maori customary practices or behaviors) through comments such as;

*“I was 18 when (when I found out I was pregnant) and obviously I did not know what to do. I had a friend at Otago who was like “look, we’re just going to go to student health and we’re going to get this sorted and get you the help you want and that you need” and that was fine. But now looking back at that experience I’m thinking ‘why didn’t I maybe have some Maori health practitioners in the same room as me who would have been able to guide me in that space?’ The care I received was fine, but now looking back I think ‘why don’t we have more specific cultural empathy or care for people who aren’t just pakeha. I didn’t know what the Tikanga was around that sort of process for me. I didn’t know if it was even ok for somebody in my culture to get one, so I haven’t actually told a lot of people (about my abortion).”*

*“Yes and no - kanohi-ki-te-kanohi I received very good medical care and advice, but two experiences stand out in my mind where I felt that staff’s logical calls/treatment of me (necessary for paperwork and procedures) felt very isolating or judgemental, but a part of me realises that that may have been because I was young and scared and didn’t have great trust in people at the time.”*

*“Māori - cultural knowledge and ideally the opportunity to work with a Māori clinician if possible”*

*“Cultural competency - especially for rangatahi Māori, who might be struggling with the idea of abortion. For me, I didn’t know the spiritual ramifications of abortion in my Māori community (for those unaware, it’s often that the wairua of your pēpi still exists and can become a guardian for you in your life), and I had already started forming a connection to my pēpi when I had my abortion, although I don’t regret my abortion at all, and I think I gave them the right send-off when I did undergo my abortion. But I wish someone had given me some ao Māori guidance regarding abortion. I’ve mostly kept quiet about my experience for seven years because I’m innately worried about how my Māori community will treat me, even though realistically my community would most likely awahi me and my choice. I was also young and relatively alone when I had my abortion and am no longer in contact with the main support person who helped me through it, and I know I now fit into some racially negative stereotypes which could possibly be used against me, so it has made retelling my story quite difficult and isolating.”*

*“Māori, Pasifika, rangatahi could be offered culturally appropriate aspects of abortion services.”*

The third aspect I want to bring up as apart of this section is the feedback around trauma. Our participants spoke of care following sexual violence and medical trauma as a result of poor medical care. This experience on its own could be an entire project itself, but here is what our participants had to say;

*“It would be amazing to see an expansion/push for trauma informed care at all levels of medical care but especially in sexual and reproductive health care as there is so much potential overlap with the care of patients who have experienced sexual violence.”*

*“Offering ongoing trauma counselling for any individuals who access the service and who might require it.”*

An intersectional approach is a way of seeing the patient as a person, and their specific needs in their care. It also is a way of understanding how oppression works in our society, informing the extra needs a patient may have. In speaking to the participants, a lot spoke of not feeling a strong therapeutic relationship with their care provider, and that they voiced a need for stronger relationships to be developed. There is no one way to do this, so rather than a list to check off - the provider needs to be equipped with the skills to facilitate the patient trusting the provider and the provider respecting the needs of the client.

#### Theme Two: Accessing care, resources, and education:

This section includes:

- Physical access issues:
- Recommendation: Further research the development of transport funding and support
- Lack of resources and educations
- Recommendation: Further research the sexual health education that disabled people have received
- Recommendation: Develop sexual health education resources that are widely accessible for disabled people to access and that meet a wide range of different access needs.

#### Physical Access Issues:

In the survey, 22% of the participants marked access to transportation to and from sexual and reproductive healthcare appointments as a significant issue. This then carried on to conversation during the hui and interviews as well. One participant shared;

*“I use public transport though if I can I’ll Uber but most of the time I can’t really afford to Uber everywhere to get to my doctor’s appointments. I had to ask people to drive me to those appointments. I’ve never felt ashamed of going to Family Planning for anything: but it’s the whole ‘who can I trust to take me who also won’t ask me what’s going on?’”*

One participant brought up the use of a medical practice run taxi service that provided transport to client to and from appointments. This is also a model that has been used in the wider medical care sector. When a participant was asked about this, this was their response;

*“Definitely (Something that they would like to see). Especially for people living in rural communities who can’t get the access even more than me who lives in a city like me. The transport thing is so important, it’s getting people to those appointments because once you’re there you’re taken care of, well. It’s just getting there and back is the issue. If we don’t know where to go first of all that’s a major issue and then on top of that it’s how do you even get there in the first place? Can you find it yourself? Is it safe to go to that sort of place? It wasn’t very easy finding that location (Family Planning) and I still haven’t been able to do it because I don’t live very close to it and I rely on public transport” - buses being her preferred means of transport as ubers aren’t always affordable - “I can’t drive.”*

An alternative to a taxi service could be providing partial or full funding of taxi services depending on the needs of the client, the area they are travelling from and the access to public transport available. These factors and considerations surrounding client privacy would need to be investigated further.

### Lack of resources and education:

Our participants reported that they had received poor sexual health education as secondary school students and this further indicates a space where more research needs undertaking. As our survey population is mostly a part of a younger age group of 21-30 years, we can see that the insufficient sexual health education occurred in the last 15 or so years. Some of the feedback included comments such as;

*“Very low quality. I was given sex ed at two schools, the first showed resources and information more than a decade out of date (from the 90's when being taught in 2010) and the second school taught sex ed based in abstinence education. Neither were very helpful and didn't talk about anything other than cis-heterosexual sex. I was lucky that my mum was a sexual health nurse and I could get sufficient information from her.”*

*“For cisheteronormative sex ed it was great! But it wasn't inclusive of queer/trans nor disabled bodies and experiences”*

*“Poor in high school, between specialists and drs varying and contradicting information given about endometriosis”*

This respondent put it best; “For cisheteronormative Sex Ed- it was great! But it wasn't inclusive of queer/trans nor disabled bodies and experiences”. This lack of education was also echoed in other comments made by participants, specifically when asked about things that they would want in their sexual and reproductive healthcare, this was said;

*“Educational content in the waiting rooms!! Everywhere!! Lots of it!!”*

Therefore I recommend that further research be undertaken to specifically explore and examine the needs of disabled people in terms of sexual health and wellbeing resources to somewhat combat the poor sexual health education experiences reported in this survey and then use said further research to design accessible resources for disabled people to use to learn about sexual health and wellbeing.

In conclusion this is the recommendations made:

- Continuing to centralise the voices of disabled clients in future discussions of the care of disabled clients
- Teaching medical providers about basic sociological theory (such as disability theory, the pros and cons of such theory and feminist theory that underlies the care and treatment of clients)
- The development of an intersectional approach to care (Includes the needs of clients who are Maori, LGBTQIA+ and trauma informed care)
- Further research the development of transport funding and support
- Further research the sexual health education that disabled people have received
- Develop sexual health education resources that are widely accessible for disabled people to access and that meet a wide range of different access needs.

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- Hannah Pretious.

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Defining Models of Disability

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Defining Intersectionality:

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