Mermaids' Focus Groups: Cass Review

August 2023

ORGANISATION

Mermaids has been supporting transgender, non-binary and gender-diverse children, young people and their families since 1995, with thousands of individuals now accessing our services each year. We operate across the UK to provide direct support in the form of a helpline, webchat and email service, local groups, events, and youth programmes.

SUMMARY OF BRIEF & APPROACH

Mermaids was commissioned to run focus group sessions between May - July 2023, with the aim of understanding the lived experience of young trans people regarding previous and future NHS gender services. We ran three sessions with between 4-8 participants per session (9 in total) via Zoom, to enable regional diversity and increase accessibility. Sessions were facilitated by our Youth Advocacy Manager, supported by another member of staff to note-take, and a counsellor on-hand to support anyone before, during or after the session. We took a holistic, supportive, open and non-directive approach, using the questions outlined by the Cass Review team, and enabling responses verbally, via the chat function, or using visual tools.

RECRUITMENT

We recruited participants by advertising the opportunity within our internal networks, such as through our online forum, Youth Advisory Panel, and amongst stakeholders who run LGBT youth groups across England. Recruitment was open for two weeks, and we had 15 sign-ups across a variety of ages and regions, noting 6 people did not further engage. We offered one-to-one conversations with participants before the first focus group to further explain the process, and understand access needs further.

METHODOLOGY

We held three 90-minute focus groups hosted on Zoom, facilitated by Mermaids' Youth Advocacy Manager. Two other adults were present: one Mermaids staff member to take notes, and an external counsellor. In each session and between them, safeguarding procedures were in place and followed. These included verifying the identities of participants at the

start of sessions, providing mental health support (including access to a qualified counsellor during or after the session), signposting to external resources, and offering all participants well-being check-ins once the series of sessions were completed. A full risk assessment was completed for the focus groups and Mermaids' safeguarding lead was aware of the times and dates of the sessions and on hand to offer advice and be informed of any safeguarding concerns that arose from the sessions. There were no safeguarding incidents during the project.

Consent forms were shared and signed in advance, and raised again at the start of each session. This included agreement to video record the session, and agreement to share anonymised quotes and content to the Cass Review team for public use. Verbatim transcripts were also taken simultaneously by the additional Mermaids staff member, and the webchat was heavily used (hence the various misspellings in quotes). When participants were unable to attend, they were given the opportunity to feed back on the questions via email.

Sessions followed a similar format, guided by a Powerpoint presentation or collaborative Jamboard, as follows:

- 1. Introductions: of staff members and participants, logistics of the session, affirming consent to record, ground rules for engagement, and recap of previous sessions
- 2. Questions, as provided by Cass Review team, presented and conversation facilitated typically 15 minutes per question
- 3. Short break
- 4. Further questions as above
- 5. Closing session, including grounding exercise by counsellor

The three focus groups were grouped based on the following themes:

- Focus Group 1: Previous experiences or needs from gender-related care
- Focus Group 2: Expectations for a future a gender service
- Focus Group 3: Expectations for additional information and support

Focus Group 1: Session Information

DATE COMPLETED	Focus Group Topic	Moderated by
28/05/23	Previous Experience or Needs from Gender-Related Care	Youth Advocacy Manager
RESPONDENTS INFORMATION		

No of Participants

8

DESCRIBE GROUP COMPOSITION (AGE, EXPRESSED GENDER IDENTITY, WHETHER THEY HAVE ACCESSED GIDs, REGION THAT THEY ARE RESIDENT)

The group was composed of 8 young people in total.

Age: two young people aged 15, three young people aged 16, two young people aged 17, one young person aged 19

Gender identity: four young people identify as trans male and four young people identify as non binary

Region/location: Stroud, Bristol, Derby, Halifax, Manchester, Huddersfield, Kirklees, Leeds

Whether participant accessed GIDS: two young people have accessed GIDS services, two young people are currently on the GIDS waiting list and the remaining young people have not yet been referred but want to access gender services in the future.

OUTPUTS FROM THE SESSIONS

KEY THEMES IDENTIFIED

QUESTION ASKED	THEME IDENTIFIED	SUPPORTING QUOTES
Why would you go to the NHS for gender-related care (whether you chose to before, or want to)?	 Affordability: private routes are too costly Trust in the NHS 	 "I'm working class and I don't have the money to transition privately of my own free will" "[I have] trust in the NHS, less expensive"

	 Help feel more like oneself and confidence Help with gender dysphoria 	 "The fact that id feel more like myself would be the main reason" "to be able to feel more confident in myselfmore happy with my body and who I am" "hopefully help with my gender dysphoria" "I would want to use a gender service to be able to make sure I know exactly what I want when knowing whether I want to transition"
What would make you want to use a gender service? What would put you off using a gender service?	 Would want people specifically trained in trans healthcare Main barriers: the enormous waiting list, and poor experiences with the NHS Worries about specific types of care, such as surgery. Unease about questioning and level of scrutiny at a gender service 	 [I want] "people who are specifically trained in trans healthcare and not people who happen to practice it" "I've been on the waitlist for GIDS since 2017, had my first appointment this year (2023) only to be told that id have to wait another year-ish to get adult services, then another 6 months for any real treatment. Im now trying to raise funds for surgery privately because the wait is too long" "ive had horrible experiences with the nhs because im disabled as well so i really dont trust it as a whole" "im worried about surgery and if it goes wrong" [Put off by] "waiting list and being scrutinised so much"
Do you think having a diagnosis of gender dysphoria is important? What are the benefits? Disadvantages?	 Mixed opinions on the usefulness of a diagnosis. Benefits included: that it could bring more assurance on whether to transition, and can be personally important. Disadvantages included: the distress from the diagnosis process itself, the subjectivity of the diagnostic criteria, fears/experiences of ableism in the process where the presence other mental health conditions has prevented gender-related care. 	 "it helps to ensure people are sure they want to transition" "Im sure its important to different people personally but i dont think it should legally be important." "I think that its important to make sure thats DEFINITELY the route people want to take, however it can be frustrating bc some trans people dont feel MUCH dysphoria but still know they want ot go through with it" "the way that it is diagnosed is important so that disphoria is not increased it is important to be able to make sure people are safe and mentally well" "i think as long as informed consent is given then a diagnosis of dysphoria could be forgone because peoples incongruence can manifest in ways that wouldn't medically be classed as 'dysphoria' i think its very subjective and if youre landed with a bad doctor then they could be the barrier between transitioning and not" "i am worried that me being autistic may slow down the diagnosis" "it doesn't really seem needed because some mental illnesses may be blamed for it even if it has nothing to do with it" "I have adhd and it took me 4 years to get my diagnosis because of that"

Who should make that diagnosis?	 Should be trans, or have experienced gender dysphoria themselves. A team of people including mental health specialists. Self-identification was raised as a preferred method. 	 "my family believes that I am neurodivergent but I am scared to get a diagnosis for the reasons above and also there is still a lot of stigma about both being trans and disabilities" "Someone who has experience with trans people and understand them completely, ideally a trans person" "a team of people including mental health specialists, a medical side so the physical transition" "Because people who haven't had gender dysphoria before cant really know properly how it feels all they've had is what they've been told" "self identification is the only way it can be a truly fair system. A random doctor has no idea how I feel"
What do you expect from the clinicians in the gender service?	 To be respected and accepting of who they are Wouldn't want them to be denying that you are trans or blaming external circumstances 	 "id expect them to be much more accepting than other doctors typically are, maybe for some of them to actually be trans too" "to be respectful, using pronouns, not being rude, accepting of who i am" "to be accepting of who we are and also giving the same level of service as a cisgender person and using the correct name we go by" [Wouldn't want them to be] "denying that you are trans" "one time a doctor asked my mum if i was trans because i had a concussion as a kid so id quite like for that to not happen again"
What do you think the purpose of the 'assessment' in a gender clinic is? What would you like to experience in the assessment?	 Should focus on how to make the person comfortable, and focus on what they're looking for from the service. Want to experience trying out different gendered experiences, e.g. names, pronouns, binders. Should offer fertility preservation options, and for that not to preclude diagnosis or support. Would not want: being condescended to, denied because of weight, sexuality, disability or past trauma. 	 "I think the assessment should focus on how to make you comfortable, not about whether youre trans or not because nobody would spend 5 years on a waitlist just for the giggles, and it's obvious if you get to that point that youre serious" "they should ask what you want to achieve from the service" [Assessment could include] "trying different clothes pronouns exploring feelings be able to experiment using gender disphoria devices such as binders or packers or whatever the assessment should be through physical feelings not just talking" "one good thing that the nhs did for me was as soon as i mentioned starting T they offered to get me fertility preservation" "if a transmasc person says that they would be comfortable carrying their own child then that shouldn't make their doctor see them as any less trans, people have different levels of dysphoria"

		 "they always tend to be condescending and be in denial about people being transgender" "when i went through the assessment with a therapist i felt judged, looked down on and the way they kept talking to me about it made me feel like i was wrong for being trans they also always used the wrong pronouns and the wrong name no matter what i said" "they told me I wasn't trans and I was identifying this way because of my past trauma" "When I was going through the therapy they focused a lot on the past and future not the present"
Any reflections on your assessment process at GIDS?	 Feeling on trial and nervous, for fear of saying 'the wrong thing' Pressure to be unwell enough to qualify for diagnosis, but not too unwell to preclude treatment. After a multi-year wait on the waiting list, people have learned some coping mechanisms which can be seen as inadequate levels of dysphoria. 	 "I was definitely double thinking everything i said, i felt like i was on a witness stand. Especially the political climate right now, I didn't want to risk sayng the wrong thing" "they made me feel like my answers were wrong" "they expect you to hate yourself in order to be trans but if you hate yourself too much they'll think youre 'insane' and might not let you transition anyway" "they asked me different questions about my mental health and sort of pushed their opinion that I didn't feel too upset in my body and made me feel as if I had to feel negative 24/7 to be trans" "they believe that people who come to them will still be in the early stages of being uncomfortable and not knowing how to cope but the truth is that after 6 years of waiting ive learned how to managed and my dysphoria is very minimal now. That doesn't mean im not trans it just means they didn't do their job fast enough to help me when I needed it"

SUMMARY MESSAGE/CONCLUSIONS

The first focus group focused on previous experiences and needs when accessing gender-related care. Based on the conversation, captured above, the Cass Review team should consider the below:

- 1. Services moving forward:
 - Have a reasonable waiting time, i.e. far less than the current 4+ years.
 - Help people with their gender dysphoria, grow confidence, and become more comfortable in oneself.
 - Should be staffed by people specifically trained in trans healthcare, ideally including trans people themselves.
 - Ensure that neurodiversity does not preclude support for gender dysphoria.
- 2. Care the participants would like to receive:
 - Accepting, supporting and respectful team including using their correct name, pronouns etc.
 - Assessment should start from a point of respect, and feel less like being on trial.

- The process should involve asking the patient what they want to achieve.
- Would not want: being condescended to, denied because of weight, sexuality, disability or past trauma.

COMPLETION

Lee Lester

Lee Lester Youth Advocacy Manager Mermaids

To NOTE

Full transcript and additional materials available in a separate document, Appendix A.

Focus Group 2: Session Information

DATE COMPLETED	Focus Group Topic	Moderated by
18/06/23	Expectations for a future a gender service	Youth Advocacy Manager

RESPONDENTS INFORMATION

No of Participants

5

DESCRIBE GROUP COMPOSITION (AGE, EXPRESSED GENDER IDENTITY, WHETHER THEY HAVE ACCESSED GIDS, REGION THAT THEY ARE RESIDENT)

The group was composed of 5 young people in total.

Age: One young person aged 14, two young people aged 15, two young people aged 16,

Gender identity: two young people identify as trans male and three young people identify as non binary

Region/location: Manchester, Huddersfield, Derby, Leeds x2

Whether participant accessed GIDS: 1 young people is currently on the GIDS waiting list and the remaining 4 young people have not yet been referred but want to access gender services in the future.

OUTPUTS FROM THE SESSIONS

KEY THEMES IDENTIFIED

QUESTION ASKED	THEME IDENTIFIED	SUPPORTING QUOTES
What should the building look like?	 Less of a clinical environment, ideally calming/relaxing 	 "looks like somewhere people would want to go" "it should be more welcoming" "relaxing colour scheme and environment"

What should the clinic be called?	 Clinical environments can feel very intimidating Relationship with autism and sensory overload Accessible, unintimidating name, avoiding sounding too medical Should say 'gender' More simple - focus on what they actually do. Moving beyond dysphoria - not a good term. 	 "not overly bright" "i have autism aswell that would probably give me sensory overload so a less clinical environment may be more accessible" "Something without intimidating vocab" "I think it should involve the word gender for clarification on what it is" "something that doesn't make people feel secluded" "i cant lie i dont really like the term dysphoria because i think the trans experience is more that just that"
What should you see when you walk in?	 Calming environment Decoration and plants Privacy Sensory Room Trans people working at the space People should know it exists, but perhaps not bells and whistles (in terms of privacy) 	 "something that would make people feel calm and welcomed" "supportive messages" "places to speak privately with a professional thats there" "a sensory room would be good for neurodivergent people" "there should definitely be some people there that have felt the same way and understand and are trans themself" "every medical centre has a specific name not relative to what its for anyway so im sure it wouldnt be an issue"
What treatment/care would be offered there?	 Mental health services should be offered Caution that mental health or neurodivergence support must not prevent gender care or dismiss one's trans identity Should also offer voice training, laser treatment and working with LGBT groups 	 "i think mental health services not just gender therapy should be offered" "its important to remember the not to use neurodivergency or mental health issues as a reason to try and 'excuse 'them being trans because ive seen that being an issue" "i think autism makes it easier for u to recognise ur trans because you struggle with social ques and gender roles are part of that so you know ur trans its not just being gender non conforming" "i think voice training would be really good" "i think laser treatment could be good"
What might be some of the potential issues with this new service?	 Neurodiversity being used as an excuse to delay gender healthcare Waiting Times Gender stereotyping Dismissal because of age Regional inequality Inadequate medication Parental permission 	 "autism and mental health issues being framed as the cause of being trans" "long waiting times" "[having] to tell professionals the stereotypical trans story they want to hear" "not being taken seriously because of age" "some areas having services and some having none" "being put on no/ridiculously low doses of puberty blockers/hrt"

		 "needing 'parental permission'. ur parents being transphobic doesn't prove if your trans or not"
How could those issues be resolved?	 Protest Trans joy Less assumptions Training for GPs 	 "Peacefully protest for funding if its not given" "don't just focus on the suffering of trans people see our joy in being able to live as ourselves" "dont assume anything" "treat the person like you would any other person" "make sure GPs have to be training in trans issues"

SUMMARY MESSAGE/CONCLUSIONS

Based on the conversation, captured above, the Cass Review team should consider the below:

- 1. Services moving forward:
 - Building look and feel: less clinical, more welcoming and relaxing (including plants and supportive messages), and accessible in a broad sense (including a quiet room and reducing sensory overload)
 - Clinic name: should say 'gender' in the title so it's clear, but avoid being overly medicalised (e.g. avoid diagnosis-based wording like dysphoria)
 - Importance of hiring trans staff
 - Assumed that treatments could include voice training, laser treatment, and connections with supporting LGBTQ youth groups.
- 2. Care the participants would like to receive:
 - Fears raised throughout the focus group of neurodiversity being used as an excuse to delay or dismiss gender healthcare. Participants would expect care to support their neurodiversity needs as well as gender dysphoria needs, without the former preventing the latter.
 - Calming, welcoming approach and spaces which aren't as clinical, understanding the high level of stress and anxiety starting this process.
 - To see and work with trans people who understand their experiences.
 - Reasonable waiting times for care.

COMPLETION

Lee Lester
Youth Advocacy Manager

Lee Lester

To NOTE

Mermaids

Full transcript and additional materials available in a separate document, Appendix B.

Focus Group 3: Session Information

DATE COMPLETED	Focus Group Topic	Moderated by
09/07/23	Expectations for additional information and support	Youth Advocacy Manager

RESPONDENTS INFORMATION

No of Participants

5

DESCRIBE GROUP COMPOSITION (AGE, EXPRESSED GENDER IDENTITY, WHETHER THEY HAVE ACCESSED GIDS, REGION THAT THEY ARE RESIDENT)

The group was composed of 5 young people in total.

Age: One young person aged 14, two young people aged 15, one young person aged 16, one young person aged 17. **Gender identity:** two young people identify as trans male and three young people identify as non binary

Region: Bristol, Huddersfield, Derby, Leeds x2

Whether participant accessed GIDS: all five young people have not yet been referred but want to access gender services in the future.

OUTPUTS FROM THE SESSIONS

KEY THEMES IDENTIFIED

QUESTION ASKED	THEME IDENTIFIED	Supporting Quotes
Who are your trusted sources for advice and guidance around gender identity and available services?	 Primary source is other/older trans people, who can understand their experiences. Other family members. 	 "older transgender people, they understand and actually know what you're going throughthey also dont patronise people" "me and most of my friends/ trans people i know mostly have to rely on eachother for resources

	 LGBT youth groups. Largely do not trust GPs or other professionals Online sources of 	most of the time gps an professionals are uneducated" • "My trans friends my therapist and my sisters" • "parents bc [because] they have wisdom and
	information, such as Reddit	mine personally do a lot of research around it" • "the source i use most often for trans-related questions is reddit, specifically r/transgenderuk. i know reddit has a bad rep what with the types of communities that it can host, but for trans-related questions it is the most useful as it is all from people who have transitioned or are transitioning in multiple different ways" (submitted via email)
What general information would be helpful for young people thinking about gender identity? How would you want to access this?	 Seeking general information about LGBTQ+ people, and about gender services. Sources of information include: LGBT youth groups; LGBT groups in schools; in person and online webchat or text service. Visual aids (e.g. practical walk-through of the process) and a reliable text chat online. In person options, including from LGBTQ youth groups Various comments on not trusting information from a GP or existing NHS services Would seek information at schools, but note teachers tend not to have adequate training. 	 [I'd like to have information on] "what you have to do to be able be referred to a gender service where your nearest gender service is and the process with your first appointment maybe with a videoWhat it entails and whether or not you would feel comfortable with the process and maybe meet some of the people first" "More visual aids I would like a reliable text chat online because I can't always use the internet and my phone is restricted so a phone line would not help" "I go to a lgbtq youth group and its very helpful and nice to be around people that know what theyre on about" "I don't feel comfortable going to a GP because they are normally older and force your views on youThey don't have enough education" "Have lgbt groups in schools with certified trained staff"
What was your referral process like? What worked? What didn't work?	 Past experiences of GPs being uninformed of how to refer, or young person being intimidated away from pursuing one. There should be multiple sources of referrals for those with unsupportive clinicians. Difficulties in getting a referral if someone has unsupportive parents Multiple comments about how hopeless the referral process can feel with massive waiting times. 	 "i went to the gp when i was 11 and she said we 'dont have services like that in the uk' and even when i tried explaining she just refused and now i have been forced to go through female puberty and that had a really detrimental effect on my mental health and still does to this day" "There should not be a list of who can or cannot refer an individual to gender services. i think anyone should be able to, with the individual's consent." (submitted via email) "It was intimidating and felt judgemental and it was a long waiting time they made me feel like i was wrong which is something that shouldn't have happened they tried blaming it on my past" "i also think having parental consent is unnecessary and all it does is help transphobic parents push that on their kids"

	 Would have benefited from support on the waiting list such as: knowing how long the wait would be through letters/texts/emails, and other ways to indicate emotional health to the service. Service should be aware of the prevalence of DIY healthcare behaviours, and understand the factors that lead to this. 	 "im not going to bother going to even a new gp now bc its a waste of my time now bc even if i wait with current waiting times i will have been out around a minimum of ten years by the time i even get a first appointment" [Would recommend that] "When you get that text about the update [on waiting time] it is also a text u can reply too to tell the, how you are feeling" " i also think gps and trans services need to change the way they think about diy healthcare to be focused on harm reduction rather than 'just dont do it' because it is a reality that thats the only option for a lot of our community"
Who do you think should be able to refer you to a gender service?	 Schools Yourself (i.e. self-referral) Youth groups Doctors Social workers Parents (but not required) Importance of having a process if a professional refuses to make a referral 	 "Youth groups, doctors, social workers, schools, parents (but not necessary)" "there should be a process for if someone refuses to refer u what to do"
What support should families be offered?	 Work with a youth worker to be upskilled on how to be supportive More information on how to support and discuss mental health Options for talking therapies and informational sessions for parents Suggested having an app to support young people and families Information for social services regarding risks around unsupportive parents Discussion of how social media has radicalised some family members to be anti-trans 	 "to tell the youth worker how they are dealing with it and then they can recieved tips or tricks to be able to cope with it better" "more information about it so that they know how to support you with it talking to someone that knows about it and getting things that can help better support the person and their mental heath" "support for families should include things like talking therapies for the trans individual and for family members, including group therapies. there should be informational sessions that families can attend to help them to take care of their trans family member, and to attempt to get rid of any stigma that they still hold around being trans." (submitted via email) "i think social services need to pay closer attention to unsupportive parents of trans kids bc with me id spoke abt it but professionals didnt take it seriously and the situation got very unsafe (i live w my nan now tho shes amazing)" "i think social media and the media in general is causing transphobic views the most"

SUMMARY MESSAGE/CONCLUSIONS

Based on the conversation, captured above, the Cass Review team should consider the below:

1. Services moving forward:

- Most trusted sources for information are likely to be peers, trans people, LGBT youth groups, and supportive family members rather than medical professionals.
- Young people requested a wide variety of information from general information about LGBTQ+ experiences, to very specific information about the gender service itself - including: the building, the staff, how the process worked, what to expect in your first appointment, and more.
- o Information should be available virtually and in person, and ideally involve an interactive tool such as an app or webchat.
- Referral process: there should be a wide pool of potential referrers (self-referrals, schools, youth groups, doctors, social workers and family), and unsupportive parents shouldn't preclude referrals. Support should be offered while waiting.
- Support for parents should be provided, including information and connecting with youth workers.
- Service should be aware of the prevalence of DIY healthcare behaviours, and understand the factors that lead to this, taking a harm reduction approach similar to BMA guidelines.
- 2. Care the participants would like to receive:
 - o That medical professionals they interact with are training in a respectful, supportive approach.
 - o Information and communication options are varied to virtual and in-person options, including a webchat to get further information.
 - That the process in the gender service is explained in detail, including with visual aids, to help with accessibility and reduce nervousness.
 - Treated with support by the gender service regardless of whether their parents are transphobic or accepting.

COMPLETION

Lee Lester

Lee Lester Youth Advocacy Manager Mermaids

To NOTE

Full transcript and additional materials available in a separate document, Appendix C.