LGBT FOUNDATION
CASS REVIEW LIVED EXPERIENCE FOCUS GROUPS REPORT

ORGANISATION

LGBT Foundation are a national LGBTQ+ health and wellbeing charity. One of our core purposes is reducing healthcare inequalities between LGBTQ+ communities and the wider population through offering a variety of specialised LGBTQ+ health and wellbeing services. We also do this through offering a range of LGBTQ+ education programmes to equip people and organisations with the skills they need to better understand and eliminate the barriers LGBTQ+ people face to receiving equitable care. Our links to LGBTQ+ communities are strong, particularly in Greater Manchester, with a 25-year-long history of completing the essential work we continue today.

SUMMARY OF BRIEF & APPROACH

LGBT Foundation successfully partnered with 42nd Street and The Proud Trust to host nine lived experience focus group sessions commissioned by The Cass Review. These nine sessions were split evenly between the three organisations with LGBT Foundation hosting three focus groups throughout July and the start of August for people with relevant lived experience aged between 18-25. The purpose of these sessions was to collect the thoughts, feedback and experiences of young adults who engaged with GIDS. These focus groups were held on Zoom, to enable people to join from across the UK, with thirteen different attendees across the three sessions. Sessions lasted between 1hr 15 – 1hr 45 and involved working through the questions provided by the Cass Review team with each session assigned a different one of the three question sets. All attendees were well engaged, and the data collected was detailed and insightful.

RECRUITMENT

Recruitment was largely completed through LGBT Foundation's social media channels. Our social media posts linked to an event page hosted on the events section of our website. Here, a more comprehensive summary of the focus group sessions and how to sign up was provided, this included a more detailed description of eligibility criteria as well as a summary of the Cass Review and the purpose of these focus group sessions. As the three focus group sessions were spread over the course of a month, this allowed us a period of six weeks of consistent advertising via posting on social media.

We also recruited through specifically sharing the event webpage with a variety of local LGBTQ+ community groups in Greater Manchester. As we partnered with 42nd Street and The Proud Trust to host the block of nine focus group sessions, we also recruited through asking these organisations to signpost anyone over the age of 18 to us, as these people would not be eligible for their focus group sessions which were for under 18s only.

To register, we instructed people to email us expressing their interest. From here, we asked them to confirm they had the relevant lived experience for these focus group sessions, to read the additional information sheet the Cass Review asked us to share as well as agreeing to read and adhere to our safer spaces agreement throughout the session. This agreement outlined simple ground rules for the session, including treating all with respect, not being discriminatory towards or prejudiced against any communities of people, ensuring that people's anonymity outside of the sessions and that content warnings are given before any potentially distressing experiences were shared. Once they'd completed these tasks, we sent them the Zoom links to join the session.

Due to low sign-ups for the second of our sessions, we invited people who attended our first session to attend our second, the majority of which did. To aide attendance we also changed our planned in-person session to online, like the other two sessions, as attendees from other sessions were located across the UK and so few were able to attend further sessions if they were in-person.

Before each session, we asked all of those registered if they had any questions before the event, stressing that we wanted to do whatever we could to reduce the accessibility barriers sessions such as these may present. Although many did not have any accessibility needs which they choose to share with us, approximately five people across the three sessions shared that the session would be more accessible if they were regular breaks and we shared the questions and session layout with them before the session – we made sure to meet these accessibility requests.

It's important to note that in our advertising for the initial two focus group sessions, we did not make it clear in our social media posts that there was a financial incentive to attend these sessions. However, with sign up to the final session poor, we decided to make the financial incentive more explicit in the advertising for the final session. This resulted in a highly significant increase in the number of sign-ups, with approximately eighty enquiries sent to us. When analysing these enquires, we realised that they were most likely all from people who were ineligible for the focus groups. One of the initial emails we received from this influx mentioned seeing this advert on a Nigerian Facebook page, confirming our thoughts that we had received enquiries from people who were not eligible. Following this, we analysed all emails and marked the majority as ineligible through noticing emails sent with identical text and across proceeding minutes in the middle of the night (UK time), other emails seemed to be written by AI writing software with unusually formal language, that was often very vague and demonstrated no awareness about what specifically they were registering for. After this initial ruling out, there remained approximately twenty emails that we were uncertain as to whether they were eligible. With the final focus group session scheduled for the Tuesday evening following this large influx of enquiries over the weekend prior, we did not have enough time to engage with each of these people and confidently identify who from these twenty were eligible. As we did not want to take any risks by inviting people who we were not confident of their intentions or eligibility to the focus group space, we decided to only invite people who had attended previous focus group sessions to the final session.

As a result of the combined factors of poor sign up to the second session and the influx of ineligible enquiries to the third session, there was very significant overlap between attendees of all three focus group sessions. Thirteen different people attended across the three sessions with eight of these attending all three sessions, three attending two and one attending only one session.

METHODOLOGY

With three people at LGBT Foundation hosting the sessions, we ensured consistency across the focus group sessions by creating a firm structure for each session. This structure was outlined in a document shared between the three of us prior to the first session (see Appendix A).

Each session was attended by at least two LGBT Foundation staff, one person was assigned transcriber, responsible for making detailed notes of the discussion throughout, and the other one or two people were assigned moderator, asking the questions and responding to comments in the chat. The LGBT Foundation staff involved in this project were the Deputy Director of Education, Policy Coordinator and Trans Advocacy Officer/Policy and Research Coordinator (Trans Programme).

Each session begun with the lead moderator talking through the session, explaining what the purpose of these sessions are, ensuring that all those present had relevant lived experience, and reminding all that they had agreed to adhere to the safer spaces agreement in these sessions. After we shared this information, we introduced ourselves with our names and pronouns, asking everyone present to introduce themselves to the room with their name, pronouns and sharing details of the lived experience they have which makes them eligible for these sessions.

As each session was held online, via Zoom, this enabled participants to interact with the session in whatever way made them feel most comfortable. Participants were split between those who engaged with their cameras on, unmuting to speak; others who left their camera off but spoke via unmuting and those who kept their cameras off and interacted solely via the chat. Regardless of how they choose to interact with the session, each person consistently engaged across every session.

After these introductions we followed the questions in the order provided by the Cass Review. The first focus group was assigned question set one, the second set two and the third set three. To encourage conversation, we prepared some suggested follow up questions for each question. These follow up questions were all simple and not leading, most were based on the additional information provided by the Cass Review under several of the questions provided when the question sets was circulated to us. Aside from these preplanned additional questions, the only further questions we asked were asking people to clarify their answers. This clarification was often needed when participants loosely referred to their experiences in a way that could be understood by others with similar lived experience but not necessarily by those later reading the session transcript. For example, one person would say 'GPs just don't seem to understand what we need', although within context and surrounded by people with similar lived experiences, this statement felt complete, we wanted to ensure this by asking follow-up questions such as ‘why do you think this?’ or ‘what do you think you need from GPs?’.

Each session lasted between 1hr 15 and 1hr 45 and we had a 5–10-minute break halfway through each of the sessions. We also encouraged anyone to leave the session at any time if they felt they needed to do so to look after their wellbeing, recognising the emotional strain sharing and hearing people’s experiences may cause. As far as we’re aware, no one was away from the session for a prolonged period of time as consistently all, if not the majority, of the people present responded to every question either verbally or through the chat.

After finishing the question set for that session, we concluded each session with the same information. We thanked all for attending and welcomed people to get in touch over email with any additional thoughts or comments they didn’t share during the session. We then discussed what would happen to the discussion today, speaking again about this report and the implications of the Cass Review more broadly. We covered payment before signposting to a variety of LGBTQ+ wellbeing services that they could access for any support they needed following the discussion of difficult experiences during the sessions.

HOW THE SESSIONS WERE RUN

Detailed above.

SESSION INFORMATION (REPLICATE FOR EACH FOCUS GROUP)

GROUP TITLE & KEY QUESTIONS

DATE COMPLETED	FOCUS GROUP TOPIC	MODERATED BY
4th July 2023	Question set 1 – The present	Deputy Director of Education and Trans Advocacy Officer / Policy and Research Coordinator (Trans Programme) with notes taken by Policy Coordinator.

RESPONDENTS INFORMATION

NO OF PARTICIPANTS

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

1. Age: evenly spread between 19-25; expressed gender identity: predominantly trans men with two trans women and two non-binary people and one person who is gender fluid/questioning their gender; all but one person had accessed GIDS, with this one person ageing out of the service whilst on the waitlist; residents of: Manchester, London, Newcastle, and South Wales.

OUTPUTS FROM THE SESSIONS

KEY THEMES IDENTIFIED (BY QUESTION)

QUESTION ASKED	THEME IDENTIFIED	SUPPORTING QUOTES
1. **Why would you go to the NHS for gender-related care?**	Trusted and respected free source of healthcare, which their parents often preferred them accessing instead of private healthcare providers. For many, the NHS was their only choice as they couldn't afford private healthcare. But, they wished they could've accessed a different gender-related care provider which offered a higher standard of care without very long waitlists. The very limited number of gender-related care providers in the UK was noted.	'I'm from a very low-income family, and private care just wasn't an option. The NHS is the only choice that my family could afford and I'm massively grateful for it.' 'In my case, social transition was a lot more important to me initially, but medical transition was definitely an intended part of my journey. I needed the validation from the GIDS to almost "prove" that I was trans to the people

	Criticism was raised of the highly medicalised nature of accessing gender-related care on the NHS.	around me.’
2. What do you think the purpose of assessment in the gender clinic is?	Validating your trans identity through having a medical specialist confirm that you were transgender. Having to carefully consider what information you shared with clinicians to increase the likelihood that they’ll be diagnosed with gender dysphoria. Criticism of the criteria being used to confirm or reject someone’s trans identity. It was felt that clinicians were looking to dismiss people’s trans identity if they didn’t match a strict set of criteria. Criticism of the clinicians who were seen as unnecessarily paternalistic, adopting a “we know best” approach and trying to cover themselves from any future implications of giving incorrect diagnoses or prescribing treatment that the young person later regretted taking. It was not felt that clinicians were listening to SUs (service users) or acting in their best interests. Criticism was raised of the impact that the opinions of their parents were allowed to have on the care they received, particularly if their parents were transphobic. Criticism of the regular use of CAMHS as a referral pathway between GPs and GIDS. People shared experiences of transphobic CAMHS clinicians and unnecessary delays in eventually receiving a GIDS assessment.	‘Family dynamics are important, but I was the patient, why were my wants and needs invalidated?’. ‘You should be finding out with clinicians who you are but instead you’re proving who you are [that you’re trans] to clinicians, not working with them.’ ‘It felt like everything in my life was being analysed, when in fact there wasn't any logic behind it other than just knowing I'm trans.’ ‘Despite the psychiatrists at GIDS being fully in agreement with me regarding my transition and it being the right thing for me, they were unable to give me any sort of hormone blockers until 6 months after my assessment period at the clinic. It felt like so much of the process was just stunted by the bureaucracy of "we don't care what's best for you we have to follow this specific procedure, so we don't get sued".’ ‘I even lied about liking girl’s toys as a child, as I felt it would delay treatment. It likely wouldn't have delayed anything but it felt like I had to be perfectly exactly masculine.’
3. Is it important to you to have a diagnosis of gender dysphoria?	The diagnosis was a lot more important when they were a young person compared to now. This was because a diagnosis was seen as the key to accessing medical transition through GIDS and that a diagnosis would affirm that they are trans after years of interrogation and questioning by clinicians and family members. Criticism of having to have this diagnosis was raised, particularly as dysphoria can manifest itself in so many ways that strict diagnosis criteria is hard to define. Criticism of the importance placed on this diagnosis was raised. One/a small team of clinician(s) should not be given the power to decide whether you are trans.	‘The diagnosis was important for me to have that acknowledgement from a medical professional, something helping me to be treated as male through the NHS and the rest of my life going forward. It feels like as a trans person going through puberty, it's so hard to find your identity, so having a medical diagnosis of "yes this is the issue you're having, and we'll help you through it" is so validating when I felt like I was going mad.’ ‘The diagnosis feels like you need a professional to tell you who you are, I can see this about me, why can’t we talk about individualised care for me and my needs, instead of jumping through standardised hoops.’

	Diagnosis as unimportant, with one person comparing their certainty in their trans identity to the certainty they have in their hair colour, so the diagnosis did not come as a surprise or relief.	
3a. What do you think having a diagnosis means in relation to: them personally; parents, family members and carers; healthcare; school; socially.	A diagnosis was important to many people's family, particularly if their family weren't initially willing to accept their child's trans identity. It was important to healthcare as this meant they could access gender affirmative care. Minimal impact at school or socially, with friends and peers not understanding gender dysphoria so a diagnosis, or the whole process of accessing gender related healthcare in general, not being understood by them.	'My Mum initially took me to the GP thinking I would get some form of conversion therapy.' 'My Mum just wanted me to be happy and fix whatever is going on with me. When hearing the confirmation that it was gender dysphoria, I think it gave her peace of mind that it was the right thing for me to transition.' 'I think me being more outwardly masculine socially and the way I presented meant more to the people around me in terms of "proving" my transness than a diagnosis.'
4. What do you expect from the clinicians in the service?	They expected clinicians to be much more personable, friendly and welcoming than they were. Instead, clinicians were overly formal, procedural and didn't seem to cater their approach to the needs of each service user (SU). Participants criticised clinicians for not providing trauma-informed care. For example, parents were invited to every appointment but at no point was the child/young person (CYP) asked if they wanted this or how this impacted them. Participants believed that there should've been time for them to express their own needs and desires to clinicians in a safe space. Many participants agreed that they would've much preferred it if their clinician had relevant lived experience (e.g., were trans themselves) as this would've helped them to be more open and honest in appointments.	'Conversations [with clinicians] felt more like a tick box exercise and getting to know me in an unnatural way.' 'I was the patient, not my family.' 'I expected an exploration of my gender, with clinicians trying to evaluate what was right for me. I was expecting a lot more hostility, but in my experience with GIDS Leeds they were very friendly, but it felt like there was a constant analytical undertone.' 'I felt a bit left in the dark, everything was uncertain. I expected to have a better idea of my treatment, support, and time scale.' 'They probed me so hard for any "alternative" reasons I may have been trans initially (such as other childhood trauma, with emphasis on sexual assault) and it just felt like they were finding any reason to "disprove" me being trans in my first appointment.'

5. Did the service do anything to make the service more accessible for you as the patient? Noting how often autism, neurodiversity, mental health, and gender diversity intersect. *Note:* This question was not part of the given sets but asked as the moderator felt this issue had been raised in the other questions so wanted to discuss this directly.	Many stated that they chose not share their neurodiversity with clinicians due to fear that this may impact the amount of gender affirmative care they can receive. Noted that the above concerns were validated by the ableism present in the proposed interim service specification for GIDS (published alongside public consultation in October 2023). Limited number of GIDS clinics as a huge accessibility barrier. Criticism of being originally referred to CAMHS instead of GIDS felt like a pathologisation of both their neurodiversity and trans identities.	'Having to go through CAMHS contributed a lot to me seeing my transness as a problem and something I needed to solve. Completely unnecessary step that'd elongated the process of being referred by about 8 months, but also encouraged my opinion that there was something wrong with me.' 'CAMHS is holding us back and stopping our referrals [to GIDS] and often this is to do with families rather than you'.

SUMMARY MESSAGE/CONCLUSIONS

Brief overview of main conclusions from the focus groups. Focusing on:

1. How services could be organised going forward.

Services should be free, easily accessible and trustworthy with a good reputation amongst LGBTQ+ communities and the wider population. Services should prioritise offering a range of services to CYP, adopting a flexible approach that's able to meet the unique needs and affirm the gender of each SU. Being transparent about the variety of different forms of medical and social transition, providing high quality information and then allowing the CYP to decide which care is best for them.

2. The care the participants would like to receive.

Clinicians should be personable, friendly and welcoming, ideally, they will also have lived experience of being LGBTQ+ and, preferably, accessing gender affirmative care. Clinicians should truly listen and engage with SUs, ensuring that they provide the highest quality care to each person they see instead of following a rigid and procedural one-size-fits-all approach. Care should be trauma-informed and far more accessible to neurodiverse people than the current service.

COMPLETION

Alex Matheson

Alex Matheson
Deputy Director of Education

TO NOTE

Full transcript available in Appendix B.

SESSION INFORMATION (REPLICATE FOR EACH FOCUS GROUP)

GROUP TITLE & KEY QUESTIONS

DATE COMPLETED	FOCUS GROUP TOPIC	MODERATED BY
22nd July 2023	Question set 2 – The Future.	Deputy Director of Education, Policy Coordinator took notes.

RESPONDENTS INFORMATION

NO OF PARTICIPANTS

10

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

- Age: evenly spread between 19-25; expressed gender identity: four trans men with two trans women, three non-binary people and one person who is gender fluid/questioning their gender; all but one person had accessed GIDS, with this one person ageing out of the service whilst on the waitlist; residents of: predominantly Manchester with people also from London, Birmingham, Newcastle, and South Wales.

OUTPUTS FROM THE SESSIONS

KEY THEMES IDENTIFIED (BY QUESTION)

QUESTION ASKED	THEME IDENTIFIED	SUPPORTING QUOTES
1. **How important is the location of the service?**	All participants described having to travel long distances to access the service with adverse side effects including: missing school, parents needing to take time off work, financial impacts from travel and hotels, reliance on parents who were often unsupportive of their child accessing the clinic, additional stresses of travel long distances worsening other anxieties held about the appointments (particularly for neurodivergent people). The inconveniences listed above felt not worthwhile for short and procedural appointments where SUs gained nothing other than being allowed to progress on to the next stage of assessment. It was suggested that short, procedural appointments were completed online to eliminate these stresses and increase the comfort for SUs. Indigo Gender Service was listed as good practice in this respect.	'Location makes [the service] seem so inaccessible when it's far away – just [having the service located in] Leeds and London is absolutely ridiculous, particularly if your parents aren't on board, they won't be willing to take you to a clinic.' '[S]ome appointments were longer but when it was a short quick one it felt like such an effort and drain for little result, it made my transition feel more difficult'. '[Having to travel great distances] makes an already stressful situation more of an ordeal.' 'That appointment could've been on Skype. I didn't have any questions […] I travelled hours for a 10-minute check-in appointment.'
a. **What is important in relation to the environment of the clinics?**	Several people criticised the current service environment as overly clinical and unwelcoming as a result. This overly clinical environment was further criticised as participants felt that this tied into the wider issue of the over and unnecessary medicalisation of trans identities. People suggested changes to make the space more comfortable including being a visibly LGBTQ+ space, employing mostly LGBTQ+ staff, having LGBTQ+ reading materials, comfortable seats, and more relaxed layouts. Clear signposting and advertising for related community support groups of activity would also be welcomed. Ensuring that the clinic space was age appropriate was highlighted by several people. Participants felt that clinics were designed for children rather than young adults and noted how that this felt particularly out of place as the majority of SUs were aged between 15-18.	'The whole of the service, from questions to environment in general, felt very designed for kids. Leading to 16–18-year-olds feeling like they were falling in-between the cracks.' 'There needs to be the removal of the feel of power imbalance. Walking into Tavi felt like you were walking into a doctors' office, surrounded by strangers.' '[I want] the [service] space not to feel like you're walking in and being told what to do and where to sit'.
b. **Would you prefer a hospital or community location for the service?**	A strong preference was stated for a community location, with people describing these environments as spaces where they felt they could be more at ease and	'I think it would be great if the service worked with community LGBTQ+ youth clubs, potentially even allowing some groups to give evidence for people's

	express themselves more easily compared to the intimidating and uncomfortable hospital settings. The only times where a hospital was preferred to a community location was for times where medical interventions, for example, top surgeries, were taking place. Participants wanted a versatile community space that was accessible to a variety of different needs and experiences. For example, the centre could have spaces dedicated to different needs such as social, quiet and relaxation spaces making the most of the inside and outside environments available.	assessments or allowing group leaders to help with referrals.' 'it's important to make [the service space] look like there's been some care put into it.' The service should be 'A place that feels like it's there to support you rather than "fix" you.' 'The service should be somewhere you could take a selfie in and no one would second guess that you weren't in a community service. The space should be so flexible and comfortable that a trans community group could be hosted there outside of clinical hours without anyone feeling out of place.'
2. What do you see as some of the challenges for the new services?	Multiple people flagged the lack of awareness of the service amongst wider clinicians (e.g., GPs) and the general UK population meaning that 'you can create the perfect service but if you don't spread awareness of it, people won't refer you to it.' Participants also shared experiences of GPs and CAMHS clinicians refusing to refer them to GIDS due to these clinicians not deeming them "right" for the service. One person noted that a significant challenge will be how little treatment or care the new service will be able to provide to CYP due to the amount of scrutiny and attack the service and trans people, in general, are withstanding at the moment. Significant increases in misinformation about and discrimination towards trans people. As a result, parents who hear that their children are trans are more likely than ever to be fed misinformation about trans people. GIDS will need to proactively respond to this through being a reliable and trustworthy source of information for parents, helping them to be supportive of their children. GIDS has a responsibility in reducing the number of CYP prevented from accessing the	'I had two appointments at CAMHS. The first clinician I saw decided that I wasn't "ready" to be seen by GIDS and it took seeing a different CAMHS clinician who let me be referred to the GIDS waitlist. I should've been referred to GIDS by my GP and not CAMHS, that added a huge delay and meant that I never got to the top of the GIDS waitlist.' 'By limiting the pathways into the service, if someone has a bias or they don't agree with [the service] then this person has no hope [into reaching to GIDS]' 'the point of the Tavistock is to talk about [your gender incongruence] and figure it out with you, that's not the role of the GPs but gatekeeping and extra referral steps allows people to be inappropriately screened out of the service.' 'I want a clinician that doesn't feel like a spokesperson for the NHS, 'I believe you, I know this is frustrating, we can work through this together. It feels like there's no human side to the clinicians at the moment.' 'I found my transition hard, restrictive enough and things are only getting worse now. I feel like I only just got through it, there were times that I

	service due to the transphobia of their parents.	thought I wouldn't. I'm scared for young people who are having to go through a much more difficult time than me.' 'Parents don't just need help, they need re-educating.'
a. What ideas do you have to address those challenges?	Employing more LGBTQ+ people and/or people who have lived experience of accessing the gender clinic. These people should be involved in the design and monitoring of the new service. A programme of mass (re-)education for practicing clinicians was also suggested to resolve misinformation about the gender clinic and, more broadly, about the healthcare needs of trans people. Consistently addressing complaints lodged by trans people against medical practitioners who they feel have treated them poorly due to their trans identity. Clinicians should be more sympathetic and transparent with SUs. People shared the huge emotional benefit that would have come from a stronger relationship with their clinician. Clinicians should not assume that SUs have no knowledge about transition-related care and how GIDS operates as this is rarely the case. Greater access to gender affirming treatment was stressed by multiple participants. Puberty blockers should be more accessible and prescribed more often. The eligibility criteria for puberty blockers should also be expanded. Young people are competent and able to make their own decisions when it comes to transition related healthcare, this should be recognised and accepted by the service. Rejection of the one-size-fits-all approach adopted by the previous service. SUs should receive the treatment that they need when they need it rather than having to wait certain pre-determined and standardised timelines. The service should host regular sessions where parents/carers are able to ask questions about transgender people and	'The clinician should be facilitating not dictating, 'I don't know you, you know you and you know what you want.''

	the care the service offers to its SUs. This way, parents/carers have a reliable and trustworthy source of information.	
3. Are there any aspects of the current service you think should be built into the new services?	Individual clinicians were praised as they adopted a friendlier approach with their SUs, deviating from the strict list of questions other clinicians followed and tailoring their approach to the needs of the particular SU they met with. Multiple people praised the reduced wait time that SUs of GIDS had for GICs. One person stated that this reduced wait time was ‘the one thing that [GIDS] did for me and I was with you for 18 months.’ Several people firmly stated that CAMHS should not be used as a mandatory, or even commonly used, referral pathway to GIDS. Involvement of SU’s family as helpful but the opinions of family should not be prioritised over the SU’s. Very significant and resounding criticism of the wait times built throughout the whole process from first referral to final appointment with the gender clinic.	‘The conversations [the clinician and I] had felt a lot more friendly than clinical or questioning. He was more than happy to explore my gender than interrogate me about it.’ In reference to being seen by a trans clinician, ‘he understood what it would sound like to be asked those questions so he could ask them in a sensitive way’. ‘I wanted to feel like the clinician was on my side.’ ‘I wished [the fact that I am trans] wasn’t true because even though I knew it was better in the long-term, I knew I had to go through so much to be the person I knew I was.’
4. Do you have a sense of the type of support or treatment you would personally like to be offered?	Praise was given to support workers who worked for LGBTQ+ charities/support groups and were not part of the gender clinic. These people are able to mediate conversations and tension between parents and CYP, answer questions about transition they have in a safe and trusting environment, supporting social transition in schools and accompanying them to appointments are gender clinics. Several people echoed the importance of GIDS working with the (LGBTQ+) communities local to their SUs. These local services are able to host support groups where they can connect with other young people in their local communities. Through communicating with these groups, GIDS could learn more about the patients they’re seeing, tailoring the care they provide according to this. They could also refer patients to community groups that are local and appropriate to them.	‘I just wanted to get my bloody hormones, that was what I was there for, that’s what I wanted, that would’ve been my therapy, all my distress was related to needing to get on hormones and I was expressing this, I had a trans history, I was clearly aware of what I wanted and what care was on offer.’

	The importance of the clinician listening to the SU and completely engaging with the conversation being held. GIDS should also organise parents support groups. Here, misinformation could be dispelled, and parents could build supportive connections with other parents. This would better enable parents to support their child’s transition. GIDS could offer more holistic appointments through, for example, hosting support groups, drop-in information clinics, a pharmacy (with trans-specialist pharmacists) and youth workers available on request.	
5. Do you have any suggestions about what the services should be called?	There were no particularly strong opinions across the group. Several people agreed that it was unimportant if ‘gender’ was in the title of the service. Particularly as the language used around gender in the clinics is often overly medicalised and outdated. Several people preferred a vague name so that the service couldn’t be identified as a gender clinic by people who weren’t aware of the unique healthcare needs of trans people, reducing the likelihood of discrimination. The service could be called something that can be easily abbreviated to reveal more or less about the service depending on who they are talking to. For example, ‘Indigo Gender Service’ can be shortened to ‘Indigo’ and it still be clear to those aware of the service what they are referring to.	

SUMMARY MESSAGE/CONCLUSIONS

Brief overview of main conclusions from the focus groups. Focusing on:

1. How services could be organised going forward.

There should be multiple services throughout the UK meaning that no SU has to travel great distances to access care. There should also be the option for some appointments to be held via video call. Clinics should be in community over hospital settings. Great effort should be put into improving the clinic environment, making it more visibly LGBTQ+, welcoming, age appropriate, relaxed and comfortable – ideally a space which could also be shared with community groups, and this does not feel out of place.

The challenges for the new service are numerous. It felt that the lack of awareness around the existence of the service has not improved, preventing appropriate referrals. Significant increases in societal transphobia also presents a challenge to the number of people willing to refer to the service as well as to the amount of gender affirmative care the service can provide. To address these challenges, more LGBTQ+, particularly trans people, should be employed by the service. There should also be a nation-wide programme of re-education for all medical practitioners to reduce transphobia, eliminate misinformation and, more broadly, educate about the healthcare needs of trans people. Parents should also be (re-)educated by the clinic.

2. The care the participants would like to receive.

Clinicians should be more sympathetic and transparent with SUs, genuinely listening to their individual needs and rejecting the one-size-fits-all approach adopted by the previous service. Family opinions should be considered but not prioritised over those of the CYP. There should be greater access to gender affirming treatment, including puberty blockers and cross-sex hormones. CAMHS should not be used as a referral pathway to the clinic. Wait times should be reduced as much as possible across the entire referral pathway to final appointment at the clinic.

COMPLETION

Alex Matheson

Alex Matheson
Deputy Director of Education

TO NOTE

Full transcript available in Appendix B.

SESSION INFORMATION (REPLICATE FOR EACH FOCUS GROUP)

GROUP TITLE & KEY QUESTIONS

DATE COMPLETED	FOCUS GROUP TOPIC	MODERATED BY
1st August 2023	Question set 3 – Wider support and information	Trans Advocacy Officer / Policy and Research Coordinator (Trans Programme) with notes taken by Policy Coordinator.

RESPONDENTS INFORMATION

NO OF PARTICIPANTS

13

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

- Age: evenly spread between 19-25; expressed gender identity: five trans men with two trans women and two non-binary people and one person who is gender fluid/questioning their gender; all but two people had accessed GIDS, with these two people ageing out of the service whilst on the waitlist; residents of: predominantly Manchester with people also from London, Newcastle, and South Wales.

OUTPUTS FROM THE SESSIONS

KEY THEMES IDENTIFIED (BY QUESTION)

QUESTION ASKED	THEME IDENTIFIED	SUPPORTING QUOTES
1. **Aside from specialist gender services what other services or support are/would be helpful (both within and outside the NHS)**	A greater amount of information about the clinic, including the care available, routes for accessing this care, appointment schedules, a map of the centre, information on clinicians, potential shared care arrangements (e.g., between GPs and pharmacies). In absence of the above information, people often had to rely on community groups where they found this information from people who had already accessed the clinic. More information on the clinic and how to refer to it for GPs was requested.	'I was my GP's first trans patient, therefore I had to learn everything myself to teach the GPs how to navigate the system'. 'I didn't have any trans people in my life besides myself, so it was very much a guessing game & my own research of what I needed to do and where I needed to go.' 'A lot of trans kids come out and don't want to go into school because of the stress or other mental health issues. Often schools don't want to

	Consensus that more outreach with schools would be helpful, including more comprehensive sex education and specific trans pupil guidance. Criticism of CAMHS as a step in the referral pathway between GP and GIDS was raised here. CAMHS offered little practical support and caused further delays in the young person accessing GIDS – who were offering the support they needed.	accommodate so will just let the child go off school (it happened to me). But you can't just let kids not attend school.' 'CAMHS also refused to refer me to Tavistock because my dad was transphobic and didn't agree.' 'CAMHS are completely useless in regard to being trans, my counsellor refused to refer me to the GIDS because I am asexual so "there might be something deeper going on"'.
2. What support should/could be given to parents/families/carers?	Peer support from other parents was felt to be incredibly important – for some this was vital in getting their parents to support their transition. Some expressed the need for more holistic support, such as clearly signposted parental support systems, support groups or counselling, provided as a separate support network to what the service provides. Many spoke of the personal damage that lack of parental support had had on their adult relationships with family. General consensus that resources provided or signposted by the service had more credence to parents than resources found by the young person themselves and may help challenge negative perceptions that parents already hold about trans and non-binary people. Attendees supported the idea of space in which parents could ask questions with trans adults, to challenge existing perceptions of trans and non-binary people and feel more hopeful about their child's future. Some expressed concern that as more information has become available, there is also more misinformation, and so an NHS produced 'myth busting' resource might be helpful.	'There should be clearer parental support systems (such as support groups or even just counselling sessions to some degree). It feels like GIDS was partially filling that role, but there really should be some sort of separate support there to help parents to understand what their child is going through and how to support their needs.' 'Especially with the current environment for trans people in the UK, having a concrete support system in the NHS for parents of trans people is desperately needed.' 'I found Tavistock will also very much side with the parents because their "patients" are minors. I don't think this helps parents adapt their views if the clinicians are appeasing them rather than listening to the child.' 'I honestly feel really bad about kids coming out in this climate, there's so much misinformation. At least when a lot of us came out there was no information. Combatting the misinformation is going the be the main thing that the NHS needs to work against with parents of trans kids.'
3. What and/or where/are your trusted sources of information, if any?	Sources of information listed included The Proud Trust (particularly their Afternoon Tea group), TMSA Facebook group, youth groups and online browsers such as Yahoo. The above sources were used to find information about the service and general advice and getting updates on waiting times for first appointments.	'One of my CAMHS therapists was really helpful, she directed me to a local trans support group.' 'To be fair, my GIC nurse was very up to date in regard to most things and was incredibly helpful with treatment options and side effects.'

	Attendees were generally more trusting of the information provided by other community members creating these resources than clinicians, however they noted that community resources were not always accessible, and the same information should be readily provided by the NHS. Mistrust of clinicians was a theme amongst participants, noting that one bad experience can impact willingness to receive care from any healthcare professional in the future. Many participants cited YouTubers as a good source of information when they initially came out, particularly Alex Bertie. The reliance on YouTube was felt to be due to a lack of resources or community information elsewhere, including the NHS website.	‘I just searched "I want to be a boy" [on an online search engine] and opened a can of worms.’ ‘I found out what trans people were from Yahoo Answers.’ ‘Youtubers - They're all icons and were my only form of useful information of navigating the NHS as a trans person.’
4. What general information would be helpful for young people thinking about their gender identity? **a. How would you want this information to be provided?**	4- Answered in previous question. A: Attendees spoke of the importance of language, and not using language that implies that the young person is “going through a phase” or not sure of their own feelings. One participant suggested paying trans influencers to create content about their experiences with gender clinics and provide information about the process, recognising that trans children and young people are more likely to trust other trans people rather than cisgender clinicians. Similarly, it was felt that having visible trans and non-binary people in healthcare would help community members access care without fear of stigma or oppression. All agreed that a variety of information sources was preferable, noting that it was often unsafe to bring physical resources into their homes as parents would be searching their rooms.	‘My school actually had a lesson about trans people in Year 10 as part of sex ed, and I think that was very helpful for people around me to be understanding when I came out. They were suspiciously progressive for a catholic school, and they were incredibly open regarding the existence of LGBTQ+ people during teaching. I think having that as a more of a commonality in schools would be very helpful for both trans kids and their peers.’
5. What information would you need to know if you were thinking about medically transitioning?	All agreed that information provided by trans and non-binary people themselves about their own experiences would be valuable. A positive experience with a clinician was given as an example of good practice, in which a doctor admitted that the participant ‘probably knew more than they did’, and let them explain what they knew, filling in any information gaps. The participant said that	‘It’s not weird talking to trans people about bottom growth because they’ve been through it.’ ‘GIDS did a really good session about hormone blockers when I was supposed to go on them, they were very transparent about the effects, the pros, and the dangers. My parents were in attendance,

	this made them feel like 'he saw me as a human being'. Collaborative approach such as this were generally accepted as being useful. Indigo Gender Service was cited as a good practice example, specifically in reference to trans and non-binary care navigators. Attendees wanted transparent information about how quickly hormones would have an effect on their body, and a recognition that mental health may still be a concern while they are waiting for changes to take effect.	and they were very open to answer any worries my parents had.'

SUMMARY MESSAGE/CONCLUSIONS

Brief overview of main conclusions from the focus groups. Focusing on:

1. How services could be organised going forward.

The clinic should orchestrate and manage a widespread information spreading campaign about and supporting trans people, which particularly focuses on the people/environments that trans CYP are likely to encounter (for example, schools and GP surgeries). This campaign should include targeted information at parents, including hosting regular parents' groups. Information about the service and the care it offers should be detailed and freely accessible to all.

2. The care the participants would like to receive.

A greater amount of information about the clinic and the services they offer should be made readily available to SUs before their first appointment, this should form part of a wider effort to make the clinic more transparent to SUs. CAMHS should not form a part of the referral pathway to the gender clinic and referral to CAMHS before the gender clinic should be an exception.

COMPLETION

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TO NOTE

Full transcript available in Appendix B.