

THE KITE TRUST

FOCUS GROUP 1

ORGANISATION

The Kite Trust

At The Kite Trust we envisage an inclusive society where LGBTQ+ young people are healthy, successful and celebrated. We support the wellbeing and creativity of LGBTQ+ young people in Cambridgeshire, Peterborough and surrounding areas, not only supporting young people directly but also seeking to change the environments and remove the barriers that prevent them from achieving their full potential. We do this through our Youth Work, Advocacy, Training and Research programmes.

Within our Youth Work programme, we provide many opportunities for social connection - youth social groups, individual support, family activities, inclusive sporting opportunities, workshops and residential opportunities. Each of these activities builds young people's confidence, self-esteem, sense of belonging and seeks to develop their skills and knowledge to enable them to thrive. We support over 500 young people each year.

Our Schools and Training programme recognises that many of the challenges LGBTQ+ young people face originate through environments and interactions with other people. We tackle bullying in schools through our Rainbow Flag Award, taking a whole-school approach to LGBTQ+ inclusion. We also work within other sectors that impact the lives of young people - healthcare, social care and a variety of employers - to ensure that LGBTQ+ inclusive practice becomes the default.

We also undertake a wealth of advocacy work and research, seeking to effect positive change for the LGBTQ+ community. All of our work at The Kite Trust centres around improving the lives of LGBTQ+ young people, with a particular focus on supporting trans and non-binary young people, as these make up the majority of our service users.

SUMMARY OF BRIEF & APPROACH

The Kite Trust (TKT) was engaged to undertake research/consultation with TKT service users, to explore the views of young people on gender identity services for children and young people and how these could be improved. We aimed to gather the most relevant and useful data possible while ensuring the research sessions remained safe and supportive spaces for young people.

We undertook this project by conducting three focus groups and a survey with TKT service users who had accessed, tried to access, or considered accessing NHS gender services when they were aged 18 or younger. The groups and survey explored questions provided by the Cass Review team, relating to experiences of NHS gender services and how these services could be improved, as well as the wider context of support for young people and their families in this area. More details of the recruitment, methodology and how the sessions were run are given below.

RECRUITMENT

All current TKT service users were invited to take part in the focus groups, if they had accessed, tried to access, or considered accessing NHS gender services when they were aged 18 or younger. This included young people who were aged 18 or over at the time of the focus groups but had views to share that related to their experiences of NHS gender services when they were younger. Information about the focus groups and survey was included in the newsletter sent out to all current TKT service users and parents/carers who have opted in to receive this. Young people (or parents/carers on their behalf, for younger participants) were able to sign up for the focus groups by email or by registering using Eventbrite, the same process used for signing up to regular TKT youth groups and other events. The survey was completed through Microsoft Forms, via a link that was included in the TKT newsletter.

METHODOLOGY

Three focus groups were undertaken, each based on one of the topics provided by the Cass Review team: 'the present' (session 1), 'the future' (session 2) and 'wider support and information' (session 3). In some cases, the questions were explored fully with time to spare, so participants were also asked questions from the other question sets. This is made clear in the 'key themes identified' section below where relevant.

All focus groups were transcribed verbatim by another member of TKT staff. Data was anonymised at the point of transcription. Transcripts and audio recordings of the focus groups were analysed by TKT staff members, alongside written notes from the focus groups. Thematic analysis was undertaken, guided by the questions provided by the Cass Review team.

Following feedback from TKT service users that the focus group format was not accessible to all, a survey was also created and circulated to TKT service users via the newsletter. This was discussed with, and approved by, the Cass Review team before circulation. The survey included all questions asked in all three focus groups.

Numbers of participants and relevant demographic information are given below.

Verbal consent was given by participants before each focus group began. Additionally, for the groups that were recorded via Zoom, a warning was given before recording commenced, where participants were advised that by staying in the call they consented to be recorded. In session 3, a written consent form was also used. In sessions 1 and 2, an amended consent form was circulated by email and written consent was given retrospectively.

HOW THE SESSIONS WERE RUN

Each of the focus groups took two hours and was facilitated by a TKT staff member. In all cases, a TKT youth worker was also present to support the young people. Each group took the same format:

- Initial introduction, review of the project information, and explanation of the focus of the specific focus group;
- TKT staff and young people introductions (name, pronoun and role if relevant) and icebreaker;
- Addressing Cass Review questions;
- Space for young people's questions and final comments (young people were also encouraged to ask any questions and share thoughts as they arose throughout the groups);
- 'Check-out' - young people sharing how they were feeling, youth worker and facilitator identifying any support needs to follow up;
- Discussion of next steps and reminder for young people of how to request payment for participation.

Participants were encouraged to contribute in whatever way felt most accessible to them. In all sessions, written notes were taken in addition to an audio recording. These notes were written collaboratively between participants and facilitator(s); In the first two groups, a Google Jamboard was used to record written notes. Participants had access to this Jamboard and could add their own notes, and the facilitator also made notes of their verbal comments. In session 3, participants and the facilitator made notes on A0 paper throughout the session, to which participants could contribute at any time during the group.

Participants were encouraged to speak freely and honestly, and steps were taken to ensure they were as relaxed and comfortable as possible. For example, snacks and drinks were provided, and participants were encouraged to move around freely and use fidget toys or other tactics to support their wellbeing. Breaks were taken where needed and facilitators ensured adequate time was available at the end of the sessions to ensure that any wellbeing needs or challenges could be addressed with young people.

SESSION INFORMATION (REPLICATE FOR EACH FOCUS GROUP)

DATE COMPLETED	FOCUS GROUP TOPIC	MODERATED BY
29 June 2023	The present (question set 1). Note that this group also explored questions from set 2 and 3 as there was time in the focus group after set 1 had been fully discussed.	A Staff Member from The Kite Trust

RESPONDENTS' INFORMATION

NO OF PARTICIPANTS

4

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

The group ranged from 16 to 26 in age and included trans women, trans men, non-binary identities and those questioning their gender. The participants were from predominantly rural parts of Cambridgeshire.

OUTPUTS FROM THE SESSIONS

KEY THEMES IDENTIFIED (BY QUESTION)

QUESTION ASKED	THEME IDENTIFIED	SUPPORTING QUOTES
Why would you go to the NHS for gender-related care?	<ul style="list-style-type: none"> Free healthcare To access gender affirmative surgeries To access HRT The opportunity for shared care which is reliable Continuity of care across all NHS services 	<ul style="list-style-type: none"> free, cheaper, don't have to pay wild amounts for the prescription relationship with shared care via GP - more reliable care (GIC) hoping that other NHS services will recognize and respect name and gender marker changes in your own medical file I think that most people are aware of the current news of how long the wait times are, and so they end up leading the action to get them referred top surgery wanting to get on the list so if you want trans care in future it's less far away bottom surgery HRT care and related regular testing that's required GPs might refer to GIDS because they feel the case is very complex and GPs don't have the right training or knowledge to support them
What do you think the purpose of assessment in the gender clinic is?	<ul style="list-style-type: none"> To ensure patients "are trans" before commencing treatment Ensuring patients have an understanding of the healthcare options available. 	<ul style="list-style-type: none"> offer therapy to help you understand your gender identity. Possibly to "make sure you're trans" and in the right specialist clinic. Just to make sure before more treatment is recommended assessments are there to reduce "regret rates" which are already very low in trans+ care. Unlike with cis counterparts searching for similar HRT arbitrary barriers to make sure that you're <i>*actually*</i> trans/gender diverse assessment as a part of HRT treatment
Is it important to you to have a diagnosis of Gender Dysphoria?	<ul style="list-style-type: none"> There were differing views across the group as to whether or not it was important to get a diagnosis of Gender Dysphoria. 	<ul style="list-style-type: none"> personally, yes it is. A diagnosis would help me find more acceptance within myself. It makes it more official in my mind overall, a diagnosis though could limit people. It just depends on the person no, I don't feel the diagnosis information is very relevant to what dysphoria is. The diagnosis is just a tool to access care. It isn't meaningful to me. Medical proof shouldn't be needed
Is it important to you to have a diagnosis of Gender Dysphoria? What do you think	<ul style="list-style-type: none"> To help support explanation to families 	<ul style="list-style-type: none"> I think a diagnosis code could help explain this to my family more. They think this is a choice, so a

<p>having a diagnosis means in relation to: yourself, parents/family/carers, healthcare, school, socially?</p>	<p>and acceptance by families</p> <ul style="list-style-type: none"> To increase families' understanding Help understand the interplay surrounding gender identity and mental health 	<p>diagnosis code could show them this isn't a choice for me to be trans+</p> <ul style="list-style-type: none"> I don't think a diagnosis would help my family understand my gender identity any better a diagnosis could give you more understanding of your own mental health - i.e recognizing that dysphoria symptoms are similar to depression symptoms.
<p>What do you expect from the clinicians in the service?</p>	<ul style="list-style-type: none"> To be treated with respect and autonomy Increased understanding around autism especially given the significant overlap between neurodivergence and trans identities, and the interplay between the two. Increased disability inclusion Increased acceptance and understanding of non-binary identities To not be misgendered. Removal of gendered language. 	<ul style="list-style-type: none"> understanding of autism because lots of autistic ppl are trans/trans people are autistic awareness posters, more disability inclusion. There should be more signs that they are inclusive of all folks with disabilities of all backgrounds get rid of the gendered terminology as much as possible "sir" "young man" "lady" etc. It's so frustrating and disappointing to be generally misgendered a lot of trans friends will act 'more binary' to the gender clinic if/when they talk to them because they don't 'get' nonbinary, they should be good at that considering gender clinic I would go to the GP more if I knew they would use the right name, titles, and binary words in reference to me. Not just the GP, but also all the staff. I would like to be treated with respect and autonomy. I don't want to be treated like I'm mentally ill and fragile It hurts to be called Sir, to be misgendered right upon arrival
<p>How important is the location of the service?</p>	<ul style="list-style-type: none"> Increased accessibility options e.g. remote services. Combination of face-to-face and remote services to ensure safety More local services are required as travel can be difficult, especially in more rural areas - e.g. Fenland. 	<ul style="list-style-type: none"> remote options for appointments available if wanted for access reasons, but also in person because wifi/not safe to talk at home makes remote not safe in relation to remote online services, folks living in rural areas still struggle to gain reliable internet access during office hours as well consider public transport - so in rural areas transport into bigger cities can still be very difficult. More local services are still needed for rural areas
<p>What is important in the relation to the environment of the clinics? Would you prefer a hospital or community location?</p>	<ul style="list-style-type: none"> Less "medical atmosphere" Understanding that medical offices can be triggering Spaces to be warm and comfortable Everyone to be welcome and included. 	<ul style="list-style-type: none"> not looking too 'hospital-y', less cold medical setting medical offices can be scary and traumatising places for lots of folks. It can be hard to adapt and process information in spaces like this the setting should look more warm and comforting so people feel safer and everyone's included

<p>Are there any aspects of the current service you think should be built into the new services?</p>	<ul style="list-style-type: none"> • Including email correspondence as opposed to only postal was a good development of the current service. • The group did not identify any other areas of the current service that should be built into the new services. 	<ul style="list-style-type: none"> • no there needs to be major changes! There isn't much about this current service that should continue • *tumbleweed blows past* • it's probably good that they switched to email correspondence instead of post
<p>Do you have a sense of the type of support or treatment you would personally like to be offered?</p>	<ul style="list-style-type: none"> • Improved communication especially surrounding waiting lists and regular updates. • Transparency surrounding waiting lists • The provision of trans+ positive. • Improve provision of information surrounding what services are available and how to access them. • Discouraging GPs from enforcing their own "waiting periods" before referral. 	<ul style="list-style-type: none"> • pretending it's not a long waiting time does not make the waiting time any less • real time regular updates would be helpful, even an auto email would be good. Just a regular check in so we feel progress is happening as we are in the waiting list • concerned therapy might discourage them or inhibit them from pursuing a life lived in their own identity. Closely related to conversion therapy perhaps • yes I knew what kind of treatments and care I would like before I went to ask for a referral • I would appreciate transparency for how long it could be before I receive diagnosis. Getting long wait time updates that aren't accurate are really painful. Tensely waiting is painful • I would like to receive therapy that is very trans+ positive. I'm scared it's closely related to proving I'm trans or they would blame neurodivergence for my dysphoria. • I feel like the information around the services not readily available or accessible. They share info on what they "don't do" not what service they "do do" • would like the GP to not wait to refer 'so you have time to think', because we have plenty of time during the wait.
<p>Aside from specialist gender services, what other services or support are/would be helpful (both within and outside the NHS)?</p>	<ul style="list-style-type: none"> • Increased understanding and knowledge across the healthcare sector on how to interact with trans people • A network for trans charities so support can be easily identified in specific areas. • Peer support groups • Local LGBTQ+ community spaces • Easier access to vocal training • One-to-one peer counselling e.g. LGBT Youth Worker. 	<ul style="list-style-type: none"> • GPs, therapists, other NHS staff knowing how to interact with trans ppl (not misgendering, understanding dysphoria) • a combined network for trans charities divided by location (Proud Trust had a similar function to this, but it's no longer available- a way to find groups by post code) • peer support groups are especially helpful for folks who are stuck on long waiting lists, decreases isolation • local LGBTQ+ community spaces, a pamphlet or link that shows local groups like TKT directly (since only a google search got me any help/info) • peer support groups for people on the waitlists • more advice and support on medical procedures, more information available freely on a website, face to face support. • easier access to vocal training • face to face support reassures me the information is coming from a reliable accountable resource

		<ul style="list-style-type: none"> • one to one peer counselling, LGBT youth worker counselling
<p>What and/or where are your trusted sources of information, if any?</p>	<ul style="list-style-type: none"> • The Kite Trust • Reddit • Friendship and peer groups • Social media • Pink News • LGBTQ+ sources • The focus group highlighted their distrust of mainstream sources and news outlets. 	<ul style="list-style-type: none"> • The Kite Trust – youth workers, other young people, our social media posts and campaigns, information resource from the website, queer library • Reddit • asking my friends with lived experience – how did you talk to the GP? How was your appointments? • Peterborough Pride, Norwich Pride social media accounts – they post things throughout the year, respond to big news cycles • pink news • I only get my information from LGBTQ+ sources, not mainstream sources. • social media and my friends • I don't trust news outlets to give reliable information about Trans+ people.
<p>What general information would be helpful for young people thinking about their gender identity? How would you want this information to be provided?</p>	<ul style="list-style-type: none"> • Increased promotion of what support is available, through pamphlets and websites. 	<ul style="list-style-type: none"> • https://genderkit.org.uk/ • pamphlets with local groups • websites with local groups by post code (more accessible)

SUMMARY MESSAGE/CONCLUSIONS

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

1. How services could be organised going forward.

There needs to be increased accessibility to gender clinics with a greater local offering. It was highlighted that having remote services alongside face-to-face service would be very beneficial, especially from an accessibility perspective.

Gender healthcare services need to have much better communication and provide regular and consistent updates to people on waiting lists.

There needs to be more transparency regarding waiting list lengths and additional support provided for the interim period.

There needs to be a clear place where information can be found on the types of services provided and how to access these, to reduce the reliance on unreliable sources.

2. The care the participants would like to receive.

The overarching message from all participants of the focus group was that they wanted to be treated with respect and autonomy, with their identities understood. This would require more in-depth training for healthcare providers as it is not currently being experienced by the young people within the focus groups and their peer networks.

It was also noted that there need to be increased understanding surrounding autism especially given the significant overlap between neurodivergence and trans identities, and the interplay between the two. In addition, gender healthcare services need to be more disability inclusive as a whole and welcoming to all.

KEY MESSAGES IDENTIFIED

MESSAGE IDENTIFIED	SUPPORTING QUOTES
The need to be treated with respect and autonomy.	"I would like to be treated with respect and autonomy. I don't want to be treated like I'm mentally ill and fragile."
Transparency surrounding waiting lists.	"Pretending it's not a long waiting time does not make the waiting time any less."
Improved communication throughout gender healthcare services.	"Real time regular updates would be helpful, even an auto email would be good. Just a regular check in so we feel progress is happening as we are in the waiting list."
Improve provision of information surrounding what services are available and how to access them.	<p>"I feel like the information around the services are not readily available or accessible. They share info on what they 'don't do' not what service they 'do do'."</p> <p>"More advice and support on medical procedures, more information available freely on a website, face to face support."</p>
Increased understanding and knowledge across the healthcare sector on how to interact with trans people.	"GPs, therapists, other NHS staff knowing how to interact with trans ppl (not misgendering, understanding dysphoria)."
Clinics should have less of a "hospital" feel and be more inclusive and comfortable.	<p>"Medical offices can be scary and traumatising places for lots of folks. It can be hard to adapt and process information in spaces like this."</p> <p>"The setting should look more warm and comforting so people feel safer and everyone's included."</p>

COMPLETION