

THE KITE TRUST

FOCUS GROUP 2

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
9 Jul 2023	The future (question set 2)	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)

Participants were aged between 15 and 17 years old an their expressed gender identities included: Non-binary, Genderqueer, Trans Boy, Demigirl and Agender. Participants came from predominantly rural parts of Cambridgeshire. One young person had accessed GIDS, and other young people had attempted to access referrals to GIDS but had not been seen by the service.

OUTPUTS FROM THE SESSIONS

KEY THEMES IDENTIFIED (BY QUESTION)

QUESTION ASKED	THEME IDENTIFIED	SUPPORTING QUOTES
<p>How important is the location of the service?</p> <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"> • The location of services is really important. • There is a large need for more local services; two national hubs are not sufficient to support the entire community. Having only two, creates accessibility issues regarding time, income and ease of access. • It was highlighted that having a combined approach with local services would be very beneficial. • Clinical settings are often uncomfortable and have not previously supported the community. However, it was noted that clinical settings can be beneficial for people to find and to affirm to others that gender affirmative healthcare is healthcare. • It was raised as to whether clinical settings can be made to be more inviting and comfortable. • Reluctance for local GPs to undertake shared care for hormone injections/blood tests etc creates additional access needs. Young people are forced to travel to the main hubs to get routine checks done which is costly, time intensive and presents accessibility issues. • Agreement that it would be highly beneficial for more local GPs to undertake shared care to improve access and to reduce the burden on trans healthcare. • Lack of joint working and communication between local GPs and GIDS have led to lack of care, seriously poor communication with young people, referrals not being actioned, and lengthy waiting lists aggravating each of these factors. • The need for local healthcare to undertake shared healthcare provision. • Many young people are choosing the “private” route both to reduce the significant waiting times but also to get more local services. 	<ul style="list-style-type: none"> • A clinical setting is more practical, but far less comfortable. This setting is too formal and makes folks less likely to feel able to express their own feelings which can be quite difficult • A more relaxed community setting would be less stressful, but a clinical setting would make it feel more "proper and safe". • My GP has refused to send in my referral due to MH conditions and testing. Because of depression and anxiety, but also because I'm on the waiting list for testing for autism • My GP told me that getting referred to the waiting list for testing for autism would help my speed up my GIDS referral. • Less clinical settings are more comfortable, because clinical settings so far have not worked so we aren't comfortable there. • a community space that deals with medical care • Clinical settings/hospital settings are easier to find, especially for folks who are used to that medical system vs community system. More practical re-use of current wards. • It would be great if there was a "secure and proper way to do things, as long as the system actually works." • it would be better if there were lots of local places to visit, with a bigger central location in London. • Clinical settings would help some folks take this information more seriously. Treating this as proper health care • Travel for me to go to London from Cambridge 1x every 3 months - £20 return ticket + it takes me a full day to travel there and back. • GP refuses and local hospitals refuse to carry out my blocker injections, so I have to go to London every 3 months for private medical care. • It's a long journey for me to go to London or up North to go to the clinic in person. It's also a very large travel cost and difficult with my schedule.

	<ul style="list-style-type: none"> • The possibility of “pop-up” clinics if establishing many local static clinics is not possible. 	<ul style="list-style-type: none"> • I only went private because I knew I wouldn't be seen by any NHS service before the age of 18. I did try going through my GP to get a GIDS referral. • I had one appointment with my NHS GP to discuss the info for the GIDS referral, but I did not hear anything back from my GP and I did not receive a confirmation at all • similar to Canada’s services - local services can assess and prescribe for simple cases, more complicated cases can be referred to a larger more central service. • Both would be good– local community spaces and local clinics – ability to easily self refer to both • Pop up clinics, wards that work during set hours, could be a good bridging way to start up these clinics if more permanent settings are too difficult to secure • I have ADHD and my GP is compliant with shared care testing around blood tests so I can get my ADHD medication. But they refused shared care blood tests for gender care • only having 2 places to go seems like too few clinics to support the entire country • my GP has refused to do shared care with my private gender support services. Is there a way to make a clinical setting more inviting and warm? For instance, how do children's wards feel more comfortable for their patients? • Is there a way to make a clinical setting more inviting and warm? For instance, how do children's wards feel more comfortable for their patients? I did speak to my GP about it, and my GP was supportive and put the referral through, but she additionally advised I go private due to the 2-3 year waiting list. • Going to London every 3 months for medical care can be really difficult.
<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"> • There were no elements of the current service that our focus group agreed should be built into the new services • The Focus Group raised some additional concerns about the current provision including <ul style="list-style-type: none"> ◦ Lack of communication generally, lack of consistent communication, lack of communication between GPs and gender services and the issues this creates for referrals. 	<ul style="list-style-type: none"> • Honestly I can't think of anything. Referral system is not working, Counselling is not working from what I've heard. I've only heard bad things about appointment structure • probably not communicating with GPs and other professionals about which gender services are available – so even professionals can't refer well • All the info I received about GIDS was from outside services and sources- reddit, The Kite Trust, social media.

- Professionals aren't communicating well even with each other, so professionals don't know what services are available for gender-affirming care and/or can't refer appropriately.
- No centralised hub of information to access to understand what gender services are available – young people are being forced to use unreliable sources such as reddit and social media. The focus group noted that even the GIDS website doesn't have good information regarding what services are provided or the referral process.
- The admin structure of the current system is very poor.
- Repeat appointments are too far apart and are therefore not providing effective care.
- Unnecessary repeated testing was believed by the Focus Group to be a "gate-keeping" measure.
- Young people are forced to become experts in gender services and to be strong advocates to access healthcare. This doesn't appear in any other health care services. Young people are more knowledgeable than the medical professionals they are seeing, creating a concern around them providing sufficient healthcare services.

- No correspondence from GIDS at all- just digital updates from my GP. No confirmation from GIDS that my referral was received
- Admin structure is very poor so not much they should keep there
- this was built to be a preventative service- back when the NHS was looking for a cure for gender diversity – so this systemic structure can not be adapted to support current views
- you have to be a very strong advocate for yourself in this service, to the level of being an expert about what care they need to fight for. This is not the case with any other NHS services
- their own website doesn't have good information about what services they have or how to get referred. Their self-referral form is hard to find.
- repeat appointments are so far apart, and testing keeps getting repeated- this seems to be a strategy to delay prescribing blockers

Do you have a sense of the type of support or treatment you would personally like to be offered?

- More ease of access to puberty blockers to allow young people time to explore their gender identity and better understand their identities.
 - Blockers should not mean that young people are automatically heading down a transition route.
 - Blockers reduce the huge anxieties that young people have around the "ticking clock of puberty".
 - The need for more clarity within resources surrounding any risks or "unknown risks" of puberty blockers so young

- Why would we ask for blockers if we really genuinely want HRT? We ask for blockers because we want time before deciding about HRT or typical puberty etc
- More specific knowledge around risks for blockers, something that can be discussed by individuals so individuals can consent to known and "unknown" risks
- SWIFT, EFFECTIVE CARE
- services should be aware of community groups like TKT and what services are offered- knowledge about Safe Spaces and waiting list support groups
- trans people often have to know what they want and need well in advance

people can make informed decisions.

- The need for swift and effective care
- Gender services should be aware of community groups and charities that provide safe spaces and support whilst on waiting lists.
- The possibility of self-referral especially given the lack of knowledge and understanding of local GPs.
- Again, it was noted that young people have to be highly knowledgeable on the care they want to receive to access gender affirmative healthcare – this is not apparent in any other healthcare setting.
- The required gender specific counselling is seen as a box-ticking exercise rather than actual support for the young person.
- Waiting lists are too long.

- GP specialist – maybe a GP that has more emphasis in gender services and can advise other local GP practices. This GP can also advise where more training is needed
- Reviewing the Cass review- people who authored the report were very obviously not-gender diverse based on language and how research was explained in a cis-biased way
- needing many other referrals before being given a referral for gender services
- there's so much anxiety around the ticking clock of puberty- so there's a strong need for blockers to prevent hormonal changes that could happen at any time
- it should be possible to easily self-refer, especially when your local GP is not knowledgeable about how to do this!
- more neutrality around blockers- this is not a gateway drug to HRT automatically. This is a neutral pause so we can figure things out before permanent changes happen
- Gender specific counselling shouldn't be required after being on such a long waiting list. There's no helping the YP at that appointment, it's just questions to justify services requested
- Many people go in with ideas of what you want before you even speak to the GP/clinician
- the waiting list is long, and there are other counselling options outside of the NHS gender clinic right now, so it shouldn't be required between gender care appointments

Do you have any suggestions about what the services should be called?

- The name should include “gender”
- Removal of “development” due to the inferences made
- Use “youth” instead of children and young people
- The name should be objective, factual and simple
- “Gender Youth Care”
- “Gender Health Care”

- The service name needs to include the word gender, otherwise the gender aspect of the services rendered could be minimized
- GIDS - the word Development isn't ideal here, as this alludes to a process or certain change
- suggested Youth instead of Children and Young people, suggested Children and Teens.
- It just be a name that shouldn't be twisted and used against us by hate groups
- name should be objective and factual to decrease confusing
- "Gender Health Care"
- GIDS – the focus on development focuses on emphasis on processing. Adding more barriers and more focus on making YP "think about it" more
- Gender Youth Care for under 18's
- Children and Adolescence Gender Care or Gender Health care

- a name that doesn't emphasize counselling focus ALONE. There cannot be an excuse for them to trim services down to counselling alone
- Tavistock and GIDS were terms used interchangeably, so any bad press associated solely with Tavistock was then applied accidentally to all gender care services

SUMMARY MESSAGE/CONCLUSIONS

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

1. How services could be organised going forward.

Young people shared how having two main clinics to cover the whole country and community was not sufficient. This poses significant accessibility challenges. In addition, young people shared the need for more local services and effective working procedures and processes for local GPs and gender healthcare services - it was raised multiple times, that communication and collaborative working is minimal and not fit for purpose. This has led to missed referrals, lack of appropriate care and sub-standard care.

Increased joint working must be established between local healthcare and gender healthcare services. It would be highly beneficial for GPs to take on shared care, supporting the administration of HRT and blood tests to avoid unnecessary travel/time constraints/accessibility issues and burdens on the gender healthcare services.

The lengthy waiting lists and lack of support during these periods was identified as a key issue. Additional support needs to be provided for young people on waiting lists and these waiting lists need to be reduced significantly so that young people can receive effective care.

The focus group shared that they would like there to be clear information available on what services are provided and what support is available for these, including local support.

2. The care the participants would like to receive.

The focus group shared that they simply want swift and effective care.

Increased communication was raised as a key area for development. At present communication is wholly lacking both to the young people and among medical professionals. Young people shared the need for consistent communication/updates so they are aware of where they are in terms of accessing gender healthcare services. This would reduce anxieties considerably.

More knowledgeable local healthcare providers. It was highlight that the provision of additional training to local healthcare providers surrounding gender healthcare services would be highly beneficial. Many young people noted that they have to become strong advocates and "experts" in gender healthcare, and to be able support their GP's understanding in order to access the healthcare they need. This is unlike any other area of healthcare.

The focus group shared that they would like there to be increased access to puberty blockers to allow them time to explore their gender identities without the "ticking clock of puberty".

KEY MESSAGES IDENTIFIED

MESSAGE IDENTIFIED	SUPPORTING QUOTES
The need for more than two clinics to cover the country and the need for localised services.	<p>“It’s a long journey for me to go to London or up North to go to the clinic in person. It’s also a very large travel cost and difficult with my schedule.”</p> <p>“It would be better if there were lots of local places to visit, with a bigger central location in London.”</p>
<p>Reduction in waiting times. Young people are waiting years to receive healthcare, and many are “aging out” of the system before being able to access.</p> <p>Many young people are also being forced to access gender healthcare privately to access the services they need.</p>	<p>“The waiting list is long, and there are other counselling options outside of the NHS gender clinic right now, so it shouldn’t be required between gender care appointments.”</p>
Improvement in communication – the need for consistent and clear communications amongst medical providers and to young people.	<p>“No correspondence from GIDS at all- just digital updates from my GP. No confirmation from GIDS that my referral was received.”</p> <p>“Admin structure is very poor so not much they should keep there.”</p>
Improvement in educational resources available that highlight what gender healthcare services are available and how to access them.	<p>“Their own website doesn’t have good information about what services they have or how to get referred. Their self-referral form is hard to find.”</p> <p>“It should be possible to easily self-refer, especially when your local GP is not knowledgeable about how to do this!”</p> <p>“Services should be aware of community groups like TKT and what services are offered– knowledge about Safe Spaces and waiting list support groups.”</p>
Increased knowledge amongst local healthcare providers on gender healthcare services so the burden is not placed on young people to “educate” their healthcare providers to receive the healthcare they require.	<p>“You have to be a very strong advocate for yourself in this service, to the level of being an expert about what care they need to fight for. This is not the case with any other NHS services.”</p> <p>“Trans people often have to know what they want and need well in advance.”</p>
Shared care to be adopted amongst local healthcare providers for HRT administration and regular blood tests.	<p>“I have ADHD and my GP is compliant with shared care testing around blood tests so I can get my ADHD medication. But they refused shared care blood tests for gender care.”</p> <p>“GP refuses and local hospitals refuse to carry out my blocker injections, so I have to go to London every 3 months for private medical care.”</p> <p>“My GP has refused to do shared care with my private gender support services.”</p>

COMPLETION