A service evaluation project exploring the experiences of parents and guardians in accessing an Under 10s telephone call pathway provided by the Leeds Gender Identity Development Service (GIDS).

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# Introduction

This is a report of a service evaluation project (SEP) conducted by a psychologist in clinical training for the Gender Identity Development Service (GIDS) in Leeds. The aim of the SEP was to assess whether a pilot pathway for parents of children under 10 was meeting its aims from a service user perspective. This report will cover some introductory literature, followed by the full aims, methods, results, discussion and finally some recommendations.

Gender dysphoria refers to a difference between one's experienced or expressed gender and one's assigned gender that causes significant distress or problems in everyday functioning (Butler et al., 2018). Over the last decade, the number of referrals to the GIDS, the specialist service for under 18s in the UK, has risen significantly from 77 in 2009/10 to over 2700 in 2019/20 (Care Quality Commission, 2021). The existence of gender dysphoria in childhood has been controversial in the UK media, with some arguing that health services are pathologizing typical cross-gender behaviour that often emerges in young people as part of identity exploration (Sedgwick, 1991). Gender critical feminists argue that this is harmful to children, who in their view can be pressured by the GIDS to transition to the opposite gender prematurely (Wren, 2019). What these arguments overlook is the fact that children referred to the GIDS must be supported through a period of careful consultation and assessment before they can access any physical interventions (Rickett et al., 2021). Nevertheless, this issue has gained unprecedented media attention in recent years, contributing to a pressurised environment for transgender children and their families.

Meanwhile, research has shown that transgender youth struggle with higher rates of depression, suicidality, self-harm and eating disorders compared with their peers (Connolly et al., 2016). In contrast, research has also shown rates of mental health problems decrease to similar to those observed in a typical sample when children are given early support with social aspects of transition (Olson et al., 2016). There is also evidence of reduced rates of psychopathology in children whose parents were advised to support their gender expression (Hill et al., 2010), although this study has been criticized for methodological weaknesses (Singh et al., 2011). It may therefore be important for services to enable children to access this early support with transition.

Whilst guidelines suggest direct support for children is important in discussing medical interventions (World Professional Association for Transgender Health, 2012), enabling younger children to express their gender comfortably may be more readily achieved through working with systems around the child, including parents and schools (Olson et al., 2016). Recent research looked at the experiences and expectations of healthcare of parents of gender diverse primary school age children (Rickett et al., 2021). This study found that there were two major difficulties for parents; waiting and isolation. Waiting was a very common experience for parents and was perceived as causing harm to their child due to the loss of time. Parents struggled with not knowing what to do for the best for their child in the time they were waiting for professional information. Many parents had been delayed in securing a referral to the GIDS for their child and found that primary and secondary care services lacked awareness and expertise in gender identity issues. These delays and frustrations often amplified worries when on the GIDS waiting list. Many parents also struggled with uncertainty and isolation during this time and were unable to access support from other parents or their social circles. The researchers commented that these experiences were very common among parents. Any services hoping to support parents of transgender children would therefore need to take these support needs into account.

#### Service context

The Leeds GIDS is one of two national gender identity services for children and adolescents. At the GIDS, the original service model recommended that once children were picked up for assessment, parents should be regularly seen face to face (NHS England, 2017). Over the past decade, clinicians at the GIDS have observed increased acceptability of cross-gender behaviour among parents, resulting in many of the children referred under 10 having already made a social transition to their preferred gender by the time they were seen by the GIDS. Whilst the parents still had some residual needs in terms of reassurance and advice, they did not have much need for full appointments at the service. Conversely, clinicians felt under pressure to 'provide a service' because some parents had travelled a long way to get to the clinic or taken time off work. It was therefore decided to pilot a new

pathway for children under 10. It was hoped this would meet the needs of both families and the service, reducing overall waiting times by saving clinicians time and therefore accelerating access to clinicians for more families. Time saving was achieved by moving to shorter and less frequent telephone support whilst families were on the waiting list, avoiding the need for clinicians to take clinical responsibility for the case. This had a knock-on effect of reducing administration and risk management responsibilities.

It was recognised that some families needed more support and a different pathway into the service was required. This included families with more complexity or risk, for example looked after children or children with complex or severe physical, mental health or neurodevelopmental difficulties.

Whilst the service had collected some positive feedback from their staff about how the pathway was working, they wanted to evaluate this new service from the perspective of families using it.

# **Pathway specification**

Once screened onto the pathway, families were offered a thirty-minute telephone consultation to discuss what they would like from the service at the time. The clinical aims of this consultation were to provide the correct information about the service, gather information about the young child, offer brief advice, signposting, information on gender development and problem solving where relevant. Appropriate families were kept on the pathway with follow-up phone calls every six to twelve months. A flowchart of the service can be found in <u>Appendix 1</u>.

# Aims

The aims of this SEP were:

• To evaluate whether the pathway was meeting its aims of:

- Providing the correct information about the service, gathering information about the young child, offering brief advice, information on gender development and problem solving and signposting where appropriate
- Meeting the unique needs of families of children under 10 whilst on the waiting list
- To evaluate whether there are unmet needs of families of children under 10 that may suggest amendments to the pathway
- To make recommendations to improve the pathway from the perspective of the families using it

# Method

# Design

This service evaluation used a mixed methods design. Participants were recruited from families who were accessing the Under 10s Pathway at the Leeds GIDS or families who had previously accessed the pilot pathway and had proceeded to the access clinical assessment services at the GIDS. Families that had left the service or were no longer accessing the pilot were not approached. Quantitative data collection was via online survey (Appendix 2), which was chosen to gather as many views as possible. Qualitative data collection was via semi-structured interview (Appendix 3), conducted via video call. Interviews were chosen to add greater depth and understanding to the data.

### Participants and recruitment

An email was sent out by the SEP commissioner to all relevant families (n=50) containing an invitation to participate in the SEP and a link to the online survey (<u>Appendix 4</u>). The link took the participants to an introductory page containing information about the project (<u>Appendix 5</u>). Participants were then required to tick a box confirming their informed consent for their data to be collected. At the end of the survey, participants were invited to tick a box to express their interest in participating in follow-up interviews.

The first email was sent to families in August 2021. Two reminders were sent for survey completion; one halfway through the data collection window and another one week prior to data collection closing. The SEP aimed to recruit as many participants as possible to the survey and at least 5 participants for interviews.

### Data collection and materials

All SEP materials were developed by the SEP author, the SEP commissioner, and a research psychologist at the GIDS. The quantitative survey questions were adapted from the Experience of Service Questionnaire, which was developed by the Commission for Health Improvement as a means of measuring service satisfaction in Child and Adolescent Mental Health Services (Brown et al., 2014). Some questions that were not relevant to this service, such as those pertaining to a physical building, were removed. The quantitative portion of the survey consisted of eleven categorical questions. Others were adjusted to be more relevant to the service aims. Five open-ended free-text questions were added to add some depth to the data. Whilst participants were required to answer the quantitative questions in order to submit the survey, they were not required to answer the free-text questions. This decision was taken to prevent participants from dropping out of survey completion at this stage. Interview questions were developed on the basis of the SEP aims.

Fourteen participants were recruited for the survey, of which eight participants consented to be interviewed. Seven interviews were conducted, with one participant being unable to attend for interview. Interviews took place between August and October 2021 by video call.

### Data analysis

There two types of qualitative data were analysed using two different methods. The survey data was analysed using content analysis (CA) (Erlingsson & Brysiewicz, 2017). CA uses

a descriptive approach to analyse data qualitatively and at the same time quantify counts of the codes (Downe-Wamboldt, 1992). CA puts more emphasis on describing data and less on interpretation (Vaismoradi et al., 2013) and was chosen for the survey data for this reason. Figure 1 shows the steps followed.



Figure 1 Steps followed in content analysis of survey data

The interview data was analysed using thematic analysis (TA) (Braun & Clarke, 2006). As the interview data was more in depth, it was felt a method with more emphasis on context and interpretation (Braun & Clarke, 2020) would be more appropriate. Figure 2 shows the steps followed.



Figure 2 Steps followed in thematic analysis of interview data

Once themes were developed, they were structured using a 'Strengths, Weaknesses, Opportunities and Threats' (SWOT) framework. SWOT is widely used in strategic and organisational planning and academia due to its simplicity and ability to capture a project's current impact (strengths and weaknesses) and future developments (opportunities and weaknesses) (Gürel & Tat, 2017).

# **Ethical considerations**

Ethical approval was granted by the University of Leeds Medicine Ethics Committee on 13<sup>th</sup> July 2021 (reference number: DClinREC 20-009). All participants were given information sheets about the study prior to data collection commencing (<u>Appendix 6</u>). A consent form for the interviews was read out to participants (<u>Appendix 7</u>), who confirmed their agreement on the record. Data was anonymised prior to storage to protect data security.

### Credibility

Credibility for this SEP was improved through two checks. Two coded interview transcripts and one coded survey question were sent to another psychologist in clinical training with the aim of ensuring data had been coded evenly and fairly. The themes and associated codes for both the thematic and the content analyses were checked for coherence by the lead researcher's main academic supervisor.

# Results

#### Quantitative survey data

Fourteen participants completed eleven ordinal scale questions that are shown in <u>Table 1</u> and Table 2. All questions were phrased positively, meaning "Agree" or "Strongly agree" answers were broadly indicative of support for the service. These responses will be referred to from now on as positive responses. The responses to the survey were largely positive, with 127 responses (91%) indicating that they agreed or strongly agreed with the questions. There were no "Strongly disagree" responses. Question 3.10 had the lowest proportion of positive responses, with only 64% in agreement, one neutral response and two negative.

# Table 1 Quantitative survey results

	Excellent	Good	Average	Fair	Poor
2.1. Overall, how would you rate the service that you have received as part of the Under 10s Pilot Pathway?	6 (43%)	7 (50%)	0 (0%)	1 (7%)	0 (0%)

# Table 2 Quantitative survey result

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
3.1. The information I received from clinicians about the service was useful	4 (29%)	8 (57%)	1 (7%)	0 (0%)	0 (0%)	0 (0%)
3.2. I received information about gender development that was useful	4 (29%)	8 (57%)	1 (7%)	1 (7%)	0 (0%)	0 (0%)
<b>3.3. I found it helpful to be able to speak with clinicians on the phone</b>	8 (57%)	5 (36%)	1 (7%)	0 (0%)	0 (0%)	0 (0%)
3.4. It was important for me to have phone contact whilst on the waiting list	11 (79%)	3 (21%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
3.5. It's important for families to have phone contact whilst waiting	11 (79%)	3 (21%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
3.6. The advice I received from clinicians was helpful	7 (50%)	6 (43%)	1 (7%)	0 (0%)	0 (0%)	0 (0%)
3.7. The phone contact with GIDS clinicians helped me to feel less stressed about being on a waiting list	7 (50%)	7 (50%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
3.8. The phone contact with GIDS clinicians helped me feel supported	8 (57%)	5 (36%)	1 (7%)	0 (0%)	0 (0%)	0 (0%)
3.9. The GIDS clinicians that I spoke to were able to answer my questions	9 (64%)	4 (29%)	0 (0%)	1 (7%)	0 (0%)	0 (0%)
3.10. I had my gender-related needs met by the phone contact with GIDS clinicians	6 (43%)	3 (21%)	1 (7%)	2 (14%)	0 (0%)	2 (14%)
3.11. The appointments were usually at a convenient time	8 (57%)	4 (29%)	2 (14%)	0 (0%)	0 (0%)	0 (0%)
Totals	83 (54%)	56 (36%)	8 (5%)	4 (3%)	0 (0%)	2 (1%)
1 01815	139 (9	0%)	8 (5%)	4 (3	3%)	2 (1%)

# Qualitive survey data

Fourteen participants completed five open-ended free-text questions. The themes generated from the content analysis are shown in <u>Table 3</u>.

## Important aspects of service

### **Clinician warmth**

When survey participants were asked about their experience of the pilot pathway and what had been helpful or unhelpful about the pathway, many talked about the clinicians. Participants felt clinicians were friendly, helpful, accommodating, encouraging and supportive. This stood out in the analysis a helpful aspect of the service and was the most frequent code in the data.

• "Fully able to give advice where needed and had genuine concern for circumstances."

### Advice and information

The second most frequent code related to advice and information and many participants felt that this was a helpful aspect of the service. Parents valued being able to discuss and explore issues.

• "The clinicians helped us to reflect upon situations and sometimes also offered practical advice to the problems we had at the time."

### **Professional availability**

Participants felt that it was helpful to have professionals available who were able to give expert advice when needed.

• "Just speaking with a professional and receiving feedback and having someone who my child could raise questions and concerns in a safe environment"

## **Connection to the service**

Some participants felt that being in the pathway had helped them to feel connected to the service and like they had been held in mind whilst on the waiting list.

• It was a positive experience, we knew we had not been forgotten about and we still connected to the service despite being on the waiting list.

# **Suggested improvements**

### More child contact

Participants felt that it would have been helpful to have more direct contact with their child.

### More face to face

Some participants felt that they would have preferred some or more face to face sessions.

Table 3 Themes and codes developed from the content analysis of the free-text survey responses

Theme	Codes	Number of codes
Important aspects of the	Clinician warmth	12
service	Advice and information	11
	Professional availability	10
	Connection to the service	3
Suggested improvements	More child contact	3
	More face to face	3

## Qualitive interview data

Seven of the survey participants completed follow-up semi-structured interviews consisting of seven questions shown in <u>Appendix 3</u>. A thematic analysis of the responses generated 7 themes and 6 subthemes, shown in <u>Table 4</u> and <u>Table 5</u>. They were organised into a SWOT framework.

# Strengths

# Positive interactions with clinicians & clinician warmth

The first strength was positive interactions with clinicians, which contained two subthemes. The first subtheme related to a reassuring and calm manner of the clinicians. Participants felt reassured by the phone contact, many of whom felt anxious about whether they were supporting their child with their gender identity in the right way. Participants valued clinicians giving them time to explore these issues and felt that their views were respected. Some appreciated that they were not pressured by clinicians, and the contact felt calm.

The second subtheme was supportive and helpful clinicians. Six participants felt that the phone contact had been helpful and supportive because of the advice given, having their questions answered fully, reviewing how to talk to their child about gender-related issues, responding quickly to incidents, signposting and supporting decision making.

# Service approach

The second strength identified was the service approach. The first subtheme was feeling connected. Three participants felt that being on the pathway was helpful because they knew that they hadn't been forgotten on a waiting list and felt connected to the service while they were waiting.

The second subtheme was early intervention, referring to a feeling participants had that dealing with issues early whilst they were on the waiting list had minimised distress, and prevented these issues from becoming unmanageable.

The third subtheme was knowledge of the service, in which participants felt contained by knowing exactly what to expect from the service. Participants commented that it was helpful that they knew when the next contact would be and what to expect from the service once puberty commenced.

Finally, all participants felt that the remote nature of the contact was acceptable for supporting parents. A further four participants felt that the remoteness was actually beneficial because of their distance from the GIDS clinic in Leeds, saving them time and expense.

# **Opportunities**

# Peer support

Some participants talked about a previous model of the Under 10s Pathway, which had involved a support group of parents facilitated by clinicians. The service chose to move away from this model due to the risk of parents feeling pressurised to act in particular ways. Two participants felt that this group had been helpful, and others highlighted the importance of peer support in being a parent of a young gender diverse child. This represents an opportunity for the service to meet additional needs of parents of children under 10.

Linked with this theme, some participants talked about the intense judgement they experienced from others as a result of being the parent of a younger child. Some participant felt that other parents were more understanding regarding parents of adolescents, as there was an agreement that children of that age knew what they wanted. This was not afforded to children under 10, and some participants who had allowed their children to transition at a young age felt more judged and criticised. Hearing from other parents in similar situations therefore may be especially helpful for parents of younger children.

### Weaknesses

# Age and puberty

Some parents felt that the light support given by the pilot pathway was appropriate when their child was very young because there was less need for urgent decisions to be taken. Once their children got older, however, and puberty started, the pathway started to feel less suitable. Some parents felt distressed at a lack of access to comprehensive support quickly when their child started puberty. Some parents felt that it would have been preferable to start face to face meetings with their child earlier.

# Depersonalised

Some parents felt that the contact could at times be a little depersonalised and would have preferred to have more information tailored to their individual situation. Some felt that clinicians were not listening at times. Three participants experienced communication issues from the service in terms of lack of appointment letters or appointments being organised on time and felt more checking in would have been helpful.

# Threats

# Waiting list

Finally, all participants mentioned the anxiety of being on a long waiting list. Most of the participants felt that their waiting time, although not entirely comfortable, had been tolerable because their child was so young. Many felt that if it had been longer, this would have been a problem. Some parents had turned to alternative sources of support whilst waiting and had found inaccurate information online that had created significant distress. Some felt they would have benefited from getting access to information earlier. This represents a threat because the service could be significantly impacted by an increase in waiting time.

Table 4 Strengths generated from interviews with participants

Strengths				
Theme	Subtheme	Illustrative quotation		
Positive interactions with clinicians	Reassuring and calm manner	"The fact that there was no pressure." "The fact that there's nothing pushy from the psychologists' end, it was all just quite free and easy." "They never rushed me through the conversation or tried to get me off the phone or anything. I didn't feel like there was a designated time slot, I knew there probably would be, but you didn't get that feeling."		
	Supportive and helpful clinicians	"It gave you the opportunity to air your views, I found it quite practically helpful really because we were able to share difficultiesfor example social things at school, becoming upset by bulge in her pants, so we would talk about practical things like, oh what can we do to help with that and just to talk through things."		
		"It gave us the opportunity to ask any questions which was really useful and she would always answer very honestly and very fully."		
		"We don't feel that we've been rushed into anything. Everything's been quite consideredIt's not like decisions are being made hastilybecause obviously it's a very delicate, difficult situationand we feel that hasn't, it's just sort of supported us through you know these few years."		

Service	Feeling connected	"It's nice to just to already have contact with like a specialist organization and who can advise you."
approach		"I did appreciate the phone calls from the psychologist, it made you feel part of the service, like you hadn't been forgotten"
	Early intervention	"Knowing there's that contact there, that support, if we need it, but I think having that is reassuring so you're probably less likely to have kind of a flare up, like a kind of a crisis situation, because you know you've got up support is there"
		"Emotionally it was helpful, you could talk about anything and any of your worries. and then those worries didn't escalate into anything bigger, because you're able to talk about them and resolve anything that needs to be resolved."
	Knowledge of the service	"Because she's under 10 its more see how each day goes rather than like actual intervention. I think that's the next stage of what goes on because of puberty coming up."
		"We agreed on timescales, so we knew in so many months, we'd get a phone call and then we'd agree at that time things were still going well, checking in, didn't need weekly/monthly, just every few months."
	Remoteness	"I think it's good how it's done because at such a young age you don't need to be back and forth from the clinic all the time."
		"I thought that helped, because it was only me for so long, it was fine, because it was always over the phoneso that fits in really wellbut I just didn't see the point of going all the way on my own."

Table 5 Themes	generated fi	rom interviews	with participants

Theme	Subtheme	Illustrative quotation
Opportunities	Peer support	"Just being in a forum where you can keep an eye on other people's situations and just see if there's anything similar to what you're going through."
		"Residentials were brilliant because I got to meet others in the same shoes as me, and I got to see young trans role models, and I thought well, they're great, so maybe things will be ok. So yeah they were incredible. We also used to go to a local group, but that was mostly older teens so it wasn't entirely suitable, but that was the only local network we had." "It was good to be able to meet other families and meet clinicians and ask questions."

Weaknesses	Age and puberty	"From what I can remember, it took a lot longer than I thought, the initial bit, but I wasn't overly worried because of his age, I wasn't worried on that front."
		"We were pretty chilled at that time because she was so young. There wasn't that anxiety that's came
		later, with trying to access practical, medical treatment, accessing the emotional side has never been an issue and that's absolutely fine."
		"It's a very different experience having a young trans child compared to an older childwith an older child there is an urgency you don't have with a younger child."
		"So we're now waiting for a face to face appointment at the moment, so I think the under 10s pathway
		is absolutely fine if you don't need anything, so like if your child is 5 or 6, yeah finebut once your
		child is getting older, and starting getting annoyed and upset about things and puberty changes and whatever, you need more than a phone call"
	Depersonalised	"Little bits of advice that GIDS are going to provide but that didn't resonate with us, it was general advice not personal advice which would have been preferential."
		"A bit more keeping in touch, even if it's just an email saying remember that we're here if you need us, here's our next appt. Just to know that you're still there and in the system."
	Distance from clinic	"The one thing that [child] pointed out is that it would be better if it was more localised, so we're not too bad but it took us an hour and fifty minuets, which is a long time."

Threats	Waiting time	"When a parent learns that their child is trans, especially a young child, that parent has a lot of
		questions because the parent is making decision for that child. The parent needs support straight
		away. By the time we'd been on the waiting list for 18mo we had figured things out already."

# Discussion

This SEP was designed to evaluate whether the pilot pathway at the GIDS for parents of children under 10 with gender dysphoria was meeting its aims, whether there were any needs that the pathway was not meeting and to identify any suggested changes to improve the pathway from the perspective of its users. Findings from the SEP included widespread support for the pathway in its current form. There was some suggestion that the pathway may be less suitable for parents of older children, who begin to develop more complex needs as puberty starts. There was also a suggestion that an element of peer support may be of benefit. This section will now discuss these results considering the aims of the SEP.

# Pathway aims

The qualitative analysis found that parents demonstrated knowledge of the pathway and its next steps, valued advice given, received information, and found that exploration and discussion aided in decision making. These are strongly linked with the first aim of the pathway and it therefore seems likely that the pathway is meeting this aim. The quantitative results were consistent with this, with 86 per cent of parents agreeing that they received useful information about gender development, 93 per cent agreeing that they received helpful advice and 93 per cent that clinicians were able to answer their questions. There was consensus in the data that this support was valued by parents, with the clinician warmth and advice and information codes in the content analysis being present twelve and eleven times respectively. This is in line with research that suggests parents struggle with uncertainty when waiting for specialist input and information and advice is highly valued (Rickett et al., 2021).

There was also support for the second aim of the pathway; to meet the unique needs of under 10s. From a service perspective, as set out by NHS England (2017), this largely means a 'watchful waiting' approach as there is not yet a need for any medical intervention. The service approach subtheme indicated that this was helpful to parents. Participants felt that being able to discuss issues early and feeling connected with the service helped to

minimise distress. There was a consensus that younger children often did not need as much support and therefore brief telephone contact was appropriate.

Caution must still be exercised, however, as there was contradiction in the data, with some parents feeling that the advice and information given could be depersonalised, that clinicians were not always listening and others reporting communication issues. This stands in contrast to the strengths identified. A balance is required between the timesaving, light-touch purpose of the pilot pathway and the need for parents to receive adequate support, which may not always have been gauged right. To ensure that all parents are receiving the required level of support, it may be helpful for clinicians to elicit regular, brief feedback from parents after each phone call. There is evidence that regular feedback can improve patient outcomes in healthcare settings (Knaup et al., 2009), and with this information, clinicians could forward plan the care provided.

### **Unmet needs**

Another aim of the SEP was to explore whether there were any unmet needs of those using the pathway. There was widespread agreement in the data that participants struggled with waiting times and that this had created significant anxiety for parents. This is unsurprising given evidence that struggling with waiting was a common experience for parents of gender diverse children (Rickett et al., 2021). The pilot pathway was designed to provide support whilst parents are on the waiting list and may therefore ameliorate this issue. It may take some time for the impact of the pathway to be felt on waiting times, and those interviewed may have been among the first pathway users, who had a particularly long wait before entering the pathway. On the other hand, as commented by a recent CQC inspection report, the waiting times at the GIDS are too long to ensure safe practice due to the unprecedented number of referrals in recent years (Care Quality Commission, 2021). It is likely that further reduction in waiting times may be of benefit to users of the Under 10s Pathway and may require additional funding.

Another possibility to contain the anxiety of waiting, and particularly of feeling as though time is being wasted, could be to provide some generic information to parents upon entry to the service. Some parents were turning to internet forums for support, and often were met with incorrect or inflammatory information, which increased anxiety. One participant wrote persuasively about how access to information earlier would have been of significant benefit to her mental health:

"So I look back now and there were massive gaps in my knowledge that were there for years that would have been really helpful right in the beginning, especially emotionally. So I was told if trans boys didn't have a hysterectomy they would have a higher risk of cancer, which I now know isn't true, but I lived with that for 3 years before I found out the truth and that has a big emotional impact. That help and information even if just phone calls at the very very beginning is really critical."

If it is not possible to reduce the time for parents to see a clinician, the opportunity of accessing written information and guidance about gender identity prior to contact with the service may go some way to supporting parents at a difficult time.

Another finding was that the pathway was most suitable for young children who have not yet reached puberty, with older children who had started puberty needing additional support and advice more urgently. NHS England (2017) guidelines suggest that children start individual sessions once they reach puberty, in recognition of the need for more input. It may therefore be more appropriate for puberty to be used as a guide to whether a child should remain on the Under 10s Pathway, rather than age. This could mean than some children remain on the pathway after the age of 10 and some are taken off it earlier. Whilst this may improve the service experience for parents of older children, it raises questions about how this could be operationalised. Additional time would be required or administration in order to monitor each child's progress through the pathway and secure appointments once puberty was reached. There could be difficulties associated with ensuring equal access to the service if those referred via the Under 10s Pathway then had a shorter wait compared with those referred in adolescence. The pathway may benefit from a separate process for older children, but it would need to be carefully planned and considered to avoid these issues.

Finally, some parents highlighted that they had found peer support helpful. This is an interesting finding, as the original proposal for the Under 10s Pathway was a group model. The GIDS found this to be ultimately unhelpful due to the dynamics between parents. Research has shown that many families feel isolated and cut off from other parents due to having a gender diverse child (Rickett et al., 2021). A peer support provision within the GIDS could also help to reduce the pressure on their clinicians, and parents may need less reassurance and guidance from clinicians as a result. On the other hand, peer support would require governance and resources that the GIDS may not have access to given the long waiting lists. Parents may prefer for GIDS to focus on reducing the time to be seen by clinicians, as suggested by the fact that professional availability was viewed by many parents as an important aspect of the service. Some parents reported being able to access helpful peer support from other, third sector organisations. An alternative course of action to ensure parents' social support needs are met could be to ensure consistent signposting to these organisations. In the survey question relating to signposting, only four responses (29 per cent) indicated that they had been signposted. On the other hand, there were two parts to this question, so it is unclear whether the responses apply to being signposted or whether parents subsequently used the service that had been recommended. This is a weakness of this question and has limited the conclusions that can be drawn. It may therefore be helpful for the GIDS to consider surveying more parents about their access to peer support services.

# Limitations

This SEP was able to recruit 30 per cent of pathway users, which enables some confidence that the views are representative of the parents on the pathway. On the other hand, the interviews and survey data came from the same participant sample and therefore some participants views were counted twice. There may have also been some social desirability effects. Despite the researcher being independent from the service, it was evident that there were affiliations with the NHS and participants may therefore have still felt under pressure to respond favourably. It would be beneficial to repeat this evaluation with further participants. Participants were only recruited from parents currently on the pathway or those that had progressed through the service. As a result, there is no representation in the results of parents that have dropped out of the service. This is likely to have led to a skew in the results towards those that view the service positively. There is evidence of high drop out from gender identity services for children, but it is generally felt that those who do not go on to use specialist services have resolved their gender dysphoria, as is common in young children (Rickett et al., 2021). On the other hand, there may be parents who declined to take up the Under 10s support but would engage with a clinical assessment. Whilst it was beyond the scope of this project, further research could focus on assessing how many parents fall into this category and their reasons for declining the pathway.

# Recommendations

The following recommendations are made resulting from the above findings, with the aim of improving the service for its users:

- A different or more flexible process for older children approaching puberty to ensure adequate support is provided for this age group.
- Collect regular feedback about the service so that all parents are given the support and communication that is required.
- Further reduce the waiting times for support, which was found to be a problem for some parents.
- Produce some written information for parents and children that can be sent out at the beginning of the pathway. This may help families to feel more reassured and contained.
- Conduct further research around the importance of access to peer support for parents whilst on the pathway, as well as how consistently parents are signposted to helpful organisations. It may also be of benefit to implement measures to ensure parents are signposted upon entrance to the service. This could be added to the documentation associated with the service and followed up in the first phone contact.

• Assess whether some parents are declining the Under 10s Pathway and the reasons for this.

# Dissemination

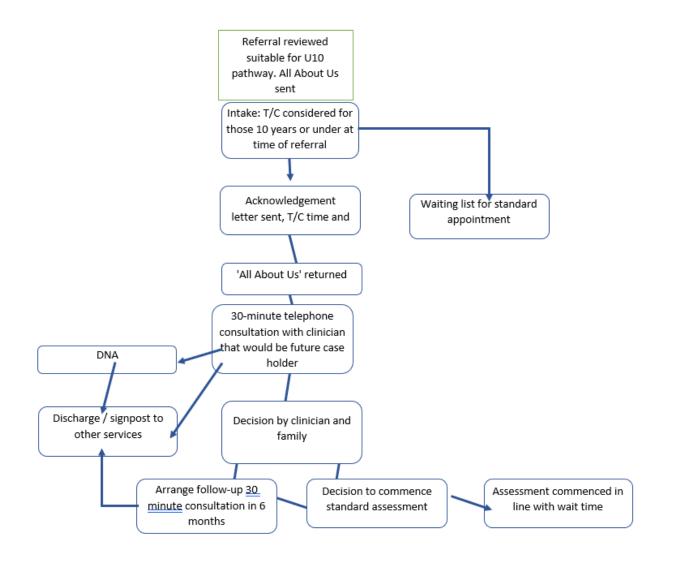
A summary of this SEP was presented at the University of Leeds Programme in Clinical Psychology SEP conference and will be made available on the programme website. This report and an executive summary will be developed for circulation at the Tavistock and Portman NHS Foundation Trust.

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# **Appendix 1: Under 10s Pathway flowchart**



# **Appendix 2: Online survey**

Please answer the questions below by putting a marker in the box that best describes your experience.

		Poor	Fair	Average	Good	Excellent	N/A
1.	Overall, how would you rate the service that you have received as part of the Under 10s pilot pathway?						

Please indicate to what extent you agree with the following statements by placing a marker in the relevant box

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	N/A
2	The information I received from clinicians about the service was useful						
3	I received information about gender development that was useful						
4	I found it helpful to be able to speak with clinicians on the phone.						
5	It was important for me to have phone contact whilst on the waiting list.						
6	It's important for families to have phone contact whilst waiting.						
7	The advice I received from clinicians was helpful						
8	The phone contact with GIDS clinicians helped me to feel less stressed about being on a waiting list						
9	The phone contact with the GIDS clinicians helped me feel supported						
10	The GIDS clinicians that I spoke to were able to answer my questions						
11	I had my gender-related needs met by the phone contact with GIDS clinicians						
12	The appointments were usually at a convenient time						

13. What was your experience of the phone contact with GIDS clinicians?

14. What did you find most helpful or unhelpful about the phone contact with GIDS clinicians?

15. Was there anything that you weren't able to discuss in the phone contact with GIDS clinicians?

16. Do you have any suggestions that might have improved your experience of the phone contact with GIDS clinicians or how we could do things differently in future?

17. Were you signposted to any services by clinicians and if so, did you access them?

# 18. We would like to contact some respondents for a follow up <u>30 minute</u> interview by phone or via video call. If you would like to take part in a follow up interview, please tick this box to confirm that you consent to be contacted and leave your details in the box below.

I confirm that by ticking this box, I consent to be contacted for a follow up interview in relation to my experience of the pilot pathway for under 10s at GIDS.

Name:	Phone number	
	or email	
	address:	

# Thank you for taking the time to complete this questionnaire

# **Appendix 3: Interview schedule**

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# Service Evaluation Project for the Gender Identity Development Service (GIDS) in Leeds

#### INTERVIEW SCHEDULE

- 1. Can you tell me about your experience of using the GIDS under 10s pilot pathway?
  - a. Prompt: What did you use the pilot pathway for?
- 2. What were the things that you thought worked well in the under 10's pilot pathway?
- 3. What were the things that you thought didn't work so well in the under 10's pilot pathway?
- 4. Was there anything you thought the clinician could do better?
- 5. Was there any aspect of the process of using the pathway you thought could be improved?
- 6. Was there anything that you weren't able to discuss with the GIDS clinicians that you might have liked to?
  - a. Prompt: Could you tell me why you felt unable to discuss this with the GIDS clinicians?
- 7. Is there anything else that feels important to tell me about the pilot pathway that you haven't already mentioned?

Version 3

# **Appendix 4: Recruitment email to all pathway users**

Dear parent, guardian or family member,

You are receiving this email because you are being invited to share your views and experiences of the pilot pathway developed by GIDS for children under 10 that you have been involved with. The pilot pathway looks at ways of engaging with families over the telephone, while they are awaiting assessment. The aim of these telephone calls is to provide interim support, containment and advice.

This evaluation will help to gain understanding of how the pathway is being used by families, whether it is helpful to them and whether any adjustments might be needed to fully meet the needs of all families.

If you click the link below, you will be taken to a page containing further information about the project, followed by a consent form. You will then be invited to complete the online survey, which will take approximately 10-15 minutes to complete. You will be asked for your views on how you have found the pathway and whether you have any recommendations for its improvement. At the end of the survey, you will be asked if you would like to participate in a follow up interview and to give contact details for this. Please note the follow up interview is optional, and you may choose to complete the survey alone.

The results of the survey will be analysed and written up into a report to be shared with GIDS, which will contribute to the development of better services for parents, guardians and families in the future. I hope that you will consider participating, as your views are very important to the organisation.

[Data collection for this service evaluation will close on xx/xx/xxx. At this point you will no longer be able to participate.] – to be added into reminder emails but not the original, as the closing date may not be established at the first recruitment point.

Thank you for taking the time to read this email and for supporting the project.

# **Appendix 5: Survey first page and consent form**

School of Medicine, Faculty of Medicine and Health Worsley Building, Clarendon Way, University of Leeds, LS2 9NL



#### A service evaluation project exploring the experiences of parents, guardians and families in accessing an under 10's telephone call pathway provided by the Leeds Gender Identity Development Service (GIDS)

You are being invited to participate in a service evaluation. This evaluation is being completed by Jessica Pugh, Trainee Clinical Psychologist from the University of Leeds and has been commissioned by the GIDS.

The purpose of this service evaluation is to collect the perspectives and experiences of families using the pathway for parents, guardiaos and families of children under 10 and will take you approximately 10-15 minutes to complete. Your participation in this study is entirely voluntary. As your answers will be collected anonymously it will not be possible to withdraw your data once the survey is completed. If you change your mind before the survey is complete, you may close the survey and your data will not be stored. Nobody will be made aware that you have completed this survey, including the GIDS. There will be no consequences from choosing not to take part. You do not have to answer any questions you do not want to.

This survey invites you to discuss your experiences of the pilot pathway for Under 10s and as a result there is a small risk that you may experience some distress in doing so. On the other hand, it is hoped that the results of this survey will help to develop better services in future, and as such your views are important. The website used to host this survey is secure.

Ethical approval for this project has been granted by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (project number: DClinREC.20-009). To the best of our ability your participation in this study will remain confidential, and only anonymised data will be published. Only the project lead (Jessica Pugh) will have access to the unedited survey data. We will minimise any risks by encrypting research data and storing it securely. Further information is available via the University of Leeds <u>Privacy Notice</u>.

The results of this evaluation will be written up into a report, shared with the GIDS inpresentation and presented as a poster presentation at the University of Leeds. Direct quotations from survey respondents may be used in the report and the poster but steps will be taken to remove anything that may identify you.

 By ticking this box, I consent to my data being used for the <u>above named</u> service evaluation project.

Version 3

# **Appendix 6: Interview participant information sheet**

School of Medicine, Faculty of Medicine and Health Worsley Building, Clarendon Way, University of Leeds, LS2 9NL



#### Participant Information Sheet

#### Title: A service evaluation project exploring the experiences of parents and guardians in accessing an under 10's telephone call pathway provided by the Leeds Gender Identity Development Service (GIDS).

You are being invited to take part in a service evaluation. Before you decide it is important for you to understand why this evaluation is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

#### What is the purpose of the project?

A new pathway has been piloted in the GIDS which looks at ways of engaging with parents, guardians or families of young children, aged 10 and under, over the telephone, while they are awaiting assessment. The aim of these telephone calls is to provide interim support, containment and advice.

This evaluation will help to gain understanding of how the pathway is being used by families, whether it is helpful to them and whether any adjustments might be needed to support more families.

#### Why have I been chosen?

You have been chosen either because you are currently using the Under 10s pathway for GIDS or because you have previously used it and are now receiving an assessment from GIDS.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form). During the interview, you will have the option of not responding to any questions that you don't wish to answer without having to give a reason for this. You can withdraw from the study up to one week after the interview is complete without giving a reason.

#### What do I have to do?

You will be asked to take part in an interview with the lead researcher of approximately 30 minutes. This interview will be conducted remotely and therefore no travel will be required. The interview will either be conducted over the phone or via a video conferencing platform. You will be asked questions about your experience of using the pilot pathway and any recommendations for improvement that you might have.

#### Will I be recorded, and how will the recorded media be used?

With your permission, an audio recording of your interview made during this research will be used only for data analysis. No other use will be made of the recording and no one apart from the project lead (Jessica Pugh – Trainee Clinical Psychologist independent from GIDS) will be allowed access to the original recordings. The recording will be destroyed once data analysis is complete.

Version 1.1

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#### What will happen to my personal information?

The lead researcher will take notes during the interview, which will be used for analysis. The notes will be typed up, password protected and securely stored. All identifiable research data will be kept confidential, including from all GIDS staff and the service. One week after your interview, your contact information will be destroyed and your data will only be identifiable by your participant number. We will take steps wherever possible to anonymise the research data so that you will not be identified in any reports or publications. The anonymised research data may be shared with others at the University of Leeds for the purposes of quality checking and peer review. To find more information on the guidelines of the University of Leeds that have been followed to protect your personal information click here.

The information that you provide will be treated as confidential from all GIDS staff unless you disclose something that indicates you or somebody else may be at risk of harm. If this happens, only information that is relevant to the risk issue will be passed on to Dr Rose Hatton, Clinical Psychologist at GIDS. Dr Hatton will then take action in accordance with the organisation's safeguarding policies.

#### What will happen to the results of the research project?

Direct quotations from what you have said may go into the evaluation report but care will be taken to ensure that you cannot be identified from this. The evaluation report will be shared with the Leeds GIDS alongside a presentation of the findings and may be shared more broadly within GIDS. There is a possibility the results will be published in an academic journal. All those using the pilot pathway will be sent a copy of the service evaluation poster, containing a summary of the findings.

#### Who is organising the research?

The service evaluation is being organised by the University of Leeds as part of the Doctorate in Clinical Psychology programme. It was commissioned by the Leeds GIDS. Ethical approval for this project has been granted by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (Reference number: DClinREC 20-009).

#### Contact for further information

If you have any questions or what to talk about participating, you can contact:

Lead researcher: Jess Pugh, umip@leeds.ac.uk or

Academic supervisor: Dr Rebecca Yeates, r.a.yeates@leeds.ac.uk

Thank you for taking the time to read this information sheet. You will be given a copy of this sheet to keep.

# **Appendix 7: Interview consent form**

School of Medicine, Faculty of Medicine and Health Worsley Building, Clarendon Way, University of Leeds, LS2 9N UNIVERSITY OF LEEDS

\*\*This consent form will be read out to the participant and a verbal consent protocol will be used

### A service evaluation project exploring the experiences of parents and guardians in accessing an under 10's telephone call pathway provided by the Leeds Gender Identity Development Service (GIDS)

	Tick this box if you agree
I confirm that I have read and understand the information sheet explaining the above service evaluation project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw until one week after the interview and without there being any negative consequences. In addition, should I not wish to answer any padicular, question or questions, I am free to decline. Should I wish to withdraw, all interview data will be destroyed. In order to withdraw, I can contact the project lead by emailing umip@leeds.ac.uk	
I understand that members of the University of Leeds research team may have access to my anonymised responses for the purposes of quality checking and peer review. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I understand that my responses will be kept strictly confidential and that anonymised quotations of what I have said in this interview may be used in the research report and presentations.	
I understand that the data I provide may be archived at the University of Leeds.	
I consent to my interview being recorded.	

Name of participant	
Date	