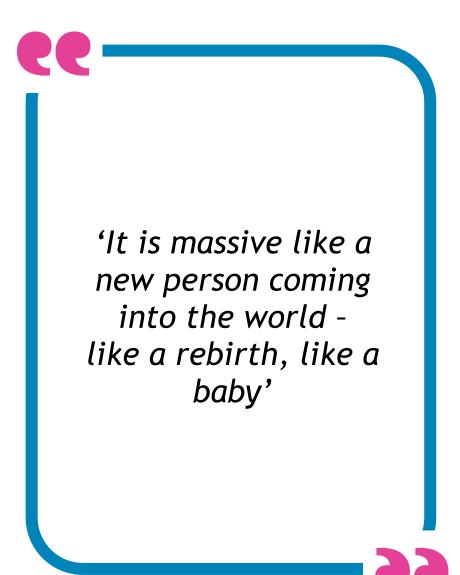




# Gender Reassignment Case Study April 2021



Comment from participant



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# Who are Healthwatch Nottingham & **Nottinghamshire?**

Healthwatch Nottingham & Nottinghamshire is the independent patient and public champion that holds health and social care services more accountable to their communities for the services they commission and provide.

We have 3 key roles:

Scrutiny of local health and care commissioners to ensure that they: listen to the public, provide excellent care, provide quality signposting and are totally transparent

Make a difference: We collect & provide insight from patients & communities, and use these to make recommendations to improve services for the public. We will then scrutinise how this insight helps to influence improvements.

To work in partnership across local, regional and national networks of Healthwatch and the CQC to ensure big issues/opportunities are acted upon & best practice is shared, whilst ensuring that our independence is maintained

#### Why is it important?

You are the expert on the services you use, so you know what is done well and what could be improved.

Your comments allow us to create an overall picture of the quality of local services. We then work with the people who design and deliver health and social care services to help improve them.

#### How do I get involved?

We want to hear your comments about services such as GPs, home care, hospitals, children and young people's services, pharmacies and care homes.

You can have your say by:

**2** 0115 956 5313



www.hwnn.co.uk





Facebook.com/HealthwatchNN

Healthwatch Nottingham & Nottinghamshire Unit 1, Byron Business Centre, Duke Street, Hucknall, Nottinghamshire, NG15 7HP

Healthwatch was created in 2013 as part of the Health and Social Care Act 2012. Healthwatch Nottingham & Nottinghamshire (HWNN) is an independent organisation that helps people get the best from local health and social care services.

This project involved a longitudinal case study made up of ten interviews with an individual who was undergoing gender reassignment. At key points during the reassignment pathway between March 2017 and September 2020 the individual was asked about the highs and lows of their experience, their treatment by health care professionals and recommendations on how the service could be improved.

During this time period the individual was seen by their GP, a Gender Clinic and a Hospital.

This case study provided an in-depth knowledge of gender reassignment. The report documents a number of positive experiences from the individual which include the encouraging and supportive approach from health and social care professionals, networks of support, a shared decision making approach and the involvement of the individual in the transition process. The time restrictions associated with the process were identified as a key area where improvements could be made to reduce the anxiety experienced by those experiencing the gender reassignment process and use of future provisions. In addition, improved knowledge of the costs involved with transitioning should be a key consideration of health and social care provisions.

### Recommendations

- Primary care for individuals undergoing gender transition should be provided by one named person throughout the process. It is essential for such persons to be fully trained on trans issues and provides compassionate care.
- Primary and specialist care providers must ensure that individuals who are considering gender transition are given detailed medical advice and whole process with reference to time line should be explained at a pace that the individual is able to take in. Further consideration should be given to explain practical advice and support on allied matters such as life style changes due to uptake of hormones, impact on cost of living.
- Individuals undertaking gender transition should be provided detailed information in format other than just verbal consultation for e.g. leaflets in plain English, video clips, website address etc. explaining in detail all the clinical steps and surgical processes that person will have to undergo so they can engage with shared decision making.
- First consultation to final completion of gender transition is a long arduous process for individuals. This process has numerous periods of waiting times in between procedures and treatments. It is acknowledged that waiting times are inevitable, however, it is essential that during such period of intermittent waiting times individuals receive (a) continuous and compassionate support from primary care (b) specialist services keep patients fully informed of timelines. They assess patient's support needs and ensure that support is available both for physical and mental health needs(c) better links with voluntary sector should be established by service providers so that they can signpost patients for additional support where necessary.

# Introduction

In March 2017 Healthwatch Nottingham an individual became known to Healthwatch through the LGBT+ Project, 'Exploring healthcare experiences of the LGBT+ Community.' The individual valued the work Healthwatch was doing with the LGBT+ community and was open to being a Healthwatch case study about gender reassignment.

The case study model was chosen as our methodology because, "a case study is an empirical inquiry that investigates a contemporary phenomenon in depth within its real life context" (Yin 2013, p.18). This project has undertaken a longitudinal study of the individual in order to collect data, analyse information, and report the results.

Prior to undertaking this case study we had found from the LGBT+ project (2017) that:

- Over a third (n=28) of people who completed the survey felt that their experiences of health care services had been affected by sexual orientation and/or gender reassignment.
- The most commonly (n=31) stated health service resulting in a negative experience was GP services.
- Over a third (29%; n=9) of negative experiences were attributed to the health care professionals that were encountered.
- Negative health care experiences had a long-term impact on members of the LGBT+ community.
- Positive health care experiences had a long-term impact on members of the LGBT+ community.
- 48% of people told us additional training around awareness and understanding of the LGBT+ community for healthcare professionals would be beneficial

This 2017 survey contained limited open-ended questions and qualitative information. Therefore carrying out a detailed case study is an opportunity to close this knowledge gap in order to provide useful insight for the local gender reassignment service.

This case study provides real life experience from an individual user of a Gender Clinic, which could be used to improve these services.

# Key aims of the project

- To capture an in-depth subjective account of one person's experience of undergoing gender reassignment from first seeing their GP, through referral to a Gender Clinic and finally to Hospital for the procedure.
- To understand the support, information, and advice a person undergoing gender reassignment is given and how helpful this is.
- To determine whether the case study felt that their experiences of health care services had been affected by sexual orientation and/or gender reassignment.
- To identify recommendations for providers and commissioners to improve health and care for people undergoing gender reassignment.

In July 2015 Stonewall published 'Unhealthy Attitudes', a report of the treatment of LGBT individuals within health and social care. Stonewall asked 3001 health and social care staff about LGBT healthcare and employment. Findings included that 24% of patient-facing staff had heard colleagues make negative comments about LGBT people, or using homophobic slurs at work in the last five years; 16% of patient-facing staff would not feel confident challenging such behaviour from staff or patients; 10% had heard staff at work saying that people can be 'cured' of being LGBT; 72% of patient-facing staff had received no training on LGBT health needs, LGBT-friendly language and practise, or same-sex partner/parent rights and 33% said that more needed to be done for LGBT people in the NHS and social care (Stonewall 2015).

Stonewall made a variety of recommendations to combat these problems. These were acknowledged by NHS England, which published 'Improving Lesbian Gay Bisexual and Trans (LGBT) equality across the NHS: a paper for the Equality and Diversity Council' in October 2015.

Healthwatch England wrote to NHS England in 2015 in response to experiences gathered by local Healthwatch that indicated long waiting times for gender reassignment surgery (Healthwatch 2015). Despite the target to transfer patients from their GP to a gender identity clinic in 18 weeks, many patients wait a year or even two years for appointments and operations. This can have a detrimental impact on patients' wellbeing.

Healthwatch Merton produced 'Merton Lesbian, Gay, Bi-sexual and Transgender (LGBT): Community Engagement Workshop' in 2015, a report that detailed a one-off engagement event with 12 participants. They found that there was a lack of access to gender identity services, with one participant reporting an eight month wait for a clinic with no support in between. Healthwatch Merton also reported the group they spoke to described feeling that LGBT awareness was lacking in much of the NHS and social care. They recommended LGBT awareness training for health and social care staff.

# Methodology

An individual was identified as a subject due to their willingness and openness to be 'followed' through the gender reassignment service, their trust of HWNN to accurately record their experiences and the statutory responsibility and 'weight' that Healthwatch has to influence person-centred care.

This was a longitudinal case study which comprised of ten interviews with the individual between 22nd March 2017 and 17<sup>th</sup> September 2020. This was considered the best way of gathering qualitative information about a service user's experience over the time frame of their gender reassignment.

Full written consent was gathered from the individual before data collection began. Detailed written notes were taken during the one-two hour interviews and the individual also provided their interview preparation notes as further evidence. These notes were typed up and checked by the individual and used as additional data before the data was thematically analysed. The data was analysed using Interpretative Phenomenological Analysis (IPA) which explored the thoughts, feelings and perspectives (Smith and Osbourne 2007) of the service user's experiences of gender reassignment through the selection of themes from the interview data and preparation notes.

This section details the events, experiences, observations, feelings, and stages that the individual has reported to have experienced with health and social care services as part of the transition process.

Table 1: Main themes and sub-themes from the case study

Treatment	Time restrictions	Financial burdens	Sources of Support	Emotions related to the transition
Positive experiences	Waiting times	Transition costs	Network of support	Significant life event
Specialist knowledge	Impacts of age	Support costs	Lack of support	Difficult times
Process of gender reassignment	Missed appointments/staff availability			Positive aspects
Service user Involvement				

# 1. Treatment by health and social care professionals/provisions

#### Positive experiences with health and social care professionals

The positive experiences detailed by the individual are reflective of a consistent approach to the care provided from the GP services in which the same GP was seen for each appointment 'she is awesome and understanding on trans issues'. Indeed, the positive experiences during the early days of the gender reassignment process also extended to a Centre for Dysphoria where the detailed and caring approach 'lifted a massive weight off me like an iron girder'. 'I felt listened to ... I understood what they told me'. This quote illustrates the importance of positive health and social care provisions during a significant time in the service user's life who is transitioning gender.

The positive experiences, especially in relation to GPs, were not expected by the individual. These positive experiences were related to the individual treatment that has been provided by the health and social care professionals, which has supported the individual during a significant life event '*They have saved my life basically is in essence what they have done for me*'.

#### Specialist knowledge of gender reassignment professionals

A subsequent theme from the data is the importance of specialist knowledge of gender reassignment from the health and social care professionals, which removes anxiety and *'instils confidence'* in the individual regarding their decision to transition.

The positive nature of the care provided was experienced from a variety of health and social care professionals at The Gender Centre and those with specialised knowledge (Psychologist) provided reassurance for the service user, 'took away a massive lot of fear' as they are 'specialised'. A common theme from the data for the individual, which is evidenced here, is that, because the

professionals specialised in gender reassignment, this provided a level of reassurance '*I believed them as they are qualified specialists*'. The individual detailed the positive experiences in relation to all of the professionals/providers involved in their gender reassignment process which includes the chemist supplying hormones, to the experts providing treatment.

One aspect of care which the individual did not receive during this process was support for adult ADHD and anxiety. They had sought support from their psychotherapist but was advised that they couldn't be prescribed medication at that time (it is important to note that there was a gap in service provision in Nottinghamshire around Adult ADHD diagnosis, this service is now in place however further delays are expected).

#### Process of gender reassignment from health professionals

The initial process of gender reassignment is very important to ensure health professionals provide detailed information about the process which is tailored for the individual undertaking the treatment. Indeed, for this to be achieved an increased amount of time should be dedicated to consultation. The limited amount of consultation time in this case study resulted in the individual feeling apprehensive as a limited explanation of the process of assessment had been provided 'I had no written information on the process but got inference of Gender Clinic journey from appointment sheet with three appointments outlined'.

The limited amount of time during consultations was also experienced when the individual attended an early appointment to discuss the gender reassignment process with a psychiatrist '10 mins into the interview the psychiatrist kept looking at the clock', 'I was a bit worried about this given the nature of our conversation'. This illustrates how important increased consultation times are during the early stages of the reassignment process to ensure the individuals are able to discuss the process and ask any questions they have at a pace which enables them to absorb the information. The individual told him they had changed their name and had been living as the opposite sex for a year and a half. The psychiatrist suggested steps taken were positive, saying the individual was accepted into the hormone treatment programme. Overall, they felt good and 'had some optimism' after the second appointment.

Despite feeling apprehensive during the early days of the gender reassignment process, the support from the professionals providing medical advice alongside preparing for the appointment left the individual feeling encouraged and optimistic for the future appointments and support from the health and social care professionals

The individual detailed an informed and supportive process provided from a variety of health and social care professionals for every step of the gender reassignment process; which involved both medical and practical advice, this was illustrated with the Gender Psychiatrist providing details of the potential concerns around hormones and cancer, although these were outlined by the professionals to be minimal risks. The individual detailed significant parts of the process such as details of the hormone treatment, where the professionals demonstrated a caring and considered approach *'I was very happy when the Psychiatrist told me he would help me with hormone treatment'*, this resulted in the individual feeling supported for the gender reassignment process

Moreover, the individual provided further information which supports that professionals within this case study were informative and supportive during the gender reassignment process, and considerate of the individual journey 'Very understanding, excellent and helpful & focused and caring, empathy for people looking for help and sympathy. They understand about people in that situation'. They described this process with the professionals as encouraging as they explored their journey prior to the appointments 'you've done all the right things', or words to that effect. They detailed that for the past '17 months working, living full time/dress/name changed by deed poll, old name relinquished, fully out, working as well'. The Gender Psychiatrist said the individual had done more than enough and was pleased with their transitioning process. The support from the Gender Psychiatrist had again been informative and encouraging which had reduced the individual's anxiety which is a common theme throughout the data.

The informed and supportive nature of the professionals involved in this case study continued when the individual had their pre- treatment. The laser treatment staff continued to demonstrate a considered approach with the process of gender reassignment. The laser treatment staff were very knowledgeable, accepting and focussed about transgender people receiving this specific treatment to help them. 'They were empathetic, they were tuned in and the technician explained how she was treating other trans people too', this illustrates that practical advice has been provided which is individualistic which enabled the individual to process the information whilst feeling supported from the health care professionals.

The specialist medical knowledge of gender reassignment with a supportive approach was extended to aftercare. The surgeon asked the individual if there was anyone to support them post operatively for a 12 weeks recovery period after the operation. The individual replied they were using their neighbours and some district nurse support which could be accessed through their GP. The individual acknowledged that the surgeon enquired because *'he knew from my notes that I had no support or acceptance from my family'*. This illustrates a supportive and informative approach from health and social care professionals, alongside a detailed knowledge of the process, the individual's personal situation and needs of service user's post-surgery.

Whilst the individual in this case study provided details of a supportive and informative process some recommendations were acknowledged by the individual as the service user. Indeed, an increase in the amount of time provided during consultations during the early part of the process would have reduced the levels of apprehension and anxiety experienced by the individual. Furthermore, it is suggested that more detailed practical advice is required, for example on preparatory treatments before service users have their consultation with the surgeon. They felt the health care professionals should stress the importance and significance of successful electrolysis prior to surgery because if this area is not clear then their surgery is delayed.

#### Service user involvement

The case study identified the importance of the service user being educated and conducting their own research to be actively involved in the decision-making process. The individual described how throughout the gender reassignment process they were informed and enabled to make decisions. This is illustrated when they were given two choices of laser services and also in relation to choices about their surgery, where they were offered a choice of four surgeons, two in London and two in Brighton. The individual was encouraged to research these surgeons to make their own choice. They subsequently looked on the internet at reviews and biographies of all the surgeons and their clinical backgrounds. They chose a surgeon and particularly liked the review around his skills and experience including stitching during surgery.

The involvement of the individual as a service user is further illustrated during their consultations in Brighton which they had shared with another patient who like themselves was at the hospital for a gender reassignment referral. Both individuals were given a two-page questionnaire to complete about their health. After completion both the individual and the other patient met with the lead nurse who showed them pictures of how their body parts would change following surgery. This was to demonstrate the standard surgery offered at their hospital but also they were shown other photos of international surgery which can result in causing excessive damage. The individual and the other patient were shown these different pictures to offer reassurance around the standard of the Hospital's surgery and to explain how the surgery would change their body. The individual reported that both patients were allowed to ask questions about the forthcoming surgery which illustrates the opportunity for shared decision making between service users and health professionals during the gender reassignment process.

This approach is further supported by the individual as they felt 'you have to really engage with professionals and explain what you are going through such as low moods etc. in order to get help'.

Also, it is paramount that health professionals understand all types of transgender and non-binary people, to provide an individualized approach which meets their needs.

### 2. Time restrictions

A main theme from the data was the impact of time during the gender reassignment process and how this could be detrimental to the overall process and experience for the individual.

#### Impacts of waiting times for gender reassignment

The individual detailed the significance of the length of time it took for them to transition and how this has led to them feeling depressed and fatigued. As a result they would encourage others who are thinking of transitioning to start the process early as this involves lots of appointments and felt they wished they'd done it sooner. In the end the individual paid to have private surgery as their predicted NHS surgery would have not taken place until at least a year later in November 2020 (due to delays in the gender reassignment process).

The experience of the gender reassignment process has enabled the individual to provide some recommendations from a service user perspective, such as increasing the number of surgeons, 'l would say there should be more surgeons in the field of transitioning to carry out operations as there is a big waiting list'. Furthermore, they suggested that waiting lists may be increasing as more people are identifying and requesting support. In addition, they suggested that the waiting list should be brought down for Trans people in all areas because they are suffering with gender dysphoria, 'There should be more specialist[s] and resources in every area'.

The emotional impacts of time were also discussed, particularly in how you can feel as an individual if you delay transitioning, the individual advised others if they feel like they have a gender incongruence to ask their GP to refer them to the centre for transgender health as *'the longer you leave it the harder it will be on yourself'*.

In addition to the wait to transition the individual experienced other long waits for treatment, which impacted on their mental health 'having to wait 18 months to get an assessment for Adult ADHD is wrong. It's a very long time and transgender people are already having to deal with a lot already'.

#### Impacts of age for gender reassignment

Due to the individual's age they felt that they may not have much time once they had transitioned because of the waiting times 'counting the days all the day I have immediacy in me due to being 52'. This leads to the suggestion that older transitioning people and their needs should be recognised because in 1980s and 1990s there wasn't support available.

#### Missed appointments/staff availability

The availability of staff was also considered as a key restriction in regards to the timing of the gender reassignment process. The individual described how appointments were cancelled with limited notice provided and that sometimes letters to change appointments were not received.

# 3. Financial burden

A major theme from the data is the financial commitments involved in the gender reassignment process which include transitional and support costs.

#### Transition costs

Some of the key transition costs include purchasing clothes and hormones online which led to the individual asking the clinic to prescribe the hormones because of the cost implications. They acknowledged *'there is help in the UK for you, if you haven't got the money for private treatment'*. Private treatment is costly, for example one element would cost a minimum of £4750 privately. Additionally, they had already spent £1600 on laser treatment as the NHS do not currently fund this.

The transition costs had an impact on the individual who has been short of funds due to funding the laser treatment themselves. However, this treatment was important to them as the electrolysis was needed to clear the genitalia in order for the surgeon to give them a date for surgery. There are also other transition costs to include such as funding travel, accommodation for surgery consultations and aftercare packs. Their private surgery cost £13,976.00. When they received a substantial back payment in social security benefits in September 2019, they made a decision to spend the majority of this money on a private genital surgery.

The substantial transition costs leads the individual to advise that clinicians should advocate for an increase in funding to reduce the patient costs of transitioning operations. In addition, they suggested more information regarding transitional costs and NHS funding should be provided, so that people are aware that they may need to raise funding themselves for certain aspects of the gender assignment process.

#### Individual cost implications of gender reassignment

The individual detailed that support during the gender reassignment process is very important, yet this also has cost implications. Consequently they attended the Friary drop-in group for homeless and vulnerable people in West Bridgford for a meal and for them to do their laundry which costs £2.50. This signifies that there are not only physical transitioning costs but also support costs associated with the gender reassignment process, which can place an excessive burden on patients.

### 4. Sources of support for gender reassignment

A major theme from the data is the importance of support networks within the gender reassignment process and how these can improve or detract from the experience of transitioning.

#### Network of support

The individual identified the importance of obtaining support through the gender reassignment process, this involved community support, voluntary support services, health care provisions and religious support. The individual discussed that some people have been supportive of the gender reassignment process such as their '*nice neighbours*' who had been bringing shopping. They acknowledged that whilst they have had some '*nice neighbours*' it is important to have a support network, yet recognised that they did not have a full support network. However, they did receive support from a number of providers such as the ASRA Housing Association Leicester and the Trans Hub meetings (Nottingham) that they attended. Peer support is another element of support, with another attendee giving their advice on the care needed after the transition operation.

The individual felt the NHS, Healthwatch, the Police and Housing were helpful and supportive within the limits of their respective roles.

A new source of support which the individual accessed more recently is the church. The church helped them spiritually as they felt it was *'reflective and peaceful'* and they got to meet other people.

The individual had also been attending a group for transitioning people who have had different levels of surgery (but most have had a genital surgery). This is a support group for post-operative trans people and is facilitated by the psychotherapist at the Gender Clinic. They found this very helpful, both meeting the other trans people and the facilitation by the psychotherapist. They reported that this was a supportive group with lots of ideas shared.

#### Lack of support

Limited support has been received from the support groups (Trans hub) that they would usually attend, as a result of COVID-19; Trans hub has been described by the individual as 'the highlight of her transition to meet people like me'. Whilst online meetings have been arranged this 'can't replace that human feeling'. The Gender Centre provided them with the report that they needed for the Gender Recognition Certificate. They gave the individual the report outside, and they had a chat outside the door of the Centre. Their gender psychotherapist said they would be in contact for another meeting, but the individual hadn't heard anything since the end of May 2020.

The individual attended group meetings at The Centre for Transgender Health and had missed this support group following the COVID-19 pandemic. They were surprised at how nice the other people were to each other and how good the clinicians are. 'You're not without support and have helpful and valid things to say about your life, they affirm you as a human being. They help you to overcome the self-stigma you feel, leading to mental health problems'. Evidently, support groups such as the Centre for Transgender Health provide essential on-going support for the individual and the gender reassignment process, which unfortunately has been providing limited support as a result of COVID-19.

# 5. Emotions related to the transition

One theme from the data is that the individual experienced a variety of emotions to the gender reassignment process which relate to this as a *significant* life event, with *positive* events, and challenging times during the process.

#### Significant life event/experience

The individual identified aspects of the process as important and illustrated the gender reassignment process as a significant life event, in particular, the second appointment with Centre for Dysphoria was a life changing moment for them. The process of obtaining documents to change their identity also are given considerable importance as significant milestones in the gender reassignment process, '*This is to me considered important, this is a gender marker and a major part of who I identify/live as*'. However, it is the physical changes in their body that they identified as making them feel 'happy', which is considered to be a significant life event '*It is massive like a new person coming into the world - like a rebirth, like a baby*'.

#### Difficult times during the reassignment process

The process has not been without challenges; the individual reflected that taking on too much as an Involvement Centre Volunteer as a low point. In addition, they were apprehensive about electrolysis in the genital area. Additional challenges relate to the unpleasant behaviour of their neighbours, which the individual is aware had impacted on their mental health and resulted in medication from the doctor to support them with sleeping and depression.

The process of gender reassignment has led the individual to experiencing anxiety as there is 'too much paperwork and anxiety with each stage'. Furthermore, this had also impacted on their mental health, which they felt is not fully understood by clinicians 'they don't understand as clinicians how this impacts us'.

#### Positive aspects of the gender reassignment process

The individual detailed a number of positive aspects of the gender assignment process which included their consultation date at the Hospital and the realisation that all the hair on the donor issue had gone.

A high had been getting a consultation date for 26th February 2019 at the hospital, they described this as the *'ultimate high'* which they were *'ecstatic and grateful'* for.

Further positive aspects for the individual have been having the transitioning surgery which they felt meant *'they can be in the world'* whereas before they were *'pre-op'* and now they are *'post op'* they described feeling different. This has enabled them to delete all their pre-op photos which made them feel a lot better. They no longer have to wear clothes whilst living with the other sexes genitalia underneath and now felt more emotionally comfortable. Another positive for the individual was they felt that they can be *'truly presentable'* as a Trans person and have a lasting relationship, which is extremely important. For the individual, getting the Gender Recognition Certificate has been the high point in the last six months. This means they can now get their birth certificate changed. This is straightforward by comparison with the Gender Recognition Certificate, because after the issue of the certificate, HMRC and the Registrar General are informed automatically that the legal steps are complete.

### **Reflections on gender reassignment**

- To be aware that you may need electrolysis on the donor tissue used. This area will be inspected prior to surgery and if not clear the surgeon will not book you on the operation.
- To be aware of the surgical risks.
- The individual felt that trans people should be examined prior to surgery consultation and if they still have hairs on their genitalia, they should be given help to remove it or else this felt like a wasted journey for the individual (to the setting where the actual sex change surgery will take place). They stressed this as often these consultations necessitate a long journey which can involve an overnight stay.
- The individual's privately funded genital surgery took place on 7th November 2019 in Hospital they stayed in the hospital for seven days. The operation took place on day one of their stay, they had a private bedroom and had their operations in the afternoon, these lasted approximately two and half hours. Post operatively they had a catheter and bag to pass urine and experienced very little pain due to pain killers and were nursed in bed for three days. They reported that they couldn't move around in the bed due to feeling weak and aching and wanting the stitches to heal.

Analysis of the interview transcripts revealed the following findings:

#### Positive aspects

- 1. A consistent approach to the care was provided from the GP services in which the same GP was seen for each appointment.
- 2. Health and Social care professionals were encouraging and supportive throughout.
- 3. A range of networks provided support that were beneficial.
- 4. A Shared Decision Making approach was applied throughout all consultations involving the service user in all decisions throughout the transition process.

#### Negative aspects

- 1. The waiting time was longer than the individual was told and longer than was advertised on the Gender Dysphoria website in March 2015. 21 months in comparison to 6-8 months. Below is an exert from the Centre's FAQs downloaded from their website on 15/12/17. 'How long will the process take? This will vary from person to person. The assessment period is usually around six months. If you wish to have genital surgery, you must live in your preferred gender role for more than a year with the expected period to surgery being in the region of two years. This must include at least one year in some form of occupation appropriate to your ability level. This is dated from the start of full-time gender role transition, with associated paperwork.'
- 2. The waiting time had a detrimental effect on the individual 'The long wait was making me depressed and fatiguing, and buying the hormones made me short of money'.
- 3. The individual felt the wait was more difficult because of their age 'The wait stretched me as I am 52 and will not have as long to live as the other sex. I needed immediacy because I am a late transitioner'.
- 4. There was a lack of written information; information was too often given verbally at the appointments 'I had no written information on the process'.
- 5. The individual had to buy hormones over the internet until they were prescribed. There is no centralised body to monitor the quality of these drugs which is a risk for the user.
- 6. Appointment dates and times were changed without notifying the individual by email or letter.
- 7. The individual was told in May 2018 that the surgery would take place in Spring 2019. When they were told the surgery would not take place until November 2020 and having come into some money they went ahead with private surgery in November 2019.
- 8. The cost of some treatment is prohibitive for some trans people at £4750, as is the cost of laser hair removal £1600.

# Conclusions

This case study has provided an in-depth knowledge of gender reassignment. It provides real life insights which aid our understanding of the process and provide suggestions from a service user perspective, which is paramount to the improvement of provisions in the future and reflective of the role of Healthwatch in promoting improvements in health and care systems.

The report documents a number of positive experiences from the service user which include the encouraging and supportive approach from health and social care professionals, networks of support, a shared decision-making approach and the involvement of the service user in the transition process. The time restrictions associated with the process were identified as a key area where improvements could be made to reduce the anxiety experienced by those experiencing the gender reassignment process and use of future provisions. Indeed, service providers should be encouraged to develop support mechanisms for service users during this waiting period. In addition, improved knowledge of the costs involved with transitioning should be a key consideration of health and social care provisions.

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# Recommendations

This case study details an individual perspective of the gender reassignment process and is suggestive of the following recommendations:

- Primary care for individuals undergoing gender transition should be provided by one named person throughout the process. It is essential for such persons to be fully trained on trans issues and provide compassionate care.
- Primary and specialist care providers must ensure that individuals who are considering gender transition are given detailed medical advice and whole process with reference to timeline should be explained at a pace that the individual is able to take in. Further consideration should be given to explain practical advice and support on allied matters such as lifestyle changes due to uptake of hormones, impact on cost of living.
- Individuals undertaking gender transition should be provided detailed information in a format other than just verbal consultation for e.g. leaflets in plain English, video clips, website address etc. explaining in detail all the clinical steps and surgical processes that the person will have to undergo so they can engage with shared decision making.
- First consultation to final completion of gender transition is a long arduous process for individuals. This process has numerous periods of waiting times in between procedures and treatments. It is acknowledged that waiting times are inevitable, however, it is essential that during such period of intermittent waiting times individuals receive:
  - $\circ$  (a) continuous and compassionate support from primary care.
  - (b) specialist services keep patients fully informed of timelines. They assess patient's support needs and ensure that support is available both for physical and mental health needs.
  - (c) better links with voluntary sector should be established by service providers so that they can signpost patients for additional support where necessary.

In July 2015 Stonewall published 'Unhealthy Attitudes', a report of the treatment of LGBT people within health and social care. Stonewall is an organisation which works within institutions to promote positive change for the LGBT community (Stonewall, 2020). They asked 3001 health and social care staff about LGBT healthcare and employment. Some of the key issues they uncovered centred on:

- Bullying and discrimination
- Lack of support for LGBT patients
- Fear of challenging discrimination
- Lack of knowledge on how to challenge prejudice
- A belief that more needs to be done for LGBT equality

'Unhealthy Attitudes' provided extensive qualitative and quantitative evidence. Particularly illuminating figures include the fact that 24% of patient-facing staff had heard colleagues make negative comments about LGBT people, or using homophobic slurs at work in the last five years; 16% of patient-facing staff would not feel confident challenging such behaviour from staff or patients;. 10% had heard staff at work saying that people can be 'cured' of being LGBT; 72% of patient-facing staff had received no training on LGBT health needs, LGBT-friendly language and practise, or same-sex partner/parent rights and 33% said that more needed to be done for LGBT people in the NHS and social care (Stonewall 2015).

Stonewall made a variety of recommendations to combat these problems. These were acknowledged by NHS England, which published 'Improving Lesbian Gay Bisexual and Trans (LGBT) equality across the NHS: a paper for the Equality and Diversity Council' in October 2015.

Healthwatch England wrote to NHS England in 2015 in response to experiences gathered by local Healthwatch that indicated long waiting times for gender reassignment surgery (Healthwatch 2015). Despite the target to transfer patients from their GP to a gender identity clinic in 18 weeks, many patients wait a year or even two years for appointments and operations. This can have a detrimental impact on patients' wellbeing.

Healthwatch Merton produced 'Merton Lesbian, Gay, Bi-sexual and Transgender (LGBT): Community Engagement Workshop' in 2015, a report that detailed a one-off engagement event with 12 participants. They found that there was a lack of access to gender identity services, with one participant reporting an eight month wait for a clinic with no support in between. Healthwatch Merton also reported the group they spoke to described feeling that LGBT awareness was lacking in much of the NHS and social care. They recommended LGBT awareness training for health and social care staff.

Healthwatch Lancashire produced a report entitled 'Lesbian, Gay, Bisexual & Trans people accessing routine healthcare' in 2015 that encompassed the experiences of 116 respondents. 26% of transgender and gender-variant responders had changed GP because their previous one was unhelpful or unknowledgeable in regards to transgender issues.

Healthwatch Hackney commissioned City and Hackney Mind to investigate how mental health impacts the LGBT community in their area. Of the 28% of respondents who considered themselves to have a disability, 49% (so 14% of respondents overall) of these had mental health difficulties. 76% had experienced poor mental health such as depression, anxiety, and stress. They also found varied results on health. While over a third of respondents exercised daily, 27% smoked regularly, 25% consumed alcohol almost daily, and 48% had taken recreational drugs.

Healthwatch Sheffield spoke to LGBT people at Pride in June 2015 and while their experiences were mostly positive, 24% felt that their sexuality had led to them being discriminated against.

Additionally, the absence of any options besides 'male' and 'female' on medical records was criticised.

In the 'Joint Response from Healthwatch Lewisham, Southwark and Lambeth to the LSL Sexual Health Strategy Consultation' in July 2014, the three boroughs responded to an upcoming sexual health strategy review. They pointed out that many patients do not trust their GP to uphold confidentiality, and avoid using GP services for sexual health matters. They also mentioned: long waiting times; overly confusing, inconsistent patient pathways; and a lack of patient understanding of treatment/medication due to hindrances such as language barriers.

Overall, the experiences gathered suggest that aspects of the health and social care spheres can impede LGBT individuals from accessing and receiving good quality care.

#### **Interview Questions**

- What has happened since we last met?
- What have been the highs of your experience?
- What have been the lows of your experience?
- What have you noticed about the awareness of trans issues by clinicians, other professionals and support staff since we last spoke?
- What have you noticed about the attitudes toward people seeking help from clinicians, other health professionals and support staff since we last spoke?
- On the basis of your experience over the last x months since we spoke:
  - What advice would you give someone else who is thinking of Gender reassignment?
  - What advice would you give to health professionals?
- How do you feel transitioning affected the way other providers/groups interacted with you whilst being treated for other conditions for example, alcohol/drug dependency, depression etc.?
- What support structures/bodies/people have you accessed?
- How did this help/hinder you?
- Could anything be done to improve on the above experiences for other users?

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Healthwatch Nottingham & Nottinghamshire Unit 1, Byron Business Centre, Duke Street, Hucknall, Nottinghamshire, NG15 7HP Phone: 0115 956 5313 Web: www.hwnn.co.uk Twitter: @\_HWNN

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