

## Healthwatch Birmingham and Solihull's Response to the NHS Children and Young People's Gender Service Specification Survey

Healthwatch Birmingham and Solihull responded to the following online survey questions as part of the NHS Children and Young People's Gender Service Specification

### 1. In what capacity are you responding?

Other – Local Healthwatch

### 2. Are you responding on behalf of an organisation?

Yes – Healthwatch Birmingham and Solihull

### 3. To what extent do you support the inclusion of the holistic assessment of needs (*Appendix A in the service specification*)?

Neither agree nor disagree

We are pleased to see that the person's situation is being considered holistically and especially that individual experiences play a significant part in the assessment itself. This enables the child or young person's views to be considered alongside the views of the family and any other factors which could traditionally act as a barrier to gender affirming care.

Despite this approach to assessment, we feel that the service provision may lack flexibility to cater to the differing needs identified by this holistic approach. As shown in this service specification, the primary intervention for this type of care has already been determined which may limit flexibility based upon the needs identified during the assessment process. People should be offered choice in the type of care they receive to ensure that they



**Healthwatch Birmingham and Solihull**

4th Floor, Latham House, 33 – 34 Paradise Street, Birmingham, B1 2AJ  
[www.healthwatchbsol.org.uk](http://www.healthwatchbsol.org.uk) | [info@healthwatchbsol.org.uk](mailto:info@healthwatchbsol.org.uk) | 0800 652 5278  
Company Registration No: 08440757

feel their needs are being met by services, particularly in sensitive situations such as those that lead people to seek care from specialist gender services.

#### **4. To what extent do you agree with the approach to the management of patients accessing prescriptions from un-regulated sources as explained above?**

Disagree

Whilst we agree that there are clear risks associated with accessing medications from unregulated sources and people should be discouraged from doing so, we also feel that further consideration should be given to this area. While we are pleased to see that advice services are in place to inform families of the risks associated with these medications, we know that there are further considerations which may impact on the decision to access medications from these sources. We feel that a lack of additional support for those who may have already begun to take these medications, beyond safeguarding and psychosocial concerns may lead to additional harm for these people. We are also aware that whilst this service has been under review, access to the wait list for children and young people's gender services have been closed. The draft EHIA acknowledges that in particular, people or families on a low income may be more affected by this decision as they may have accessed unregulated medicines with the expectation The Service will then take on responsibility for prescribing and are now left worse off. Strongly cautioning people not to use medications from unregulated sources does not consider why people have been driven to access them. We would therefore urge the service to reconsider this approach especially for patients who have been affected by the service being under review.



**5. To what extent do you support the following other proposed changes to the specification as described above:**

**a. The description of the role and function of the National Provider Network.**

Agree

We are pleased to see the role of the National Provider Network in acting to maintain consistency in service delivery. We would like to see that qualitative patient experience data is included in the considerations made by this body alongside any statistical outcome measures. This can then be used to better understand any challenges those who seek gender affirming care are facing and enable specific changes to provision to reflect their needs.

**b. The description of the arrangements for data collection, audit and evaluation.**

Neither agree nor disagree

We feel that to properly represent the needs and experiences of people accessing specialist gender services, patient experience data including but not limited to complaints should be included in this core registry. This is to enable a more comprehensive understanding of the clinical data that is being collected as part of this process which enables services to better understand and represent the needs of the people they serve.

We are pleased to see that data from patients who have been identified as not benefitting from this service is included in the evaluations being undertaken. Once again, we feel that to properly represent their experiences with services, detailed patient feedback should be included in the evaluation. We hope that this can then be used to reflect on not only the process of accessing services but also the criteria being used to identify



individuals who may benefit from accessing this service and any barriers which may prevent them from doing so.

**c. The role of the Children and Young People's Gender Service in leading a network of Designated Local Specialist Services.**

Agree

We are pleased to see a focus on local networks within this service specification. This will enable services to tailor care to the specific needs of people within local communities and better understand their specific experiences. This also enables experiences at a local level to be fed back to the network as a whole, enabling specific experiences within a community to inform provision at a national level where appropriate.

**d. The inclusion of endocrinology as a core function within the Children and Young People's Gender Service's Multi-disciplinary Team.**

Neither agree nor disagree

Whilst we support the inclusion of this function as it will enable patients of the multi-disciplinary team to access this type of care in theory, we do have concerns around the capacity of endocrinology services to support these additional patients. We feel that if this is to be the case, NHS England needs to ensure that there is capacity within paediatric endocrinology clinics to take on referrals as part of this pathway to ensure timely interventions for people assessed as needing their services and not cause further delays in people's care.

**e. The separate pathway for pre-pubertal children.**

Agree

We are pleased to see the inclusion of this pathway in the service specification as it reflects the differing individual needs of pre-pubertal children who wish to seek care from specialist gender services.



**6. The proposed provider-reported metrics aim to help monitor and assess the quality of the service. To what extent do you agree with the inclusion of the metrics?**

Neither agree nor disagree

As previously stated, we would like to see patient experience data included in the reported metrics which are used to monitor the quality of services. This type of data adds clarity to statistical reporting and ensures that any changes that are made to services are informed by the needs and past experiences of people who have accessed the services, which allows provision to better meet people's needs in future.

**7. Are there any other changes or additions to the revised service specification that should be considered?**

We feel that there are several areas where integration with other services could be strengthened to improve experiences for people accessing specialist gender services. Whilst improvement and monitoring are mentioned within the service specification we wonder whether there is any room for feedback from patients provided to these services regarding people's gender needs to be used across the system to improve care and education for professionals.

As part of this integration we wonder whether the specification could include any additional education or measures that are in place to ensure that GPs are not acting as a barrier to accessing specialist gender services. Within Birmingham and Solihull, we have received feedback from people who told us that their needs were not taken seriously by their GP which prevented them from accessing the care they need.

*"Very poor understanding of trans/non binary identities. [...] Have been told false information by them many times due to their lack of knowledge about certain topics"*



**Healthwatch Birmingham and Solihull**

4th Floor, Latham House, 33 - 34 Paradise Street, Birmingham, B1 2AJ  
[www.healthwatchbsol.org.uk](http://www.healthwatchbsol.org.uk) | [info@healthwatchbsol.org.uk](mailto:info@healthwatchbsol.org.uk) | 0800 652 5278  
Company Registration No: 08440757

*“Getting the appointment is not the problem, it's getting the gender affirming care, I find it quite hurtful. Needs to be more training for staff and more resources on gender affirmation.”*

We would like for it to be clear whether work is being done to ensure that this pathway from GP to specialist services is clear and that barriers that exist at the GP level are being addressed to ensure that patients can access the services described in this specification.

It is also stated that people may be referred to mental health services or their GP from the specialist gender service. We would also like to see it made clear what safeguards are in place to ensure that people are not discriminated against as a result of being referred from this service; to make sure they are able to access the care that they require following this referral.

Locally in Birmingham and Solihull we are aware of severe pressures on youth mental health services. Although services are doing their best to address these pressures, we are concerned that patients referred back to local mental health services after assessment are being sent to a system with capacity issues and long waiting lists. Attention needs to be given to ensuring that these patients can access the care they need in a timely manner. NHS England needs to look at whether further resourcing of these services is needed, to prevent harm to these patients whilst on waiting lists between services.

**8. To what extent do you agree that the Equality and Health Inequalities Impact assessment reflects the potential impact on equalities or health inequalities which could arise because of the proposed changes?**

Neither agree nor disagree

Whilst we are pleased to see that considerations have been made for people who may wish to access these services at the age of 17 and how the transition to the adult clinic is handled, we have concerns regarding the



**Healthwatch Birmingham and Solihull**

4th Floor, Latham House, 33 - 34 Paradise Street, Birmingham, B1 2AJ  
[www.healthwatchbsol.org.uk](http://www.healthwatchbsol.org.uk) | [info@healthwatchbsol.org.uk](mailto:info@healthwatchbsol.org.uk) | 0800 652 5278  
Company Registration No: 08440757

pathway going back through their GP. As previously stated, we have been told that people have had issues with not being taken seriously by their GP regarding this type of care. Some people may have had issues being put on the children and young people's wait list due to issues of this nature and having to return to their GP may introduce an additional barrier to accessing care.

We also feel that this service could make better use of demographic monitoring to better understand the individual needs of the people who are waiting for care. We know that according to NHS England, the ethnicity of nearly a third of individuals is unknown. Demographics including ethnicity are important to ensure that appropriate considerations are made for people attempting to access these services and ensure the holistic approach outlined within the specification.



**Healthwatch Birmingham and Solihull**

4th Floor, Latham House, 33 - 34 Paradise Street, Birmingham, B1 2AJ  
[www.healthwatchbsol.org.uk](http://www.healthwatchbsol.org.uk) | [info@healthwatchbsol.org.uk](mailto:info@healthwatchbsol.org.uk) | 0800 652 5278  
Company Registration No: 08440757