

Integrating child and adolescent gender identity healthcare in Wales.

Author: [REDACTED]

Date: 13th December 2022

Index

- 1 Executive Summary
- 2 Background
- 3 Recommendations of the Interim Cass Report
- 4 Developing a Clinical Care Model for Wales
- 5 Embedding Research
- 6 Professional Workforce Resourcing
- 7 Conclusion
- 8 Appendices
 - i. Experiences of children and young people in Wales
 - ii. Professional statement from [REDACTED]
[REDACTED]

1 Executive Summary

NHSE commission child and adolescent gender identity services from the Gender Identity Development Service on behalf of Wales. This arrangement is currently being reviewed in depth by Dr Hilary Cass. Following the release of her Interim Report in February 2022, NHSE has responded by announcing the closure of GIDS and the intention to commission a new service on an interim basis.

The proposed NHSE interim service specification has attracted international condemnation including from gender identity specialists, academics, and ethicists, raising serious concerns about transparency and alignment with best practice and the evidence base.

With local infrastructure for gender diverse young people being part of the current commissioning pathway into GIDS, Wales is arguably better-placed than England to deliver core Cass Review recommendations that call for regional and local rather than centralised care.

Key message The Welsh Gender Service Clinical Referencing Group is of the view that now is the time for Welsh Government to commission a Welsh service that better serves the needs of this particularly vulnerable population.

2 Background

The provision of lifespan gender identity services for patients registered with a GP in Wales is a commissioning commitment and listed on the Welsh Government LGBTQ+ Action Plan.

Welsh patients under the age of 17.5 years wanting to access gender identity services are referred by their GP to CAMHS; then further referral via WHSSC to join the waiting list for a NHSE-commissioned Gender Identity Development Service.

UK-wide referral rates to GIDS surged from 2015 and plateaued in 2019 to a consistent 2,500-2,700 per year. Waiting times have lengthened year-on-year, and with changes to practice in the wake of Bell vs Tavistock building in additional delays, this is approaching 4 years from the point of referral.

This long delay was specifically referenced in the interim review produced by Dr Cass:

‘Children and young people are waiting lengthy periods to access GIDS, during which time some may be at considerable risk. By the time they are seen, their distress may have worsened, and their mental health may have deteriorated.’

This has been borne out in Wales, where CAMHS is reporting rising rates of disordered eating and mental health anguish among Welsh gender diverse youth, with increasing numbers turning to unregulated private clinics for support or worse still, self-medication through grey or black-market sources. Appendix A details some patient stories which demonstrate the real-life impact this is having on young people and their families, shared with permission.

Key message Current and proposed provisioning through NHSE falls short of what would be deemed acceptable care for the circa. 300 young people in Wales who are currently on the same waiting list as circa. 7,200 English patients.

3 Recommendations of the Interim Cass Report

The Interim Cass Report recommended a fundamentally different service model – one that is accessed in a clear and equitable way; that is decentralised and has multiple local and regional hubs, with strong links to local services, such as mental health and GPs; that supports training and education for clinical practitioners.

‘Clear criteria will be needed for referral to services along the pathway from primary to tertiary care so that gender-questioning children and young people who seek help from the NHS have equitable access to services.’

Adult access to the Welsh Gender Service is via direct GP referral through the Welsh Clinical Communications Gateway. This arrangement could be readily extended to accommodate patients under 17.5 years old, with clear referral criteria and support needs communicated to primary care providers via the Welsh Health Circular.

‘Each regional centre will need to develop links and work collaboratively with a range of local services within their geography to ensure that appropriate clinical, psychological and social support is made available’

As Cass envisions, the Welsh Gender Service already sits within a hub and spoke framework, with a strong emphasis on, and links with, primary and community care. It is comprised of two regional tertiary *hubs* (Cardiff and Holywell), with multiple local gender team *spokes* in each of the seven health boards providing prescribing and speech therapy input close to home.

Respectfully, specialist centres based in England will be less familiar with local Welsh health providers and may struggle to co-ordinate collaborative working across the digital border.

‘Regional training programmes should be run for clinical practitioners at all levels, alongside the online training modules developed by Health Education England (HEE)’

The Welsh Gender Service team are fully integrated with country-wide health infrastructure, and provide education and training to health care staff at all levels to maintain professional learning and inclusive practice. This includes materials hosted by Health Education and Improvement Wales (HEIW). Under NHSE, training programmes proposed by Cass are not likely to be extended to clinical practitioners in Wales.

Key message Fundamental elements of the Interim Cass Review, echoed in the Interim NHSE Service Specification, can be effectively and safely delivered by a Welsh commissioned service.

4 Developing a Clinical Care Model for Wales

The Welsh Gender Service CRG (Clinical Referencing Group) reviewed clinical care models for England, Scotland, Melbourne, and Holland, and held a series of professional meetings. Criteria for consideration included, as follows:

- Acceptability to prospective service users
- Alignment with respected standards of care and treatment guidelines
- Integration with research
- Reproducibility in a Welsh setting including utilisation of telehealth services

This work, along with a review of existing literature covering the experiences of GIDS service users, could form the starting point for discussions with stakeholders as to the most appropriate model of care for Wales.

To this end, a series of meetings and online events could be established for trans and non-binary (TNB) young people, families, and supporters.

To ensure a Service Specification has a sound bioethical foundation and stands up to scrutiny, the WGS CRG has recommended that a comprehensive analysis of any proposed specification should be commissioned from an individual/organisation with the requisite expertise.

Key message Wales must be able to deploy a robust, internationally respected clinical care model that best meets the needs of Welsh gender diverse youth and their families.

5 Embedding Research into Clinical Practice

The Cass Review has commissioned a research programme which includes a literature review and both qualitative and quantitative research components. Both Cass and NHSE emphasize research with adequate follow up into adulthood, ‘the appropriate questions and protocols to be developed with input from a panel of academics, clinicians, service users and ethicists.’

‘Existing and future services should have standardised data collection in order to audit standards and inform understanding of the epidemiology, assessment and treatment of this group of children and young people’

The Welsh Gender Service is already engaged in structured data collection. It is the WGS CRG view that information collected *across the lifespan* is of better quality and reduces the risk of loss to follow up as an individual moves between a youth and adult setting.

The current research ambition of the Welsh Gender Service caters for all ages and could incorporate patients as they join the consolidated waiting list. Outcome measures will be developed to capture young perspectives and the primary study type will be prospective and longitudinal.

Key message The Welsh Gender Service can accommodate patient-centred research and contribute meaningfully to evidence-based practice.

6 Professional workforce resourcing

Across Wales, there is an existing network of s-CAMHS and CAMHS practitioners – psychologists, psychiatrists, and nurses – some with considerable experience of supporting gender diverse young people in the context of the current referral pathway.

Structured competency training and sensitive decoupling from the *mental health* label could create multi-disciplinary local gender teams providing the *spoke* element of care planning and support, as recommended by Hilary Cass.

‘The care of this group of children and young people is everyone’s business.’

Paediatric endocrine expertise is available in Wales, complimented through professional networking with paediatric endocrinology peers across the UK and integrated with the main *hub* psychological evaluation activities as recommended by Cass re: closer professional working.

Psychological expertise including competency training and supervision for local teams could be offered through the Welsh Gender Service following the recent appointment of a professional with relevant training and experience.

Advocacy and psychosocial support for individuals and families could continue through the health and social care professionals who link with schools and work in partnership with third sector organisations.

‘It is essential that these children and young people can access the same level of psychological and social support as any other child or young person in distress, from their first encounter with the NHS and at every level within the service.’

Key message With several GIDS practitioners currently considering their options, time is of the essence in capturing additional expert resources for Wales.

7 Conclusion

The most compelling statement in the Cass Report is that the current system is failing to see gender diverse young people in a timely fashion to assess their needs. For those requesting it, prompt and appropriate specialist evaluation is fundamentally important as delays are known to impact on psychosocial health and wellbeing.

Due to the intensity of demand across the UK, current and proposed provisioning through NHSE for Welsh youth is falling short of what would be deemed acceptable care. While efforts are being made to re-structure services in England, consultation on the proposed interim service specification has raised concern among specialists.

The WGS CRG believes that Wales can deliver UK-leading lifespan care to this population in alignment with the LGBTQ+ Action Plan and seeks the urgent backing of Welsh Government to progress this area.