GLADD Response to the Cass Review

On 10th April 2024 the long-awaited final report of the Cass Review was published. As the UK's only organisation representing LGBTQ+ Doctors and Dentists, we have carefully considered issues raised by the report and its reception in the following response.

Introduction

Over the coming months, critical appraisal of the Cass Review will occur. At the time of writing, international critical appraisal of the methodology and its evidence base has already begun. Whilst we await the response from the academic community it is important that we do not take the review's conclusions as irrefutable fact, particularly those made from recently published systematic reviews. It is imperative that policymakers take into consideration any subsequent concerns, methodological or otherwise, when implementing recommendations.

It is notable that there is a significant disconnect between the narrative text of the Cass Review and the recommendations. GLADD is broadly supportive of a number of recommendations, but we are concerned with what we believe to be an ingrained bias against the autonomy of trans people throughout the narrative text. We note that similar concerns have been raised by other recent appraisals of the report. We therefore advise caution when interpreting the narrative, to ensure a positive and constructive service for gender diverse and gender questioning children and young people.

In this statement we provide general comments on the narrative text and then interrogate each recommendation as to whether we believe it is in the best interests of patients and those we advocate for. It is important to recognise the political implications of pathologising aspects of the narrative, and GLADD remains concerned that parts of the Review will be

weaponised against gender diverse children and young people and those who advocate for and work towards equitable healthcare for them.

In this statement, we will not engage in direct critical appraisal of the methodology of the Review. We do not feel that as a committee we have sufficient expertise to do justice to such evaluation. Any criticism is of ideological stances taken and of the potential impact of recommendations on access to and quality of care.

The aim of this response is to highlight potential implications of the recommendations to policymakers and provide useful commentary on GLADD's perspective. As ever, GLADD remains committed to the advocacy of gender diverse and gender questioning children and young peoples' rights to safe and happy lives in the genders in which they identify, with the right support from the NHS to help them thrive.

General Comments

It is vital that the Cass Review is read in the context of unacceptably long waiting lists for children and young peoples' gender identity services. As such, recommendations which focus on the expansion of local and regional services to increase capacity, reduce waiting lists, and improve access are firmly supported by GLADD.

We also welcome the recommendation to engage a wider multi-disciplinary team to support holistic care. The assessment framework recommended is comprehensive and will likely be a positive addition to the patient journey in the new service. Caution must be taken, however, to avoid pathologising trans and non-binary identities throughout such an assessment, and a focus must always be centred on identifying needs and implementing support for the young person.

We are troubled by narratives which may implicitly pathologise trans and non-binary identities or perpetuate stigmatisation of this population

under the guise of scientific inquiry. Examples of these include the discussion of social transition or in the explanation of preference for gendered toys by a model of biological determinism.

Further to this, we have concerns regarding language used which implies that progression to masculinising/feminising hormones is a negative or undesirable outcome. Repeated discussion of the 'consequences' of transition without due regard for the autonomy of gender diverse and gender questioning people or the validity of trans identities indicates a bias towards pathologisation of those identities. This undermines the legitimacy of the review and risks it being weaponised against gender diverse children and young people, those who advocate for them and those who work towards equitable healthcare.

Response to Recommendations

Many of the recommendations of the review are positive and would likely serve to support the development of a supportive service. Some recommendations may risk introducing or exacerbating barriers to care. We have appraised each and explained any concerns or cautions, categorising them into recommendations GLADD supports (in green), recommendations GLADD could support on particular conditions (in orange), and recommendations GLADD does not support (in red).

Recommendation 1: Given the complexity of this population, these services must operate to the same standards as other services seeing children and young people with complex presentations and/or additional risk factors. There should be a nominated medical practitioner (paediatrician/child psychiatrist) who takes overall clinical responsibility for patient safety within the service.

GLADD supports this recommendation.

Recommendation 2: Clinicians should apply the assessment framework developed by the Review's Clinical Expert Group, to ensure children/ young people referred to NHS gender services receive a holistic assessment of their needs to inform an individualised care plan. This should include screening for neurodevelopmental conditions, including autism spectrum disorder, and a mental health assessment. The framework should be kept under review and evolve to reflect emerging evidence.

GLADD could support this recommendation provided that steps are taken to ensure that a young person who receives a diagnosis of a neurodevelopmental condition is not prevented from accessing appropriate care for gender incongruence.

Recommendation 3: Standard evidence based psychological and psychopharmacological treatment approaches should be used to support the management of the associated distress and co-occurring conditions. This should include support for parents/carers and siblings as appropriate.

GLADD supports this recommendation.

Recommendation 4: When families/carers are making decisions about social transition of pre-pubertal children, services should ensure that they can be seen as early as possible by a clinical professional with relevant experience.

GLADD could support this recommendation provided that steps are taken to avoid this being used as a means by which healthcare services seek to gatekeep decisions about social transition.

Recommendation 5: NHS England, working with DHSC should direct the gender clinics to participate in the data linkage study within the lifetime of the current statutory instrument. NHS England's Research Oversight Board should take responsibility for interpreting the findings of the research.

GLADD supports this recommendation.

Recommendation 6: The evidence base underpinning medical and non-medical interventions in this clinical area must be improved. Following our earlier recommendation to establish a puberty blocker trial, which has been taken forward by NHS England, we further recommend a full programme of research be established. This should look at the characteristics, interventions and outcomes of every young person presenting to the NHS gender services.

• The puberty blocker trial should be part of a programme of research which also evaluates outcomes of psychosocial interventions and masculinising/ feminising hormones.

• Consent should routinely be sought for all children and young people for enrolment in a research study with follow-up into adulthood.

GLADD could support this recommendation provided that steps are taken to ensure that standards of care are not compromised for those who do not enrol in research studies.

Recommendation 7: Long-standing gender incongruence should be an essential prerequisite for medical treatment but is only one aspect of deciding whether a medical pathway is the right option for an individual.

GLADD could support this recommendation provided that steps are taken to appreciate that overt gender-related distress can manifest in different ways across different circumstances e.g. culture, neurodiversity. Guidelines must allow for individualised care decided by a multidisciplinary team in partnership with patients and families.

Recommendation 8: NHS England should review the policy on masculinising/feminising hormones. The option to provide masculinising/feminising hormones from age 16 is available, but the Review would recommend extreme caution. There should be a clear clinical rationale for providing hormones at this stage rather than waiting until an individual reaches 18.

GLADD does not support this recommendation. The report does not provide sufficient detail as to an alternative policy.

Recommendation 9: Every case considered for medical treatment should be discussed at a national Multi Disciplinary Team (MDT) hosted by the National Provider Collaborative replacing the Multi Professional Review Group (MPRG).

GLADD could support this recommendation provided that steps are taken to ensure that significant delays to care do not occur as a result. If this cannot be ensured, then consideration must be had as to whether a national MDT is a justifiable and proportionate measure in keeping with standards of care in other areas of healthcare.

Recommendation 10: All children should be offered fertility counselling and preservation prior to going onto a medical pathway.

GLADD could support this recommendation provided that such counselling is factual, neutral and does not aim to influence a person's autonomy.

Recommendation 11: NHS England and service providers should work to develop the regional multi-site service networks as soon as possible. This could be based on a lead provider model, where NHS England delegates commissioning responsibility to the regional services to subcontract locally to providers in their region.

GLADD supports this recommendation.

Recommendation 12: The National Provider Collaborative should be established without delay.

GLADD supports this recommendation.

Recommendation 13: To increase the available workforce and maintain a broader clinical lens, joint contracts should be utilised to support staff to work across the network and across different services.

GLADD supports this recommendation.

Recommendation 14: NHS England, through its Workforce Training and Education function, must ensure requirements for this service area are built into overall workforce planning for adolescent services.

GLADD supports this recommendation.

Recommendation 15: NHS England should commission a lead organisation to establish a consortium of relevant professional bodies to:

• develop a competency framework

• identify gaps in professional training programmes

• develop a suite of training materials to supplement professional competencies, appropriate to their clinical field and level. This should include a module on the holistic assessment framework and approach to formulation and care planning.

GLADD could support this recommendation. Given the current absence of a functional service, this process must occur alongside and not prior to the launch of the new service and should be co-developed with patients and experts in community care, for example GPs with extended roles in gender identity care.

Recommendation 16: The National Provider Collaborative should coordinate development of evidence-based information and resources for young people, parents and carers. Consideration should be given as to whether this should be a centrally hosted NHS online resource.

GLADD could support this recommendation provided that the information is co-produced with relevant stakeholders including patients and representation from appropriate organisations in the VCSE sector.

Recommendation 17: A core national data set should be defined for both specialist and designated local specialist services.

GLADD supports this recommendation.

Recommendation 18: The national infrastructure should be put in place to manage data collection and audit and this should be used to drive continuous quality improvement and research in an active learning environment.

GLADD could support this recommendation provided that steps are taken to ensure that implementation does not delay launch of the new service.

Recommendation 19: NHS England and the National Institute for Health and Care Research (NIHR) should ensure that the academic and administrative infrastructure to support a programme of clinically-based research is embedded into the regional centres.

GLADD could support this recommendation provided that steps are taken to ensure that implementation does not delay launch of the new service.

Recommendation 20: A unified research strategy should be established across the Regional Centres, co-ordinated through the National Provider Collaborative and the Research Oversight Group, so that all data collected are utilised to best effect and for sufficient numbers of individuals to be meaningful.

GLADD supports this recommendation.

Recommendation 21: To ensure that services are operating to the highest standards of evidence the National Institute for Health and Care Research (NIHR) should commission a living systematic review to inform the evolving clinical approach.

GLADD supports this recommendation.

Recommendation 22: Within each regional network, a separate pathway should be established for pre-pubertal children and their families. Providers should ensure that pre-pubertal children and their parents/carers are prioritised for early discussion with a professional with relevant experience.

GLADD could support this recommendation provided that adequate justification is given as to why clinical priority should be given to pre-pubertal children. While separate clinical pathways are sensible, there is currently insufficient rationale behind this recommendation.

Recommendation 23: NHS England should establish follow-through services for 17-25-year-olds at each of the Regional Centres, either by extending the range of the regional children and young people's service or through linked services, to ensure continuity of care and support at a potentially vulnerable stage in their journey. This will also allow clinical, and research follow up data to be collected.

GLADD does not support this recommendation. GLADD supports the recommendation of a linked service to transition into adult services, but opposes the possibility of expanding the age range of the children and young peoples' service to 25.

Recommendation 24: Given that the changing demographic presenting to children and young people's services is reflected in a change of presentations to adult services, NHS England should consider bringing forward any planned update of the adult service specification and review the model of care and operating procedures.

GLADD supports this recommendation.

Recommendation 25: NHS England should ensure there is provision for people considering detransition, recognising that they may not wish to re-engage with the services whose care they were previously under.

GLADD supports this recommendation.

Recommendation 26: The Department of Health and Social Care and NHS England should consider the implications of private healthcare on any future requests to the NHS for treatment, monitoring and/or involvement in research. This needs to be clearly communicated to patients and private providers.

GLADD is neutral on this recommendation. There is insufficient detail as to what is being recommended to comment. GLADD is concerned that such a vague recommendation may have the potential to be more harmful than beneficial.

Recommendation 27: The Department of Health and Social Care should work with the General Pharmaceutical Council to define the dispensing responsibilities of pharmacists of private prescriptions and consider other statutory solutions that would prevent inappropriate overseas prescribing.

GLADD supports this recommendation.

Recommendation 28: The NHS and the Department of Health and Social Care needs to review the process and circumstances of changing NHS numbers and find solutions to address the clinical and research implications.

GLADD could support this recommendation provided that steps are taken to ensure that this review does not act to limit access to the ability of people to change gender on their NHS record. Further, this review should involve updates to ensure that patients are enrolled in appropriate health screening programmes once their NHS number changes.

Recommendation 29: NHS England should develop an implementation plan with clear milestones towards the future clinical and service model. This should have board level oversight and be developed collaboratively with those responsible for the health of children and young people more generally to support greater integration to meet the wide-ranging needs of complex adolescents.

GLADD supports this recommendation.

Recommendation 30: NHS England should establish robust and comprehensive contract management and audit processes and requirements around the collection of data for the provision of these services. These should be adhered to by the providers responsible for delivering these services for children and young people.

GLADD supports this recommendation.

Recommendation 31: Professional bodies must come together to provide leadership and guidance on the clinical management of this population taking account of the findings of this report.

GLADD could support this recommendation. However, there is insufficient detail provided as to which professional bodies are being called to action and how they would mitigate concerns of bias in the Review.

Recommendation 32: Wider guidance applicable to all NHS services should be developed to support providers and commissioners to ensure that innovation is encouraged but that there is appropriate scrutiny and clinical governance to avoid incremental creep of practice in the absence of evidence.

GLADD could support this recommendation provided that steps are taken to ensure that alongside this guidance, the capacity for healthcare professionals working within the service to exercise their own clinical judgement is retained, and a framework is developed to facilitate the adoption of new management options when evidence emerges.

Summary

We are concerned about what we perceive to be an ideological bias in the narrative text of the Review. Our support for recommendations does not imply endorsement of the narrative. Gender diverse identities are not illnesses and being gender diverse is not an undesirable outcome, and the

implementation of the Review's recommendations must take this into account. New services must provide holistic, evidence based and patient centred care of the highest quality for gender diverse and gender questioning young people. While many of the recommendations could achieve this, we feel a number could be improved further so as to develop standards of care and restore the trust of the patients we are aiming to serve.

We ask Dr Cass, her team and policymakers to reflect on our comments and the spirit of collaboration in which they are made.

Authored by a working group of members of the GLADD Committee.

Signed on behalf of the GLADD Committee.

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