

**NOTE TO
Sir Nick Partridge OBE
Chair of the Clinical Priorities Advisory Group (CPAG)
NHS England Specialised Commissioning**

13 June 2016

We, the undersigned, request that you consider our concerns regarding NHS England's proposals for treating gender variant children and adolescents.¹ CPAG is due to review these proposals at its meeting in July.

Gender variant adolescents are at grave risk - 23% have engaged in self harm/suicide.² There is a clear and strong case that delaying treatment for young people risks more harm than providing it.³ For many adolescents, being refused treatment during this difficult period (puberty) is a *form of psychological torture*.⁴

With regard to CPAG's responsibilities for assessing NHS England's approach to commissioning, we are particularly concerned that the above proposals have not been:

- developed with public and patient engagement to a level proportionate with the impact of the decision
- informed by the evidence base

The specific errors in NHS England's approach to developing the above proposals are:

- The Policy Working Group (PWG) that has been developing these proposals includes no stakeholders. Yet, it does include two clinicians from the service to which these proposals relate. That service has a history of resisting innovation.⁵ The other members of the PWG are eminent people but appear to have no experience of providing hormone blocking or cross-sex hormone (CSH) medication for gender variant young people.
- The Tavistock and Portman NHS Foundation Trust is the sole provider of gender identity development services (GIDS) for young people and therefore the sole employer of clinicians working in this field in the UK. Hence, it is very difficult for anyone, patients, family members or practitioners who hold different views about treatment, to challenge the policies and practices of the GIDS.

¹ - NHS England Policy Proposition (E03X16/01) and Service Specification (E13/S(HSS)/e for the Gender Identity Development Service for Children and Adolescents

² - Di Ceglie D, Freedman D, Mc Pherson S, Richardson P. (2002); Children and Adolescents Referred to a Specialist Gender Identity Development Service: Clinical Features and Demographic Characteristics. IJT 6,1, http://www.symposion.com/ijt/ijtvo06no01_01.htm

³ - Parliamentary Women and Equalities Select Committee Report on Transgender Equality; <http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39002.htm>

⁴ - Kreukels, B.P., Cohen-Kettenis, P.T. Puberty suppression in gender identity disorder: the Amsterdam experience. Nat Rev Endocrinol. 2011;7:466–472.

⁵ - Dutch clinicians pioneered early physical intervention for gender variant young people. According to Henriette Delemarre, one of the Dutch clinicians, her "colleagues in the UK had for years fiercely criticised the Dutch policy and young people there are only considered for treatment at a very late stage." – (Inside Out: Ellen de Visser and Sarah Wong (2010) Portraits of Cross-Gender Children p39 Uitgeverij d'jonge Hond, The Netherlands). At an international symposium in London in 2005, the UK clinicians expressed their opposition to the evidence-based Dutch approach. Puberty suspension according to Tanner stage was recommended in the Endocrine Society's Clinical Practice Guideline in 2009 (<http://press.endocrine.org/doi/full/10.1210/jc.2009-0345>). The UK clinicians still did not adopt that approach until 2014.

- Stakeholders were not involved, within the PWG, in the formative stage of developing the terms of reference for the evidence review or the policy proposition or the service specification.
- The PWG appears to have made no attempt to ensure parity of esteem between the gender identity service for children and adolescents compared to the services that care for those who experience equally life threatening physical conditions.
- The Mental Health Crisis Care Concordat, signed by NHS England in 2014, states that: “Early intervention should be appropriate for children and young people, so they can find and stay engaged with services which keep them safe, improve their mental health and prevent further crises.”⁶ The ponderous processes described in draft service specification seem to be out of keeping with the Concordat.
- The consultation process conducted by NHS England on the evidence review, policy proposition and service specification was hollow.
- The evidence review (a) was based on biased terms of reference, (b) was undertaken by Deloitte, which apparently has no relevant scientific or clinical competence and (c) disregarded or misquoted a substantial proportion of the available evidence. The **benefits** of providing the treatment with CSH, in accordance with need and competence, as well as the **harms and dangers** associated with delay of that treatment, were not considered.
- The PWG appeared to have made up its mind before it started evidence gathering and consultation. It stated that “additional evidence would not materially change the proposed commissioning position”.
- CSH are the treatment for dysphoria in adolescents. However, they are withheld arbitrarily by the GIDS. The policy proposition was not to change the current approach to providing this treatment despite the examples, unearthed but ignored in the evidence review, of more flexible practice, including provision of CSH at age 13, in reputable clinics in The Netherlands, the USA and Canada. Neither Deloitte nor the PWG contacted those overseas providers of earlier intervention to discuss benefits and outcomes.
- The service specification did not incorporate the improvements in treatment that stakeholders have been seeking. These would enhance the quality of care, reduce delays for urgent cases and, very importantly, reduce costs.
- There was a lack of clarity about how the policy proposition would meet the needs of non-binary young people, a growing demographic who increasingly need access to hormone blockers and CSH.
- The PWG did not respond positively to the 31 suggestions made by stakeholders during earlier NHSE consultations; it decided “no action required” with regard to 25 of them.

⁶ - Mental Health Crisis Care Concordat - Improving outcomes for people experiencing mental health crisis (page 18) http://www.crisiscareconcordat.org.uk/wp-content/uploads/2014/04/36353_Mental_Health_Crisis_accessible.pdf

- In the latest NHSE consultation, there were 50 responses from stakeholders, which included many calls for change. We do not know that any of those changes have been made.

Stakeholders are now seeking reassurance that the PWG has properly heeded their latest responses before CPAG considers the policy proposition and service specification. Stakeholders need to see these documents and be able to check that they have been revised. If not, stakeholders would reasonably expect to have the opportunity for rapid comment and amendment before CPAG makes its decision, be that in July or later.

However, NHSE Specialised Commissioning is refusing to show stakeholders the policy proposition and service specification before they are sent to CPAG. If these documents are still flawed it would be very difficult to change them after approval by CPAG.

We have sent a copy of this note to Sally Brearley, Barry Silverman, Linda Phipps and Madeline Wang, who are the Patient and Public Voice Members of CPAG.

We have also alerted Maria Miller MP, Nicky Morgan MP to our concerns. The government is due to respond to the Parliamentary Women and Equalities Select Committee Report on Transgender Equality. Maria Miller MP chaired that Committee. Nicky Morgan MP has primary responsibility for the government's response to the Report in her role as Minister for Women and Equalities. In addition, we have sent a copy of this note to Baroness Barker, Chair of the Parliamentary Forum on Gender Identity.

We would be grateful if you, please, reply via:

GIRES, Molverley, The Warren Ashtead, Surrey KT21 2SP or info@gires.org.uk

Signed:

Denise Anderson

Emma Bailey, Wipe Out Transphobia

Charlotte Baker

Greg Beere

Mahri-Claire Beere

Helen Belcher

Jenny-Anne Bishop OBE

Nic Bray

Kate Bruce

Erin Burns, Business Manager, Brighton and Sussex University Hospitals NHS Trust

Lord Cashman CBE

Dr. Jane Clark

Vivien Comley

Hilary Cooke, Medway Gender and Sexual Diversity Centre, South East Gender Initiative

Dominic Davies, Pink Therapy

Mary Deans

Rebecca Dittman

Tom Doyle, Yorkshire MESMAC

Brenda Edwardson

Finn Edwardson

George Edwardson

Jane Fae, writer and campaigner

Isabel Farrelly, Equality and Diversity Officer, Norfolk Fire and Rescue Service

Sam Feeney, Counsellor, MBACP Reg

Susan Fleming, Administrator, On behalf of the Trustees, Focus: The Identity Trust [i](#)

Lee Gale, TM Training

Pamela Gawler-Wright MSc, UKCP Reg. Psychotherapist, Director of Training, BeeLeaf Institute for Contemporary Psychotherapy

Dr Simona Giordano

Ryan Gingell, Team Leader & Trans Team Coordinator (children and young people) Allsorts Youth Project

Sarah Grayer, Project Coordinator for Space Youth Project and Lead Youth Worker Space T-Group

Bob Green, Chief Executive Officer, Stonewall Housing

Susie Green, CEO, Mermaids UK

Anthony Griffin, CEO, In-Trust Merseyside

Dawn Hardy

Deirdre Haslam

Elen Heart

Sheila Hewitt

Tony Hewitt

Suzanna Hopwood

Diane Howells

Jean Howells

Linda Howse

Chryssy Hunter, Faculty of Social Science and Humanities London Metropolitan University

Deborah Jeremiah

Susan Johnson

Danielle Leach

Beccie Louise, Oasis Norfolk

Estelle Louw, Consultant Child and Family Psychologist

Emma Lowe

Celia Macleod

Emma Martin

Cheryl Morgan

Charles Neal, UKCP accredited. Psychotherapist, gender and sexualities specialist, Hon. Clinical Associate with Pink Therapy

Dr Michelle Northcott

Chris Parsons

David Parsons

Hope Parsons

Juliet Parsons

Alice Purnell OBE, Chair Beaumont Trust

Angela Rayner, Inclusion Manager, Workforce Transformation Directorate
South East Coast Ambulance Service NHS Foundation Trust

Terry Reed OBE, Trustee, Gender Identity Research and Education Society

Bernard Reed OBE, Trustee, Gender Identity Research and Education Society

Joanna Rowland-Stuart

Heather Salmon

Alessandra Sherman, Trustee, Beaumont Trust

Frances Shiels

Tim Sigsworth MBE, Chief Executive, The Albert Kennedy Trust

Dr Carla Skinner

Brenda Lana Smith

Dr Angela Smith

Leia Smith

Louie Stafford – Trans Programme Co-ordinator, LGBT Foundation

Abigail Stain

Octavian Starr

Tara Stone. Development Manager. Trans Support and Development North

Paula J Summers

Peter Tatchell, Director, Peter Tatchell Foundation

Aearon Truffitt

Joyce Turton

Dr Helen Webberley

Dr Mike Webberley