Gender dysphoria in children and young people: ensuring an appropriate response from support services

Introduction

Gender dysphoria and the way it is treated relates both to children's health and their rights to be heard and involved in decisions that affect them.

NCB has experience and a body of evidence based on the work we do on children's health, mental health, education and care, both with children and young people themselves and the professionals that support them, which can provide insight and clarity in this confusing arena.

NCB's response speaks to two overarching issues:

Firstly, we are concerned by the reported levels of distress and unmet needs. The Annual Report[1] from the Child Safeguarding Practice Review Panel found that gender identity issues had been a significant factor in seven child suicides.

Secondly, we are also uneasy about the lack of high-quality evidence and investigation particularly around the disproportionate number of children presenting with gender dysphoria who are also on the autism spectrum, and the higher number of children registered at birth as girls who are seeking treatment.

Context

Until the recent NHSE/I long term plan children and young people have never been a priority for the health service. One manifestation of this lack of prioritisation is the low

[1] *Child Safeguarding Practice Review,* Annual Report 2020: Patterns in practice, key messages and 2021 work programme, Department for Education 2021

number of treatments administered to children that have been researched to test their efficacy or appropriacy for children.

Most drugs prescribed for children have not been tested in children. The US Food and Drug Administration estimates that only about 20 percent of drugs approved by the FDA were labelled for paediatric use. In 2000 a European study found that 67% of the children in the study were given drugs which were unlicensed for children or off label (being prescribed outside the terms of the product licence)[2]. Puberty blockers are one of these drugs. They have been prescribed for children who identify as gender dysphoric without having been licensed for that specific purpose. Use of unlicensed or off label drugs on children isn't necessarily a bad thing if that drug helps them to manage their condition. What is unacceptable is that we haven't sufficiently prioritised identifying what works for children and any possible adverse impacts.

A similar picture exists in respect to non-drug-related interventions.   A recent study of 52 occupational therapy interventions, commonly used with children, found that there was strong evidence for effectiveness for only 30%.

This is the broader background to the controversy surrounding interventions for children experiencing gender dysphoria.

A change in referral patterns

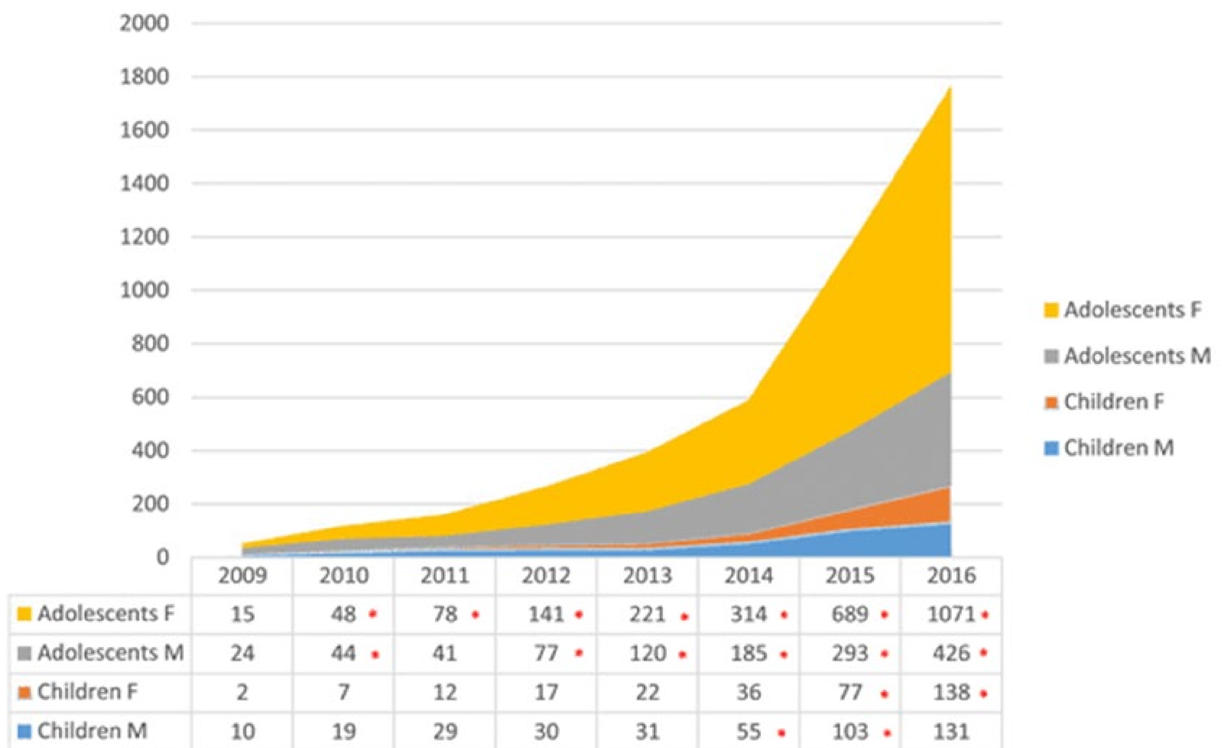
Over the last decade there has been a fifty-fold increase in the number of children and adolescents referred to the Gender Identity Development Service in England. In 2009, there were 50 referrals made for children and young people. In 2019 the figure was 2,500. There has also been a change in who is being referred, with many more teenagers registered as female at birth and young people with autism being referred. Whilst referrals have risen, service response has not expanded at the same rate. This means long waiting

[2] European law changed in 2007 to ensure that pharmaceutical companies undertake studies in children as part of the development plan for most new medicines. This will mean that as new drugs come in the percentage of unlicensed and off label prescribing will fall.

times, during which many children are not getting support for what can be very significant levels of distress. Currently many referrals are made without ensuring interim support is in place.

Little research has been done to identify the cause of this change. This means that, at the moment, we don't know if it arises solely out of reduced stigma and increased awareness of services, or whether there are other factors.

The graph below shows changing ratios over time of children and adolescents referred to the Gender Identity Development Service in England[3].



	2009	2010	2011	2012	2013	2014	2015	2016
Adolescents F	15	48 *	78 *	141 *	221 *	314 *	689 *	1071 *
Adolescents M	24	44 *	41	77 *	120 *	185 *	293 *	426 *
Children F	2	7	12	17	22	36	77 *	138 *
Children M	10	19	29	30	31	55 *	103 *	131

AFAB = assigned female at birth; AMAB = assigned male at birth
* Indicates $p < .05$ which shows a significant increase of referrals compared to the previous year

[3] de Graaf NM, Giovanardi G, Zitz C, Carmichael P. Sex ratio in children and adolescents referred to the gender identity development service in the UK (2009-2016). Arch Sex Behav. 2018;47(5):1301-1304.

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A complex condition

A number of factors may lead young people to experience gender dysphoria. Some young people will have had a long standing settled gender incongruence and for them full medical and surgical transition will be the right service response.

Others may experience gender incongruence or dysphoria as a result of the maturational process or uncertainty over sexual orientation. It is important therefore that young people are offered the space, time and support to identify the genesis of their gender dysphoria as this could impact on their desired outcome. For some children their gender incongruence may settle, opening up medical and surgical transition as appropriate treatment routes. For other children the desired outcome may be to cease pursuing transition, or to explore their gender identity in other ways. The role of social influence on increased levels of gender dysphoria has been the subject of controversy. One contested theory is that social influences may lead vulnerable young people to misinterpret their emotions and incorrectly believe themselves to be transgender. Gender dysphoria may be used as a catch-all explanation for the distress, psychological pain, and discomfort that a young person is feeling, and provides the prospect of resolution.

In such cases the young person may not explore all the possibilities in respect of their sexuality and gender before reaching their conclusion. However, it is important to note that the one study[4] evidencing this has been criticised[5] for its methodology. It must also be noted that social influences may also be important in helping young people with settled gender incongruence to feel more confident in seeking the support they need.

What is clear from clinical practice, research and young people's experience is that there are a number of factors which lead to feelings of gender incongruence or dysphoria. There are also multiple ways in which this may be resolved.

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[4] Littman L (2018) Parent reports of adolescents and young adults perceived to show signs of a rapid onset of gender dysphoria. PLoS ONE 13(8): e0202330. https://doi.org/10.1371/journal.pone.0202330

[5] Restar, A.J. Methodological Critique of Littman's (2018) Parental-Respondents Accounts of "Rapid-Onset Gender Dysphoria". *Arch Sex Behav* **49,** 61–66 (2020)

Long waiting times for treatment for those experiencing gender dysphoria may lead to young people's energy being absorbed by the search for treatment rather than an open exploration of what is the most appropriate treatment for them[6].

Gender dysphoria and autism

A number of studies have identified an increased prevalence rate of gender dysphoria in young people with autism. Around 35% of young people referred to the Gender Identity Development Service in England presented with moderate to severe autistic traits. Gender dysphoria in those with autism is sometimes characterized by atypical presentation of gender dysphoria, which makes a correct diagnosis and determination of treatment options difficult. There is no strong evidence on what might determine the link between the two conditions[7].

Consent

The court cases (Bell v Tavistock) focussed on the ability of children and young people to consent to puberty blocking treatment. The Tavistock and Portman NHS Trust's successful appeal against an initial High Court judgement allows clinicians rather than courts to decide if young people under 16 are sufficiently 'competent' to consent to treatment. A further judgement (AB v CD) found that a parents' right to consent to treatment on behalf of the child continues even when the child is Gillick competent to make the decision, save where the parents are seeking to override the decision of the child. The issue of consent to medical treatment is a complex one which we have covered in a separate briefing. Obviously, the judgement about consent is tied up with the evidence about whether or not

[6] Henriette A Delemarre-van de Waal 1 and Peggy T Cohen-Kettenis (2006) Clinical management of gender identity disorder in adolescents: a protocol on psychological and paediatric endocrinology aspects, European Journal of Endocrinology

[7] Anna I.R. Van Der Miesen, Hannah Hurley & Annelou L.C. De Vries (2016) Gender dysphoria and autism spectrum disorder: A narrative review, International Review of Psychiatry, 28:1, 70-80, DOI: 10.3109/09540261.2015.1111199

the treatment is fully reversible, which further underlines the need for better research evidence on this issue.

What needs to happen

It is essential that young people considering life-changing treatment are clear about all of the implications, both immediate and longer term. NCB therefore supports the independent review commissioned by NHS England which is looking at the use of puberty suppressants and cross-sex hormones and whether changes are required to existing clinical policies that underpin the use of these by the NHS. We hope the review will also address the need for a change in the NHS service model to ensure that sufficient mental health support is provided to those experiencing gender dysphoria. It is also important that the Government responds by resourcing services adequately, so they can meet the rising demands for support, advice and treatment without unacceptable waiting times.

The National Children's Bureau is also delighted that the thoughts and experiences of children will inform the development of new pathways of care. We believe that it is vital that those directly affected have an opportunity to have their voices heard in the review which will shape the services that they receive.

In addition, we believe more research needs to be undertaken to understand what has led to the increase in referrals to the Gender Identity Development Service and to add to the body of evidence about the most effective support for those with gender dysphoria and the long-term effects of different treatment options.

We therefore welcome the Nuffield Council on Bioethics' project on the ethical, social, and legal issues associated with the care and treatment of children and adolescents in relation to their gender identity.

Given the numbers of young people registered female at birth who are experiencing gender incongruence or dysphoria we also believe it is vital that research looks at the role of sexism, homophobia and perceptions of gender non-conformity.

Taking into account the considerable distress experienced by children and young people experiencing gender dysphoria, NCB believes that:

- Resources for parents should be produced as a matter of urgency, increasing their confidence in supporting their children in this situation.
- Wider children and young people's mental health services should be supporting children and young people who are considering or waiting for a Gender Identity Development Service referral.
- Service response must be personalised and attuned to the multiple routes through feelings of gender dysphoria to enable them to best support young people with identifying the most appropriate treatment or support choice for them.

Finally, we support the government's assertion in 2020 that schools teaching RSHE should be careful not to 'reinforce harmful stereotypes' or imply that children's bodies are 'wrong'. From our work on anti-bullying we know that children and young people find gender stereotypes harmful and believe that it provides a motivation for children who bully. We support the implementation of the new RSHE curriculum and would like to see more tools and support provided to schools about how they can manage the teaching of gender identity, LGBT rights and sexism in school.