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Dear Professor Ziebland

Meeting the transgender challenge: improving the experience of health services for gender diverse young people and their families (NIHR ref HS&DR 17/51/07)

I wanted to share some concerns about the above NIHR-funded research project. What prompted this letter was Lily Maynard's recent blog [1], but our group's unease dates from when we became aware of the project during its main recruitment phase some months ago.

I'm writing on behalf of a UK-wide support group for parents of trans kids. Your project's goal is "to prepare, inform and support those on the waiting list", "the main beneficiaries of the research are likely to be the children and young people (and families) preparing to attend specialist services." Many of our parents have children on the GIDS waiting list and are precisely the audience you are seeking to address. Like most children on the waiting list - and unlike children with life-long gender dysphoria from early childhood (for whom early medical interventions were designed & who were formerly in a majority) - our children's gender incongruence began after the onset of puberty, and in the context of pre-existing mental health or developmental problems. They have a broader identity confusion than just gender and, in the absence of good evidence, we are sceptical that 'affirmative care' - social and medical transition, involving hugely invasive and still-experimental medical interventions, which carry a life-long burden - might be a good solution for their problems, especially when considered so early in life as during adolescence. Instead, we are keen to explore what problems identifying as trans might solve for our children, and what difficulties it might help them to avoid.

There is no reliable means of knowing which child will benefit from medical intervention in the long term. As two GIDS child psychotherapists said:

Young people access our service with the clear expectation of being entitled to a physical, concrete medical 'cure' that will offer respite and a solution to the pains of growing up. [2]

And concerning assessments, a GIDS clinical psychologist has said:

We are putting responsibility back on the family because we don't have the evidence base to say 'it's these kids, or it's these kids', or how we can pick out which kids should go forward and which kids shouldn't [3]

The NHS website says of puberty blockers that:

Little is known about the long-term side effects of hormone or puberty blockers in children with gender dysphoria. Although the Gender Identity Development Service (GIDS) advises this is a physically reversible treatment if stopped, it is not known what the psychological effects may be. It's also not known whether hormone blockers affect the development of the teenage brain or children's bones. [4]

In the words of Professor Carl Heneghan, these interventions are largely "an unregulated live experiment on children." [5]

I outline all this because, so far as we can tell, your project team and the advisory board are committed advocates for affirmative management of gender dysphoria - in other words, for interfering with puberty through life-changing hormonal interventions. For example GIRES, two of whose representatives are on your advisory group, have even suggested that medical transition eliminates autism: "young people who have been successfully treated, are often described as having no residual ASD. The symptoms have disappeared once the dysphoria has been treated." [6]

We are concerned that the project's outputs will favour the invasive medical approach even though, as I've tried to sketch, it is not supported by good evidence; and therefore that content produced by your team may mislead families into believing that their child ought to follow this approach. We are concerned that you are being used by transgender activists to normalise an approach to the management of gender dysphoria in young people that is, in fact, highly contested and experimental. If so, your laudable goal of "providing a well established, reputable source of information" for young people and their families will be disappointed.

The project's bias is apparent in its approach to participant recruitment and it may also colour the analysis and presentation of findings. I'm writing in the hope that there is still time to address all this, and to recruit a more diverse range of participants that better reflects the true range of families living with gender distress. Your project proposal recognises that "the reactions and behaviour of a gender questioning person's parents and family members can be critical." At present, we think it's likely that your research will only address the health and care needs of a minority who fit a particular rights and identity agenda and who are represented by the groups your project has affiliated with.

The potential for recruitment bias was highlighted by the NIHR when they approved the project and provided feedback:

The team should consider how they would address any bias introduced by the recruitment methods used (social media etc), and these methods should be justified.

And as parents, we watched in real-time as your researchers undertook recruitment on social media exclusively among advocacy and human rights groups who campaign for the use of endocrine treatments to resolve children's gender distress, rather than careful exploratory therapy that accounts for their often complex mental health and developmental histories. These concerns are not, we think, news to your researchers. A parent recently forwarded to us a transcript of the interview they gave for your project, in which your researcher swiftly changed the subject from the "not relevant" matter of the project's recruitment bias.

R: [...] There will be a small percentage who are very pro-affirmation, the Mermaids types, the GIRES types. But there is another, larger percentage who are somewhat more sceptical and of the Tavistock and current medical practice in this field. **I:** It's interesting the percentages that people who, in my experience.

R: Is it because you are looking at a smaller base.

I: No. Not necessarily. I think it's a, it's a hard thing to evaluate perhaps, you know, the percentage.

R: Your marketing materials went out through Mermaids and GIRES so you're only gonna get a certain type, possibly. Your recruitment was going through a certain pathway.

I: Our recruitment has gone to many different pathways. This was just one of them. **R:** Was it on Transgender Trend?

I: Well I didn't recruit through it.

R: So, well, so that's, that's what you're getting a smaller percentage or you're getting a targeted percentage.

I: I think this is obviously not relevant to the interview. As a part of Twitter recruitment you always get a very certain type of participants anyway. So we are very conscious of not just limiting our recruitment through, to a recruitment through Twitter. [erm] And that is all calculated into, you know, the kind of sample that we're trying to gather. [erm] For you yourself I mentioned that you'd been recruited through Twitter. Is it kind of undoing your point.

R: No, no, no, no, it's because I follow Mermaids.

I: [erm] And I'm sure they follow you. But this is obviously not that relevant here. So coming back to your [erm] your own journey and you mentioned that you were obviously doing all this, all this work and looking at what's there and, and well, finding out what kind of [erm] therapists are at the, at the service. [erm] What kind of support was there for you as a parent? Was there anything in the healthcare system? **R:** No, no. The health service, you don't know what you are gonna get. You're gonna get some--you can get an activist, an affirming activist, they'll just get

one, there's just one point of view. I wanted someone who's gonna look at the broader picture with my daughter and understand the underlying issues of not merely affirm

Furthermore, in January we tweeted you and Drs Stepney and Mikulak, directing your attention to our 'rapid response' in the *British Medical Journal*, which ended as follows:

Currently, policymakers and researchers are receptive to only one particular segment of opinion, drawn from populations already committed to the medical pathway. The NHS is struggling to hear another, larger, constituency, of families that doubt that invasive medical interventions, unsupported by reliable evidence, is in their children's interests, especially alongside longstanding mental health and/or developmental challenges whose intersection with gender identity are poorly understood. The idea that 80% of dysphoric children desist has come under criticism recently, but it seems clear that the significant majority of children do resolve their gender ID in favour of their natal sex by adulthood. Where is the advocacy for the mental health needs of that majority? [7]

It seems that well-meaning people imagine that the major organisations are representative of the populations facing gender problems, but that is far from the case. For example, when in 2019 the National Lottery investigated concerns about Mermaids UK, its report noted that:

There appears to be a significant difference in the longer-term outcomes for children who use the services offered by Mermaids as opposed to those of the GIDS service and some of the figures suggested in the research. Mermaids say that the vast majority of young people they see will continue with their gender reassignment process whilst the GIDS outcomes appear to be the opposite. It is not clear why this might be the case but there is no evidence to substantiate the inference that this correlation is because of Mermaids support. For example, it is possible that the self-selecting nature of families and young people who choose to access the Mermaids service is a contributory factor. [8]

So why not also speak to parents with diverse views and responses to their trans children? There are at least three groups within the UK for parents of trans children who were not involved in the recruitment: *Our Duty*; our own group, *Bayswater Support*; and a UK email list administered by the US group *Parents of ROGD Kids*. Furthermore, there are boards on *Mumsnet* where parents of trans kids discuss parenting issues; an international bulletin board called *gendercriticalresources*; a UK ROGD group on Facebook; and a hugely-valued website for UK families, *Transgender Trend*, whose editor was shortlisted for the 2018 John Maddox Prize (organised jointly by *Sense About Science* and the journal *Nature* for promoting "science & evidence, advancing public discussion around difficult topics despite challenges or hostility").

Your researcher Dr Sam Martin's twitter feed makes clear the importance to them of transgender advocacy, which is of course perfectly reasonable. However, when it comes to advising our children and others like them, we feel that special care should be taken to ensure that Dr Martin's personal commitment to advocacy does not

colour their approach to research.

Dr Martin's twitter feed shows that they have promoted efforts to have a transwoman school teacher de-selected from their union LGBT+ group because she has called for a more cautious approach to medical transition in the young. A few weeks ago Dr Martin congratulated a young person, Reuben Wells, who had ordered their first supply of cross sex hormones. Reuben did not use NHS services but a private provider, *GenderGP*, whose founder Helen Webberley and her husband are currently banned from practising as a doctor in the UK. Dr Webberley also received a criminal conviction for running an unregistered gender clinic (consequently *GenderGP* is now based in Belize). Only a day before, Reuben disclosed that they had been repeatedly raped by their boyfriend but that nobody believed them. They now want to "escape this hell I call my body". For us, this is precisely where medical transition can be misapplied - surely this person deserved thorough and careful exploration of their problems first, to ensure that irreversible steps would indeed represent the best solution to their distress.

Dr Martin has retweeted the Mermaids ambassador Munroe Bergdorf's claim that JK Rowling's concern over gender identity healthcare is damaging children's mental health. Munroe joined Mermaids after being dropped by NSPCC, whose CEO explained that the association didn't support the charity's "ability to safeguard children and be influential in safeguarding children. The board decided an ongoing relationship with Munroe was inappropriate because of her statements on the public record, which we felt would mean that she was in breach of our own risk assessments and undermine what we are here to do. These statements are specific to safeguarding and equality." [9] Concerning JK Rowling, we welcome her efforts to promote a discussion about what might be behind the vast increase in the numbers of girls.

In recent weeks Dr Martin has re-tweeted messages calling the report by *BBC Newsnight* on safeguarding concerns at GIDS "biased nonsense", "fear-mongering rubbish" and "clickbait hysteria". Given that the Tavistock and Portman NHS Trust's own child safeguarding lead is one of the whistleblowers raising the alarm, and is currently fundraising for legal representation against her employers in relation to her safeguarding concerns, one might think that anyone who had vulnerable young people's best interests at heart might want to amplify the *BBC Newsnight* allegations, rather than try to shut them down. You'll be aware that *BBC Newsnight* has broadcast specific allegations against your co-investigator Dr Sarah Davidson which neither she nor the Trust has yet addressed (beyond a blanket denial of the reporting in its entirety).

The best we could say about Dr Martin's twitter feed is that it doesn't encourage us to trust that their work will show balance. Over the years of our involvement in this topic, we've witnessed so many people – with good and not-so-good motives – using our children for their own ends: to advance careers, promote societal reform, or to reframe their own life decisions. Few children can have been so instrumentalised as young people suffering distress over their gender. Although we can see that you all want to be helpful, we're sorry to say that we have a familiar weariness that, yet again, only part of the story will be told.

It could enhance your online resource if you were to interview adults who formerly

suffered gender dysphoria but who resolved their gender difficulties without the need for medical interventions and who no longer identify (if they ever did) as transgender. Such people represent the most common outcome for GIDS patients, and hearing from them would give families on the GIDS waiting list a good insight into the likeliest trajectory for their child, as well as helping them with ideas about how their child might overcome their gender problems without the need for medical interventions. It could also be useful to interview young adults who underwent a medical transition and then transitioned a second time ('detransitioned') after they reappraised their decision. Detransition is an outcome that families on the waiting list ought to consider, not least because some detransitioned people now complain that they were never told of the existence of detransitioners, and that it might have helped them to see their struggles in a different light. A growing number of young women were all helped to transition by the NHS and now feel health services let them down really quite badly, by promoting medical solutions as being the most appropriate approaches to relieve their problems. Your researchers could easily advertise the project via detransition networks or organisations; we personally know some detransitioners and desisters (those who give up a transgender identity without having undergone any physical interventions) and could help to put you in touch. Within the NHS and academia, there seems to be huge interest in young people's first transition, but a perplexing dearth of curiosity about their second transition.

You may know that Keira Bell has taken the GIDS gender clinic to the High Court, and another detransitioned young woman is considering whether to sue her NHS gender clinic for damages. Today's *Sunday Times* magazine features the stories of several other detransitioned young women let down by their NHS treatment. [10]

We wish to highlight to you, therefore, that there may come a time when bias in research, such as we are keen to alert you to here, may be widely seen as part of a culture that encouraged troubled young people to undergo unnecessary and irreversible medical interventions that caused them deep trauma and that significantly added to their life problems. There are many examples in medicine, where the clinician's compassion and desire to alleviate suffering led to the patient being harmed; there are also examples (such as the Rotherham abuse scandal, or the current Leicester clothing sweat shops) where sensitivity around protected characteristics led authorities to apply less of a critical eye on unsafe or harmful practices; and then, as the recent *First Do No Harm* report highlights, there is the reflexive dismissiveness or defensiveness of clinicians and NHS organisations in relation to reasonable concerns.[11] Responsible researchers ought to be alive to all of these risks. As James Kirkup wrote in *The Spectator* recently in relation to the GIDS safeguarding concerns: "when an independent inquiry does come, as it surely will, one of the questions that ministers and MPs will have to answer is why it took them so long to act." [12] Please take care that, in your desire to help, you are not in fact enabling a culture of inappropriate and unnecessary medical transition that may lead to serious harm.

Yours sincerely,



on behalf of

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cc

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