



The experiences of transgender and non-binary children and young people and their parents in healthcare settings in England, UK: interviews with members of a family support group

Journal:	<i>International Journal of Transgenderism</i>
Manuscript ID	WIJT-2019-0076.R2
Manuscript Type:	Original Research
Keywords:	parents, misgendering, transgender, non-binary, deadnaming, practitioner, school

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Manuscripts

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4 **The experiences of transgender and non-binary children and young**
5 **people and their parents in healthcare settings in England, UK:**
6 **interviews with members of a family support group**
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10 [author information redacted for peer review]

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14 **Abstract: The experiences of transgender and non-binary**
15 **children and young people and their parents in healthcare**
16 **settings in England, UK: interviews with members of a**
17 **family support group**
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23 **Background:** Transgender and non-binary children and young people and their
24 parents in England, UK are poorly served across a range of healthcare settings.
25 Whilst UK equalities legislation and international guidance on transgender
26 healthcare pathways protects this group from discrimination and mandates an
27 affirmative approach, services in England are not keeping pace.
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32 **Aims:** This study aims to draw on the experiences of transgender and non-binary
33 children, young people and their parents in a support group in England in order to
34 investigate their experiences of healthcare provision, and to develop some ideas
35 for improvement.
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40 **Method:** Data was collected with participants in a family support group which
41 offers a parent helpline service, social groups for children and parents, and
42 training for schools and other organisations. 65 parents and children from 27
43 families from the family support group attended participatory workshops where
44 they were given a range of briefs: “health”, “family”, “friends”, and “education”.
45 Their participation involved being asked to define their own interview questions
46 and collect data by interviewing each other. Their interview notes constituted the
47 raw data. Data was coded inductively by the author with respondent checking as
48 a second stage.
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55 **Results:** Results constitute the views of a small group of people, so cannot be
56 generalized. However, they can illustrate some of the issues which may arise.
57 Participants’ experiences elicited five key themes: professionals’ perceived lack
58 of clinical and therapeutic knowledge; mental distress caused by excessive
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3 waiting lists; professionals' stereotyped gender assumptions; direct
4 discrimination within healthcare settings; and a lack of attention to parent and
5 child voice, especially in terms of school-based experiences and where a patient
6 had a diagnosis of autism.
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10 Keywords: parents, non-binary, misgendering, deadnaming, practitioner, school
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13 **Conflict of interest:** The author declares that they have no conflict of interest
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For Peer Review Only

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3 In the United Kingdom (UK), the United States (US), and elsewhere, transgender and
4 non-binary children and young people have increasingly been presenting at both generic
5 and gender identity-related services in the healthcare system (Kualanka, Weiner &
6 Mahanchild, 2014; Pearce, 2018). In England, UK, physical and mental healthcare is
7 provided to transgender and non-binary young people by primary care physicians
8 (family doctors, known in the UK as general practitioners, or GPs). These young people
9 are often initially referred to Child and Adolescent Mental Health Service (CAMHS),
10 although this is not a requirement. There is a sole specialist gender development service
11 (GIDS) for children and young people in England. Young people can self-refer to
12 GIDS, or be referred by CAMHS or by their primary care physician. This research asks:
13 how do transgender and non-binary children, young people and their families in one
14 support group in England experience healthcare provision?
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31 This study, working with participants from 27 families from the North and South
32 of England in the UK, was conducted within (but not funded by) a family support group
33 (FSG) for transgender and non-binary children and young people and their families. The
34 FSG offers training to organisations, workshops and seminars for families as well as the
35 mutual sharing of experience through social events, enabling the parents of older
36 children to mentor those of younger children, and for older transgender and non-binary
37 children to mentor younger ones. This kind of group support can be an important and
38 healing resource for parents (Aramburu Alegría, 2018, Capous Desyllas & Barron,
39 2017; Kualanka et al., 2014, Malpas, 2011). Of significance to the focus of this paper,
40 the group is inclusive of children with autism spectrum disorders (ASD); this
41 population is thought to be constitute around 7% of transgender young people (May,
42 Pang and Williams 2017; Kualanka, Mahan, McGuire, & Hoffman, 2017).
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3 **Numbers** of young people recognised as transgender and non-binary appear to
4
5 be rising, but figures from different countries vary widely. Significantly, in the UK
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7 there is no official record (Pearce, 2018). Malpas (2011) reports that one in 500 young
8
9 people in the US can be identified as transgender. May, Pang and Williams (2017)
10
11 report that 1.2% of the US population may have gender dysphoria. Research with a
12
13 randomised sample of just over 8000 secondary school students from New Zealand
14
15 identified 1.2% who reported being “transgender” and a further 2.5% who reported
16
17 being “not sure about their gender” (Clark et al., 2014). As in research by Zucker et al
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19 (2010), this qualitative study aims to illustrate these statistics with a limited sample of
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21 individual experiences.
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27 Previous research into transgender and non-binary young people’s experiences
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29 of healthcare in the UK suggests that they tend to avoid primary healthcare because of
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31 the dysphoric feelings induced by their anticipation of gender non-affirmative
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33 experiences (Harris 2018; Fae 2018). This includes dental care (Aramburu Alegria
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35 2018). Harris (2018) suggests that school nurses have a role in supporting access to
36
37 healthcare for transgender and non-binary young people in the UK, although this
38
39 resource is now less available due to funding cuts across the education and health
40
41 sectors. Initial attempts to gain access to appropriate treatment via the GPs who offer
42
43 primary care in the UK can be fraught with financial, discriminatory, and knowledge
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45 barriers (Fae 2018; CRAE 2016). The Children’s Rights Alliance for England (CRAE
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47 2016) collected children’s views on transgender issues for the United Nations
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49 Committee to the UK, which subsequently raised concerns about trans young people’s
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51 healthcare with the UK government. However, most of the research on transgender and
52
53 non-binary children and young people’s experiences of healthcare has been conducted
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55 outside the UK. In the US, Hoffman, Freeman & Swann (2009) surveyed more than 700
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3 LGBTQ youth and found that they valued healthcare providers who had good
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5 interpersonal skills and cultural sensitivity, and who understood them within the context
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7 of their developmental stages. Their research suggests that better training is needed for
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9 practitioners working with this group, particularly in terms of more collaborative
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11 working with the home and family; this is also the conclusion of literature reviews by
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13 Tellier (2019) in Canada and Coker (2009) in the US. Tellier (2019) found a range of
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15 evidence of transgender youth avoiding treatment for unrelated conditions and
16
17 preventative healthcare in Canada, with Clark, Veale, Townsend, Frohard-Dourlent, &
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19 Saewyc (2018) confirming that non-binary youth between 14 and 25 were also
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21 affected, and pointing out that this particularly affected those living in rural areas.
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23 Goldenberg et al (2019) note that Black transgender and gender nonconforming youth,
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25 who face specific difficulties in accessing adequate healthcare in the US, were more
26
27 likely to access primary care services if their gender was affirmed. Transgender youth
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29 using healthcare facilities were found in separate pieces of research by Breland et al
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31 (2016) in the US and CREA (2016) in the UK to have experienced problems accessing
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33 puberty blockers, and a general sense that some practitioners were under-trained when it
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35 came to working with this group. This is of concern given a body of research
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37 confirming that blockers can be useful and well-tolerated when offered with supportive
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39 psychological therapies to help young people to gain some time develop their thinking
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41 around their gender identity (Zucker et al 2010; Lynch, Khandheria and Meyer III 2015;
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43 Schei Jessen and Roen 2019; Sansfaçon et al. 2019). As Tellier (2019) also found, trans
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45 young people were often misgendered and experience a general lack of coordination of
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47 care with other institutions tasked with caring for adolescents, such as schools. There
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49 are many areas within which the existing literature suggests that parents and healthcare
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51 practitioners could garner positive results through collaborative working. Hillier and
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3 Torg (2019) report on the efficacy of a clinician-led FSG in the USA, and suggest that
4 parents' voices are important in developing ideas about how healthcare providers might
5 better support these children and their families. Kivalanka et al (2018) looked at
6 healthcare for transgender and non-binary children and young people with ASD,
7 concluding that professionals in with each of these two apparently disparate specialities
8 should collaborate closely to support better therapeutic input for gender-nonconforming
9 children and support for their parents. Oliphant et al. (2018) in New Zealand outline a
10 range of best practice guidelines for primary and other healthcare which recommend
11 equitable, accessible gender-affirming care which is informed by international standards,
12 evidence-based literature, and service-user voice. They outline clear approaches to
13 collaborative working with parents, and foreground the need to be aware of youth-
14 specific healthcare issues such as bullying, drug use and the pace of puberty. Many
15 parents, pediatricians and psychotherapists working with transgender and non-binary
16 children agree that it is important to collaborate with each other to assist social
17 transition in physical and emotional safety at home and at school (Capous Desyllas &
18 Barron, 2017; Kivalanka et al., 2014; Malpas, 2011).

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21 In terms of the healthcare system for trans people in the UK, models of care are
22 slowly emerging from a binary model to a more nuanced one, open to non-binary
23 gender identities, particularly when it comes to care for adults (Pearce, 2018). This is in
24 line with broader changes: it is becoming accepted in UK adult services and for children
25 and young people outside the UK that whilst binary concepts of gender underpin the
26 idea that any kind of variance is problematic (Kivalanka et al., 2014), a depathologised,
27 affirmative model of care is increasingly becoming the norm. In 2018, the World Health
28 Organisation confirmed that it intended to reclassify "gender identity disorder" in its
29 forthcoming International Classification of Diseases catalogue (ICD-11, for
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3 implementation in 2023), changing it from a “mental disorder” to a “condition” (Beek et
4 al 2017). In making this change they cited a wish to reduce stigma and increase access
5 to healthcare (France-Presse, 2018), although in states without free healthcare
6 programmes there was some concern that this could result in restricted access to
7 treatment (Beek et al 2017). The UK’s 2010 Equality Act ostensibly aligns with this
8 approach, protecting people from discrimination and encouraging understanding of
9 those with the characteristic of ‘gender reassignment’ (clumsily worded, but clarified as
10 referring to anyone who has taken steps towards changing their gender, for example a
11 name change). Despite these changes and legal protections, the findings in this research
12 suggest that the development of adequate healthcare services for many trans young
13 people in England does not appear to have kept pace. In 2018 the UK Government
14 Equality Office released an LGBT Action Plan, with the stated aim of beginning to
15 address the needs of LGBT people across the UK. Whilst it did promise a forthcoming
16 and long awaited guidance document for schools about supporting transgender young
17 people (at the time of writing, still awaited), it has been widely criticised for failing to
18 signal much-needed changes in healthcare for trans people under the age of 18 (CRAE
19 2016). Similarly a 2018 review of the UK’s Gender Recognition Act 2004 did not invite
20 comment on lowering the age limit for gender self-identification below eighteen, and
21 non-binary people are as yet unrepresented in UK government policy documents.
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47 This study is important at this time partly because as confirmed by the United
48 Nations Committee (CRAE 2016), the UK trails behind many other countries in the
49 speed and efficacy of provision for child and adolescent gender affirmative healthcare
50 (Pearce, 2018, Vincent, 2018, CRAE 2016), and partly because of the unprecedented
51 amount of negative attention from both mainstream and social media prevalent at the
52 time of writing and focused on transgender and non-binary people, especially young
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3 people (Fae 2018). To redress the imbalance of power, it is recommended that research
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5 into the healthcare experiences of trans youth should be conducted in collaboration with
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7 trans youth (Adams et al 2017). This research contributes a participatory investigation
8
9 of the experiences of healthcare provision for transgender children, young people and
10
11 their parents in England. Drawing on a participant-researcher model ([Author name
12
13 redacted for peer review] 2012; 2016), this paper describes an attempt to invite
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15 transgender and non-binary children, young people, and their families attending a
16
17 support group to contribute their expertise-by-experience towards discussions on
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19 improving the healthcare provision available to them in England.
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25 **Theoretical approach**

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27 As well as supporting the development of better healthcare services and reducing stigma
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29 for transgender and non-binary people, research with this group about their experiences
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31 challenges structuralist models of gender, and situates gender dysphoria as a public
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33 issue rather than solely a private trouble (Mills 1959). This premise reframes ‘gender
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35 dysphoria’, which is situated within the gender nonconforming person, as at least partly
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37 attributable to ‘social dysphoria’- that is, a dysphoric pain resulting from the non-
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39 empathic response of others to a person’s perceived gender presentation or expression.
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41 An analysis of this kind prompts philosophical exploration by bringing together
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43 poststructural ideas with embodied experience: as Elling-Marchartzki (2017, p.258)
44
45 elaborates, sex and gender is both “dynamically embodied” and “discursively
46
47 constructed”. The experiences of the transgender and non-binary children, young people
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49 and their families in healthcare settings related here demonstrate the negative impact on
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51 their mental and physical health of the ‘minority stress’ (Hendricks & Testa 2012) they
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53 experience.
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Methodology: Research Participants as Experts on Their Own Lives

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3 As a lesbian and a mother I have experiences of LGBTQ+ spaces and groups and in
4 supporting and understanding my now adult non-binary child. But I am cisgender, and
5 do not share the lived experiences unique to the transgender and non-binary
6 communities. The research methods I use therefore draw on the notion of participants as
7 experts on their own lives (Kualanka et al., 2014). This work requires care around the
8 use of language, and avoiding what Vincent (2018) describes as the “iterative linguistic
9 microaggressions” (p.107) which could impact on a transgender and non-binary
10 person’s sense of safety and acceptance. In line with Vincent (2018) and other studies in
11 this area (Birnkrant & Przeworski, 2017), this paper will be using the term
12 “transgender” to refer to people who identify as other than the gender identified at birth,
13 and “non-binary” to refer to people who identify outside the binary system of gender
14 identification. Caudwell (2014) notes that the term transgender can apply to both
15 “gender conformers” (who transition from gender identity A to gender identity B) and
16 “gender transformers” who cluster more around binary-subverting genderqueer and/or
17 non-binary paradigms. Where possible, this paper recognises this diversity of identities,
18 and also uses “trans” as an umbrella term covering a range of transgender and non-
19 binary people, whether in receipt of a clinical “diagnosis” or not (Pearce, 2018).
20 ‘Transgender and non-binary’ is not a catch-all phrase. However, in the data, the
21 respondents themselves did not usually distinguish between the two when they were
22 talking about their experiences. The paper focuses specifically on trans identities but
23 “LGBT+” and variations of this acronym are quoted in the data where respondents and
24 other writers have used it. LGBT+ is understood for the purposes of this paper to mean
25 lesbian, gay, bisexual, transgender, and anyone else who fits within or around these
26 categories- potentially including people who are intersex, queer, asexual, and pansexual,
27 for example.

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3 It is particularly salient for researchers to pay attention to the emotional labour
4 inherent in asking transgender and non-binary young people and their families to
5 participate in research about their lives and experiences (Vincent, 2018). Approaching
6 research with trans people and their families therefore requires “an ethics of care”
7 (Vincent, 2018, p.105). Clark et al. (2014) propose a therapeutic approach with trans
8 young people that develops resilience, social skills and emotional growth: participant-
9 led data collection is similarly a relational and interpersonal experience, and the work
10 described here has been conducted with this in mind. Participant involvement in
11 research can offer reassurance and insights to both participants and researchers, and can
12 be empowering to participants (Adams et al 2018; Vincent 2018).
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26 Research with families draws on the fruits of intergenerational expertise
27 ([Author name redacted for peer review] and another 2018). Parents can be
28 knowledgeable; many have researched and read much about trans children (Malpas,
29 2011; Kivalanka, et al., 2014; Kivalanka, et al., 2018). Children and young people also
30 often conduct their own extensive research, especially online ([Author name redacted
31 for peer review] and another 2018). In addition, the idea that children might be experts
32 on their own lives is not only accepted but has long been seen as ethically and
33 empirically crucial in much of the research emerging from the disciplines of health,
34 education, social work, and youth work (Hart, 1992; Fielding & Bragg, 2003; Rudduck
35 & Flutter, 2003; [Author name redacted for peer review] 2012, 2016; Sansfaçon et al.
36 2019). This approach to youth voice, however, does not seem to have become
37 embedded in the healthcare experiences of trans and non-binary children and young
38 people in England, as noted by United Nations Committee members inspecting
39 children’s rights in the UK (CRAE 2016). NHS England released a five year ‘Forward
40 View’ document in 2014; in response, the British Youth Council released guidance on
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3 how to ensure youth voice is embedded in healthcare in England. Conducted in 2019,
4 this research offers evidence that although it is acknowledged to constitute useful
5 practice (Sansfaçon et al. 2019), for trans children and young people and their parents,
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10 ‘voice’-informed healthcare is still rare.

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12 The project described here sought to investigate the experiences of trans children
13 and young people and their families in their interactions with primary and secondary
14 healthcare providers in England. The findings outlined in this paper emerged from two
15 participation-researcher workshops conducted with FSG families at a Saturday drop-in
16 event and at one of the residential weekends arranged by the organisation. The data here
17 is therefore drawn from a small group of people and cannot therefore be generalized.
18 Recruitment was via a support group, so it must be recognised that respondents may
19 have been biased by their shared involvement in seeking support. However, the study
20 does i[Name of methodology redacted for peer review] the experiences of some
21 transgender and non-binary children, young people and their families.
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36 ***Participants***

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38 This research was conducted with 65 people across 27 families. Around half the
39 respondents were adults; the remainder were young people aged between twelve and
40 eighteen. Four of the participating parents had children under twelve. Most of the adults
41 were cisgender parents and around two thirds were women; one was a non-parent FSG
42 volunteer who identified as a trans man. All of the participating children and young
43 people were transgender or non-binary, with around two thirds identified as female at
44 birth. The FSG is inclusive of children and young people with autism spectrum disorder
45 (ASD); seven of the families involved in the research had transgender and non-binary
46 children with ASD diagnoses. Monthly FSG drop-in sessions and quarterly residential
47 weekends are provided free or at an affordable rate to enable participation for all: the
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3 parents' professions range from social worker and teacher to quantitative analyst, school
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5 lunchtime supervisor, club singer, and childminder (home-based day-care worker).
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8 ***The I[Name of methodology redacted for peer review] participant-researcher model***

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10 The participant-researcher model used here is called "I[Name of methodology redacted
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12 for peer review]" ([Author name redacted for peer review] 2012; 2016). It essentially
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14 presents workshop participants with a brief, and then supports them to develop their
15
16 own interview questions and to carry out data collection by interviewing each other
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18 right there in the workshop. I[Name of methodology redacted for peer review] has been
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20 subject to publication and peer review, and has formed part of a large international
21
22 funded research project (Anderson & Macleroy, 2016) as well as being trialled and
23
24 refined in over 25 schools, charities, and community organisations. It is essentially a
25
26 model designed to involve participants in data collection from many angles: to get
27
28 beyond "glib responses" to more profound insights; to draw on participants' expertise in
29
30 formulating interview questions; and to involve participants in the gathering of data. In
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32 its approach to facilitating constructive collaboration between organisations and the
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34 people who use them, it is a mediative approach, designed to maximise the potential for
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36 research findings to change structural inequities and to inform institutional policy and
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38 practice ([Author name redacted for peer review] 2013).
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46 ***From discussion briefs to emerging themes***

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48 An I[Name of methodology redacted for peer review] project starts with a brief chosen
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50 by the organisation. In this case, a range of briefs were chosen by the FSG, including:
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52 "health", "family", "friends", and "education". Whilst these briefs may play a part in
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54 informing later data analysis, they would not rigidly frame the emerging themes, but
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56 were designed to elicit findings across the range of issues that the FSG as an
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3 organisation considered to be important- hence ensuring their commitment to
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5 meaningful interest in the results.
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8 With all I[Name of methodology redacted for peer review] projects, it is
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10 important to support the participants (service users, students, or community members)
11
12 to come up with their own data-collection questions and to manage the expectations of
13
14 those in power (service managers, teachers, or charity managers) who had supplied the
15
16 briefs for the project. It was therefore careful to explain to FSG staff that the themes
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18 which would eventually emerge from the process may have, in a discursive sense,
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20 travelled some way from the original five briefs. In fact the six themes generated by the
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22 FSG I[Name of methodology redacted for peer review] workshop participants did
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24 indeed develop the original briefs into an overlapping but somewhat transformed set of
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26 foci. These included: “the trans child and their family”; “the mental health of trans
27
28 young people”; “physical health and exercise”; “experiences of healthcare providers and
29
30 treatment”; and “school”, including social, curricular and pastoral concerns. The
31
32 qualitative methods employed to draw these themes from the data are explained below.
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34 The work reported in this article refers to a subsection of the data relating to experiences
35
36 of healthcare settings, and mostly emerged from groups addressing the briefs of
37
38 “health”, “school”, and “family”.
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45 ***The I[Name of methodology redacted for peer review] workshop***

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47 The workshop begins with the presentation of discussion briefs to participants. It is key
48
49 to the process that the briefs are not questions, but single words or phrases designed to
50
51 elicit participants’ own ideas. The approach supports participants to look in depth at the
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53 briefs, develop data-collection questions of their own, and collect interview data from
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55 each other to answer those questions. The process is guided by a set of forms. In an
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57 I[Name of methodology redacted for peer review] workshop, participants write
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3 discussion notes and interview questions and responses on the forms, and these notes
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5 become the raw research data.
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8 In this case, the sessions each lasted about 120 minutes. At the FSG residential
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10 weekend, there were about 40 participants in fifteen families including trans young
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12 people and adults, cisgender siblings, parents, carers, and volunteers, seated round
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14 tables in seven groups. At the Saturday drop-in, there were about 25 participants in
15
16 twelve families, seated in four groups. The groups were partially self-formed, although
17
18 in order to encourage a range of age-specific discussions, parents were encouraged to sit
19
20 together, and young people to sit within their own groups. Parents did not sit with their
21
22 own children. The sessions began with introductions and a discussion ensuring
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24 informed consent.
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28 Following the informed consent discussion, each participant was given a standard
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30 I[Name of methodology redacted for peer review] “Getting to a Question” form. Using
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32 the forms in their small groups, workshop participants brainstormed the meanings,
33
34 questions, thoughts, and ideas stimulated through a discussion of each brief. Through
35
36 the guided process, they refined their thinking into a range of interview questions.
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40 The next step requires participants to interview each other in the workshop. They
41
42 draw on the notes and questions recorded on their “Getting to a Question” forms to help
43
44 them design a set of five to eight open interview questions. Participants interviewed
45
46 each other first within their small discussion groups, partly to collect data, and partly to
47
48 refine their interview questions. They were then invited to find someone in another
49
50 small group in the workshop to interview, using the same (albeit refined) questions.
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52 Each interview was therefore conducted with at least two respondents. During their
53
54 interviews, participants are asked to write down as many verbatim quotes as possible.
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56 Along with the “Getting to a Question” forms, all sets of interview questions and the
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3 responses written down form the body of data collected at the end of the workshop. The
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5 process is noisy and messy and not everyone participates in each step, but this is built
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7 into the model: I[Name of methodology redacted for peer review] workshops are
8
9 designed to work flexibly with a range of people, abilities, and interests, and tend to
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11 produce a good level of data in a relatively short amount of time.
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Developing Themes and Subthemes from the Briefs: Methods of Analysis

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20 At the end of the two FSG I[Name of methodology redacted for peer review]
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22 workshops, around twenty notated “Getting to a Question” discussion forms and around
23
24 thirty five interview forms were collected, complete with their questions and responses.
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26 Later, the forms were read through to gain a broad overview of content and then themes
27
28 and subthemes which emerged consistently across the groups were identified. These
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30 themes were outlined and evidenced in a workshop report document and FSG parent
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32 volunteers were invited to give feedback. Subsequent analysis was refined by this
33
34 feedback. The thinking behind the data analysis was inflected by the initial briefs and
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36 informed in part by the literature summarised above, but was primarily concerned with
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38 avoiding researcher bias by allowing the participants’ own voices and ideas to emerge.
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45 Through this process, the themes under which the “Results” section below has
46
47 been organised materialised under a variety of the original briefs provided in the
48
49 workshops. For example, the groups which had the briefs for “health” and “family” both
50
51 discussed the impact on trans children of the relationship between healthcare providers
52
53 and parents or carers, so this data was filed under the theme for “The trans child and
54
55 their family”.
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57

Ethics

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2
3 All workshop participants read an information sheet (or according to need, had it read
4 and explained to them), and signed a consent form. These materials have been designed
5 in line with the guidelines of the British Educational Research Association and agreed
6 by an ethics committee at the author's university. Confidentiality is maintained by the
7 exclusion of names in this article. Given the hostile media environment surrounding
8 trans children, young people and their families in the UK, where necessary, special care
9 has been taken to change other identifying details.

10
11 I[Name of methodology redacted for peer review] has been designed as a data
12 solicitation methodology which is responsive to content matter which may be sensitive.
13
14 In allowing participants to develop their own interview questions, the method gives
15 control of the subject matter to the participants. Recognising the work involved in data
16 collection, I[Name of methodology redacted for peer review] also aims to exchange
17 participation for skill development. It is therefore designed to help respondents learn
18 and practice transferrable speaking, listening, writing, critical thinking, and analysis
19 skills at the same time as their participation in the research ([Author name redacted for
20 peer review] 2012). It is designed on the basis that people of all ages are experts on their
21 own lives and experiences. It is built on the dialogic and critical consciousness-raising
22 models of pedagogy and research developed by Freire (1968) to redress the power
23 imbalance which can arise between people of different subjectivities (teacher and
24 student, researcher and researched, or doctor and patient, for example).

50 **Results**

51
52 The overarching sense emerging from the FSG workshops was the dissatisfaction,
53 frustration, and distress both parents and children or young people felt with healthcare
54 providers- both primary carers and gatekeeper referrers such as GPs and CAMHS, and
55 the specific gender-focussed GIDS provision itself. The NHS in general is very highly
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1
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3 regarded and appreciated in the UK, and some respondents were able to recall
4
5 interacting with some helpful staff members. However, the experiences summarised
6
7 below were identified by workshop participants as key sources of the mental ill-health
8
9 and distress experienced by both trans young people and their parents. They emerged
10
11 strongly through the collaborative I[Name of methodology redacted for peer review]
12
13 process as clear themes.
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15

16
17 The results section starts with an overview of the impact of healthcare experiences
18
19 on the trans child in the context of their family; including parents' and siblings' need for
20
21 support and parental expertise. The section goes on to address the mental health of trans
22
23 young people and how they experience discussions between clinicians and parents.
24
25 Many practitioners were felt by the families to have been under-trained, and as a result
26
27 to lack adequate knowledge of appropriate clinical research. Participants also discussed
28
29 painful misgendering and deadnaming experiences which they also ascribed to a lack of
30
31 education about gender identity issues. This, together with waiting list times and
32
33 lengthy treatment pathways; disregard for service user expertise, particularly in relation
34
35 to what might help at school; and a lack of patient and family input into clinical and
36
37 therapeutic planning was found to have a negative impact on the whole family. These
38
39 effects were often magnified in situations where the trans child also had an ASD
40
41 diagnosis.
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46 47 ***Parents' and siblings' need for support*** 48

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50 As one parent in the workshop explained in her discussion notes, 'family support is of
51
52 paramount importance to the young trans person for acceptance, help, support, and
53
54 friendship. All need to be united and well-informed'. However, despite this, the FSG
55
56 parents' mental wellbeing was often described as being undermined by their
57
58 relationship with CAMHS (Child and Adolescent Mental Health Services). Parents in
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60

1
2
3 the I[Name of methodology redacted for peer review] workshops characterised their
4 relationship with CAMHS and GPs (general practitioners; sometimes known as family
5 doctors) as one of “struggle”. It is worth noting here that GPs and CAMHS are not
6 gender specialists, but generalists in the area of healthcare and child and adolescent
7 mental health respectively. Most parents felt that they were battling healthcare services
8 for adequate support for the whole family, with many talking about how the whole
9 household was experiencing mental and emotional distress. One of the workshop parent
10 participants recounted a difficult family weekend away where her trans child was
11 ‘trying to stab himself with a knife’ and his cisgender sibling also cut her arms with a
12 piece of plastic. She said that when they returned home, she ‘just felt flattened’. Another
13 parent, a father, talked about the need to include parental mental health and family
14 dynamics in future research about trans children and young people, explaining that he
15 felt he was seen merely as the person who brought his child to their appointment, and
16 asserting: “we are patients too”.

17 *Parental expertise*

18 Many of the parents in the session had considerable knowledge and understanding of
19 the issues and concerns surrounding the care and support of trans children and young
20 people, partially derived from their experience with their own trans children, and
21 partially from their professions, prior experience, and independent research and reading.
22 One parent who was a social worker received support from her workplace. She was able
23 to mitigate against the effects of the long wait for CAMHS input (before a potential
24 referral to GIDS was even contemplated) by drawing on her own social work skills to
25 do reflective “journal work” with her child at home. However, this kind of expertise
26 was not often acknowledged or called upon by professionals in the healthcare
27 appointments she attended with her child.

Clinicians' advice to parents.

An area of frustration for the FSG workshop participants related to the advice some GPs and CAMHS practitioners gave to parents and carers. Examples which participants shared included advice not to take a child's thoughts on their own gender seriously; or to ignore or punish self-harming behaviours relating to body dysphoria. The parents reported that this was counter to what they had read in their investigations into best practice, so often led to confusion. It can also cause disagreements between parents and their children, leading to a loss of parental support. In her workshop notes, one FSG parent-volunteer described a helpline phone call with another parent asking for advice about their family's experience with the Gender Identity Development Service (GIDS) clinic:

The professional refused to refer [her trans son] on to adult services because he was 'too feminine'. He went to his own GP but the [young people's GIDS clinic] had advised them not to refer. So he has not got access to the adult GIC [Gender Identity Clinic]. The parents' support (or lack of) has been influenced as they have faith in the professional's opinion. The young person's ability to consent and make informed decisions is not being heard.

A lack of adequate information

Some of the workshop participants - both cisgender parents and trans young people - partly ascribed problems with their mental wellbeing to the lack of information and research available from GPs, CAMHS practitioners, and the children's and young people's Gender Identity Development Service (GIDS) on important issues such as medication. Parents and young people in the workshop particularly mentioned the lack of adequate knowledge about the research available on cross-gender hormones and blockers from both endocrinologists and from other GIDS and primary care practitioners. One fifteen year old participant said that he had been told at one time that

1
2
3 six months of testosterone would be enough to remove any chance of reproduction
4
5 using his own biological material, but he had noted that clearly there were trans men in
6
7 the media who had become pregnant and given birth after more than six months on
8
9 testosterone. This lack of clarity was a source of considerable distress. He asked for
10
11 practitioners who were knowledgeable enough to share “actual research on hormones
12
13 for trans people ... actual studies on delaying hormone treatment and impact on mental
14
15 health”, adding “... give us statistics!”
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20 ***Misgendering and deadnaming***

21
22 Many of the workshop participants described being misgendered when they interacted
23
24 with their family doctor (GP), both for a non-gender-related appointment and when
25
26 approaching their primary care practice to request a referral for GIDS. Misgendering
27
28 can be direct, or can be caused by deadnaming- calling the person their previous
29
30 gendered name- which if done in public has the effect of “outing” them. For three of the
31
32 workshop families, the misgendering and deadnaming happened in a busy waiting
33
34 room, in front of other patients and their caregivers and families. One young
35
36 transgender man in the workshop said that being misgendered by his GP led to him
37
38 being “denied the right to have a referral”, and being “advised that I would be ok after
39
40 therapy, which resulted in a decline in mental health”. He also felt “like an outcast, not a
41
42 valid member of society worth listening to... I stopped work. I nearly felt like giving
43
44 up”. He was recently misgendered again at a new GP surgery. He said: “I felt vulnerable
45
46 when this happened... totally exasperated. Like, ‘really?!’ And a letter from my GIDS
47
48 clinic which had previously been correct reverted back to my previous name”. This
49
50 experience of deadnaming caused him to feel “invalidated, worthless, judged, and
51
52 frustrated”. Many workshop participants felt that healthcare staff had been under-served
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2
3 by their training providers, particularly on misgendering, deadnaming, non-binary
4 people, and stereotyped ideas about gender presentation and expression.
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8 ***Lack of training and understanding about gender issues, and the impact on families.***

9
10 In the experience of some of the young people in the workshops, the lack of training for
11 healthcare staff led to stereotyped assumptions about their gender, and a lack of
12 adequate treatment. For example, when one young transgender woman attended an
13 appointment wearing jeans and trainers, she was described by her GIDS practitioner as
14 “not serious” enough to warrant support for clinical intervention. One parent who is also
15 a paid trainer for the FSG worried about the impact of “uneducated professionals’ lack
16 of knowledge, understanding, and poor use of language” in schools, social services, and
17 the NHS on family relationships, mental wellbeing, and physical health. One parent
18 described how CAMHS “... were supposed to be helping with [the child’s gender
19 identity] and anxiety but because they had no trans knowledge they only treated the
20 anxiety, leaving the family unsupported on the trans issue”. Once back at home, “...
21 anxiety increased, as the CAMHS worker was not addressing the trans issue”.
22 Consequently [there was] increased anxiety before each appointment, causing stress for
23 the family”. The impact on the family manifested in feelings of tension and being
24 “overwhelmed”. The whole family “... began to avoid places and situations which
25 caused tension” and the parent became increasingly “frustrated”.
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49 ***Waiting list times and lengthy treatment pathways***

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51 Several parents in the workshops questioned the economic logic applied to waiting list
52 management, reasoning that the short term cost savings of seeing fewer patients might
53 result in more expensive longer term mental health needs. One felt it was important that
54 service providers should look at “the impact and consequences of waiting lists on trans
55 people’s lives and outcomes”. They felt that waiting times can negatively affect family
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1
2
3 dynamics. A parent of a seven-year-old child described how for their family there was
4
5 “no provision from CAMHS” relating to trans issues due to a several months long wait
6
7 for a place on the waiting list for an assessment for a referral to the GIDS, which she
8
9 knew had its own long waiting list- up to eighteen months. She “was told by CAMHS to
10
11 self-refer to a charity (FSG). That was two months ago- we are still waiting”. Because
12
13 of the wait, her child “feels insecure and is unhappy”. Several other parents reported
14
15 being referred by CAMHS to the FSG charity for support while they waited several
16
17 months for the next available appointment. As referrals to GIDS can come directly from
18
19 GPs, or even from young people themselves, this added waiting for CAMHS can often
20
21 seem particularly fruitless.
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24
25

26 Almost all of the FSG workshop participants who had been to the GIDS reported
27
28 experiences where lengthy timeframes were applied in an arbitrarily universal manner-
29
30 for example, certain medications were given for a set period of time before the child
31
32 could move on to the next stage according to the clinic’s policy, despite the child’s age
33
34 and stage of puberty at the start of the time period and without applying nuanced
35
36 clinical reasoning for each individual. They thought that it would be better if these
37
38 policies were research-informed and specific to each child’s needs. A triage system trial
39
40 was suggested by some parents to try and work out how best to prioritise children and
41
42 young people in need of faster input.
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48 ***A lack of collaboration with service users and other organisations (such as schools)***
49
50 ***into clinical and therapeutic planning***
51

52 The participants in the workshops – both parents and young people- reported scant or
53
54 tokenistic efforts to include their voices in treatment planning and service provision.
55
56 There was in particular a dearth of collaboration between the healthcare practitioners,
57
58 parents, and with the schools of the trans and non-binary children accessing healthcare
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1
2
3 services. One young person with autism in the workshop described school as being
4
5 'loud', with 'lots of stupid people' in 'small spaces- I hate small spaces or rooms with
6
7 lots of people'. Many of the young people felt frustrated with their schools' lack of
8
9 understanding. One described 'teachers being weird' and also mentioned how 'splitting
10
11 boys from girls' was problematic: 'I'm non-binary so it felt wrong'. Another young
12
13 person said that because their school refused access to appropriate toilets she had spent
14
15 an hour every lunch time walking down the road to the local university to use their
16
17 facilities. Many of the young people in the workshop also identified the fact that there
18
19 were little or no LGBT+ people or issues featured across the school curriculum. This
20
21 led to feelings of insignificance and invisibility, and was particularly noticeable within
22
23 the super-gendered arenas of physical education and sex education. One young person
24
25 wrote: 'I didn't know what 'trans' meant until I was 15. I grew up in a
26
27 sheltered/conservative area. If trans and LGBT+ issues were mainstream, I would
28
29 have realised at a younger age. This would have saved a lot of time and distress'.
30
31 Another young person said that if he had had earlier education about LGBT+ issues he
32
33 'would have known sooner' and been 'less stressed about life in the future'. He said that
34
35 'it's not ok for LGBT+ people to go through puberty if they don't know what's going
36
37 on'. One felt that the information should not be 'hidden away from kids' and that
38
39 'children are very open to things like this- it's better to teach them early when they are
40
41 more likely to understand'. The school context illuminates the need to listen to service-
42
43 users: they are the only people who spend time in the home, health care and school
44
45 settings.
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53
54 As well as school-based experiences exacerbated by both being transgender or non-
55
56 binary and autistic, some workshop participants talked about how the combination of
57
58 diverse gender expression and autism was inexplicably bewildering for healthcare
59
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1
2
3 practitioners. They felt that the presence of an autism diagnosis tended to slow down
4 clinical and therapeutic input on their child's gender identity still further. One parent
5 talked about how her daughter's referral for ASD had neglected to mention the fact that
6 she was trans. The GIDS referral, submitted a few months later, had nothing about her
7 autism diagnosis on it. This student, aged eight and in primary school, had a particular
8 wish to continue using the teachers' toilet facilities as she transitioned into the next
9 year's class. She had been allowed to use it as a younger student as a support strategy to
10 deal with as a noise-related anxiety associated with her autism. When she socially
11 transitioned to female, the school, exhibiting a supportive approach, assumed she would
12 want to use the girls' toilets. She refused: she still had her noise-related anxiety; this
13 was nothing to do with her gender. Her mother explained that if the healthcare
14 practitioners who had undertaken her GIDS and autism diagnoses had collaborated with
15 each other and the school, it may have prevented a considerable period of discomfort for
16 this student.

17 **Discussion and Limitations**

18 *Discussion*

19 The research participants related a consistent sense of disempowerment in their
20 experiences with healthcare providers. They felt that this contributed to poor mental
21 health. Trans young people's mental health is a well-evidenced concern: a high level of
22 self-harm and suicidal ideation is reflected in a range of studies (Capous Desyllas &
23 Barron, 2017; Clark et al., 2014; Fae, 2018; Katz-Wise et al., 2018; Kivalanka et al.,
24 2014; 2017). However, trans young people's mental health issues could perhaps more
25 constructively be framed as influenced by what was described in the "Theoretical
26 Approach" section above as 'social dysphoria', deriving from a public issue rather than
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3 a private trouble (Mills 1959). This situates the mental distress of trans young people
4 and their families within a framework of personal and institutional prejudice, stigma and
5
6 isolation rather than as being derived solely from individual pathology (Birnkrant &
7
8 Przeworski, 2017; Capous Desyllas & Barron, 2017; Hendricks & Testa, 2012;
9
10 Kuvalanka et al., 2017, 2014; Katz-Wise et al., 2018). The sense of being seen (or
11
12 constructed) by doctors as a medical condition as opposed to a whole person with
13
14 nuanced experience was theorised by Foucault (1975) in his explication of the
15
16 undermining impact of 'the clinical gaze'. The result was that both parents and children
17
18 in the workshops felt that their negative experiences with healthcare practitioners had
19
20 exacerbated their mental health concerns. The data points towards the need to perhaps
21
22 foreground service-user voice more explicitly in practitioner interactions with children
23
24 and families.

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29
30 Previous research demonstrates that supportive parents of trans children tend to
31
32 advocate for them across a range of contexts, including in healthcare settings, as well as
33
34 home, at school, and on social media (Birnkrant & Przeworski, 2017; Kuvalanka et al.,
35
36 2014; Malpas, 2011). Oliphant et al (2018) elucidate that it is important for healthcare
37
38 providers to work with parents to help them to understand their child's gender
39
40 expression, to see potential identities beyond the gender binary, and to achieve a sense
41
42 of acceptance, leading to reduced anxiety and then to increased support of their child.
43
44 Malpas (2011) recommends a constructive therapeutic response that involves drawing
45
46 on systemic family support to help the child with their experience both at home and
47
48 elsewhere -including in school and with friends and extended family. Despite this body
49
50 of research, FSG participants related a wide range of incidents demonstrating how their
51
52 knowledge and experience was not being taken seriously by healthcare providers. The
53
54 leveraging of parental expertise (where parents are supportive of their child's transition)
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1
2
3 and a healthy family functioning is recorded in the research literature as a crucial
4
5 element in supporting the mental wellbeing of trans children and young people
6
7 (Oliphant et al 2018, Birnkrant & Przeworski, 2017; Katz-Wise et al., 2018; Malpas,
8
9 2011). Sansfaçon et al. (2019) found that the voices of transgender and non-binary
10
11 children and young people and their families are crucial in developing effective
12
13 treatment plans. The FSG parents suggested that their parental expertise could be better
14
15 engaged in support of their children, whilst maintaining support for their own mental
16
17 wellbeing. Young people are also recognised to have insights into their own lives which
18
19 could be usefully deployed in healthcare settings ([Author name redacted for peer
20
21 review], 2012, 2016; Fielding & Bragg, 2003; Hart, 1992; Rudduck & Flutter, 2003).
22
23 This analysis does not claim that parents know more than their child's endocrinologist
24
25 about hormone treatment, for example, or that a trans twelve-year-old will know more
26
27 than their GP about generalised anxiety disorder. But their insights are often a key part
28
29 of the therapeutic picture, and collaborating with children and their families in their own
30
31 physical and mental healthcare is established practice in many other parts of the world,
32
33 including in the case of trans children and young people (Kualanka et al., 2014;
34
35 Malpas, 2011; Hoffman, Freeman & Swann 2009).
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42 Eliciting the experiences of trans and non-binary children and young people and their
43
44 parents in relation to school experiences may be particularly important to developing a
45
46 successful care plan. Schools were universally described as problematic by the parents
47
48 and young people in the workshop. They can be difficult places for people with
49
50 symptoms of anxiety or depression (or ASD- Kvalanka *et al* 2017), even without the
51
52 issue of being trans. Birnkrant and Przeworski (2017) cite studies reporting
53
54 victimization against trans and non-binary students perpetrated by both students and
55
56 teachers in US high schools. Because of the difficulties with school, therapeutic and
57
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1
2
3 clinical assessments should include investigations into how school is experienced
4 (Malpas 2011). When children transition to the upper age groups in school the situation
5
6 (Malpas 2011). When children transition to the upper age groups in school the situation
7
8 can become even more traumatic and complicated, partially due to a less accepting peer
9
10 group more prone to 'gender policing' (Malpas 2011). In addition, whilst primary
11
12 school children will have one main teacher with whom they must build a relationship,
13
14 mainstream secondary schools in the UK (for children aged 11 to 18) require students to
15
16 walk from class to class, with a different teacher for each subject. It is possible to create
17
18 a safe space at school ([Author name redacted for peer review] and another 2018;
19
20 Birnkrant and Przeworski 2017; Kuvalanka et al. 2017), and in these circumstances a
21
22 therapeutic collaboration with healthcare providers could prove invaluable.
23
24

25
26 In line with UN Committee findings in the UK (CRAE 2016), previous US-based
27
28 research by Breland et al (2016) and a review of several studies by Tellier (2019) in
29
30 Canada, a gap in clinical knowledge relating to the care of transgender youth and
31
32 particularly the use of blockers reportedly caused many of the current study's
33
34 participating young people great mental distress. Blockers are a hormonal intervention
35
36 which can slow down or pause the usual physical developments of puberty. This allows
37
38 time for a child to think through their gender identity (Lynch, Khandheria and Meyer III
39
40 2015; Sansfaçon et al. 2019). It can also prevent the development of unwanted sexual
41
42 characteristics to improve body image and to enable a smoother physical transition
43
44 process, where appropriate (Brill & Pepper, 2008; Zucker et al 2010; Malpas, 2011;
45
46 McGuirea, et al., 2016), although some young people choose not to transition after some
47
48 time on blockers (Zucker et al. 2010; Lynch, Khandheria and Meyer III 2015;
49
50 Sansfaçon et al. 2019). Kuvalanka et al. (2014) interviewed mothers who had received
51
52 uninformed advice from untrained health care professionals on this topic. Whilst the
53
54 current study's participants noted that the long term impacts of blockers on fertility are
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1
2
3 indeed not yet fully known, they were frustrated at the lack of practitioner knowledge,
4
5 and suggested that practitioners might be better served by training programmes which
6
7 included this content.
8
9

10 Further distress was experienced by the participant young people in relation to
11
12 experiences of misgendering and deadnaming, often in public doctors' waiting rooms,
13
14 in line with Breland et al's (2016) findings. Misgendering a trans patient means that
15
16 they are being associated with their birth gender, and both Malpas (2011) and Sansfaçon
17
18 et al. (2019) similarly found that this can cause distress and damage potential
19
20 therapeutic relationships. Previous research outlines systemic stereotyped assumptions
21
22 about gender (Pearce, 2018) and sexual orientation (Brill & Pepper, 2008) by healthcare
23
24 providers in England. Hoffman, Freeman & Swann (2009), Coker (2009) and Breland et
25
26 al. (2016) also recommend training for healthcare practitioners in serving the specific
27
28 needs of LGBTQ youth, including the use of their appropriate name and gender.
29
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32

33 The anxiety induced by long waiting lists discussed at length by FSG participants
34
35 has also been noted in previous UK studies (Pearce, 2018, CRAE 2016). The issue is
36
37 exacerbated by the fact that the clinical needs of trans children and young people are
38
39 time sensitive due to the onset of puberty and associated physical changes (Oliphant et
40
41 al 2018, CRAE 2016). Waiting lists are difficult to address (Fae, 2018). They reflect
42
43 financial cuts to government funding for the NHS and mental health services in general;
44
45 increases in referrals to GIDS; and the length of training people require. However, some
46
47 FSG parents reported on a new approach by GIDS to offer telephone support to families
48
49 of children under ten years old while they were awaiting face to face appointments.
50
51 They did not feel confident that this meant their children would get an appointment
52
53 before the age of ten. However, it remains to be seen whether these phone calls can be
54
55 used to effectively triage waiting lists. Sansfaçon et al. (2019) advise triaging on a case-
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1
2
3 by case basis (delivering equality according to need) rather than offering the same wait
4
5 time to each person.
6

7
8 The proportion of trans children and young people amongst those with ASD
9
10 diagnoses may be around 7% as compared to 1% within the general population
11
12 (Kusalanka et al., 2017), although because, as some parents report, the Gender Identity
13
14 and Development Service may encourage screening for ASD in many cases, there may
15
16 be a higher than average likelihood of the diagnosis in their children. ASD is a
17
18 neurological, life-long spectrum of conditions which can involve a triad of impairments
19
20 relating to social interaction; social communication, especially nonverbal; and an
21
22 inflexibility of thought which can result in repeated behaviours, rigid thinking, and a
23
24 lack of social imagination (Lanou, Hough & Powell, 2012). These issues can result in a
25
26 highly developed ability to focus and to become expert on often useful skills and
27
28 knowledge sets (Lanou, et al., 2012). They can also result in a feelings of social
29
30 isolation which is profoundly unhelpful when coupled with the stigma often familiar to
31
32 trans young people (Kusalanka, et al., 2017; Hillier et al 2019). In line with research by
33
34 May, Pang and Williams (2017) and Hillier et al. (2019), autism diagnoses were
35
36 identified by many FSG participants as bewildering their healthcare providers and
37
38 slowing down their therapeutic responses to a frustrating degree. Practitioners can
39
40 sometimes doubt the understanding of young people with autism to the extent that it
41
42 undermines their testimony about their own gender identity and some clinicians have
43
44 suggested that in a minority of these patients, gender variance could be an element of a
45
46 pathological autistic hyperfocus (Kusalanka et al., 2017, May, Pang and Williams 2017;
47
48 Hillier et al. 2019). However, gender-variant autistic young people refute this (Hillier et
49
50 al. 2019). More recent analyses suggest that young people with autism might simply be
51
52 less aware of the negative judgment of others towards their gender non-normative
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1
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3 behaviour and appearance (Kusalanka et al., 2017, May, Pang and Williams 2017;
4
5 Hillier et al. 2019). It may be that some children and young people with ASD are
6
7 'gender defiant' (May, Pang and Williams 2017), or perhaps resilient to
8
9 heteronormativity and cultural cisgenderism (Kennedy, 2013), and more likely to
10
11 adhere to the evidential logic of their embodied experience (Kusalanka, et al., 2017).
12
13 Also of note is the idea, reflected in the FSG participants' experiences, that symptoms
14
15 of stress and social anxiety can be mistaken for autism and autistic trans people who are
16
17 able to live authentically have lower levels of life stress and are better able to cope with
18
19 the stresses that may be associated with being autistic, including developing more
20
21 satisfying and supportive friendships and school experiences (Kusalanka, et al., 2017;
22
23 Hillier et al. 2019). More research and training in this area is called for (May, Pang and
24
25 Williams 2017; Hillier et al. 2019) and this is crucial to the delivery of adequate
26
27 healthcare provision for children who have ASD diagnoses and who are transgender or
28
29 non-binary. In particular, therapeutic and clinical assessments are recommended to
30
31 incorporate discussions about the social and educational experiences of trans children in
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33 school (Breland, 2016; Malpas, 2011).
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41 ***Limitations***

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43 The parents and carers involved in this project were generally positive about seeking to
44
45 learn about how to best support their children in their interactions with healthcare
46
47 services. The data presented here therefore excludes the experiences of families where
48
49 parents are not accepting of their trans children. This is a conundrum across this field of
50
51 research, and more needs to be done to elicit the experiences of families where parents
52
53 are unsupportive (Birnkranz & Przeworski, 2017; Kusalanka et al., 2014). Another
54
55 limitation here is the lack of ethnic and cultural diversity amongst respondents: the
56
57 majority of the participants identified as white British. In addition, the researcher is
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3 white British and Jewish, middle class and cisgender, which may have limited channels
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5 of investigation, important questions, and areas of analysis. While I[Name of
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7 methodology redacted for peer review] aims to centre the perspectives of the
8
9 participants, their own perspectives are also limited by their characteristics and
10
11 experiences. For example, participants in this study were all members of the same
12
13 support group, and may have offered similar viewpoints as a result of being part of the
14
15 same support-seeking organisation. Because of these limitations and the fact that the
16
17 number of people involved in the workshop was relatively small, the data presented
18
19 here cannot be considered to be representative of all trans young people and their
20
21 families in England. However, their experiences are in line with the previous
22
23 international research findings referenced here, and set out an interesting range of ideas
24
25 to potentially prompt or inform larger scale investigations into the experiences of trans
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27 young people and their families in relation to healthcare settings.
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34 **Conclusion and Recommendations**

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36 The FSG I[Name of methodology redacted for peer review] workshops unearthed some
37
38 specific areas which could benefit from targeted changes in healthcare practice.
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41 Broadly, areas for potential development include how healthcare services might
42
43 better leverage the insider knowledge and extensive research conducted by parents. The
44
45 support needs of parents and siblings also emerged strongly as a theme. The literature
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47 does discuss the importance of employing parental support as part of a constructive
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49 therapeutic plan (Oliphant et al 2018; Birnkrant & Przeworski, 2017; Katz-Wise et al.,
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51 2018; Malpas, 2011). However, the participants felt that this was not in evidence in the
52
53 GIDS and CAMHS services they accessed. They suggested that parents could be better
54
55 supported by healthcare practitioners with their own mental wellbeing.
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3 Better training programmes for general health practitioners and specialist clinicians
4 alike were recommended, particularly around the impact of misgendering and
5
6 deadnaming, and on the implications of a trans child's experience for their family- this
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8 is also reflected in the literature (Capous-Desyllas & Barron, 2017; Coker, 2009; Fae,
9
10 2018; Malpas, 2011; Pearce, 2018; Tellier 2009). Similar to research in Canada by
11
12 Sansfaçon et al. (2019), waiting lists were a significant stressor reported by the families-
13
14 not least because puberty proceeds along its own timeline, and long waits for treatment
15
16 or universally prescribed times on specific treatments can have disconcerting physical
17
18 impacts. There is therefore scope for renewed thinking into ways to triage waiting lists
19
20 and treatment timetables (Sansfaçon et al. 2019). A lack of apparent practitioner
21
22 knowledge – for example, on issues such as autism spectrum disorder and the long term
23
24 effects of puberty blockers and future fertility- were additionally cited by the workshop
25
26 participants as a source of anxiety. This points towards the possibility that healthcare
27
28 practitioners in England have traditionally been under-served by their training
29
30 programmes when it comes to issues relating to transgender and non-binary children
31
32 and young people. It may be that the increase in referrals in recent years means that
33
34 training is now more likely to include this material, but an issue remains in the fact that
35
36 training takes a long time to emerge into practice. This could potentially be mitigated
37
38 for the time being by the production by the UK government Department of Health of a
39
40 widely distributed and easily accessible set of treatment and support guidelines in line
41
42 with the world protocols produced by WPATH.
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52 An ecological perspective which includes school, friends, and the wider community
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54 and which recognises family expertise is also recommended in line with the literature
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56 (Oliphant et al 2018; Kuvalanka et al., 2014; Malpas, 2011). Schools are more likely to
57
58 feel comfortable to support trans children when they have deliberately put well-planned,
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3 robust policies and training in place ([Author name redacted for peer review] and
4
5 another 2018; [Another and Author name redacted for peer review] 2018; Brill and
6
7 Pepper 2008). As Malpas (2011:464) asks, ‘If the child were to transition, would this be
8
9 fully supported by the school administration? Are the primary teachers, school
10
11 counselor, and staff trained to protect and empower the child in his/her ‘new’ gender
12
13 expression?’ The workshop consensus was that teachers need more research-informed
14
15 training on how to use pronouns and how to incorporate LGBT+ issues across the
16
17 curriculum ([Author name redacted for peer review] and another 2018). School leaders
18
19 also need more training on policy decisions around issues such as uniform and toilet
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21 provision ([Another and Author name redacted for peer review] 2018). GIDS and
22
23 CAMHS practitioners could play a significant role in recommending this kind of advice.
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28 All of these ideas point towards a need for healthcare providers to take pragmatic
29
30 steps to weave the voices of their patients and their patients’ families into their research
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32 and their practice; to recognise them as partners in a successful treatment or support
33
34 plan, where needed; and as experts, at least on their own lives. Family members are
35
36 interdependent (Cox and Paley; Minuchin cited in Katz-Wise et al. 2018), and an
37
38 ecological perspective which takes family, community and school contexts into account
39
40 (Kusalanka *et al* 2014) invites any supportive approach to working with trans and non-
41
42 binary children and their families to consider them within the full range of experience.
43
44 Constructive approaches to working with trans children and their families include
45
46 understanding that parental coaching can be effective and empowering (Malpas 2011).
47
48 Kusalanka et al. (2014) suggest that ‘even “experts” have much to learn from these
49
50 families’ (371). The children and young people too have their own embodied and
51
52 empirical expertise to share. It is hoped that the findings outlined here will go some way
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3 towards informing professional practice, and improving the lives of trans children and
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5 young people and their families in England.
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10 **Statement of human rights**

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13 All procedures performed in studies involving human participants were in accordance with the
14
15 ethical standards of the institutional and/or national research committee and with the 1964
16
17 Helsinki declaration and its later amendments or comparable ethical standards.
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