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Support for parents/carers of primary school aged gender diverse children in England, UK: a mixed-method analysis of experiences with health services

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Abstract

The politics of trans health has drawn considerable attention in recent years, and yet little is known about the support needs and experiences of primary school age children and their families. This paper presents findings from a UK mixed-method study that aimed to understand parents/carers' views and experiences of support received from health services for primary school age (4-11) gender diverse children and their families. Data was collected via an e-survey including 10 open-ended questions with 75 parents/carers addressing experiences with (i) primary health services, including general practice (GP) clinics and child and adolescent mental health services (CAMHS) (ii) specialist gender identity development services (GIDS) (iii) non-health related support including transgender groups and online resources. Findings are organised into four themes comprising two which draw on the cross-sectional survey data ('journey to health service provision' and 'view on health services used') and two from the open-text qualitative data ('waiting' and 'isolation'). Contemporary discourses about gender diversity and childhood and the validity of trans healthcare for children and adolescents shape parental experiences, including their desire for better information, more certainty in healthcare pathways and more expedient access to support services to reduce anxiety, distress and isolation. The emotional costs of waiting are compounded by the material costs of accessing the limited number of specialist services. Experiences could be improved through ensuring both GPs and CAMHS are better prepared through appropriate training, expanding access to trans-specific support groups for families and others involved in caring for children and young people, and exploring the provision of school-based support for gender diverse primary-age children.

Keywords: transgender, gender variant, child, healthcare

Introduction

In the last decade, the United Kingdom (UK), like many other high-income countries, predominantly in the global north, has witnessed a rapid rise in referrals of gender diverse¹ children and adolescents to specialist under-18s Gender Identity Development Services (GIDS) (Kaltiala et al, 2020). For example, in 2009-10 the Portman and Tavistock Clinic, the sole provider of GIDS in England and Wales, had 77 young people referred to their services. By 2017-18 (the time period in which our data was collected) this rose to 2445. The most recent figures suggest this rate is beginning to level off with referral numbers at 2590 in 2018-19 (Tavistock & Portman, 2019). In a population estimated to be 65.64 million (mid 2018), with 18.9% of that total population aged under 18 (ONS, 2018), these numbers are still very small. However, concern about the size of the annual increases in referrals, along with questions about who is being referred and how long they have to wait, has garnered unprecedented national media attention and a government inquiry (Women and Equalities Select Committee, 2016). Alongside expanding numbers, data has shown that referrals of clients who were assigned female at birth referrals were 3 times higher than for clients assigned male at birth; a significant shift since 2009. This pattern has drawn specific attention from broadsheet newspapers, the Women & Equalities Select Committee, and so-called ‘gender critical’ activists (Gilligan, 2019), resulting in UK public discourse currently featuring deeply inflammatory, polarised and politicised accounts of trans people’s lives, identities and healthcare needs.

In the UK, this is the context in which children, young people and their families come to understand the stigma and discrimination associated with gender diverse identities and health service provision. Evidence shows that gender diverse children and their parents are most likely to access information through a range of online sources (Carlile, 2020). Their knowledge,

¹ We use gender diverse in this paper to recognise children’s gender expressions that do not conform to socially expected norms. Gender diverse can also be referred to as gender variant, trans, non-binary and gender queer, although some of these terms are more readily associated with adolescent and adult identifications rather than primary age children.

understanding, expectation and experience of trans and non-binary identities and health service provision will inevitably be shaped by the concerns raised in these sources. In this paper, we outline in more detail the contested status of gender diversity in childhood and in the UK healthcare system, before reflecting on our empirical data documenting parent/carer expectations and experiences of accessing health care for primary school-age gender diverse children within this context.

Gender diversity in childhood: a contested possibility

There has been significant research and debate about appropriate treatment and support pathways for transgender experiences since the 1950s, but terms such as ‘transgender’ or ‘gender dysphoria’ were rarely applied to children or adolescents. UK-based education researchers have argued that transgender children have always existed, but should more accurately be categorised as ‘apparent and non-apparent’ in terms of their visibility within social systems (Hellen, 2009). Writing prior to the increase in numbers of children and adolescents seeking referral, Kennedy and Hellen observed that ‘*apparent* transgender children are relatively rare’ (2010 p. 26). They argued that rather than not existing, children with these feelings chose to actively conceal them in order to achieve conformity with the heavily policed gender norms of early childhood. Despite this, trans people are very much ‘aware they are transgender at much younger ages than previously considered’ (Kennedy & Hellen, 2010 p. 25).

The diagnostic term ‘gender identity disorder in childhood’ first appeared in the Diagnostic and Statistical Manual of Mental Disorders (DSM) III in 1980, not long after the removal of ‘homosexuality’ in 1973. This term was initially critiqued by feminists and queer theorists (e.g. Sedgwick, 1991) for operating as a psychomedical device for normalizing expressions of the cross-gender behaviour that sometimes emerged as part of a lesbian or gay identity. This argument has more recently been challenged as ‘cisnormative’ (Ansara & Hegarty, 2011),

indicating a prejudiced ideological approach that privileges the social norm that gender expression and sex characteristics always align.

As referral rates have risen, there has also been an increased focus on confirming the validity of gender diversity classifications and treatment for those who are under 18. ‘Gender incongruence in adolescence’, the terminology applied by International Classification of Diseases, eleventh revision (ICD-11), has become accepted within trans healthcare as a diagnostic category that justifies access to medical support for gender affirmation (WPATH, 2012). The model of care available in the UK, like other global north countries such as US and Australia, has shifted towards ‘trans-affirming approaches that aim to promote gender exploration and affirmation without constraints or barriers by facilitating access to different forms of transition’ (Sansfaçon et al, 2020 p.1). However, concerns continue to be expressed by a minority of clinical and feminist commentators about the potential risk of adverse long-term effects of hormone treatments, the strategies employed to determine informed consent to accessing gender affirming medical care among children or youth, and if so from what age those strategies should apply (e.g. Ashley, 2019; Heneghan & Jefferson, 2019; Wren, 2019).

What is often overlooked in the media representations of these issues is that medical options for affirming gender among gender diverse young people, such as puberty blockers, are only one mode of support available for those aged 12-16. In line with WPATH (2012) recommendations and NHS England GIDS service specifications (NHS, 2017), full consideration of an individual’s competence and capacity to consent is made during a period of careful consultation and assessment before any form of medical care is able to be accessed. Access to an appropriate process of reflection is supported by evidence that only approximately 40 per cent of young people who contact the leading GIDS clinic in the UK go on to undergo physical treatments (Carmichael, 2016). Additionally, for those that do, the key purpose of ‘puberty blockers’ is to open up a temporal space in which the bodily transformations associated with the development of

secondary sex characteristics can be paused, allowing time for further reflection about future gender pathways, while reducing the intense gender dysphoria and distress reported by these adolescents (Roen, 2011). Puberty blockers do not prevent growth or other dimensions of normal adolescent development, and so are regularly (and safely) used to delay ‘precocious puberty’, reduce the impacts of adolescent endometriosis or support an extended period of pre-pubertal growth among children with idiopathic short stature (Giordano, S., & Holm, S. (2020).

Controversy is more apparent for the ICD-11 diagnosis ‘gender incongruence of childhood’, which is applied to gender diverse children who have not yet reached puberty. Many leading trans-affirmative clinicians working with gender diverse youth are against the inclusion of this diagnosis in the ICD (e.g. Winter et al, 2019). They argue that there is no need for a psychomedical framework to be applied to pre-pubescent children who are exploring their gender: “These young children do not need puberty suppressants, masculinising or feminising hormones, or surgery. Rather, they need a safe emotional space with the freedom to explore, embrace, and express their gender identity” (Winter et al, 2019 p. 672). The need for these forms of early social support is increasing with substantial evidence demonstrating that transgender youth report higher rates of depression, suicidality and self-harm, and eating disorders when compared with their peers (Connolly et al, 2016; Strauss et al, 2020). Parents, advocates and transgender affirmative researchers also highlight the risk of delayed access to supportive healthcare (e.g. Carlile, 2020; Pearce, 2018), compared to evidence of the positive impact that early support with the social aspects of gender transition can have on the mental health and wellbeing of gender diverse children and adolescents (Olsen et al, 2016).

In England, the preferred route of referral to GIDS is through the local Child and Adolescent Mental Health Service (CAHMS). This is in line with WPATH (2012) guidelines that recommend that any underlying mental health concerns be explored and managed prior to progressing to the stage of accessing gender affirming care. GIDS also accept referrals through

the primary care system, from a general practitioner/doctor (GP), and from other health, education and social care professionals including LGBT+ and trans-specific groups who support gender diverse young people and their families. With greater visibility of gender diversity, parents and carers have become more knowledgeable and cognisant of early indicators of gender diversity, and are seeking information, support, advice and treatment for younger aged children (Carlile & Paechter, 2018). The rapid rise in referrals has undermined GIDS ability to meet these needs in a timely way. Despite expanding service provision through NHS investment and the operation of satellite clinics in cities outside of London and Leeds, waiting times have increased from 9-10 months in 2015 to 2 years in 2020. The negative impacts of waiting and delay are now widely expressed in social media, by both young people and their families, in contrast with the accusations by a minority of voices that the process does not provide sufficiently in-depth care or time for consideration before commencing clinically supported forms of care (Swerling, 2020).

There are several theories currently circulating about why we might be seeing an increase in the presentation of gender diverse young people to clinical care settings, often linked to a presumed correlation between gender identity and media representations. Research has found evidence of an association between increased media coverage of topics related to trans and gender diverse people and increasing numbers of young people presenting to gender clinics (Pang et al, 2020). Controversially, some have argued that these positive media representations are fuelling an imagined phenomenon described as ‘rapid onset gender dysphoria’ (Littman, 2018). Interest in this unsubstantiated theory has been driven by the distress of some parents who believe that their child (adolescent or young adult) only expressed signs of gender dysphoria after having accessed information about gender diversity online. This perspective has been robustly critiqued for its lack of scientific evidence, its association with ‘transantagonistic websites’, and for attempting to ‘weaponise scientific-sounding language evidence’ to refute research evidence that demonstrates the important benefits of supporting gender affirmation (Ashley, 2020 p. 779). An alternative interpretation is that wider access to information about trans lives enables young people to have

access to the language they need to describe their experience, and the confidence to seek out health services earlier, rather than waiting for adulthood. The sociologist Ken Plummer (1995) wrote saliently about the socio-political flow of stories, social change and the ways in which stories can be transformed from inner whispers to being articulated in wider public discourse. Following Plummer (1995), we propose that it is possible we are currently witnessing an important shift in our social world, one that permits us to be better able to hear and affirm stories of gender diversity in childhood and adolescents, including within health services.

Expectations and experiences of health services among parents/carers of gender diverse children

Parental expectations of healthcare for their gender diverse children are framed by the psychosocial discourses governing gender, sexuality and child development (Johnson, 2018). These discourses include normative assumptions about gender and sexuality expressions, which can both manifest in terms of gender variance, alongside assumptions about child developmental ‘stages’ or ‘phases’, ‘neuro-plasticity and the developing brain’, and associated development risks such as mental ill-health and suicidal distress (Johnson, 2015; McDermott & Roen, 2016). We and others have argued elsewhere (Johnson, 2018; Winters et al, 2018) that it is also important to understand the support needs of trans and gender diverse children within these discussions, emphasising their voices and including them from a much younger age. For primary age children this dialogue will usually happen within the parent/carer dyad.

Parental expectations will also be shaped by exposure to the polarised contemporary discourses about trans healthcare for under 18s and competing interpretations of the impact of waiting for access to care. The first position, often articulated by trans-affirmative parents of gender diverse children, is that delayed access to specialist services increases the risk of gender dysphoria having devastating impacts on a child’s mental health. The opposite position, often articulated by ‘gender critical’ authors in the UK (e.g. Brunsell-Evans & Michele Moore, 2017), is that access

to gender affirming medical care is provided too early to young people who may regret it when they are older. The latter interpretation deliberately frames access to care as an ethical question of whether and when clinical treatment should be made available for children and adolescents. However, these issues are typically expressed using divisive and dismissive terminology e.g. ‘the fabrication of the transgender child’, ‘the transgender experiment on children’ and ‘the transgender trend’ (Brunskell-Evans & Michele Moore, 2017), and make unsubstantiated associations between support for gender diverse young people and the erasure or devaluing of homosexuality, particularly lesbianism (Shrier, 2020). The gender critical approach (e.g. Stock, 2018) has gained significant populist appeal in recent years through the support of specific journalists and media platforms and particular forms of Twitter dissent aiming to discredit proposed changes to the Gender Recognition Act (GRA, 2004) as well as GIDS. The GRA review proposed improving self-identification processes for gender diverse adults by allowing birth certificates to be changed without evidence of a medical diagnosis. Critics of this proposal (Stock, 2018) argued that the proposal would lead to the erasure of cisgender women’s rights and safety (see Serrano, 2007 and Hines, 2019 for extended discussions of the false dichotomy between transgender and feminist politics, and Zanghellini, 2020 for a review of the problematic philosophical position proposed by gender critical commentators on trans inclusion).

In contrast to debates about whether or not trans healthcare should be made available, some researchers have begun to focus on documenting experiences of trans healthcare for under 18s (Carlile, 2020). Our research builds on this by introducing an innovative focus on the experiences of parents/carers of primary school-age children. Most young people who access GIDS are in the 14-16 years old category. This is not surprising given the lengthy waiting times after a referral is secured, and because they specialise in puberty specific treatment pathways. However, GIDS also receive referrals for much younger children, reflecting an emerging need for information and support for pre-pubescent children and their families. The aim in this study was to understand the

health care expectations and experiences of parents/carers seeking support for gender diverse children aged 4-12 years.

Methods and Analysis

This paper forms part of a larger, mixed methods project which utilised participatory research principles to engage stakeholders and practitioners (a local Trans Network, a national charitable organisation and the England-based GIDS) in the design of the study. This paper reports findings from the first study, a mixed methods e-survey, delivered via Survey Monkey, which was completed by 75 parents/carers of gender diverse primary school-aged children in the UK. The aim was to gather both metrics and qualitative, open-text data related to primary school-aged gender diverse population parent/carer experiences and expectations of health services used. The survey design and recruitment benefitted from stakeholder and practitioner collaboration in two ways. First, it increased the validity and relevance of survey items and ensured we were asking questions that filled gaps in current practitioner and on-the-ground knowledge. Secondly, the use of public social media recruitment adverts was supplemented by recruitment through our stakeholders' networks. A limitation was that our sample may have been overly representative of parents who had contact with these stakeholder networks.

The Mixed Methods E-Survey

The cross-sectional survey included 52 questions in 4 sections, 14 of which were open-text. First, a background and initial presentation section included six questions, e.g. 'How old is your child at the moment?' Second, an involvement with services section contained 7 questions about GP/Doctor, GIDS, Child and Adolescent Mental Health Services (CAHMS), School and Educations Services and Other services, e.g. 'Can you please give an example of how your Doctor / GP Service/ GIDS/CAMHS/ School Education 1) was helpful?' The third section focused on overall views of services provided. Finally, we collected 10 demographic information responses about the parents/carers, the children and their families. The survey generated 86

responses. For quality purposes, only 75 survey respondents who answered 75% of key survey questions were included in the analysis.

Analytic Methods

The quantitative data was summarised using SPSS software to establish frequency data for all 38 quantitative items in the E-survey. The qualitative data set was derived from the 14 open-text questions, generating 14,029 words across 441 responses, ranging from one word to 977. This data was analysed thematically by coding and identification of overarching themes about family experiences of health care service provision. Thematic Analysis is a flexible type of qualitative analysis that is useful for identifying broad patterns of meaning across a data set, including open-text survey data (Braun & Clarke, 2006).

Findings

In this section we present key descriptive statistics from the quantitative survey data including ‘demographics’, as well as two themes: ‘journey to health service provision’ and ‘views of health services used’. We then outline two overarching themes generated from the qualitative open-text data, ‘waiting’ and ‘isolation’, and interpret these in relation to the literature.

Demographics

All of the respondents confirmed they were ‘parents/carers’. Just 26/75 reported their gender identity, and of the 26, most identified as women (just three as men) and cisgender, and one person as a trans parent/carer. Most were ‘White’, except one ‘mixed heritage’ respondent. All were either in the 41 – 50 years old (50%) or the 31 - 40 years old (47%) age groups. The study sample was geographically distributed across Scotland, Wales and England, however no parents/carers responded from Northern Ireland. This is broadly representative of UK population estimates (Office for National Statistics (2020), with 83.5% living in England, and the English sample scattered fairly representatively around all main regions, with the exception for the North-

West and South-East which were represented at 2-3 times higher than the UK national population estimates at region level (Statistica, 2020).

The average age of the child concerned, at the time of the survey, was 8.5 years old (ranging between 4 and 12 years old). These children were equally as likely to have been assigned male or female at birth (51% presumed male, 49% presumed female). Just over half were 'currently living all the time as the gender they identify with' (53%), 13% were 'living some of the time as the gender they identified with' and 17% had not socially transitioned. Most of the gender diverse children were defined as 'White' (86%), 9% 'mixed/multiple' heritage, 2% 'Black' and 3% 'other'. The sample closely matched the national heritage profile, in addition to family household data (Office for National Statistics, 2011 Census) and reported family income (Office for National Statistics, 2017).

Journey to health service provision

Once families became aware that their child was displaying gender diverse characteristics, most (68%) indicated that they conducted online research to explore the subject, with 56% then contacting a gender support group. Most respondents (64%) reported they had discussed these observations with someone else within a month, but for a small number (16%) it took more than a year to do so. There was a 4 year gap between the average age of the child when their parent/carers became aware that they were displaying gender diverse characteristics (median age = 3 years old), and the average age of the child when parents/carers initially consulted the first of the statutory services (i.e. GP/CAMHS/GIDS.).

Views of health services used

Eighty-five percent of parents/carers had consulted their GP service about their gender diverse child (Mean age = 7 years old). Of these participants, most felt their initial concerns had been taken seriously (65%). However, only a small proportion agreed their GP was knowledgeable

about the needs of primary-aged gender diverse children or their parents/carers (16%), that they had received good advice (24%), that they had received good support (38%) or that they were happy with the service (34%). While over half of the respondents (59%) reported that they had been referred on to other services, many parents/carers reported they had to often direct their GP service to appropriate resources or provide them with the specific information about where they needed the GP to refer them on to.

Mostly following a GP referral, 62% of the sample had consulted their CAMHS with the average age of first contact for their gender diverse child at 8 years old. Some parents/carers indicated (in the open-text responses) that they viewed contact with CAMHS as a necessary ‘gateway’ to access a referral to GIDS. Again, most (65%) agreed that CAMHS took their concerns seriously, but the vast majority disagreed with the statement that the service was knowledgeable about the needs of gender diverse children (64%) or their parents/carers (67%). As with the GP service, a lack of good advice (only 15% agreed) and lack of good support received (27% agreed) often accompanied a disagreement with the statement that CAMHS was knowledgeable about family needs.

A large proportion of families (66%) reported they had consulted a GIDS (Mean and Median age = 9 years old), nearly all using Tavistock services in England (e.g. London or Leeds), and the remainder accessing Sandyford (Scotland). Most who had not yet accessed a GIDS were on the waiting list to access one. Most respondents (76%) agreed that the GIDS clinics took their concerns seriously, but only half agreed that GIDS were knowledgeable about the needs of gender diverse children and their parents/carers (53%). Only 39% agreed that the waiting time to see the GIDS team was acceptable, and less than half (42%) were happy with the service they received. Nevertheless, most (65%) agreed they would be happy to return to the service in the future. Finally, a third of parents/carers selected a community-led group for supporting gender

diverse children and their parents in the UK as the most useful form of support (32%), followed by Schools (20%), GIDS (13%), GP (8%) and CAMHS (2%).

'Waiting'

The first overarching theme in qualitative accounts of the support provided by health services for gender diverse children was the experience of waiting, which was frequently entwined with a feeling of loss. This theme was described by participants in three main ways. First, waiting was a feature at every step of the journey through healthcare and was described as unwanted and unnecessary. Second, waiting was associated with a loss of time which caused unnecessary harm to their children. Third, waiting was experienced as a feeling of being suspended in a vacuum, not knowing what to do for the best to support their child, while awaiting official information. All of these experiences created significant frustration, worry and anxiety for parents and carers, as in the following example:

Extract 1: The waiting lists are too long, and our commute to the GIDS is two hours on a train each way. It's expensive... I lose a day's pay and have to pay £60+ in train fares...we have to stay overnight in a hotel (Parent/Carer 38).

The parent/carer here describes the temporal and material dimensions of waiting, including the 'loss of time' involved in waiting to be seen, as well as the time spent on lengthy journeys to GIDS due to the limited geographical spread of specialist provision in the UK. The material cost of travel, accommodation and lost wages also had an impact on personal finances; an experience shared widely amongst parents and carers needing access to specialist services.

Waiting was also experienced as a vital loss of time in the development of the children for whom the participants were caring. Slow access to GIDS meant that some children had begun to experience adolescent-related physical changes associated with gender dysphoria and distress,

particularly secondary sex characteristics such as breasts. For this parent/carer and many others, the degree of distress expressed by their child was keenly felt, despite finding the services helpful and useful:

Extract 2: [GIDS] waiting list is very long (around 12 months), but they were very approachable. Still waiting for appointment. Hopefully more funding would be available to expand service. Hormone blockers would be good to be prescribed by GP as waiting lists are so long. Having well developed breasts and periods is quite a source of distress for my child. (Parent/Carer 49)

As already noted in the themes on the journey to and experiences of health services, children, young people and their families have often been living with gender diversity for a significant amount time before they family chose to seek out health service support. For those with a clear idea about the appropriate pathway for their child, the length of time spent waiting for an appointment at GIDS, followed by a further period of exploration and reflection, can feel like an unnecessary delay to achieving relief from the bodily distress created by the development of secondary sex characteristics associated with puberty. This is one of the challenges faced in navigating the current system in the UK, in which years can stretch out from the initial discussion within the family to accessing GIDS, and during that time significant changes can happen to the child as they enter puberty. Being prescribed puberty blockers is for some parents a way to put these changes on hold, described as a chance to ‘pause’ and reflect on the experience of gender development through adolescence (Roen, 2011). This aspect of time for reflection after having accessed GIDS was welcomed by some parents:

Extract 3: It's giving my child time to process life and future as he is and will provide blockers to allow the extra time (Parent/carer 56).

Many parents/carers also reported feeling that they and their child were stuck in a knowledge vacuum during long periods of waiting. This led to ‘anxiety and other issues’ which were perceived as being avoidable (extract 4). Here, parents felt lost and unsure without expert guidance and left to rely on ‘unofficial’ information found online, which was largely aimed at older trans and non-binary people:

Extract 4: Real need for child focused literature. My child is experiencing dysphoria but has not yet decided to socially transition despite it being a year since she came out. She is reliant on YouTube based guidance for peer support and is nervous about next steps. This is causing anxiety and other issues that could be avoided if we had access to more child friendly info whilst waiting on professional intervention. (Parent/Carer 43)

We note here that feelings of uncertainty can be exacerbated by the period spent waiting for expert intervention, or for trusted information from a GP. Parents and their children may be well-versed in accessing online media and resources but raised concerns about the availability of more appropriately child-focused resources for younger age groups. The impact of this lack of official information left these parents feeling isolated and unprepared to support their children in an informed manner. In this vacuum of guidance, many referenced the information and support offered by a national UK parent support group as vital to their survival while waiting to access statutory services (see extract 5 & 8).

Extract 5: Need more [information]- it’s a lonely place being on a waiting list for 9 months, [charity name] are a saviour and should get funding (Parent/Carer 20)

‘Isolation’

Linked to the theme of ‘waiting’, the second overarching theme related to feelings of isolation. This presented in three main ways. First, many parents/carers shared accounts of feeling lonely

and cut off from other parents. Second, many experienced their journeys through the healthcare system as a solo ‘fight’ or ‘battle’. Finally, parents/carers reported feeling isolated as a result of their own fears of being judged and misunderstood by others.

The geographic spread of families with a gender diverse child was identified in the data as contributing to feelings of isolation and challenges in meeting other parents:

Extract 6: Can be isolating. Don't know anyone else locally parenting [a] transgender ASD (autism spectrum disorder) child. Confidentiality prevents professionals from making helpful links. Process is long and a battle to get into services for vulnerable child. No blueprint to muddle through. (Parent/Carer 51)

The coalescence of ASD and gender diversity is gaining more attention within GIDS, but this is less common within the general population. The child of the parent/carer in extract 6 has a particular set of support needs and a lack of contact with other parents/carers in a similar situation is central to their feelings of isolation, loneliness and exhaustion. For these caregivers, this sense of isolation is exacerbated by a perception that healthcare professionals could facilitate connections to other parents/carers in a similar position but are unable to do so for reasons of confidentiality, privacy or data sharing regulations. In addition, the lack of information available for parents/carers of primary-aged children (e.g., ‘no blue-print’) also adds to their sense that their experience is one of isolation, disorientation and combat. In extracts 7 and 8, caregivers explain their experience of having to ‘battle’ or ‘fight’ to gain access to healthcare services, largely because of a lack of knowledge about primary-aged gender diverse children at GP and CAMHS level. A sense of survival comes from seeking out information, particularly from the ‘internet’ (extract 7), or by getting support from a UK charity (extract 8), or GIDS (extract 8):

Extract 7: I have had to dig my way and approach people myself and fight and pester services for appointments and come across as a pushy parent, which I am not. I think GPs should all have a person in the practice that is familiar with this subject to help guide families in the right direction. Goodness know what state we would be in if it weren't for the internet. (Parent/Carer 30)

Extract 8: Be more knowledgeable! That is all. I felt like everything came from me; if I hadn't had the support of [Charity name] / GIDS God knows where we would be now. (Parent/Carer 58)

The lack of knowledge experienced within primary care and the pressure to provide information to services, such as GPs, CAHMS and schools, contributed to feelings of isolation. Parents/carers also reported feeling judged as a 'pushy parent' (Extract 7) by service providers, which – given their aim was simply to access the care their children needed – contributed to feelings of stigmatisation and isolation. This was described by one parent as 'isolating, judgemental and unsupportive', Parent/carer 55).

These experiences were so marked in the data that parents/carers often made a point of reporting when a service provider was *not* experienced as 'judgemental' (extract 9), which suggests there is much work to be done in better preparing the healthcare workforce for supporting parents and children from the first time that the issue of gender diversity is raised in consultation:

Extract 9: 20 year[s] of practising as a GP... he saw that we needed support and he wasn't judgemental. (Parent/Carer 26)

Discussion

Our findings demonstrate a desperate need for improved knowledge to better support parents/carers of gender diverse primary age children. A lack of knowledge was reported in caregiver experiences of advice seeking from GPs and CAMHS, which although not acceptable, is not particularly surprising given that the numbers of gender diverse children who seek healthcare are low from a general population perspective. However, given the pathway to GIDS generally requires a referral via CAMHS, and a referral to CAMHS requires input from the GP, a more complex picture emerges whereby it is easy to understand how some parents/carers and children may experience barriers or delays if their local GP or CAMHS were not informed or supportive. Our findings also illustrate the negative experiences of waiting, the impacts of a loss of time and money on family circumstances, the cumulative impacts of uncertainty and isolation and the significant anxiety and emotional labour involved in navigating health services that are not sufficiently prepared to support gender diverse primary-age children. In addition to the emotional costs experienced by families, it is important to note that we also observed evidence of the structural and material impacts of lengthy and expensive travel times that could discourage engagement with appropriate services among families from lower socio-economic backgrounds.

Waiting has been described as ‘one of healthcare’s core experiences’ (Baraitser & Salisbury, 2020 p. 128), and indeed, these parents/carers described feeling intense distress while waiting and watching for the feared impacts that puberty was likely to have on their child’s gender dysphoria and mental distress. Others described waiting to be seen at a specialist clinic with the hope of accessing essential information and possibly reduce their child’s and their own anxieties. Within the context of GIDS, clinicians have reported feeling very much aware of the impact of current waiting times on young people and their families and have publicly noted that the recent levelling off of referral rates should lead to improvements. As Polly Carmichael (Tavistock & Portman, 2019) states:

We appreciate how distressing it can be for young people and their families who are waiting to be seen ... Whilst we still have a substantial waiting list, this levelling off, if sustained, should allow us to more effectively anticipate the resources required to reduce waiting times. This is positive news for the young people and families referred to the service.

We argue that this phrase ‘waiting to be seen’ has particular resonance for those who are trans and non-binary. What we may well be witnessing in the increased referral rates and numbers seeking support for gender diverse children is a critical moment in which trans and non-binary genders are finally ‘being seen’ as a legitimate experience, and one that is deserving of access to medical and social care and support, if desired. What remains problematic is an overreliance on information from online sources that are unmediated and potentially inaccurate about appropriate forms of support for pre-pubescent children. Improvement in the knowledge of GPs and CAMHS has the potential to improve health service experiences of parents and their gender diverse children in primary care. A more nuanced understanding of referral pathways using age-appropriate gender diverse support groups could also reduce pressure on GIDS.

Our sample was drawn from trans-affirmative parents/carers and demonstrated how challenging and isolating their experiences can be. They flagged a lack of knowledge in many generalist services (GP/CAMHS), of waiting for access to ‘expert’ knowledge in specialist service (GIDS) and chronic experiences of uncertainty, anxiety and distress. While it is understandable that parents/carers desire more certainty and reassurance in seeking the ‘next steps’ for their gender diverse children, focusing too much on issues of ‘certainty’ also risks perpetuating an overly limited narrative of medical transition or affirmation as the only or at least most familiar pathway for gender diverse children. The notion of achieving certainty regarding gender implies an either/or discourse that privileges binary assumptions about how gender is experienced. This is contra to UK and Australian school-based research that suggest young people’s understanding,

experience and language around gender is expanding as the social imaginary becomes ever more infused with the values and rights frameworks relating to gender equality and gender diversity (Bragg et al, 2018; Jones et al, 2016).

We argue, then, that what is needed for parents/carers of gender diverse primary-age children, children who are not yet ready to engage with the medical services provided by specialist clinics – even if this ends up the preferred pathway – is better and earlier access to knowledge and support. Earlier access to high quality health services which include supports of a range of kinds may help families mediate and manage anxiety, distress, loneliness, and isolation and provide a safe environment in which to explore gender, celebrate diversity and develop new ways of living with uncertainty. In a sector where the waiting lists for a specialist service are extremely long, improvements need to take place to make primary care services better prepared to provide accurate knowledge and interim supports, and for support services to be more broadly resourced and accessed in other settings, including social support groups for children and their caregivers. Well-informed GP and CAMHS services could be referring parents/carers and their young children to third-sector support groups. Indeed, our findings suggest that community-run groups for gender diverse young people and parental support groups are an effective source of knowledge and support. With appropriate funding and training, they could play a more vital role in supporting parents/carers and gender diverse children, to complement the pathways into and services provided within specialist clinical care settings. Although not explored here, schools also have an important role to play in supporting the needs of young gender diverse children and should be meaningfully engaged in the design and delivery of a more integrated and well-informed system of support services (Carlile, 2020).

Conclusion

International guidelines for advancing transgender health focus on recommendations for provision of affirmative pathways into care, with the expectation that appropriate forms of

healthcare will be accessible, albeit within the constraints of local health systems and cultural practices (WPATH, 2012). Our research demonstrates that even if there is a commitment to this model of care, as there is in the UK, experiences of healthcare are shaped by material challenges within a public health system that is often overloaded and under-resourced. In our analysis of the experiences and expectations of the caregivers of gender diverse children, the issues faced in the UK context include long waiting lists, barriers to physically accessing specialist services that require significant time and travel, potentially excluding lower income families, and a referral pathway that often creates further delay because of a lack of initial knowledge and support in both primary care and CAMHS. These issues are located in a context in which the knowledge of many people about trans issues, including parents/carers and those working in generalist primary care settings, is shaped by a highly emotive and divisive public ‘debate’ about the legitimacy and value of trans lives. This context therefore adds in additional, and unhelpful, questions about the safety and appropriateness of trans healthcare models for under 18s and invites parental anxiety to be heightened about the issue of children and young people’s right and ability to consent. The current context also features shaming discourses about the role of ‘pushy parents’ and implies they are motivated by a desire for ‘gender normality’ in their children, which is believed to be driven by a form of homophobia. In this context, it not surprising that parents describe themselves as feeling isolated and judged, struggling to find support appropriate for their children and themselves. We look forward to more positive frameworks and pathways being developed in the coming years to improve the experience of gender diverse children and their caregivers.

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