

**Understanding Gender Identity Development in Gender
Variant Birth-Assigned Female Adolescents with Autism
Spectrum Conditions**

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Thesis Declaration Form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that it has been indicated in the thesis.

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Overview

This thesis focuses on understanding gender identity development in gender variant birth-assigned female adolescents with Autism Spectrum Conditions (ASC), with the aim of elucidating the association between ASC and gender dysphoria identified by Gender Identity Development (GID) services worldwide.

Part 1: This section presents a systematic review of the literature investigating the characteristics of children and adolescents referred to GIDs and other specialist services with gender dysphoria. The review focused specifically on demographics, psychiatric comorbidity and associated risks. There were 24 articles that met the criteria for review. The review indicates that there could be a notable delay between reported age of onset of gender dysphoric feeling and presentation to clinical services; shows that more birth-assigned females, compared to birth-assigned males, have been referred in recent years; more referrals come from white, compared to non-white, ethnic backgrounds proportional to what would be expected given the countries' demographics; and the majority are sexually attracted to individuals of the same birth-assigned sex. There is also a high level of co-occurring mental health difficulties among gender dysphoric children and adolescents, and they are at elevated risk of self-harming and suicidal behaviour.

Part 2: This section shows the results of a qualitative study using Constructivist Grounded Theory method. Interviews were conducted with ten clinically-referred gender variant adolescents aged between 15 and 18, who were birth-assigned female and had a diagnosis of ASC. Analysis of the semi-structured interviews identified a core category of 'Journey Towards Understanding', which consisted of three major categories that represent the consecutive stages of this journey: 'Awareness of Difference', 'Experience of Incongruence', and 'Understanding Difference'. A final major category 'Neurodiversity as a Facilitator of

Change' reflected the intrapersonal and interpersonal processes associated with having ASC that may have enabled the participants to make the transition towards living as (trans) males.

Part 3: This section presents a critical appraisal outlining the political, socio-cultural and clinical context for the research, and how this influenced the researcher's position. It also includes reflections on the conceptual and practical challenges faced by the researcher in designing and conducting qualitative research with gender variant young people with ASC. It demonstrates how specific methodological challenges, arising during four phases of the research process, were (or could have been) addressed: study design; recruitment; interviews with participants, and transcription and data analysis. Further implications for future research and clinical services are also considered.

Impact Statement

A significant proportion of recent referrals to Gender Identity Development (GID) services worldwide are gender variant birth-assigned female adolescents with complex and later-onset presentations. This includes a high instance of psychosocial and neurodevelopmental difficulties, including Autism Spectrum Conditions (ASC). There is limited extant qualitative research exploring experiences of gender dysphoric young people with ASC with the aim of elucidating the association between these two conditions. This study advances research by Strang et al (2018) exploring the experiences of gender diverse adolescents with ASC, and it is the first study focusing solely on the experiences of birth-assigned adolescent females with ASC.

Since this is a previously understudied population, the study was necessarily broad in scope; however, it offers insights into gender identity development among birth-assigned adolescent females with ASC and generates hypotheses for future research. For instance, the results suggest that delayed diagnosis of ASC and early onset puberty could be factors in explaining the prevalence of gender dysphoria among birth-assigned females with ASC. It also reinforces existing hypotheses that ASC may predispose birth-assigned females with ASC to more ‘masculine’ ways of self-expression and relating to others, or to hold more narrow, stereotyped views about what it means to be ‘male’ or ‘female’. This is held in tension with the fact that results underscore suggestions that gender variant, adolescent birth-assigned females with ASC may present to services more readily than their neuro-typical peers because they are less socially conformist and more questioning about gender norms, as well as subject to less direct peer influence due to their relative social isolation. A potential consequence of this relative social isolation may be increased exposure to indirect peer influence online.

Further, this study may help clinical services understand why birth-assigned females with ASC are presenting with gender dysphoria in such significant numbers worldwide. It

demonstrates the complex interaction between gender variance and ASC, reinforcing suggestions that neuro-diverse young people progress through gender identity development along differing timelines or frameworks compared to their neuro-typical peers. It also offers clinicians insights into possible areas for thorough exploration with birth-assigned females with ASC during assessment, and how young people with ASC may experience the assessment process differently to their neuro-typical peers. The study further underscores the need for GID services around the world to introduce an extended diagnostic period for young people with ASC. This is because there is a need for clinical decisions to proceed more slowly due to the myriad neurodevelopmental and psychosocial complexities of this population.

In the UK, implementation of this recommendation will be contingent on additional, earmarked funding for National Health Service (NHS) GID services. More funding will also be required to develop accredited training programmes within these specialist services so that they can equip the Child and Adolescent Mental Health Service (CAMHS) clinical workforce with the knowledge and skills to explore gender and sexuality with gender non-conforming young people with and without ASC, and help teams to think about these aspects of young people's experiences in a more general way. This would ensure that more generic clinical teams are able to provide comprehensive therapeutic support to young people, with the aim of reducing gender-related distress and helping specialist services manage the increasing number of referrals. There is an additional need for training aimed at improving General Practitioners' (GPs) and other clinical professionals' recognition of signs of ASC in females to facilitate diagnosis and access to support at an earlier stage.

Table of Contents

Overview	3
Impact Statement	5
Acknowledgements	10
Paper 1: Literature Review	11
Abstract.....	12
Introduction.....	13
Background	13
Aims.....	18
Method	18
Search strategy	18
Quality and relevance assessment.....	18
Inclusion and exclusion criteria	19
Results	21
Study selection process	21
Demographic characteristics	26
Age of onset	26
Age of presentation	26
Proportion of birth-assigned males to birth-assigned females	27
Sexual orientation	28
Ethnicity	28
Psychiatric co-morbidity	29
Autism Spectrum Conditions (ASC)	30
Internalising problems	31
Eating disorders	33
Attention Deficit Hyperactivity Disorder (ADHD)	34
Other co-morbidities	35
Associated risks	35
Discussion	36
Methodological limitations	42
Research recommendations	45
Clinical implications	46
References.....	47
Paper 2: Empirical Paper.....	62
Abstract.....	63
Introduction.....	64
Background	64
Aims.....	72
Research questions.....	74
Method	75
Setting	75
Participants.....	75
Inclusion criteria	75
Exclusion criteria	75
Sample framework and characteristics	75
Measures	77
Semi-structured Interview.....	77
Strengths and Difficulties Questionnaire (SDQ) with Impact Supplement.....	77

Additional information.....	78
Debrief and feedback	78
Recruitment procedure.....	78
Ethics.....	79
Analysis.....	79
Testimonial validity	81
Researcher's perspective.....	81
Results	82
Strengths and Difficulties Questionnaires (SDQ) scores	82
Results from semi-structured interviews	82
Discussion	94
Methodological Limitations	102
Clinical implications	106
References	110
Part 3: Critical appraisal.....	126
Introduction.....	127
Political, sociocultural and clinical context for the research	127
Research process: Methodological challenges.....	130
Study design.....	130
Recruitment.....	132
Interviews with participants.....	133
Transcription and data analysis.....	136
Implications for future research	137
Appendices.....	143
Appendix A: Letter of Approval from National Research Ethics Service Committee..	144
Appendix B: Sample Information Sheets – Young Person.....	151
Appendix C: Sample Information Sheets – Parent/Guardian	154
Appendix D: Sample Informed Consent Form – Young Person	158
Appendix E: Sample Informed Consent Form – Parent/Guardian	160
Appendix F: Sample Informed Assent Form – Young Person (Under 16).....	162
Appendix G: Interview Schedule.....	164
Appendix H: Strengths and Difficulties Questionnaire (SDQ) with Impact Supplement	170
Appendix I: Sample Feedback Form	172
Appendix J: Gender Terminology	173
Appendix K: Example of Initial and Focused Coding.....	175
Appendix L: Diagram of Major Category, Core Categories and Sub-Categories	178
Appendix M: Genderbread person.....	179
Appendix N: Summary of Results for Participants.....	180

List of Tables

Part 1: Literature Review

Table 1.1. Summary table of reviewed studies – Demographics (1).....	22
Table 1.2. Summary table of reviewed studies – Demographics (2).....	23
Table 1.3. Summary table of reviewed studies – Prevalence (1).....	24
Table 1.4. Summary table of reviewed studies – Prevalence (2).....	25

Part 2: Empirical Paper

Table 2.1. Characteristics of the sample.....	76
Table 2.2. Strengths and Difficulties Questionnaires (SDQ) scores.....	82
Table 2.3. Core Category, Major Categories and Sub-Categories.....	83

List of Figures

Part 1: Literature Review

Figure 1: Flow diagram showing studies identified through database searching	21
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Paper 1: Literature Review

Characteristics of children and adolescents referred to Gender Identity Development

**(GID) clinics and other specialist services with gender dysphoria: demographics,
psychiatric comorbidity and associated risks**

Abstract

Aim: To review recent literature investigating the characteristics of children and adolescents referred to Gender Identity Development clinics (GIDS) and other specialist services with gender dysphoria. The review focused specifically on demographics, psychiatric comorbidity and associated risks.

Method: Systematic literature searches were performed using PsychINFO, OVID MEDLINE and EMBASE. These searches identified 24 articles meeting the relevant criteria for review.

Results: The articles reviewed indicate that there could be a notable delay between age of onset of gender dysphoric feeling and presentation to clinical services; show that more birth-assigned females, compared to birth-assigned males, have been referred in recent years; more referrals come from white, compared to non-white, ethnic backgrounds proportional to what would be expected given the countries' demographics; and the majority are attracted to individuals of the same birth-assigned sex. There is also a high level of co-occurring mental health difficulties among gender dysphoric children and adolescents, and they are at elevated risk of self-harming and suicidal behaviour.

Conclusions: Gender dysphoric children and adolescents need specific care and management within clinical teams. Clinicians should be aware of associated risks to help prevent self-harming behaviour and suicide attempts among young people with gender dysphoria.

Introduction

Background

Gender dysphoria involves marked incongruence between a person's experienced or expressed gender, and their physical or birth-assigned sex (American Psychiatric Association, 2015). The psychiatric diagnosis of gender identity disorder was introduced in the Diagnostic and Statistical Manual-III (DSM-III) in 1980, but it was reclassified in DSM-5 in 2013 as gender dysphoria with the intention of avoiding pathologising the condition (Pyne, 2014). The International Classification of Diseases (ICD-10) includes the following diagnoses: transsexualism, and gender identity disorder of childhood (World Health Organisation, 1992). Transsexualism is defined in the ICD-10 as a desire to live and be accepted as a member of the opposite sex, and a wish to have surgery and hormonal treatment to make one's body as congruent as possible with one's preferred sex (Ibid, 1992). Gender identity disorder of childhood is a desire to be of the opposite sex that manifests in early childhood, with persistent preoccupation with the dress and activities of the opposite sex and repudiation of the individual's own sex (Ibid, 1992). If a young person has reached or has entered puberty, they are likely to be diagnosed with sexual maturation disorder: when an individual suffers from uncertainty about their gender identity or sexual orientation, which causes anxiety or depression (Ibid, 1992). The term "transgender" is typically used as an umbrella, non-clinical term referring to a broader variety of gender identities (see Appendix J for a list of definitions of all gender-related terminology used in this study). While gender dysphoria and transsexualism are associated with clinically significant distress or impairment in social, occupational or other important areas of functioning (Ibid., 1992; & American Psychiatric Association, 2015), not all who identify as transgender experience dysphoria.

Specialist Gender Identity Development (GID) clinics have been set up around the world to respond to the needs of those experiencing gender dysphoria. Recent years have witnessed a significant increase in referrals of children and adolescents to these services, and the number

of referrals is expected to rise further (Chen, Fuqua & Eugster, 2016; Zucker, Wood, Wasserman, VanderLaan & Aitken, 2016). The reason for the increase in referrals is subject to debate. It is likely due to a number of factors, including the increased positive presence of transgender people in the media, and the associated de-stigmatisation of gender dysphoria and awareness of available psychological and/or medical interventions (Chen, Fuqua, & Eugster, 2016; McInroy & Craig, 2015). Concerns have also been raised regarding the impact of social media, and whether the increase in referrals is, in part, a consequence of social influence or ‘contagion’, especially among young people whose concerns regarding their gender emerge in mid-adolescence without any prior indication (Littman, 2018).

Demographics

This review is interested in understanding the demographic characteristics of children and adolescents referred to specialist gender services around the world. In particular, it aims to synthesise the following information: the reported age of onset of gender dysphoric feeling; the age of presentation at GID services; the proportion of birth-assigned females to birth-assigned males; the sexual orientation and the ethnicity of referrals. Leibowitz & De Vries (2016) suggest that the age of onset, sex ratio and sexual orientation are relevant because adult studies show that late-onset gender dysphoria, birth-assigned maleness and a sexual attraction to individuals of a different gender to the young person’s birth-assigned sex may be predictive of a more challenging treatment course and less favourable outcomes. Ethnicity is relevant in terms of recognising which groups have access to specialist services and whether minority groups are appropriately represented.

Psychiatric co-morbidity

This review is further interested in co-occurring mental health conditions. Studies show that gender dysphoria is characterised by significant psychiatric co-morbidity (Di Ceglie, Freedman, McPherson, & Richardson, 2002). It has been suggested that mental health

difficulties experienced by gender dysphoric young people receive less attention from mental health providers (Bechard, VanderLaan, Wood, Wasserman, & Zucker, 2016). It is important for clinicians to understand the psychological characteristics of children and adolescents referred to GID clinics and other specialist services around the world. Understanding this is necessary to determine appropriate treatment plans and ensure that individuals have access to vital targeted support from services. It also helps identify areas for future research.

Specifically, the review will look at the prevalence of Autism Spectrum Conditions (ASC) in children and adolescents presenting at specialist gender services. ASCs are lifelong neurodevelopmental conditions characterised by impaired social communication, restricted interests, repetitive behaviours and sensory issues. In addition, the study will explore the co-occurrence of gender dysphoria and internalising problems, including depression/mood disorders and anxiety. It will further consider the association between gender dysphoria and eating disorders, as well as Attention Deficit Hyperactivity Disorder (ADHD). ADHD is a neurodevelopmental disorder characterised by inattentiveness, hyperactivity and impulsiveness. The review will also document other co-morbidities identified in the literature.

Associated risks

This review also considers the association between gender dysphoria in children and adolescents and risk, including suicide attempts and self-harm. This is important in helping guide the development of appropriate treatment plans by GID clinicians and informing risk management within teams.

Limits of the review

A number of studies have attempted to establish the aetiological factors associated with gender dysphoria. For instance, research has focused on a number of possible predictive factors, including early pubertal timing (Sumia et al., 2016); birth order and sibling sex ratio (Hughes et al., 2017; Schagen, Delemarre-van de Waal, Blanchard & Cohen-Kettenis, 2012;

Vanderlaan et al, 2014); adopted status (Matthews, Holt, Sahin, Taylor, & Griksaitis, 2018; Shumer, Abrha, Feldman, & Carswell, 2017); poor peer relations (de Vries et al., 2016; Wallien, Veenstra, Kreukels, & Cohen-Kettenis, 2010); and differentiation in brain activity between young people with gender dysphoria and controls (Hoekzema et al., 2015; Soleman et al., 2013). The review did not seek to incorporate this work, as this risked making the scope of the review too broad. Further, the current study does not examine potential protective factors, such as social support, which has been shown to be important in relation to how young people manage the experience of gender dysphoria (Simons, Schrager, Clark, Belzer & Olson, 2013). This is however an important area of research, and would warrant being a subject for review.

The review also does not include papers pertaining to an adult population. This is because recent years have witnessed a sharp decline in age at which medical interventions aiming at gender reassignment are being requested in Europe and North America (Steensma, Kreukals, de Vries & Cohen-Kettenis, 2013). Studies of people with gender dysphoria have also shown that the period of adolescence, with its changing social environment and the onset of puberty, seems to be crucial for the development of a gender variant identity (Ibid., 2013).

Previous reviews

Previous literature reviews conducted in this area have focused on exploring the relationship between gender dysphoria and specific psychiatric diagnoses. For instance, two papers have synthesised the literature pertaining to the co-occurrence of gender dysphoria and ASC (Glidden, Bouman, Jones, & Arcelus, 2016; Van Der Miesen, Hurley, & De Vries, 2016). In addition, there has been some attempt to synthesise cross-clinic data. For instance, de Graaf et al., 2017 compares psychological functioning in adolescents across four specialist GID clinics in Europe.

There are three papers that are similar to the present study in that they seek to draw together the literature exploring the relationship between gender dysphoria and co-occurring psychiatric

diagnoses (Dhejne, Van Vlerken, Heylens, & Arcelus, 2016; Leibowitz & de Vries, 2016; Ristori & Steensma, 2016). Dhejne et al. (2016) differs though in that it examines psychiatric co-morbidity in adult populations, while Leibowitz and de Vries (2016) is focused specifically on exploring the characteristics of referred adolescents and Ristori and Steensma (2016) focuses solely on referred children.

The present study further departs from the aforementioned papers in that a systematic literature search was undertaken. By contrast, the former reviews took a less formal (and therefore less replicable and potentially more biased) approach to synthesising the literature. The present study also includes papers that pertain to children referred to specialist gender clinics, as well as adolescents.

The closest paper to the present study is Connolly, Zervos, Barone, Johnson, & Joseph (2016), which includes literature focused on both children and adolescents. Although the paper is a systematic review, it was conducted two years prior to the current study. Therefore, it does not incorporate significant findings from the past two years, which represents a substantial and valuable body of literature. Connolly et al. (2016) further differs from the present study in that it includes studies that are based on community, as well as clinical, samples. The present study is only focused on reviewing studies based on clinical samples. Understanding the characteristics of young people referred to GIDS or other specialist gender-related services (e.g. services in paediatric hospitals) is necessary to determine whether this population requires specific care and management within clinical teams. The current review also has a slightly broader focus than Connolly et al. (2016) in that it examines demographic characteristics, and the co-occurrence of anxiety, ASC and ADHD (as well as the prevalence of depression, suicide attempts, self-harm and eating disorders among referred young people).

Aims

The aim of this study was to review and synthesise recent literature investigating the selected characteristics of children and adolescents referred to GID clinics and other specialist services with gender dysphoria. The review focused specifically on demographic characteristics, psychiatric co-morbidity and associated risks, including suicide attempts and self-harm. The review asked a series of questions: (i) what is the typical reported age of onset of gender dysphoric feeling among referrals; (ii) what is the typical age that young people present to services with gender dysphoria (iii) what is the proportion of birth-assigned females to birth-assigned males among referrals; (iv) what is the sexual orientation of referrals; (v) what is the prevalence and nature of co-occurring mental health difficulties among referrals; (vi) what is the prevalence of associated risks among referrals. An additional aim was to explore whether the answers to these questions were consistent over time, and across different localities.

Method

Search strategy

A systematic search of the PsychINFO, Ovid MEDLINE and EMBASE computerised databases was undertaken from 1 January 2007 to 11 September 2018. The search terms "Gender dysphori*", "Gender nonconformi*", "Gender varian*", "Gender questioning", "Gender expression", "Gender identity disorder*", or transgender were combined with Child*, Adolescen*, "Young people", Youth*, Minors, Teenage*, Pre-teen*, Pre-adolescen*, or Paediatric* in a search of abstracts of studies entered in these databases. The search results were limited to English language. The reference lists of the included papers were also searched by hand.

Quality and relevance assessment

No formal quality and relevance assessment tool was used in this study because the

majority of tools are designed to assess the quality of intervention studies and studies with randomised design, whereas this review involved synthesising descriptive data. A formal measure of study quality was also not considered appropriate for this type of review, given the heterogeneity of the reviewed studies (e.g. in relation to country and population under study). Despite not using a formal tool, each study was appraised for its relevance to the research questions and its methodological quality.

Inclusion and exclusion criteria

Inclusion criteria

This review included studies meeting the following criteria: (i) the target population included children and adolescents (aged 25 or below); (ii) the sample included individuals who had been referred to a GID clinic or another specialist service presenting with gender dysphoria; (iii) the article reported on the target populations' demographic characteristics, psychiatric co-morbidity and/or associated risk factors (suicide attempts or self-harm); (iv) the article reported an original piece of research; (v) the study was published in a peer-reviewed journal; (vi) the study was published between January 2007 and September 2018.

The target population included children and young people aged 25 or below. This is because the study took the conventional definition of adolescence, which now extends to the mid-20s (Sawyer, Azzopardi, Wickremarathne, & Patton, 2018). This means that six studies included in the review included an emerging adult population. For example, the sample in Olson, Schragger, Belzer, Simons, & Clark (2015) comprised self-identified transgender youth between the ages of 12 and 24 years. As discussed below, any studies focused solely on an adult population were excluded.

Previous reviews have included studies based on community samples. To ensure that only studies based on clinical samples were included, the emphasis was upon individuals referred to GIDS or other specialist gender-related services (e.g. services in paediatric hospitals). Any

studies focusing on transgender youth attending community centres, secondary schools etc. were excluded.

The review was limited to studies published after 2007. A study period of ten years was selected because the focus of the research was on exploring recent, rather than historic, trends in referrals to specialist gender services. It is also only in recent years that specialist gender identity clinics have started to publish their findings related to the psychological functioning of referred young people with gender dysphoria (Leibowitz & de Vries, 2016). The search was originally conducted from 2007 to 2017, but was extended to 2018 after the researcher had a year of maternity leave while conducting the review.

Eligible studies were scanned to assess whether they contained data relevant to the review. These data were then extracted and converted into means or percentages so that they could be synthesised and compared alongside data from other eligible studies.

Exclusion criteria

Articles were excluded if they were in any of the following categories: (i) studies that were primarily looking at predisposing or aetiological factors e.g. studies showing increased incidence of gender dysphoria among adopted children etc.; (ii) studies that solely comprised an adult sample population; (iii) studies based on the same sample as another paper (e.g. referrals to a particular clinic), but that did not yield additional relevant information; (iv) studies focused on a subset of referrals rather than looking at the entire cohort (e.g. birth-assigned females); (v) studies based on community, rather than clinical, samples; (vi) narrative studies where there was no sample; and (vii) studies where the abstract was in English, but the main article was in another language. When a study was identified as using the same sample as a previous paper, the decision was made to initially include the most recent paper unless the earlier paper contained additional relevant information.

Results

The PsychINFO, Ovid MEDLINE and EMBASE searches identified 2505 studies (after duplicates were removed) within the specified date range. Abstracts of these studies were screened according to the inclusion criteria. There were 24 studies that met the inclusion criteria (i) to (v), and as well as the exclusion criteria (i) to (vii) above (see Figure 1 for the study selection process; see Tables 1.1-1.4 for a summary of reviewed studies).

Study selection process

Figure 1: Flow diagram showing studies identified through database searching

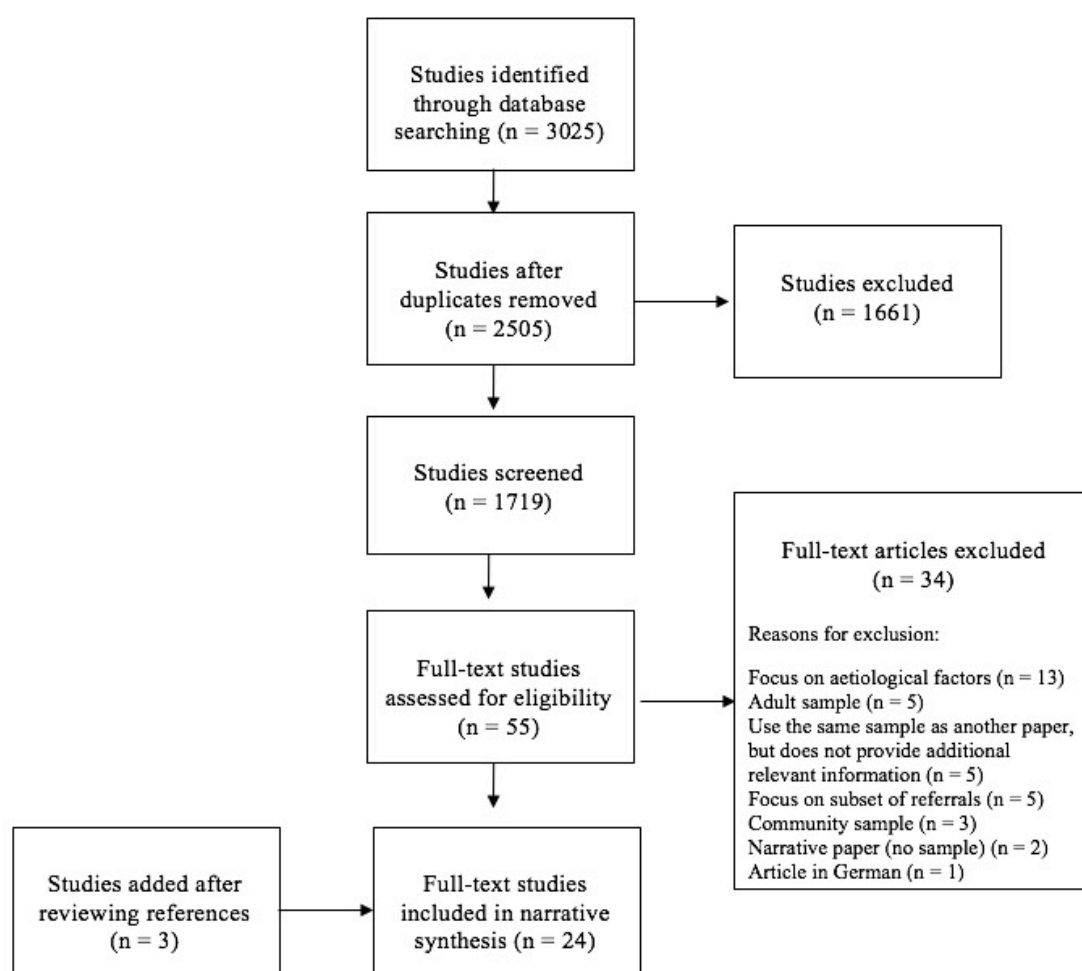


Table 3.1. Summary table of reviewed studies – Demographics (1)

Demographics								
Study	Year	Country	N	Age of onset, Mean (SD)	Age at presentation, Mean (SD)	Sex (% AF/AM)	Sexual orientation* (%)	Ethnicity (% W/NW)
Wallien et al.	2007	Netherlands	120			28.3/71.7		
De Vries et al.	2011a	Netherlands	105		14.6 (2.2)	49.5/50.5		
De Vries et al.	2011b	Netherlands	83		15.7 (1.67)		100	
Hewitt et al.	2012	Australia	21	3.3 (1.11)	10.0 (4.13)	38.0/62.0		
Spack et al.	2012	USA	97		14.7 (3.4)	55.7/44.3	69.1	
Zucker et al.	2012	Canada	192			45.3/54.7	65.1	75.0/25.0
Wood et al.	2013	Canada	830				56.7-76.0**	78.4/21.6
Khatchadourian et al.	2014	Canada	84		16.6 (2.2)	53.6/46.4		
Steensma et al.	2014	Canada	396		8.97 (3.7)	24.2/75.8		
		Netherlands	332		9.9 (3.4)	37.0/63.0		95.7/4.3
Aitken et al.	2015	Canada	202			63.9/36.1		
		Netherlands	201			63.7/36.3	56.7	
Kaltiala-Heino et al.	2015	Finland	47	****	16.0	87.2/12.8		
Olson et al.	2015	USA	101	8.3 (4.5)		51.5/48.5	55.0-59.6***	52.0/48.0

* Percentage of young people sexually attracted to individuals of their birth-assigned sex.

**56.7% of birth-assigned females, 76.0 of birth-assigned males.

*** 55.0% of birth-assigned females, 59.6% birth-assigned males.

****32% reported starting to consciously question their gender before age 12; 62% at 12 or later, and 6% could not define this.

Table 1.2. Summary table of reviewed studies – Demographics (2)

Study	Year	Country	N	Age of onset, mean	Demographics			
					Age at presentation, mean	Sex (% AF/AM)	Sexual orientation* (%)	Ethnicity (% W/NW)
Skagerberg et al.	2015	UK	166		14.3 (2.68)	62.7/37.3		93.7/6.3
Arcelus et al.	2016	UK	268			45.2/50.7		89.9/10.1
Bechard et al.	2016	Canada	50±			66.0/34.0	64.0	74.0/26.0
Chen et al.	2016	USA	38			57.9/42.1		81.6/18.4
Holt et al.	2016	UK	218	**	14.0 (3.1)	62.8/37.2	60.8	90.9/9.1
Edwards-Leeper et al.	2017	USA	56			46.4/53.6		
Feder et al.	2017	Canada	97		15.7 (1.4)	61.9/38.1		
Fisher et al.	2017	Italy	46	***	16.0 (1.5)	56.5/43.5	80.4	
Peterson et al.	2017	USA	96		17.1 (2.3)	56.3/43.7		
Yildirim et al.	2017	Turkey	20	6.92 (4.15)	9.60 (4.32)	45.0/55.0		
Chiniara et al.	2018	Canada	203		16.7 (1.6)****	76.6/23.2		74.0/26.0
Röder et al.	2018	Germany	126		15.61 (1.42)	81.7/18.3		

* Percentage of young people sexually attracted to individuals of their birth-assigned sex.

**42.7% reported having their first gender dysphoric feelings between 0 and 6years of age, 34.9% between 7 and 12years of age and 17.9% between 13 and 18 years of age.

*** GD onset <6 years old – 47.8%

****This study compared the first 100 adolescent charts to the subsequent 100 charts, and found that the mean age of referrals declined from 16.7 (1.6) to 15.7 (1.6) over the course of 2.5 years.

Table 1.3. Summary table of reviewed studies – Prevalence (1)

Study	Year	Data Collection	N	Prevalence (%)							Associated Ris	
				2+ Diagnoses	ASC	Depression	Eating disorder	Anxiety	ADHD	Other	Suicide attempt	Self-harm
Wallien et al	2007	Diagnostic Interview Schedule for Children administered to parents of gender dysphoric children aged 4-11 years referred to a gender clinic in the Netherlands in Mar. 1998-Dec. 2004.	120	52.0		6.0		31.0		23.0****		
De Vries et al.	2011a	Diagnostic Interview Schedule for Children administered to parents of gender dysphoric adolescents aged 10-18 years referred to a gender clinic in the Netherlands in Apr. 2002- Dec. 2009.	105	32.4		12.4		21.0	2.9	1.0*		
De Vries et al.	2011b	Questionnaires completed by adolescents aged 13-18 years attending a gender clinic in the Netherlands in 2000-2007.	83			21.7						
Hewitt et al.	2012	Retrospective chart review of patients 0-17 years old attending a paediatric referral centre in Australia, in 2003-2011.	21		24.0	*****		*****				
Spack et al.	2012	Retrospective chart review of patients <21 years old attending a gender clinic in Boston, USA, in Jan. 1998-Feb. 2010	97		1.0	25.7	3.1	7.2	2.1	3.1***	9.3	20.0
Zucker et al	2012	Questionnaires completed by parents and adolescents/emerging adults aged 13-22 years attending a gender clinic in Toronto, Canada, in 1976-2009.	192									
Wood et al	2013	Questionnaires completed by parents/children and adolescents/emerging adults aged 3-20 years attending a gender clinic in Toronto, Canada, in 2008- 2011.	830									
Khatchadourian et al.	2014	Retrospective chart review of adolescents aged 11-19 years with gender dysphoria attending a gender clinic in Vancouver, Canada, in 1998-2011.	84	26.0	7.0	35.0	5.0	24.0	10.0	7.0*	12.0	
Steensma et al	2014	Questionnaires teachers of children and adolescents (mean age 9) referred to a gender clinic Toronto, Canada, in 1986-2007.	396									
		Questionnaires teachers of children and adolescents (mean age 9) referred to a gender clinic in the Netherlands in 1993-2007.	332									
Aitken et al	2015	Retrospective chart review of children and adolescents (mean age 9) referred to a gender clinic in Toronto, Canada, in 2006-13.	202									
		Retrospective chart review of children and adolescents (mean age 9) referred to a gender clinic in the Netherlands in 2006-13.	201									

*Substance misuse , **psychosis ***bipolar disorder ****disruptive disorders (ADHD or oppositional defiant disorder)

*****All referrals reported symptoms of depression and anxiety

Table 1.4: Summary table of reviewed studies – Prevalence (2)

				Psychiatric Comorbidity							Associated Ri.	
				Prevalence (%)								
Study	Year	Data Collection	N	2+ diagnoses	ASC	Depression	Eating disorder	Anxiety	ADHD	Other*	Suicide attempt	Self-harm
Kaltiala-Heino et al.	2015	Retrospective chart review of adolescents (mean age 16) attending a gender clinic in Finland in 2011-2013.	47	75.0	26.0	64.0	2.0	55.0	11.0	13.0**		53**
Olson et al.	2015	Survey of adolescents and emerging adults aged 12-24 years attending a transgender youth clinic in Los Angeles, the USA, in Feb. 2011-June 2013	101			35.0					30.0	
Skagerberg et al.	2015	Questionnaires completed by parents of children and adolescents (mean age 14) attending a gender clinic in London over an 18-month period.	166		54.2							
Arcelus et al.	2016	Questionnaires completed by adolescents (mean age 19.9) attending a gender clinic in in Nottingham in Nov. 2012-June 2015.	268									46.
Bechard et al.	2016	Retrospective chart review of 50 consecutive referrals of adolescents aged 13-20 attending a paediatric gender clinic in Toronto, Canada, in Feb. 2011-June 2012.	50	60.0	4.0	38.0	6.0	22.0	18.0		26.0	36
Chen et al.	2016	Retrospective chart review of adolescents (mean age 14.4) referred to an endocrinology clinic in Indianapolis, the USA, in 2002-2015.	38	63.1	13.1	31.6			15.8			13.1*
Holt et al.	2016	Retrospective chart review of children and adolescents ages 5-17 years attending a gender clinic in London in Jan. 2012-Dec. 2012.	218		13.3	41.7	13.3	22.5	8.3	5.0**	13.3	39.
Edwards-Leeper et al.	2017	Retrospective chart review of adolescents aged 8-17 attending a paediatric gender clinic in Boston, the USA, in 2007-2010.	56			10.0		7.7				7.7
Feder et al	2017	Retrospective chart review of adolescents aged 12-18 attending a paediatric gender clinic in Ottawa, Canada, in Oct. 2007-July 2015.	97				15.5					
Fisher et al.	2017	Questionnaires completed by adolescents (mean age 16) attending gender clinic in Italy in Sep. 2014-Feb. 2016.	46							17.4*	13.0	
Peterson et al.	2017	Retrospective chart review of adolescents and emerging adults aged 12-22 assessed in a paediatric hospital in Cincinnati, the USA in July 2013-June 2015.	96	58.0	3.0	38.0	5.0	28.0	13.0	5.0***	30.3	41.
Yildirim et al.	2017	Questionnaires completed by adolescents aged 5-17 attending a psychiatry outpatient clinic in Turkey in 2012 -2016.	20	90.0		25.0		25.0	75.0	5.0*		
Chiniara et al.	2018	Retrospective chart review of adolescents aged 12-18 referred to a children's hospital in Toronto, Canada, in Jan. 2014-June 2016.	203		5.4	37.4		28.1				30.
Röder et al.	2018	Questionnaires completed by adolescents aged 5-18 attending a gender clinic in Germany in 2013-2016.	126				50					

*Substance misuse **psychosis ***bipolar disorder ****Authors combine self-harming and suicidal behaviours

Demographic characteristics

Age of onset

The reviewed studies showed that the self-reported age of onset of gender dysphoric feelings among the referred children and adolescents tends to be early, usually by the start of puberty (see Tables 1.1 and 1.2). While the majority of studies in the review did not report on the age of onset (18 out of 24 studies), those that did were relatively consistent in their findings. In a retrospective chart review of patients presenting to a paediatric referral centre in Melbourne, Australia between 2003-2011, Hewitt et al. (2012) showed that the mean age of onset was as young as 3.3 years old. The early onset of gender dysphoric feeling (<12) was verified by studies from Italy, the UK, the USA and Turkey, respectively (Fisher et al., 2017; Holt, Skagerberg, & Dunsford, 2016; Olson et al., 2015; Yildirim, Perdahlı Fis, Yazkan Akgul, & Burcu Ayaz, 2017).

A study of 218 children and adolescents presenting to a gender clinic in London showed that 42.7% of referrals reported first experiencing gender dysphoric feelings between 0 and 6 years of age; 34.9% between 7 and 12 years of age and 17.9% between 13 and 18 years of age (Holt, Skagerberg, & Dunsford, 2016). The only exception to this finding came from a Finnish study of applicants to a gender clinic desiring sexual reassignment (Kaltiala-Heino, Sumia, Työläjäarvi, & Lindberg, 2015). This study found that 32% of referred adolescents reported starting to consciously question their gender before age 12; 62% at 12 or later, and 6% could not define this (Ibid., 2015).

Age of presentation

Most studies in the review commented on the age of presentation of the children and adolescents at specialist gender services (16 out of 24 studies). Tables 1.1 and 1.2 show the mean age of presentation was between 14 and 17 years old in the majority of these studies (Chiniara, Bonifacio, & Palmert, 2018; De Vries, Kreukels, Steensma, Doreleijers, & Cohen-

Kettenis, 2011; De Vries, Doreleijers, Steensma, & Cohen-Kettenis, 2011; Feder, Isserlin, Seale, Hammond, & Norris, 2017; Fisher et al., 2017; Holt et al., 2016; Kaltiala-Heino, Bergman, Työläjärvi, & Frisen, 2018; Khatchadourian, Amed, & Metzger, 2014; Peterson, Matthews, Copps-Smith, & Conard, 2017; Röder et al., 2018; Skagerberg, Di Ceglie, & Carmichael, 2015a; Spack et al., 2012). There were some exceptions. Three studies showed a mean age of presentation of between 8 and 10 years old (Hewitt et al., 2012; Steensma et al., 2014; Yildirim et al., 2017). The overall finding though is that there have been more adolescent referrals compared to children in recent years.

Proportion of birth-assigned males to birth-assigned females

Studies included in the review (see Tables 1.1 and 1.2) that were based on samples prior to 2007 show that more birth-assigned males were referred to specialist gender dysphoria services than birth-assigned females (Steensma et al., 2014; Wallien, Swaab, & Cohen-Kettenis, 2007). However, more recent studies based on post-2007 samples show a shift in the sex ratio from one favouring birth-assigned males to one favouring birth-assigned females (or to near parity), and demonstrate that this a global phenomenon (Chen, Fuqua, & Eugster, 2016; Chiniara, Bonifacio, & Palmert, 2018; Feder, Isserlin, Seale, Hammond, & Norris, 2017; Holt et al., 2016; Kaltiala-Heino et al., 2015; Röder et al., 2018; Skagerberg, Di Ceglie, & Carmichael, 2015).

This trend is perhaps best illustrated by a comparison between Steensma et al. (2014) and Aitken et al. (2015), which both chart referrals to gender clinics in Canada and the Netherlands over two timeframes: 1986-2007 and 2006-2013, respectively. Steensma et al. (2014) show that the percentage of birth-assigned females referred during the earlier time period was just 24% in Canada and 37% in the Netherlands. By contrast, Aitken et al. (2015) showed that the proportion of referred birth-assigned females had increased over the subsequent eight years to 64% of total referrals in both localities.

Sexual orientation

Only 9 out of 24 studies reported on the sexual orientation of adolescents with gender dysphoria (see Tables 1.1 and 1.2). Almost all studies (8 out of 9) showed that over 55% of referred young people were sexually attracted to individuals of the same birth-assigned sex (Aitken et al., 2015; Bechard et al., 2016; de Vries, Steensma, Doreleijers, & Cohen-Kettenis, 2011; Fisher et al., 2017; Holt et al., 2016; Olson et al., 2015; Spack et al., 2012; Wood et al., 2013; Zucker et al., 2012). A study from the Netherlands showed that all of the adolescents who were evaluated for eligibility for pubertal suppression reported being sexually attracted to individuals of the same birth-assigned sex (de Vries et al., 2011b). According to a recent study, about 20% of the population of the US is same-sex attracted, which is nearly double typical estimates of about 10% (Coffman, Coffman, & Ericson, 2017).

Ethnicity

Ethnicity data was not available for the majority of studies (10 out of 24 studies), which suggests it may be under-reported. Those that reported ethnicity showed that the majority of children and adolescents referred to gender services were from white, as opposed to non-white backgrounds. This was most striking in studies from the UK which showed that between 90-94% of referrals are white (Arcelus, Claes, Witcomb, Marshall, & Bouman, 2016; Holt et al., 2016; Skagerberg, Di Ceglie, & Carmichael, 2015). According to the 2011 UK census, 87% of the UK population identify as white (Office of National Statistics, 2011). Studies from Canada show that on average 75% of referrals were white (Bechard et al., 2016; Chiniara et al., 2018; Zucker et al., 2012). Chiniara et al. (2018) reported that, although 74% of the referrals reported their ethnicity as Caucasian, more than half of Toronto's population describes themselves as visible minorities. A study of children and adolescents referrals to a gender clinic in Los Angeles, showed that 52% of referrals were white (Olson et al., 2015). According to the 2005-2009 American Community Survey, 41.3% of people in Los Angeles identify as white, while

the majority (48%) identify as Hispanic or Latino.

Psychiatric co-morbidity

Recent studies demonstrate that gender dysphoria is characterised by psychiatric co-morbidity. Of eight studies presenting relevant data, six reported co-occurring conditions in excess of 50% of referred young people (see Tables 1.3 and 1.4). A study of children and adolescents presenting to a psychiatric outpatient clinic in Turkey showed that 90% had a least one psychiatric diagnosis in addition to gender dysphoria (Yildirim et al., 2017). A Finnish study showed that more than three-quarters of adolescent applicants for sexual reassignment had needed and/or currently needed specialist-level child and adolescent psychiatric services due to psychiatric problems other than gender dysphoria (Kaltiala-Heino et al., 2015). This high level of co-morbidity is verified by studies from the USA, Canada, Finland and the Netherlands, which show rates of co-morbidity of between 52% and 63% (Bechard et al., 2016; Chen, Fuqua, & Eugster, 2016; Peterson, Matthews, Copps-Smith, & Conard, 2017; Wallien et al., 2007). Bechard et al. (2017) stated that the level of co-morbidity identified in the study (60%) may have been underestimated since the study relied on information gathered during the intake interview and background reports, which may have been incomplete.

There were two exceptions to these findings. For example, a study of adolescents referred to a gender clinic in Amsterdam showed that 32% of referrals met DSM-IV criteria for more than one co-occurring psychiatric disorders; however, this is still more than in the general population (De Vries, Doreleijers, Steensma, & Cohen-Kettenis, 2011). In addition, Khatchadourian et al. (2014) reported that 26% of their clients had two or more diagnoses. The lower incidence of psychiatric co-morbidity identified by Khatchadourian et al. (2014) in Canada could be explained by the fact that the authors, like Bechard et al. (2017), relied on retrospective clinical notes to identify whether referrals had more than one diagnosis, which they acknowledged may have been incomplete. Most studies included the administration of

psychiatric assessment as part of the study design, which varied between studies. For example, some used the Diagnostic Interview Schedule for Children (DISC) (Ferdinand & van der Ende, 1998), which is a very structured, respondent-based psychiatric interview, to assess DSM Axis I mental disorders (e.g. Wallien et al., 2007). Other studies used the Minnesota Multiphasic Personality Inventory (MMPI), which is a questionnaire to assess psychological functioning (e.g. De Vries, Kreukels, Steensma, Doreleijers, & Cohen-Kettenis, 2011).

It is perhaps harder to understand the prevalence rate of 32% identified by De Vries et al. (2011a), which also relied on the DISC to assess co-morbid DSM Axis I mental disorders. In order to interpret this, it may be necessary to set these results in their wider context since the prevalence of psychiatric co-morbidity among young people with gender dysphoria is also likely to vary according to the level of general mental health difficulties within a given population. For instance, there is evidence to suggest that there has been a general decline in adolescent mental health in the UK in recent years (Patalay & Fitzsimons, 2017). By contrast, other European countries, including Denmark, Finland, the Netherlands and Norway, have not witnessed increased mental health difficulties among young people to the same degree (Bremberg, 2015).

Autism Spectrum Conditions (ASC)

Of the studies included in the review, 10 out of 24 reported on the prevalence of ASC among referred children and adolescents. Most demonstrate notable co-occurrence between gender dysphoria and ASC in children and adolescents. For instance, Skagerberg et al. (2015) explored the association between ASC and gender dysphoria by using the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2005) for those attending a gender identity service in London. The SRS measures the social ability of children from 4 to 18 years old and is used primarily with individuals with ASC, family members of individuals with ASC, and others with social impairments. It is, however, not a formal diagnostic tool. This study

showed that 54% of clients assessed scored in the mild/moderate to severe range on the SRS (Skagerberg et al., 2015).

Studies relying on more formal diagnoses show a lower prevalence rate. For instance, a Finnish study used more formal assessment tools, including the Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, DeLavore & Risi, 1999, 2001, 2002, 2008) with minors and the Developmental Diagnostic and Dimensional Interview (3Di) (Skuse et al., 2004) or Autism Diagnostic Interview Revised (ADI-R) (Le Couteur, Lord & Rutter, 2003) with parents, to diagnose 26% of referrals with ASC (Kaltiala-Heino et al., 2015). This exceeds the prevalence of 0.6% suggested for the general population in Finland (Ibid, 2015). Other studies show a prevalence of between 1% and 24% of comorbid gender dysphoria and ASC among referrals (Bechard et al., 2016; Chen, Fuqua, & Eugster, 2016, 2016; Chiniara et al., 2018; Holt et al., 2016; Hewitt et al., 2012; Khatchadourian, Amed, & Metzger, 2014; Peterson et al., 2017; Spack et al., 2012). The comparatively low prevalence rate of 1% identified by Spack et al. (2012) could be attributed to the fact that the study relied on information based on patient or parent recall and supplemented by information in referral letters, which may not have provided a comprehensive psychiatric history or accurate indication of a patient's current mental health.

Internalising problems

The reviewed studies show that gender dysphoria is associated with internalising problems, including depression/mood disorder and anxiety (de Vries et al., 2016; Röder et al., 2018). Most studies in the review commented on the prevalence of depression among children and adolescents at specialist gender identity services (15 out of 24 studies). In a study of 47 adolescents attending a gender clinic in Finland, 64% were having, or had undergone, treatment for depression (Kaltiala-Heino et al., 2015). In a study of 97 young people (age <21 years) referred consecutively to a gender clinic in Boston, Spack et al. (2012) showed that 25.7% had

a diagnosis of depression. In a study of 96 young people attending a gender clinic in Los Angeles, Olson et al. (2015) showed that 20% had scores in the moderate to severe range on the Beck Depression Inventory (Beck, Ward, Mendelson, Mock & Erbaugh, 1961). This is higher than the estimated 6.7% of general population of adolescents aged 12-17 (Olson et al., 2015). Other studies show that between 6% and 42% of children and adolescents referred to gender identity clinics have a dual diagnosis of depression and gender dysphoria, with most studies (11 out of 15) reporting this number to be over 25% (Bechard et al., 2016; Chen, Fuqua, & Eugster, 2016; Chiniara et al., 2018; De Vries et al., 2011a; De Vries et al., 2011b; Edwards-Leeper et al., 2017; Holt et al., 2016; Khatchadourian et al., 2014; Peterson et al., 2017; Wallien et al., 2007; Yildirim et al., 2017). In a study of referred children aged 4-11, Wallien et al. (2007) showed a prevalence rate of depression of 6%. This lower prevalence rate can be at least partly explained by the fact that the study was based on parent reports. It has been suggested that parents may underestimate anxiety and depression symptoms in their children because in general children are better at describing their internal states (Ibid., 2007). It may also be explained by the fact that the sample population did not include adolescents. There is evidence to suggest that referred adolescents, compared to the children, have higher rates of depression (Di Ceglie et al., 2002), which is most likely associated with the onset of puberty.

Gender dysphoria among clinically referred young people is also associated with anxiety disorders (including general anxiety disorder, separation anxiety disorder, social phobia, specific phobia etc.), with 9 out of 12 studies reporting on the prevalence of anxiety showing a range of between 21% and 55% in comorbidity (Bechard et al., 2016; De Vries et al., 2011a; Holt et al., 2016; Kaltiala-Heino et al., 2015; Khatchadourian et al., 2014; Peterson et al., 2017; Yildirim et al., 2017). However, a study from Australia stated that all referrals to a paediatric referral centre reported symptoms of anxiety (Hewitt et al., 2012). This higher prevalence rate

may be accounted for because the figures are based on reported symptoms, rather than a diagnosis derived from the use of formal measures.

Other studies showed lower prevalence rates of anxiety, which may have been because they relied on more formal measures of diagnosis. For instance, in a study of 120 children referred to a gender clinic in the Netherlands, 31% were given a diagnosis of anxiety after the Diagnostic Interview Schedule for Children was administered to parents (Wallien et al., 2007). A similar prevalence rate was demonstrated in a study of 203 adolescents referred to a children's hospital in Canada, which relied on the Multidimensional Anxiety Scale for Children (MASC2; March, 2012) to assess anxiety (Chiniara et al., 2018). However, two studies of adolescents attending gender clinics in the USA showed noticeably lower rates of comorbidity of 7-8% (Edwards-Leeper et al., 2017; Spack et al., 2012). Both of these studies relied on the Revised Children's Manifest Anxiety Scale (1st edition: Reynolds & Richmond, 1978) to assess anxiety. The slightly lower prevalence rates identified by the two studies employing the Revised Children's Manifest Anxiety Scale could be explained by the fact that the measure has been shown to have greater specificity than sensitivity, meaning that it may be less good at identifying young people with anxiety than it is those without (Mattison, Bagnato & Brubaker, 1988).

Eating disorders

Of the studies included in the review, 8 out of 24 reported on the prevalence of eating disorders among referred children and adolescents. These studies show that gender dysphoria is correlated with eating disorders (Peterson et al., 2017; Röder et al., 2018). A study of adolescents attending a paediatric gender clinic in Canada noted that five of the 97 (5%) patients had been found to be suffering from an eating disorder at presentation, and further ten patients (10%) were noted to have eating disorder-related symptoms (Feder, Isserlin, Seale, Hammond & Norris, 2017). While the risk of eating disorders was elevated in trans-males and females, risk was higher in trans-males when compared to population based prevalence rates

for cis females (ibid, 2017). Similarly, Holt et al. (2016) found that 13.3% of referred children and adolescents had “eating difficulties”. According to Röder et al. (2018), 50% of children and adolescents attending a gender clinic in Germany exhibited “weight loss behaviour or the intention to lose weight.”

Attention Deficit Hyperactivity Disorder (ADHD)

Of the studies included in the review, 9 out of 24 reported on the prevalence of ADHD among referred children and adolescents. These studies show that there is an association between gender dysphoria and ADHD. A study of 20 clinical cases with gender dysphoria in Turkey showed that it was the leading comorbidity, with 75% of referrals having a dual diagnosis of ADHD and gender dysphoria (Yildirim et al., 2017). This was determined by using the Schedule for Affective Disorders and Schizophrenia for School Aged Children Present-Lifetime Version (K-SADS-PL), which is a semi-structured diagnostic interview designed to assess current and past episodes of psychopathology in children and adolescents (Kaufman et al., 1997; Gokler et al., 2004). According to Rucklidge (2008), the K-SADS-PL has a low percentage of false negatives, showing good sensitivity; however, it has a high number of false positives (26.2%), which is indicative of moderate specificity. This may partially account for the particularly high prevalence of ADHD in the Turkish study.

The majority of studies in the review showed lower levels of association between the two conditions, with between 2% and 18% of referred children and adolescents diagnosed with both gender dysphoria and ADHD (Bechard et al., 2016; Chen, Fuqua, & Eugster, 2016; De Vries et al., 2011a; Holt et al., 2016; Kaltiala-Heino et al., 2015; Khatchadourian et al., 2014; Peterson et al., 2017; Spack et al., 2012). Wallien et al. (2007) showed that disruptive disorders, which they classified as those with a diagnosis of either ADHD or oppositional defiant disorder, were prevalent among children with gender dysphoria (23%).

Other co-morbidities

The studies in the review also show a link between gender dysphoria and other co-morbidities. For instance, Fisher et al. (2017) showed that 17% of adolescents attending a gender clinic in Italy were diagnosed with substance misuse difficulties. The association between substance misuse and gender dysphoria was identified in other studies albeit with a lower prevalence rate of between 1% and 7% (de Vries et al., 2011a; Khatchadourian et al., 2014; Yildirim et al., 2017). The different prevalence rates of substance misuse identified by these studies could be partly explained by the fact that the studies had different respondents (e.g. parents, carers or teachers; children or adolescents; or psychiatrists and other clinical staff members). This is important because studies have shown that there is significant variability between child and parent reports on psychiatric problems (Jensen et al., 1999). This is because parents may be unaware of their children's substance misuse, which may account for underestimates in studies reliant on parent reports. For instance, Fisher et al. (2017) relied on self-report measures to ascertain levels of substance misuse, whereas de Vries et al. (2011a) relied on parent reports.

Although some studies screened out children and young people with psychosis from their studies (e.g. Röder et al., 2018), others showed that there is an association between psychosis and gender dysphoria (Holt et al., 2016; Kaltiala-Heino et al., 2015) and bipolar disorder (Peterson et al., 2017; Spack et al., 2012).

Associated risks

Of the studies included in the review, 7 out of 24 reported on the prevalence of suicide attempts and 9 out of 24 on the prevalence of self-harm among referred children and adolescents. Suicidality and self-harm are specific concerns in gender dysphoric children and adolescents. In a clinical study of 96 transgender adolescents and emerging adults in the USA, 27 (30.3%) reported a history of at least one suicide attempt and 40 (41.8%) reported a history

of self-injurious behaviour (Peterson et al., 2017). These findings are consistent with a study from Los Angeles, which showed that 33% of referred young people (vs. 8% of general youth according to Youth Risk Behaviour Survey data from 2013) had made an attempt on their life (Olson et al., 2015). A study of 50 consecutive referrals to a gender identity service in Ontario, Canada, showed that 26% had made an attempt on their lives and 36% had a history of self-harm (Bechard et al., 2016).

Findings from the UK are consistent with the results from the USA and Canada in regards to the prevalence of self-injury, but not for suicide attempts. For example, a Nottingham study showed that nearly half of the young people referred to a clinic had a history of engaging in self-injury (Arcelus, Claes, Witcomb, Marshall, & Bouman, 2016). However, a study of gender-referred young people in London showed that, while 39% had a history of self-harming behaviour, 13% had made an attempt on their life (Holt et al., 2015). This slightly lower rate of suicide attempts was also found among adolescents referred to gender clinics in Italy (Fisher et al., 2017); Boston, USA (Spack et al, 2012) and Vancouver, Canada (Khatchadourian et al., 2014). A Finnish study showed a rate of 53% for “suicidal and self-harming behaviours” combined (Kaltiala-Heino et al., 2015).

Discussion

The body of research that has emerged since 2007 has provided valuable insights into the demographic characteristics, psychiatric co-morbidity and associated risks of children and adolescents referred to gender identity clinics and other specialist services for people experiencing gender dysphoria. First, the studies included in the review show that young people report being aware of their gender dysphoria prior to the onset of puberty, but tend not to present to services until after puberty is underway. These studies show a gap between the age of onset and age of presentation to clinical services, over 10 years in some cases. Given that

only two studies included in the review reported both age of onset and age of presentation to clinical services, the finding regarding delayed presentation is necessarily tentative.

Yildirim et al. (2017) suggest that delayed presentation may be due to several factors, including parental belief that the gender dysphoric feelings are transient; that the symptoms are not sufficiently severe to warrant treatment, or due to the child's young age. It is only when the difficulties continue into adolescence that parents become more worried and start seeking support for their child (Ibid, 2017). There may be other barriers to earlier access to care that could be explored further. It is also important to note that records of early onset gender dysphoria rely on retrospective self-report. As Zucker et al. (2012) observed, young people referred to GID services can express certainty about medical interventions being the only solution to their gender dysphoria. Therefore, there is a possibility that, in some cases, young people may believe that reporting a longstanding history of gender dysphoria may improve their chances of accessing the desired treatment.

The review shows that in general more adolescents, than children, are presenting to gender identity clinics. Wood et al. (2013) suggests that more adolescents are seeking treatment because they have greater access to the Internet, including social media, resulting in increased awareness of transgender people and the existence of treatment interventions (e.g. pubertal suppression). In addition, Littman (2018) proposes that some young people may have been influenced by peers and immersed in trans-related online content, and introduces the term 'rapid onset gender dysphoria' as a way of describing those that report to services in mid-adolescence without prior indication of gender dysphoria. This may be connected to broader social and cultural factors related to being a member of 'Generation Z' (also known as 'Post-millennials') characterised by being technologically savvy, questioning of gender norms, espousing individuality and choice, and frequently reinventing themselves online (Doster, 2013).

Adolescence is a phase in life involving major transition, as young people go through the complex adjustment to the major physical, cognitive and emotional changes associated with puberty. It also requires the ability to navigate changing social interactions with peers and is a time when young people may have their first romantic experiences (Steensma, Biemond, Boer, & Cohen-Kettenis, 2011). Therefore, it is a period of life often characterised by significant uncertainty, upheaval, confusion and sometimes distress. Feminist researchers suggest this may particularly be the experience of young women, who often have feelings of shame in relation to their menstruating female body (Roen, 2016). For these reasons, it has been suggested that “during puberty and adolescent development there may be some overlap between normative testing of sexuality and gender roles at the one end, and gender dysphoria as a disorder at the other end of the spectrum” (Kaltiala-Heino et al., 2015: 7).

Puberty can be particularly challenging for gender dysphoric young people due to the significant physical changes young people undergo during this time (Devor, 2004; Hewitt et al., 2012), which can make the incongruence between an individual’s self-perceived gender identity and his/her biological sex more apparent. This can result in an intensified sense of distress among adolescents with gender dysphoria (Holt et al., 2016). This is supported by findings from an earlier clinical chart study of referrals to a UK gender clinic that shows that referred adolescents, compared to the children, had higher rates of depression (52 % vs. 26 %), self-harm (23 % vs. 0 %), and self-injurious behaviour (22 % vs. 2 %) (Di Ceglie et al., 2002).

Recent studies also show a shift in the sex ratio from one favouring birth-assigned males to one favouring birth-assigned females among referrals to specialist clinics. At present, the reasons for this inversion in sex ratio are unclear and hypotheses are tentative. Kaltiala-Heino et al. (2015) suggests that this may be due to more permissive societal attitudes that enable young people to “come out” as gender variant more easily. However, this would account for the increase in birth-assigned male, as well as birth-assigned female referrals. Another

possibility is that birth-assigned males face disproportionately greater stigma than birth-assigned females, which makes it comparatively easier for birth-assigned females to seek treatment (Aiken et al., 2015). However, this makes it harder to explain why historically birth-assigned males constituted the majority of referrals to specialist services. De Graaf, Giovanardi, Zitz & Carmichael (2018) propose that birth-assigned females may be increasingly worried about the prospect of puberty in childhood, compared to birth-assigned males. The sex difference in pubertal onset, which occurs earlier in birth-assigned females than in birth-assigned males, may mean that the incongruence between birth-assigned sex and felt gender identity intensifies earlier in birth-assigned females (de Graaf, Carmichael, Steensma & Zucker, 2018). It may also be necessary to take into account broader social and cultural factors in trying to understand the recent shift in sex ratio. It is possible that the influences of socially constructed and stereotyped views of “femininity” and “masculinity” (and the way they are displayed on social media) may have a bearing on the increase in birth-assigned female referrals (de Graaf, Giovanardi, Zitz & Carmichael, 2018).

The majority of studies show that referred adolescents are generally sexually attracted to people of the same birth-assigned sex. As discussed above, these findings are important because sexual attraction to individuals of a different sex from the young person’s birth-assigned sex may be predictive of a more challenging treatment course and less favourable outcomes (Leibowitz & De Vries, 2016). This is perhaps best illustrated by a quote from a birth-assigned female adolescent included in Wood et al. (2012): “If I walk down the street with my girlfriend and I am perceived to be a girl, then people call us all kinds of names...but if I am perceived to be a guy, then they leave us alone.” This could be understood in the context of concerns about ‘lesbian eradication’ (Moraga, 2011), which highlight that lesbians may be becoming more denigrated over time and in different contexts, making being lesbian more

challenging and less socially preferable to young women. A recent study from the US showed that it is perceived as socially undesirable ‘to be open about being gay’ (Coffman et al., 2017).

Further, the review shows that the majority of children and adolescents referred to specialist gender clinics are white. A possible implication of these findings is that gender clinics may be less accessible to young people from Black, Asian and Minority Ethnic (BAME) backgrounds because of potential barriers, such as lack of familiarity with services, language differences and lack of cultural awareness among professionals. However, a recent study - showing that less than 10% of referrals to a GID service in the UK come from BAME backgrounds – suggests that this may offer only a partial explanation (de Graaf, Manjra, Hames, & Zitz, 2019). This is because referrals of BAME young people to Child and Adolescent Mental Health Services (CAMHS) are elevated compared to referrals of BAME young people to GID services. This suggests that gender may be conceptualised differently cross-culturally, which make it harder for gender diverse young people coming from BAME backgrounds to “label their identity” (Ibid., 2019: 8). Further research is required to investigate the under-representation of young people from BAME backgrounds being referred to GID services.

It is evident from the review that there is a high level of co-occurrence between gender dysphoria and other psychiatric presentations; however, there is a question as to how to best understand these associations. For instance, it is important to ascertain whether these associations are a consequence of gender dysphoria (and the gender minority stress model) or attributable to other more general factors (e.g. family history of psychopathology) (Bechard et al., 2016). The gender minority stress model is based on Meyer’s (2003) minority stress model, which suggests that members of stigmatised minority groups have a higher prevalence of mental health difficulties as a consequence of interpersonal prejudice and discrimination, which creates a hostile and stressful social environment. Higher or lower levels of psychiatric

co-morbidity are likely due to the level of tolerance and acceptance of gender variant behaviours in different cultures (Fisher et al., 2017). An alternative hypothesis is that gender dysphoria may at times be better understood in the context of broader identity confusion (Churcher Clarke & Spiliadis, 2019; Kaltiala-Heino et al., 2015, 2018).

Specifically, the review shows that co-occurring gender dysphoria and ASC is prevalent. The implication is that ASC needs to be taken seriously in considering treatment guidelines for children and adolescents with gender dysphoria. It has been hypothesised that feelings of being different and outsiders among peers could play a role in children with ASC developing gender dysphoria (Kaltiala-Heino et al., 2015). It has also been suggested that gender dysphoria may arise in people with ASC because of their predisposition towards unusual interests (Williams, Allard & Sears, 1996), which means it may be representative of Obsessive Compulsive Disorder (OCD) rather than gender identity difficulties (Kaltiala-Heino et al., 2015). Vanderlann et al (2014) found an increased tendency for gender variant children to have obsessions and compulsions relative to non-gender variant children. Further research is required to elaborate the relationship between these two conditions.

The results also show that there is association between gender dysphoria and low mood/depression. As discussed above, the fact that puberty (and the start of menstruation and the development of secondary sex characteristics) can exacerbate gender dysphoric young peoples' feelings of low mood may partially account for this relationship.

There is a further association between gender dysphoria and eating disorders. Young people with gender dysphoria are understood to endorse elevated scores on measures related to body shape and weight, which may underlie the increased risk for an eating disorder (Feder et al., 2017). This is consistent with findings from adult studies (Witcomb, Bouman, Brewin, Richards, Fernandez-Aranda & Arcelus, 2015). Feder et al. (2017) hypothesise that the sense of feeling overwhelmed and powerless in dealing with one's gender identity leads to the

emergence of an eating disorder as a strategy for coping. There is also some evidence to suggest that young people may develop eating disorders in attempt to halt or control the development of secondary sex characteristics during puberty, which can be highly distressing (Couturier, Pindiprolu, Findlay & Johnson, 2015; Ristori et al., 2019). Puberty is one of the most frequently discussed risk periods for the development of eating disorders (Klump, 2013). The relationship between gender dysphoria and eating disorders is an important area of further study. There is a small body of literature that suggests a more complex interaction between the two conditions in the context of sexual trauma (Nelson & Schulz, 2012). The intersection between a young person's emerging sexuality, gender identity and relationship to their body during adolescence also requires careful exploration.

The link between gender dysphoria and ADHD is consistent with findings from studies of individuals referred for ADHD, which show that they were 6.64 times more likely to be gender variant (Strang et al., 2014). Yildirim et al. (2017) explain the high rate of comorbid ADHD by the age range of the participants, which includes young children. None of the other studies attempt to elaborate this relationship.

As shown above, gender dysphoria is strongly associated with other psychiatric diagnoses. The results demonstrate that this can lead to substance misuse, self-harming or suicidal behaviour, as strategies for coping with this distress. Gender dysphoric children and adolescents referred to specialist services are at elevated levels of risk compared to their non-referred peers. This underscores the importance of risk assessment and management in clinical services.

Methodological limitations

In addition to those identified above, there are further methodological limitations associated with this review, which should be held in mind when considering the results. For instance, the review only included English-language papers. This means that valuable data emerging from

other international gender identity clinics were excluded (e.g. Becker, Gjergji-Lama, Romer & Moller, 2014; Meyenburg, 2014). In addition, the review only included papers that included children and adolescents referred to specialist services. This means that results may not generalise to transgender individuals who do not desire therapeutic or medical interventions, or who have not been able to access specialist services.

The review also included studies pertaining to both child and adolescent samples because the literature does not currently support more fine-grained analyses. This means that the review does not elucidate any differences between the two groups. The review also does not distinguish between birth-assigned females and birth-assigned males, meaning important differences between the sexes are not addressed. For example, Arcelus et al. (2016) and Holt et al. (2015) identify important differences between sexes in relation to self-injurious behaviour. Both studies showed that self-harming behaviour was higher among birth-assigned female referrals compared to birth-assigned males, which suggests that expressions of distress follow patterns according to sex. This is consistent with recent research showing that about one in five females aged 16-24 in the UK reported engaging in non-suicidal self-harm (McManus et al., 2019). In addition, De Vries et al (2011a) and Holt et al. (2015) showed ASC to be more prevalent among birth-assigned males, while Feder et al. (2017) showed that birth-assigned females experience a 19-fold increase in risk of having a restrictive eating disorders. Differences in psychiatric co-morbidity between gender dysphoric birth-assigned females and birth-assigned males would warrant further research.

Some heterogeneity exists among the studies included in the review with regards to sexual orientation, even though they all supported the same finding: that the majority of young people are attracted to individuals of the same birth-assigned sex. For instance, some studies only used one question to measure sexual orientation (e.g. Spack et al., 2012); however, sexuality consists of various components (e.g. De Vries et al., 2011b). For this reason, Wood et al. (2013) and

Zucker et al (2012) used the Erotic Response and Sexual Orientation Scale, which is a multi-dimensional, quantitative metric of hetero-erotic and homo-erotic sexual orientation in fantasy. Olson et al (2015) raise the important point that their researcher made the assumption that the young people in the study would use their gender identity as the referent for self-labelling sexual orientation, but it is possible that birth-assigned sex might have been the referent. Further research on the intersectionality between sexual orientation and gender identifies is needed.

While most studies considered all referrals coming into the services, others applied certain criteria. For instance, some had to meet formal DSM criteria for gender dysphoria following extensive psychological assessment of the child and interviews with the child and their parents (e.g. Wallien et al., 2007). Others used measures, such as the Utrecht Gender Dysphoria Scale (Steensma et al., 2013), the Piers-Harris Children's Self Concept Scale (Piers & Herzberg, 2002), and the Gender Identity Questionnaire for Adolescents (Deogracias et al. 2007), to identify participants (e.g. Khatchadourian et al., 2014).

Most of the reviewed studies did not have a clinical control group, which meant it was not possible to determine whether the number of vulnerability factors identified would be more than, similar to or less than the number of such factors found in youth in the general population. However, where possible, studies have considered their finding in the context of population-based prevalence rates (e.g. Chiniara et al., 2018; de Vries et al., 2011a; Feder et al., 2017; Kaltiala-Heino et al., 2015).

All the studies in the review were cross-sectional. More longitudinal studies exploring the associated psychopathology in children and adolescents with gender dysphoria are needed to shed light on how psychiatric comorbidity is associated with gender dysphoria, and to ascertain whether psychological and/or physical intervention improve psychological functioning in this cohort.

Research recommendations

The review has highlighted a number of recommended areas for future research. These include identifying any barriers to earlier access to specialist services among gender dysphoric children. In addition, research is needed to ascertain why disproportionately fewer gender dysphoric children and adolescents from BAME backgrounds currently access specialist services. Work could also be done to improve understanding regarding the recent increase in referrals of birth-assigned females compared to birth-assigned males, and why historically birth-assigned males constituted the majority of referrals to specialist services. This research would also need to consider socio-cultural factors underscoring the increase in referrals, including finding ways to measure the impact of social influence, online and print media and culture on body image. Lessons could be learned from other disciplines. For instance, there is a body of quantitative research emerging from communications research departments examining the impact of social media on women's perceptions of their bodies (e.g. Eckler, Kalyango & Paasch, 2017). Additionally, it would be useful to understand how sexuality impacts treatment outcomes among referred adolescents with gender dysphoria and to explore the interaction between gender and sexual identity development.

The association between gender dysphoria and certain mental health difficulties are evident. Further research though is required to elucidate the relationship between these conditions and provide more fine-grained analysis (e.g. understanding the differences in psychiatric co-morbidity between gender dysphoric birth-assigned females and birth-assigned males). In particular, it would be useful to ascertain whether the gender minority stress model can help explain the association between gender dysphoria and certain mental health difficulties, or if it is due to other factors (e.g. distress caused by onset of puberty and the associated physical changes). For this to be possible, further work needs to be done to understand the experiences of gender identity development among gender dysphoric young

people with psychiatric co-morbidities, such as depression, anxiety, eating disorders, ASC etc. It is also important to understand more about how adolescents who obtain a diagnosis of gender dysphoria experience puberty since the onset of puberty has been shown to exacerbate gender-related distress (Hewitt et al., 2012).

In addition, researchers should also consider which factors are important in increasing resilience among gender dysphoric children and adolescents. This could include exploring the impact of community-level interventions to promote tolerance towards and acceptance of those that identify in diverse and gender non-conforming ways.

Clinical implications

The review shows the importance of improving access to specialist GID services for gender dysphoric children and adolescents from BAME backgrounds, and potentially to clinical support from an earlier age. In view of the increasing numbers of referrals, it may also be important for services to develop accredited training programmes with the aim of equipping the CAMHS clinical workforce with the knowledge and skills to explore gender and sexuality with gender non-conforming young people, and helping clinical teams to think about these aspects of young people's experiences in a more general way. Many gender dysphoric children and adolescents will continue to need specific care and management within specialist clinical teams because of the high levels of psychiatric co-morbidity and associated risks within this population to help prevent self-harming behaviour and suicide attempts. This underscores the importance of supportive therapeutic interventions for children and adolescents with gender dysphoria in clinical services.

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Paper 2: Empirical Paper

Understanding Gender Identity Development in Gender Variant Birth-Assigned Female Adolescents with Autism Spectrum Conditions (ASC)

Abstract

Aim: This study aims to generate understanding of gender identity development in birth-assigned female gender variant adolescents with Autism Spectrum Conditions (ASC).

Method: Ten birth-assigned females aged between 15 and 18 years with a clinical diagnosis of ASC were recruited from a Gender Identity Development (GID) service and interviewed using a semi-structured interview schedule. Qualitative data was analysed using Constructivist Grounded Theory method. The Strengths and Difficulties Questionnaire (SDQ) was used and data related to participants' age, ethnicity, schooling and history of mental health difficulties was collected in order to situate the sample.

Results: Constructivist Grounded Theory analysis of the participants' accounts identified a core category of 'Journey Towards Understanding', and four major categories. Three of the major categories pertained to the consecutive stages of this journey: 'Awareness of Difference', 'Experience of Incongruence', and 'Understanding Difference'. The final major category, 'Neurodiversity as a Facilitator of Change', reflected the intrapersonal and interpersonal processes associated with having ASC that may have enabled the participants to make the transition towards living as (trans) males.

Conclusions: This exploratory study has identified some important features of gender identity development among gender variant birth-assigned females with ASC. Further research is needed to expand upon the categories identified in this study.

Introduction

Background

Gender dysphoria involves marked incongruence between a person's experienced or expressed gender, and their physical or birth-assigned sex (American Psychiatric Association [APA], 2013). The psychiatric diagnosis of gender identity disorder was introduced in the Diagnostic and Statistical Manual-III (DSM-III) in 1980, but was reclassified in DSM-5 in 2013 as gender dysphoria in order to avoid pathologising identity (Pyne, 2014). The term "transgender" is typically used as an umbrella term referring to a broader variety of gender identities, including gender variance and gender non-conformity. While gender dysphoria is associated with clinically significant distress or impairment in social, occupational or other important areas of functioning (APA, 2013), not all who identify as transgender experience dysphoria. These individuals can therefore be described as gender variant, rather than gender dysphoric (see Appendix J for a list of definitions of all gender-related terminology used in this study).

Specialist Gender Identity Development (GID) services have been set up around the world to respond to the needs of those experiencing gender dysphoria. Recent years have witnessed an increase in referrals of children and adolescents to these services, and the number of referrals is expected to rise further (Chen, Fuqua & Eugster, 2016; Zucker, Wood, Wasserman, VanderLaan & Aitken, 2016). For instance, a national GID clinic in the United Kingdom saw referrals increase from 2016 in 2016-17 to 2519 in 2017-18, which represents a 25 per cent increase; fewer than 100 young people were referred to the service between 2009-2010 (GIDS Referral Figures 2017-18, 2018). The reason for the increase in referrals is subject to debate. It is likely due to a number of factors, including the increased positive presence of transgender people in the media and the associated de-stigmatisation of gender dysphoria, and growing awareness of available psychological and/or medical interventions (Chen, Fuqua & Eugster,

2016; McInroy & Craig, 2015). It is further suggested that this increase may be due to “cultural developments that promote the conceptualization of developmental challenges as being rooted in sex and gender” (Kaltiala-Heino, Sumia, Työläjäarvi, & Lindberg, 2015: 2). Concerns have also been raised regarding the impact of social media, and whether the increase in referrals is a consequence of social influence or ‘contagion’, especially among young people whose concerns regarding their gender emerge in mid-adolescence without any prior indication (Littman, 2018).

Co-occurrence of gender variance/dysphoria and ASC

A large proportion of recent referrals to GIDS services are characterised by complex and later-onset presentations, with a high degree of other psychosocial and neurodevelopmental difficulties, including Autism Spectrum Conditions (ASC) (Kaltiala-Heino et al., 2015; Kaltiala-Heino, Bergman, Työläjäarvi, & Frisen, 2018). ASCs are lifelong developmental conditions characterised by two groups of symptoms: (i) social communication and interaction difficulties, and (ii) restricted, repetitive behaviours and unusual sensory perception (DSM-5; APA, 2013). Recent research suggests that children and adolescents with ASC are more likely than those without ASC to experience gender variance or gender non-conformity: when a person’s behaviour or gender expression does not match the gender-based norms of society. Strang et al. (2014) explored rates of gender variance, as reported in the Child Behaviour Checklist (Achenbach & Rescorla, 2000): a caregiver report identifying problematic behaviour in children. They discovered that gender variance was 7.59 times more common in participants with ASC than in a large non-referred comparison group (Ibid., 2014).

While not all gender variant children and adolescents with ASC will experience distress that brings them to the attention of gender identity services, they are at elevated risk of gender dysphoria. This is supported by a growing body of research showing co-occurrence between gender dysphoria and ASC (Bejerot & Eriksson, 2014; George & Stokes, 2018; Glidden,

Bouman, Jones & Arcelus, 2016; Øien, Cicchetti & Nordahl-Hansen, 2018; Van Der Miesen, Hurley & de Vries, 2016). Skagerberg, Di Ceglie and Carmichael (2015) presented results of a study exploring the association between ASC and gender dysphoria using the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2005) - a measure used to identify ASC among children aged 4 to 18 years old by assessing social impairment - for those attending a gender identity service in London. The findings showed that 54.2% of clients assessed scored in the mild/moderate to severe range on the SRS. Moreover, VanderLaan et al. (2015) used the SRS to assess autistic traits in 49 children and adolescents with gender dysphoria. The study showed that 44.9% scored in the clinical range. The SRS, however, is not a formal diagnostic tool. Turban and van Schalkwyk (2018) caution that ASC screeners used in some studies exploring the link between gender dysphoria and ASC have poor specificity.

Studies relying on more formal diagnoses show lower, but still high, prevalence rates of ASC. For instance, a Finnish study used more established assessment tools (including the Autism Diagnostic Observation Scale (ADOS) with minors and the Developmental, Dimensional and Diagnostic Interview (3Di) with parents) to diagnose 26% of referrals with ASC (Kaltiala-Heino et al., 2015). This greatly exceeded the prevalence of 0.6% suggested for the general population of Finland (Ibid., 2015). de Vries, Noens, Cohen-Kettenis & van Berckalaer-Onnes (2010) showed that the incidence of ASC diagnoses in children and adolescents referred to a gender identity service in Amsterdam was 7.8%: approximately ten times higher than the prevalence of 0.6-1% in the general population. Other studies show a prevalence of between 1% and 24% of ASC among referrals to specialist gender services (Bechard, VanderLaan, Wood, Wasserman, & Zucker, 2016; Chen, Fuqua, & Eugster, 2016; Chiniara, Bonifacio, & Palmert, 2018; Hewitt et al., 2012; Holt, Skagerberg, & Dunsford, 2016; Khatchadourian, Amed, & Metzger, 2014; Peterson, Matthews, Copps-Smith, & Conard, 2017; Shumer, Reisnet, Edwards-Leeper, & Tishelman, 2016; Spack et al., 2012).

Gender identity development and ASC

Boskey (2014) reported that by the time a child is 8 months of age he/she is capable of categorizing adults by gender; label their own gender by age two and by three or four years old attribute behaviours and different traits specifically to males or females. Gender identity is usually well-established in most children by the early pre-school years (Becker & Kavoussi, 1994; Fausto-Sterling, 2012). There is further recognition that in their developing gender identity children are “active agents who recognize the pressures to conform and adjust their behaviour accordingly” (Brinkman, Rabenstein, Ros & Zimmerman, 2014: 837).

According to Van Schalkwyk, Klingensmith and Volkmar (2015), children with ASC may progress through gender identity development along differing timelines or frameworks compared to children without ASC due to their differing patterns of social development. It is possible that children with ASC may resist the pressure to conform to gender norms that Brinkman et al. (2014) identifies as a feature of typical gender identity development. This is substantiated by a study showing that children with autistic traits are less likely to conform to a social majority on a line judgment task compared to neuro-typical children (Yafai, Verrier & Reidy, 2014). This was taken as indication of the resistance of children with ASC to social pressure. In a study of 30 autistic children, Abelson (1981) showed that gender identity was related to mental age, chronological age, as well as physical, social, self-help, communication and academic (cognitive) skills. Tateno, Tateno and Saito (2008) suggested that confusion in the development of gender identity, or an altered development of gender identity, might increase feelings of gender dysphoria in children with ASC.

Association between gender dysphoria and ASC

A number of studies have advanced further tentative hypotheses regarding the association between ASC and gender dysphoria, but these ideas have rarely been tested. Van Der Miesen, Hurley and de Vries (2016) organised the hypotheses offered in the existing

literature into three categories, as to whether underlying assumptions are (i) biological, (ii) social or (iii) psychological.

A biological explanation is the Extreme Male Brain Theory (Baron-Cohen, 2002; Baron-Cohen et al., 2011), which posits that prenatal testosterone may not only lead to a higher disposition towards ASC, but also gender dysphoria as an expression of extreme male characteristics (Knickmeyer, Wheelwright & Baron-Cohen, 2006). This is said to explain why females with ASC appear to be more susceptible to developing gender dysphoria, but it leaves comorbidity in birth-assigned males unexplained (Pasterski, Gilligan & Curtis, 2014; Kaltiala-Heino et al., 2015). Wren (2014) cautions against simplistic views of the way that biology influences gender development.

The second category suggested by Der Miesen, Hurley and de Vries (2016) includes social factors that could explain the relationship between ASC and gender dysphoria. Limited understanding of social relationships, which is a characteristic of individuals with ASC, suggests that gender dysphoria could be a result of difficulties in social interaction (Van Schalkwyk, Klingensmith, & Volkmar, 2015). For example, Tateno, Tateno and Saito (2008) suggested that a young birth-assigned male with ASC, who was bullied by other young males, may have developed a feeling of belonging to the female sex out of aversion to males. Parkinson (2014) described two birth-assigned males who had feelings of being different and who interpreted these feelings as gender dysphoria. Therefore, “long-standing feeling of being different and an outsider among peers could play a role in children with ASC developing gender dysphoria in adolescence” (Kaltiala-Heino et al., 2015: 7).

The third and final category recommended by Der Miesen, Hurley & de Vries (2016) are psychological factors that could underpin the association between ASC and gender dysphoria. Wren (2014) stresses the importance of being open to the idea of gender identity serving many diverse psychological needs and functions. It has been suggested that young

people with a comorbid diagnosis of gender dysphoria may hold more rigid views of what it means to be male or female (Holt et al., 2014), and may misinterpret any gender nonconformity that they display as indicative that they are transgender (de Vries et al. 2010; Jacobs, Rachlin, Erickson-Schroth & Janssen, 2014). In a study of late-diagnosed women with ASC, Bargiela, Steward and Mandy (2016: 10) noted that, although no one reported being at odds with their birth-assigned sex, some women experienced a conflict between a feminine and autistic identity suggesting “one potential influence on the elevated rates of gender dysphoria and non-binary gender amongst [birth-assigned] females with ASC.” In addition, it has been hypothesized that theory of mind deficits and cognitive styles may be potential influences on the process of gender identity formation (Jacobs et al., 2014). Moreover, gender dysphoria may arise from people with ASC’s predisposition towards unusual interests (Williams, Allard & Sears, 1996), which means it may be indicative of Obsessive Compulsive Disorder (OCD) rather than gender identity related difficulties (Kaltiala-Heino et al., 2015). Vanderlann et al. (2014) found an increased tendency for gender variant children to have obsessions and compulsions relative to non-gender variant children.

Puberty and gender identity development

Adolescence is a phase in life involving major transition, as young people go through the complex adjustment to the major physical, cognitive and emotional changes associated with puberty (Churcher Clarke & Spiliadis, 2019). Roen (2016) cites a number of researchers who have written about young females’ experiences of pubertal change in general, and menstruation in particular, highlighting the particular salience of shame about their bodies. For instance, the paper references Martin’s (1996) research with adolescent females highlighting the shame they experience in relation to their bodies and pubertal development, as well as Lee (1994) and Oinas (1998) which describe young women’s sense of fear, shame and disempowerment in relation to menstruation. The writer concludes that, for someone raised as a girl, learning to

“interpret her body as shameful and potentially shaming ... may be part of the experience of becoming a woman” (Frost, 2005: 81).

The fact that puberty may be disproportionately more challenging for young women is well-evidenced. A review of children taking part in the Millennium Cohort Study, which is a representative group of children born in the UK at the start of this century, showed that from ages 3 to 11 years similar proportions of females and males experienced emotional problems as reported by their parents; however, between age 11 and 14 years prevalence in males stayed the same (around 12%), but for females it increased from 12% to 18% (Patalay & Fitzsimons, 2017). It has also been shown that, in Western cultures, young women’s self-esteem declines substantially during middle adolescence, with changes in body image (associated with exposure to unrealistic media images of female beauty) proposed as a possible explanation (Clay, Vignoles, & Dittmar, 2005). For these reasons, it is necessary at times to consider gender dysphoric young peoples’ experiences in the context of broader identity confusion and distress associated with general pubertal development (Churcher Clarke & Spiliadis, 2019; Kaltiala-Heino et al., 2015).

Puberty can present a particular challenge for young people with ASC, who can find it harder to manage these changes compared to neuro-typical adolescents (Gillberg, 1984). Similarly, puberty presents difficulties to gender dysphoric young people due to significant physical changes young people undergo during this time (Devor, 2004; Hewitt et al., 2012), which may make the incongruence between an individual’s self-perceived gender identity and his/her biological sex more apparent. This can result in a heightened sense of distress among adolescents with gender dysphoria (Holt et al., 2016). This is borne out in a clinical chart study of referrals to a UK gender clinic which reported that referred adolescents, compared to the children, had higher rates of depression (52 % vs. 26 %), self-harm (23 % vs. 0 %), and self-injurious behaviour (22 % vs. 2 %) (Di Ceglie, Freedman, McPherson & Richardson, 2002).

Recent research also shows that in general more adolescents than children are presenting to gender identity clinics around the world (Chiniara et al., 2018; De Vries, Kreukels, Steensma, Doreleijers, & Cohen-Kettenis, 2011; De Vries, Doreleijers, Steensma, & Cohen-Kettenis, 2011; Feder, Isserlin, Seale, Hammond, & Norris, 2017; Fisher et al., 2017; Holt et al., 2016; Kaltiala-Heino et al., 2015; Khatchadourian, Amed, & Metzger, 2014; Peterson et al., 2017; Röder et al., 2018; Skagerberg, Di Ceglie, & Carmichael, 2015; Spack et al., 2012).

Increasing referrals of birth-assigned females

Historically, more birth-assigned males have been referred to specialist gender dysphoria services than birth-assigned females (Cohen-Kettenis & Pfafflin, 2003). A number of more recent studies (based on post-2007 samples) show a significant shift in the sex ratio from one favouring birth-assigned males to one favouring birth-assigned females at birth (or to near parity), and demonstrate that this a global phenomenon (Chen, Fuqua, & Eugster, 2016; Chiniara, Bonifacio, & Palmert, 2018; Feder et al., 2017; Holt et al., 2016; Kaltiala-Heino et al., 2015; Röder et al., 2018; Skagerberg, Di Ceglie, & Carmichael, 2015). For instance, 1806 of the 2519 young people referred to a UK GID clinic between 2017 and 2018 were birth-assigned females (GIDS Referral Figures 2017-18, 2018).

At present, the reasons for this inversion in sex ratio is unclear and hypotheses are tentative. Kaltiala-Heino et al. (2015) suggests that it may be due to more permissive societal attitudes that allow young people to “come out” as gender variant more easily than before. However, this explanation would predict an equivalent increase in birth-assigned male, as well as birth-assigned female, referrals. Another possibility is that birth-assigned males face disproportionately greater stigma than birth-assigned females, which makes it comparatively easier for birth-assigned females to seek treatment (Aiken et al., 2015). This, however, makes it harder to explain why historically birth-assigned males constituted the majority of referrals to specialist services. It has been proposed that birth-assigned females in childhood may be

increasingly worried about the thought of puberty, compared to birth-assigned males (de Graaf, Giovanardi, Zitz & Carmichael, 2018). Further, it has been suggested that the sex difference in pubertal onset, which occurs earlier in birth-assigned females than in birth-assigned males, may mean that the incongruence between birth-assigned sex and felt gender identity intensifies earlier in birth-assigned females (de Graaf, Carmichael, Steensma & Zucker, 2018),

Broader social and cultural factors may also help explain the recent shift in sex ratio. It is possible that the influences of socially constructed and stereotyped views of “femininity” and “masculinity”, and the way they are displayed on social media, might have an impact on the increase of birth-assigned female referrals (de Graaf, Giovanardi, Zitz & Carmichael, 2018).

Aims

Knowledge and understanding of the co-occurrence of gender variance and ASC is far from complete. As illustrated above, there is a growing body of research showing the over-representation of co-occurring gender dysphoria and ASC compared to what would be expected by chance based on the prevalence of ASC in the general population. However, less research has been undertaken to examine the hypotheses that attempt to explain this relationship. There are a number of case studies that illustrate cases of gender dysphoria in children and adolescents with ASC, which have given rise to tentative hypotheses regarding this association (Damasch, 2014; Galluci, Hackerman, & Schmidt, 2005; Landén & Rasmussen, 1997; Mukaddes, 2002; Parkinson, 2014; Tateno, Tateno & Saito, 2008; Williams, Allard. & Sears, 1996), but almost all of these ideas are as yet untested (Van Der Miesen et al., 2016). Furthermore, only limited attempt has been made to generate a broader, systematic theoretical understanding of gender identity development in children and adolescents with ASC using in-depth interviewing (e.g. Strang et al., 2018).

The current study focused on understanding gender identity development in adolescent birth-assigned females with ASC who experience distress or difficulty because of the

incongruence between their experienced/expressed gender and their birth-assigned sex. While these individuals may not necessarily have met the criteria for a diagnosis of gender dysphoria, they were all part of a clinical population that had come to the attention of a specialist National Health Service (NHS) service. The evidence presented above shows a high prevalence of gender dysphoria among birth-assigned females contrary with the epidemiology of both ASC and gender dysphoria, which have historically been characterized by the over-representation of males (de Vries et al., 2010). It has also been suggested that there is under-representation of females in ASC research, which may have generated a male-biased understanding of ASC (Gould & Ashton-Smith, 2011; Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015). This study seeks to help redress this imbalance.

The study was interested in understanding gender identity development specifically in adolescents aged between 15 and 18 years old. As explored above, the reason for focusing on this age-group was because puberty presents particular challenges for gender variant birth-assigned females, and young people in this age category were likely to have undergone pubertal physical development and therefore able to reflect on their experience of puberty. Although the duration of puberty in females depends on the timing of its onset, most females reach physical maturation by about 14-15 years of age (Marti-Henneberg & Vizmanos; 1997). There is also evidence to suggest that early pubertal timing is common among adolescent female-to-male 'sex reassignment applicants' (Sumia, Lindberg, Työläjärvä, & Kaltiala-Heino, 2016).

This was a qualitative study using Constructivist Grounded Theory method. A significant advantage of qualitative approaches is that they both enable complex aspects of experience to be studied and allow the researcher to address research questions that do not easily lend themselves to quantification, such as the nature of individual experiences of a psychological condition (Barker, Pistrang & Elliott, 2016). Whereas the quantitative studies discussed above have demonstrated an association between gender dysphoria and ASC, it was anticipated that the

use of a qualitative approach would (i) enable participants to provide rich and detailed accounts of their experience of gender identity development, revealing a wider range of influences and processes than would be detected using standardised, quantitative measures, and (ii) generate clinically relevant hypotheses.

Constructivist Grounded Theory is particularly suited for researching social processes that have attracted little prior research attention, where the previous research is lacking (Milliken, 2010). It also offers a flexible approach that enables the researcher to modify his/her protocol mid-stream. Consequently, the researcher is not constrained by pre-existing hypotheses. The use of “open-ended” questions also gives interviewees a chance “to respond in their own voice and in their own way” (Barker, Pistrang & Elliott, 2016: 75). This is particularly important when working with participants who may be disadvantaged or socially excluded. The value of a constructivist approach is that it assumes that the researcher is part of the world that she/he studies, the data they collect and the analysis produced. As Charmaz (2006: 10) has observed, “we construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices.” This is also consistent with Wiseman and Davidson (2011), which stresses the importance of understanding gender dysphoric individuals in their multiple contexts.

Research questions

The primary research questions were:

- What have been the experiences of gender identity development among adolescent birth-assigned females with ASC, experiencing distress or difficulty because of the incongruence between their experienced/expressed gender and their birth-assigned sex?
- How have they come to understand or make sense of their gender identity development over time (in particular in relation to their biological sex; gender role; gender identity; gender expression; and sexuality/attraction)?

Method

Setting

All participants were recruited from a large, national NHS GID service in the UK. Interviews took place at the GID service, at participants' homes or via Skype, depending on participant preference.

Participants

The study recruited adolescents who had been referred to the GID service who had a diagnosis of ASC and who did not identify with their birth-assigned sex; were gender questioning; gender variant or gender dysphoric. They were recruited between December 2018 and March 2019.

Inclusion criteria

Adolescent birth-assigned females who: (i) were aged between 15 and 18 years old, (ii) had been diagnosed with ASC by an appropriate health care professional in the NHS, and (iii) did not identify with their birth-assigned sex/were gender questioning/gender variant/gender dysphoric.

Exclusion criteria

Adolescent birth-assigned females who: (i) were not fluent English speakers, and (ii) who had an intellectual/learning disability in addition to their ASC diagnosis.

Sample framework and characteristics

Ten birth-assigned females with a diagnosis of ASC were recruited for the study (see Table 2.1 for sample characteristics). The framework chosen for sampling was purposive, meaning that the participants were chosen according to criteria relevant to the research question (Willig, 2013). Four were seen for face-to-face interview at the GID service; three were interviewed face-to-face in their own home; one face-to-face at a location in London, and two via Skype. All participants identified as (trans) male, and had made a full social transition to

living as a (trans) male. A number did not use the term trans since they considered themselves male rather than trans male. One participant described themselves as “*stealth*” since he did not present as openly transgender in most social situations, but instead presented himself as male. For instance, his friends at college were unaware that he was birth-assigned female. All had completed a psychosocial assessment of 3-6 sessions with the GID service. All were either already receiving or had requested medical intervention.

The mean age of participants was 16.6 years old (SD = 1.1, range = 15-18) at the time of interview. The mean age of referral to the GID service was 13.7 years (SD = 1.1, range = 12-15). All identified as White British, and the majority were (or had been) in mainstream education (8 out of 10 participants), rather than specialist education. In addition to receiving a diagnosis of ASC and treatment for gender dysphoria, the majority had further historical or concurrent mental health difficulties for which they had received or were receiving treatment. These included Attention Deficit Hyperactivity Disorder (ADHD); Obsessive Compulsive Disorder (OCD); agoraphobia; anxiety or depression. The majority of participants had a history of self-harm (7 out of 10) and half a history of suicidal ideation (5 out of 10).

Table 2.1: Characteristics of the sample

Participant No.	Age at Interview	Age at Referral to GIDS	Age when ASC Diagnosed	Schooling	Other Mental Health Difficulties
P01	17	15	15	Mainstream	ADHD/Anxiety
P02	15	13	14	Mainstream	Anxiety
P03	17	14	13	Mainstream	OCD/Anxiety
P04	16	14	15	Mainstream	Anxiety/Depression
P05	16	14	14	Mainstream/Specialist	Anxiety/Depression
P06	18	14	15	Mainstream	Anxiety
P07	18	15	15	Mainstream	Anxiety/Agoraphobia
P08	15	12	8	Mainstream	-
P09	17	14	12	Mainstream	Anxiety/Depression
P10	17	12	12	Mainstream/Specialist	Depression
Mean	16.6	13.7	13.3		
SD	1.1	1.1	2.2		

Measures

Semi-structured Interview

Data was collected using a semi-structured interview schedule developed for this study by the researcher via a process of consultation with expert clinicians and researchers (see Appendix G). The interview schedule was designed to ensure that relevant areas of interest were covered, but it was the researcher's aim to be flexible about the sequencing and to ask additional follow-up questions where necessary. The interview began with the researcher and participants co-constructing a family genogram. In the process, the researcher asked the participants about how they would like to see themselves represented on the genogram as a means of introducing the research subject. The researcher then asked participants about their ASC diagnosis and to provide a developmental account of their gender identity development (e.g. exploring their gender identity, gender expression and sexuality etc.) at key stages of their life (early childhood; late childhood; early adolescence and late adolescence). The researcher also explored their hopes for the future regarding their gender identity. The interview concluded with the researcher asking participants for their personal reflections about why people with ASC tend to present in large numbers to gender identity development services. Each interview lasted between 45 and 90 minutes (average 75 minutes).

Strengths and Difficulties Questionnaire (SDQ) with Impact Supplement

The SDQ short form is a brief, self-report inventory behavioural screening questionnaire for children and adolescents (Goodman, 1997). It is comprised of 25 questions, which are grouped into five sections that cover details of emotional difficulties; conduct problems; hyperactivity or inattention; peer relationships; and pro-social behaviour. Respondents are asked to indicate whether a specific attribute is "not true", "somewhat true", or "certainly true". The version of the SDQ used in this study also included an "impact

supplement” to assess overall distress and social impairment. In this study, the SDQ was used to situate the sample (see Appendix H).

Additional information

The researcher also collected the following information about each of the participants at the point of interview: their ethnicity; age; and information on their schooling (e.g. whether they are or were home-schooled or in specialist or mainstream education). The researcher also documented any associated difficulties, including other psychiatric diagnoses and history of self-harm or suicide ideation, from the participants’ clinical notes.

Debrief and feedback

At the end of the interview, participants were offered time to talk about their experience of participating in the study and to share any concerns. They were also invited to complete a brief feedback form (see Appendix I). This allowed them to share with the researcher what they would like to change about the interview process, as well as what they would like to keep the same. Participants’ responses were used to inform how future interviews were conducted. Participants were also given the option of reviewing a summary of the analysed data. They were also provided with information about follow up, including contact details for the GID service team, in case they wished to speak to anyone should taking part in the study have caused any distress.

Recruitment procedure

In order to identify potential participants, the GID service’s research team generated a spreadsheet showing all birth-assigned females aged between 15 and 18 years old who had been referred to the GID service and had moderate to high scores on the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2005). The SRS measures autistic traits among children aged between 4 to 18 years old. It is used primarily with individuals with ASC, family members of individuals with ASC, and others who have social impairments. It is, however, not a formal

diagnostic tool. In this instance, the SRS scores served initially as proxy for a formal diagnosis of ASC since the patient record system did not allow a diagnosis of ASC to be recorded in a systematic way.

Next, GID clinicians were invited to identify, among the birth-assigned females with moderate to high SRS scores, those who had a formal diagnosis of ASC and therefore met the study's inclusion criteria. Clinicians then followed up with the young person and their parent/guardian either in clinical sessions or by phone, inviting them to participate in the research (see Appendices B and C). Once the young person and/or their parents/guardian had given their consent in principle to participate, the researcher sent them an introductory letter and information sheet about the study by post. The researcher then followed up with them by telephone to provide any further information required about the study and, if the young person was willing to participate in the study, set up a date and time for interview.

Consent forms (or assent forms for under 16s) were completed with participants prior to, or at the start of, interview (see Appendices D-F). Each participant received a £10 Amazon voucher for their involvement in the research.

Ethics

Ethical approval for this study was granted by the Harrow NRES Committee (Ref. 17/LO/1957) and by the Research and Development Department of the NHS trust in which participants were recruited (Appendix A). Prior to taking part, participants were given an electronic or hard copy of the information sheet setting out details of the study (see Appendices B and C). All individuals were asked to provide written, informed consent (or assent for under 16s) prior to participating (see Appendices D-F). All personal data collected in connection with this project was stored and utilised in accordance with the Data Protection Act 2018.

Analysis

Audio recordings were transcribed verbatim using NVivo Software by the researcher.

Transcripts were analysed using Constructivist Grounded Theory method (Charmaz, 2015). According to early exponents of Grounded Theory, the goals of systematic Grounded Theory analysis include: building a theory (rather than testing one); approaching the research process with rigour; being aware of (and attempting to circumvent) biases within research; and working towards the creation of rich theory that closely approximates reality (Strauss & Corbin, 1990, 1998). Later iterations of the method emphasize the importance of taking the researcher's position, privilege, perspective and interactions into account as an inherent part of the research reality (Charmaz, 2014). This is because, as Barker, Pistrang and Elliott (2016: 74) observe: "qualitative research is essentially a human encounter, and the researchers themselves act as the measuring instrument". Therefore, it was understood that the researcher's beliefs, understanding and feelings about the research topic would inevitably influence the collection and interpretation of the data. With this in mind, the researcher included a statement in the study to situate themselves in relation to the research topic and the clinical population under study.

Data collection and analysis was ongoing throughout the research study and progressed through the following three stages: (i) Initial Coding – line-by-line coding to identify anchors that allow the key points of the data to be gathered; (ii) Focused Coding – concentrating on the most useful initial codes and testing them against extensive data; (iii) Theoretical Coding – conceptualizes how focused codes are related, and moves the analysis in a theoretical direction (see Appendix K for an example of initial and focused coding). In principle, data collection continues until theoretical saturation has been achieved and a theory has been developed (i.e. when the collection of new data does not shed any further light on the issue under investigation). In reality, Constructivist Grounded Theory research is not as linear as suggested above. Instead, connections between categories were made throughout the research process by constantly comparing and contrasting codes between participants. Memo writing also helped

define the properties of codes, and a reflective journal was used to move the analysis towards a more theoretical explanation while remaining grounded in the data. The theoretical integration of categories and the emerging theory was also discussed with the research team

Testimonial validity

During the course of the research, several participants commented that the interviews had helped them to reflect on their experiences and that they experienced this positively. The researcher provided participants with a summary of the analysed data and invited them to provide their feedback by email as an assessment of testimonial validity: the degree to which the results are viewed by participants as an accurate representation of their respective perspectives (Stiles, 1993) (see Appendix N). It was not possible to include these reflections prior to submission as the researcher was still awaiting responses.

Researcher's perspective

I am a cisgender female, heterosexual, White British researcher completing this research as part of my Clinical Psychology Doctorate at University College London, UK. I had experience of working in specialist services with children and adults with ASC, but more limited experience working with gender variant young people prior to undertaking the research. I adhere to a strengths-based view of ASC, which I believe reflects difference; I do not take the view that ASC is indicative of a disorder. Given that discussions related to issues affecting the trans community are live within the media, I was aware of ongoing debates related to the care and treatment of young people with gender dysphoria by GID services, but tried to set these concerns aside while creating the interview schedule, conducting interviews and undertaking data analysis. One of the advantages of Grounded Theory is that it avoids making assumptions and instead adopts a more neutral view of human action in a social context (Simmons, 2006). I was aware of the need to reflect on my position in relation to the research throughout the process and particularly how the external political context could have a bearing

on my analysis. With support from my supervisors, I aimed to take a systematic approach to data analysis. In the interest of transparency, I shared the results with the participants and invited their feedback.

Results

Strengths and Difficulties Questionnaires (SDQ) scores

On average, participants scored within the “very high” range for total difficulties on the SDQ and “very high” on the impact assessment, which suggests that these difficulties had a large impact on the participants’ day-to-day lives. Overall, the results showed that participants’ internalising difficulties (emotional problems and peer problems) were elevated in comparison to externalising difficulties (conduct problems and hyperactivity scores); although participants scores were highest overall on the hyperactivity scale.

Table 2.2: Strengths and Difficulties Questionnaires (SDQ) scores

Participant No.	Total Difficulties	Emotional Problems	Peer Problems	Conduct Problems	Hyperactivity Score	Impact Assessment
P01	21	7	4	2	8	4
P02	15	7	2	2	4	1
P03	29	8	5	7	9	5
P04	21	5	5	3	8	4
P05	14	3	4	2	5	2
P06	27	9	6	3	9	4
P07	18	7	6	0	5	4
P08	28	10	7	3	8	7
P09	27	9	9	1	9	10
P10	13	4	3	0	6	2
Mean	21.3	6.9	5.1	2.3	7.0	4.3
SD	6.2	2.3	2.0	2.0	1.8	2.6

SDQ Scores: Green = Close to average, Yellow = Slightly raised, Amber = High, Red = Very high

Results from semi-structured interviews

Constructivist Grounded Theory analysis of the participants’ accounts identified a core category of ‘Journey Towards Understanding’, which reflected their progression from being aware of their difference to others towards understanding this difference as connected to their gender identity, which broadly followed the transitions from early childhood to early and then

later adolescence (see Table 2.3 and Appendix L). This core category consisted of four major categories reflecting the different, consecutive stages of this journey: ‘Awareness of Difference’, ‘Experience of Incongruence’, and ‘Understanding Difference’. The major category ‘Neurodiversity as a Facilitator of Change’ reflected the intrapersonal and interpersonal processes associated with having ASC that may have enabled the participants to enact changes to their gender identity, role and expression as part of their transition towards living as (trans) males. The participants codes used below are not the same as those in Table 2.1. and all names included in the quotes have been changed in order to preserve confidentiality.

Table 2.3: Core Category, Major Categories and Sub-Categories

Core Category	Major Categories	Sub-Categories
Journey Towards Understanding	Awareness of Difference	Delayed diagnosis of ASC Pre-pubertal gender non-conformity
	Experience of Incongruence	Gender dysphoria and early onset of puberty Shifting social norms Emerging sexuality
	Understanding Difference	Exploration and sense-making Greater self-assurance Desire for medical intervention
	Neurodiversity as a Facilitator of Change	Resistance to social pressure to conform Questioning of gender norms Social isolation

Awareness of Difference

The first major category pertains to the idea that all participants experienced and understood themselves to be “different” in comparison to their peers or family members from

early childhood, but could not account for why they experienced this to be the case. It has two sub-categories: ‘Delayed diagnosis of ASC’ and ‘Pre-pubertal gender non-conformity’.

Delayed diagnosis of ASC

All participants reported being diagnosed with ASC in later childhood or adolescence (see Table 2.1). This meant that they went through early childhood without an explanation for their “difference” compared to neuro-typical individuals, and therefore they reported that they often felt “weird” or “odd”:

“I was just weird and didn’t mind just being on my own, and just kind of very different to how most children are and they just didn’t want me around and yeah I did struggle with that in primary school.” (P10)

“There is a video of me somewhere staring at the TV while it’s off, just like static, and I’m sitting in a box and it’s like an hour long, so I just used to do weird things like that. I say they’re weird cos they are a little bit weird. I kinda forgot how visible it was to people around me, and people were saying you haven’t got autism you seem so normal.” (P09)

It was only once they had been given a diagnosis of ASC that the participants felt that they were able to finally “make sense” of some of these early experiences, as they understood that *“I’m different because of this” (P01)* and *“it put things into perspective” (P05)*:

“It sort of made me realise that it wasn’t just me...people used to say like in school that I was a naughty kid. It was more that people could be more understanding and that there was a reason behind it like with concentration and things. It made it sort of made sense.” (P03)

“It’s just confirmation and it makes me feel more secure in myself cos I know why I am the way I am and it’s not because I’m wrong or broken and need to be fixed, it’s just me and being autistic just means this is how my brain is wired. This is how my brain works and it might be harder to do these things, and easier to do these things and you know, but it’s just fun.” (P10)

Pre-pubertal gender non-conformity

All participants recalled displaying a degree of gender non-conformity from an early age, which also contributed to a sense of feeling “different” to others and was interpreted retrospectively as early evidence of their (trans) male identity. This included showing

preference for performing stereotypically ‘masculine’ roles (e.g. a prince or father) or resisting playing ostensibly ‘feminine’ roles (e.g. a mother):

“I remember when we used to play mummies and daddies and stuff, I would always be the err the cousin...the male cousin called Mitchell. I don’t know why Mitchell, but Mitchell for some reason. I probably saw it in some sort of cartoon I watched yeah. Yeah so I think I was kind of like...had those inclinations from a very young age.” (P08)

Participants also showed a preference for ‘masculine’ modes of expression, specifically in relation to their choice of clothing, mostly declining to wear ostensibly ‘feminine’ clothes, such as dresses or skirts, because it meant that they did not *“feel myself or as confident”* (P10):

“I never wore skirts and dresses and stuff anyway. I was always in tracksuit bottoms. I hated jeans at that point. I don’t know why cos I love jeans now, but you know I wore air quotes ‘men’s clothes’ or more masculine clothing.” (P06)

For most participants, preferences extended to having stereotypically ‘masculine’ interests, which were presented in a way as to suggest these activities may be incompatible with a ‘feminine’ identity:

“I was really into a lot of fantasy type stuff I remember and I remember a few years later I spent hundreds of pounds on like a war hammer um yeah I was really into that. And I was really into lord of the Rings and like Star Wars and all that type stuff, which is man-type stuff.” (P08)

“I think a lot of the time even like younger years I like had fighting dolls and had fighting teddy bears and I had lessons and hospitals and I cut them up and open and pretended to have surgeries on them a few times. I think the only doll I had was male - it was physically very male.” (P01)

Many participants felt that they *“clicked more with boys”* (P10), resulting in a general preference for male companionship. This was often based on the fact that they felt that *“they didn’t have any complicated social groups”* (P09), *“were generally a bit more relaxed”* (P08) and/or were perceived to do more “interesting” activities, such a football, tree-climbing and video games:

“I didn’t really like the other girls who would be a bit kind of two-faced about their friends, people in their class who would go and talk about make-up and you know boyfriends. Everyone was getting boyfriends when they were like 10 years old. and I

was like...at that point I was like 'who needs a boyfriend when you're 10 years old'. I was maybe quite cynical from a young age. (P05)

The majority of participants also identified as “tomboys” during primary school (P02, P04, P05, P06, P07, P09):

“I knew nothing until err mid-way through secondary. I didn’t even know about gay people. I was a tomboy that was it.” (P07)

As with their experience with ASC, participants’ early gender non-conformity contributed to a sense of being “different” compared with peers and family members. Although some reported that they felt themselves to be male from a very early age (e.g. *“I told my nan that I was a boy. I was just under four.”* P02), participants felt they had little or no language to help them understand their early experiences in relation to their gender (e.g. *“I didn’t really have the...words”* P08):

“I knew there was something different. I didn’t know because I hadn’t been told that [transgender] was even a thing. I just sort of brushed it off.” (P03)

“The problem was that I was a boy and it confused me cos I knew I didn’t want to be a boy, but I didn’t have the language to fully understand 'I am a boy', so I felt it but I didn’t understand. And it was very confusing.” (P10)

Experience of Incongruence

This second major category relates to the idea that all participants described going through a period of deepening incongruence between their experienced gender and birth-assigned sex. It has three sub-categories: ‘Gender dysphoria and the onset of puberty’, ‘Shifting social norms’ and ‘Emerging sexuality’. The first two sub-categories link to the idea that participants’ felt sense of incongruence in relation to their gender was exacerbated by the onset of puberty, and the experience of shifting gender-related social norms. These experiences were accompanied with gender dysphoric feelings. The final sub-category pertains to the parallel, but related, process of emerging sexuality.

Gender dysphoria and the onset of puberty

Many of the participants reported early onset of puberty, with the majority beginning to notice physical changes while still in primary school. All reported that they experienced distress (e.g. *“I was like crying and screaming for a very long time”* P02) in relation to the start of puberty and expressed a desire to halt it:

“I know it was really, really crap and I felt really crap about it but at that time I didn’t know why. It was just something isn’t quite right here. And it pissed me off a lot. And you know there were the girls in the group who were like ‘this is a big thing’ and they were excited about starting, and I was like “I want this to go away right now.” (P06)

Participants found menstruation particularly distressing, especially given the regularity of the occurrence:

“The reminder every time and because I was looking more male and feeling more male then suddenly it would happen again.” (P01)

Equally, the development of secondary sex characteristics, notably the development of breasts, was an unwanted and often emotionally *“painful”* (P09) experience:

“[I] just hated it. I completely hated it. Just growth in certain places and stuff...I didn’t like any of that. I used to just get changed as quick as I could and not take much notice [of my body]. Just tried to avoid it.” (P04)

As a couple of participants observed, the level of distress associated with these physical changes may have been heightened by their ASC, given that managing transitions can often be difficult for young people with ASC:

“I started going through puberty when I was about 9 which could have a lot to do with my depression at the time. And things were changing and I didn’t like change. That’s a classic autistic thing. My body was changing, and I don’t know how different my mind was, my mind has always been different so sometimes you can’t quite tell when things aren’t right, but I’m sure it definitely influenced a lot of my thinking.” (P09)

Shifting social norms

Although a number of participants experienced social isolation in primary school, participants reported that it was easier during the earlier years of school to express themselves

in a more 'masculine' way among their peers. This was because they perceived there to be less prescribed gender norms during childhood:

"People started going 'tomboy' and I'd be like 'that's me'. I play football, and love motorbikes and stuff like that. And that's not like what everyone else is into at this stage. I was just kind of un-phased by it cos I was like 10 or 11 at most and it didn't really matter." (P06)

"We'd play games and be like mummy and daddy and I would be like 'can I be the dad' and they'd be like 'oh ok'. And it wasn't really seen as weird cos as children you know they have the idea that you always have a mum and a dad, so you know, but everyone...there was someone being a dog and someone being the grandparent and all these you know....and it was just kind of kids and that wasn't seen as weird." (P10)

This started to change for participants as they entered adolescence and they experienced shifts in the ways that the sexes related to each other. This typically coincided with the move to secondary school:

"It wasn't until puberty hit that it was a thing...because everyone sort of accepted me and allowed me to be one of the lads and it wasn't something...even the girls they didn't really see me as a girl or anything. I was always just one of the lads. It wasn't an issue until secondary school when puberty hit and I became 'the weirdo' because I was like the girl who wants to be a boy." (P03)

Emerging sexuality

Some participants did not see their gender and sexuality as linked (e.g. *"I don't see the link between who you are and who you like"* P02). All participants reported being attracted to others of the same birth-assigned sex at some point, although they did not identify as lesbian (e.g. *"I knew I was a boy so I wasn't a lesbian."* P02). Participants showed heterogeneity in the ways that they chose to define their sexuality, adopting a range of descriptors: *"I just like girls"* (P03), *"gay boy"* (P05), asexual (P01), bisexual (P08) and pansexual (e.g. *"I don't see a difference with gender. I find any gender attractive if I like the person's personality."* P07). While for some sexuality was experienced as something fixed and unchangeable, for others sexuality was subject to greater fluidity (e.g. *"there's no point stressing over it and trying to find a label, as I know it's likely to change"* P01):

“Pansexuality was the one that stuck for the longest I think erm I was a gay girl for a while before err...before the gender thing I definitely thought I was gay, but I never once referred to myself as a lesbian. Erm...and I would still find like celebrity men like attractive or whatever erm but I dated two girls as a girl erm and then when the non-binary thing started I decided that I wasn’t attracted to solely one gender. Eventually after being 100% male...a few months after that I realised that I wasn’t attracted to girls at all and I do...I identify now as a gay man and I’ve got a boyfriend erm but yeah...it’s still quite strange for me to think that I went from being a girl to a gay boy cos I wonder how does that happen.” (P05)

Understanding Difference

This major category addresses how participants began to make sense of their experience of “difference” and the concomitant effects of this ‘sense-making’ process. It has three sub-categories: ‘Exploration and sense-making’, ‘Greater self-assurance’ and ‘Desire for medical intervention’. The first sub-category relates to how all participants described going through a process whereby they felt that they were able gain insight and understanding into why they felt “different” to others. As consequence of this process of ‘sense-making’, participants reported experiencing a growth of confidence and expressed a desire to pursue medical intervention to consolidate their (trans) male gender identity.

Exploration and sense-making

Each participant went through a process of exploring their gender identity, which was largely facilitated online by social media (e.g. YouTube, Facebook etc.). This was the case for all participants except one, who had restricted access to the internet growing up. Social media (as well as TV and print media) played an important role in giving them a shared language around their experience of incongruence in relation to their gender. It also helped them to feel as if they were not alone in feeling this way and helped “*make sense*” of their previous experiences, as well as feel that ‘masculine’ modes of self-expression were more acceptable:

“There was a documentary. It was on CBBC...it was about being transgender...it made me feel that it was ok to wear more male clothes and be like that. And then I watched the documentary and I felt a lot like that. It made me think that I’m not alone. It felt good. And that I was normal.” (P04)

"I was on Facebook and George Takei had shared a link to a YouTube video of a family where their young son was trans female to male, and I watched that and went 'oh that's actually a thing.' And then I think I went onto YouTube and just searched the word transgender like never heard it before and I found the YouTuber Alex Bertie and watched all of his videos and like went 'yeah, that's a thing'. That wasn't even a big surprising thing. Just 'yeah, that makes a lot of sense actually.' Now I have a word that fitted." (P06)

As a result of this process of exploration largely online, participants described experiencing something akin to an awakening (e.g. *"Sort of like a lightbulb moment in a sense."* P04), where they now felt they understood their (trans) male gender identity as an explanation for their previous experience of feeling 'different' and 'uncomfortable'. It was experienced as something *"real"* or *"solid"* that could explain these past feelings and was characterised by a significant degree of certainty:

"It was kind of like a puzzle piece...I guess that what people say. It's like I've got the whole picture seen but that makes sense because you can see the picture before all the puzzle pieces are in. So the puzzle piece doesn't really work because say you were missing a piece you could still see the picture. It's not going to change even with one piece difference even if it was a big part of the picture, but that was like when I was like I feel like a male rather than just feeling uncomfortable, I feel male." (P01)

"[Being trans male] feels 100% true to me now and I don't have this confusion or this little voice in the back of my head that tells me everything I do is wrong." (P09)

Greater self-assurance

Participants associated the experience of making sense of their gender identity with feeling more confident (e.g. *I'm more confident in what I do. I'm more confident in doing the right thing.*" P04) and comfortable in themselves (e.g. *I'm more comfortable and I can explain things better*" P06). This opened up new opportunities for friendship and/or self-expression or self-knowledge:

"I think the word that people described it is as coming out of your shell. That I more like starting to get friends and doing things with friends rather than only being invited to parties that was just the entire class, it was actually having friends." (P01)

"Well it was quite I guess empowering to know who I was. I didn't feel so silly when I was out with my Dad and we were at somewhere like B&Q cos before you know I was conscious that people would be like 'hey, this isn't a girl thing' cos I'm a real geek and I go to comic conventions, read comics and everybody says that stuff's not for girls. But

I enjoy it, so there were so many aspects of my entire life that always made me question who I was and my identity. I just never really linked that to gender 'til I understood what gender really was.” (P09)

Desire for medical intervention

Participants’ felt that the only viable way to consolidate their (trans) male identity was to pursue medical interventions that would halt menstruation and enable them to develop a more masculine physique. For instance, all participants expressed a desire to access testosterone, and undergo surgery once they were old enough to be referred to adult gender services (e.g. “[I want to change] everything... even just little things like your facial structure and the shape of your jaw” P02); although one participant had already undergone “top surgery” (i.e. a double mastectomy) and accessed testosterone privately. All participants were interested in receiving “top surgery”, but less interested in undergoing “bottom surgery” (i.e. genital surgery) (see Appendix J for gender terminology used in the study). The desired interventions were pursued with apparent determination and optimism; there was a clear sense that “if I get rid of what makes me unhappy then surely that leaves me with more space to be happier” (P09). This quote is further illustrative:

“When I get up to the adult side of things, I can start physical intervention. I’ve firstly looked into testosterone and then sort of go from there. I look at one step at a time. I make goals, and that’s my first goal and then the second goal I look at once that goal is met. I look at it that way.” (P04)

A couple of participants expressed concern about whether their ASC diagnosis may prevent them from accessing physical interventions. This was either because of their social communication difficulties or they worried that their diagnosis of ASC may be viewed by clinicians as a determining factor in their gender dysphoria:

“I’m being asked questions and I’m like “I don’t know how to respond” to them and so sometimes that will stress me out cos I will think “my future is going to be in jeopardy” cos I can’t get how I feel across enough.” (P01)

“I worried about...people not taking me so seriously, especially if I went to [the GID service] and explained how you know I feel like I’m transgender and I worry that maybe they’ll see that I’m diagnosed with Asperger’s and then go ‘we can probably just explain

this away by the fact that he's autistic and he's probably just confused and going through that time or whatever.” (P05)

Neurodiversity as a Facilitator of Change

This final major category relates to the idea that the participants’ ASC/neurodiversity may have facilitated the process of socially transitioning to being (trans) male. It has three sub-categories: ‘Resistance to social pressure to conform’, ‘Questioning of gender norms’ and ‘Social isolation’. All participants reported having experiences and ways of viewing and relating to the social world that may differ to neuro-typical young people, which this core category expands upon.

Resistance to social pressure to conform

Participants experienced times when they felt the need to adhere to certain social expectations and sensed that at times they were falling short, especially while they were in primary school. However, this was held in tension with participants’ tendency to display a degree of resistance towards or disregard social pressures to conform to gendered expectations, particularly as they entered adolescence (e.g. *“I just went with what felt right so I stopped talking as much and I didn’t try to go along with things. Things that I didn’t like”* P07). This was attributed by some directly to having ASC:

“People with autism are more kind of blunt and more likely to not care what people think about what they are doing because it doesn't occur that things aren't appropriate or socially acceptable and there is an understanding that something not being right and will just go 'yeah this is how it is' and so whether it's actually that more autistic people are trans or trans people are autistic, its more that people who are autistic will explore that without a second thought or will express it.” (P06)

“I knew how a stereotypical girl was meant to be, like dresses and pink and barbies and stuff. I did like play with them but then I wouldn't...I knew that if I didn't want to I didn't have to. And even if I knew...even if someone said you have to play with them, I wouldn't play with them cos no one tells me what I have to do in that situation, it's not up to them. That's where I am...I don't give a shit since like birth. I knew it was no one else's choice.” (P03)

Questioning of gender norms

In addition to resisting social pressure to conform, there was also a sense that young people with ASC may be more questioning of gender norms, compared to their neuro-typical peers who may be more likely to accept gender norms at face value. A couple of participants expressed the belief that their ability to “*question things*” enabled them to be less bound by the strictures of social expectations related to gender:

“[People with ASC] have a different understanding of things. If you don't understand why we gender things, why society genders things then you would be more questioning about things. If you understand the world slightly differently to everyone else. Everyone else would sort of just see something that we gender in society and just sort be 'well that's the way it is' but someone who thinks of the world differently might ask why would we gender something like that.” (P02)

“[People with ASC] always seek answers to these questions so you learn a little bit more about yourself than someone without autism might. You know they don't question things to the same degree that you do so they accept what they have and they learn to deal with that, but when you have autism it's like you're always searching for something else to link to this other thing, so that you can figure it out, like your body is one big map and you are trying to pin down every single aspect and explain it.... Whereas a lot of people, you know, they're a little bit more willing to just accept something as cut and dry, boom, done!” (P09)

Social isolation

All participants recounted times in their life when they experienced some form of exclusion or bullying by peers. At times, this led them to feel socially isolated or to align themselves with others they also considered to be “different”, “outsiders” or “*who also felt a bit weird*” (P05). A potential consequence may be that they become more exposed to indirect peer influence online, as explored above. Some observed that their relative social isolation freed them up to express their experienced gender because it did not matter because people “*didn't like me already and...I didn't need to worry about them liking me less*” (P07) or they perceived themselves to be less exposed to pressures to conform to social norms (e.g. “*you don't have...these social gender stereotypes shoved at you because you're distanced from it*” P06). The following quotes are illustrative:

“I guess autism makes you not able to relate to other people as well so you're gonna always feel uncomfortable so if you even have slightest feelings of uncomfortableness about your gender it's probably gonna be escalated by the fact that you don't fit in anyway.” (P01)

“I think there's definitely an aspect of social isolation that um attracts you to some kind of like I don't want to say some kind of alternative lifestyle cos it makes being trans sound like some choice thing, but like definitely it kind of disillusioned you of the normal ways of how a society works.” (P08)

Discussion

This was an inductive (i.e. data-driven) qualitative study exploring the experiences of gender identity development among ten gender variant birth-assigned females with ASC, referred to a GID service. It used a Constructivist Grounded Theory approach to participants' narratives elicited through semi-structured interview in order to build a systematic and comprehensive theory related to participants' development of a (trans) male identity. To the author's knowledge, this is only the second qualitative study after Strang et al. (2018) of gender variant young people with ASC, and the first to focus solely on the experiences of birth-assigned females. By enabling participants to provide detailed accounts of their experience of gender identity development, it was anticipated that this would reveal a range of influences and processes, as well as generate hypotheses that can be tested in future.

According to a large UK study, it is typical for a diagnosis of autism to be made by the age of 5.5 years, and for Asperger's by 11 years old (Howlin & Asgharian, 1999). Given that the mean age for ASC diagnosis among the participants was 13.3 years old, which is comparatively late for a diagnosis of ASC to be made. This finding is consistent with research showing that females typically receive a diagnosis of ASC later than equivalent males (Giarelli, Wiggins & Rice, 2010). On average, females with mild symptoms of ASC are diagnosed two years later than males (Begeer et al., 2013). There is a risk that females with ASC may be missed by clinical services altogether (Lai et al., 2015). This can be explained by a number of factors, including the fact that females tend to be better at camouflaging or 'masking' their

ASC (Attwood, 2007; Dworzynski, Ronald, Bolton and Happe, 2012) and are less recognisable as autistic due to lack of awareness of the female ASC phenotype among medical professionals (Lai et al., 2015; Mandy & Tchanturia, 2015). Most participants also had co-morbid diagnoses in addition to ASC and gender dysphoria. This was reflected in their SDQ scores which showed elevated levels of internalising difficulties and hyperactivity. It is possible that young people with ASC may present to services with other mental health difficulties. For instance, ADHD has been shown to be prevalent among children with gender dysphoria (Wallien, Swaab, & Cohen-Kettenis, 2007; Yildirim, Perdahli Fis, Yazkan Akgul & Burcu, 2017), as have internalising difficulties (de Vries, Steensma, Cohen-Kettenis, VanderLaan & Zucker; Röder et al., 2018). These conditions may overshadow or mask the ASC (Kopp & Gillberg, 1992).

This provides important context for the present study since all participants described experiencing early childhood as a period of time where they felt ‘different’ or ‘odd’ in comparison to family members or peers. While participants mostly attributed this retrospectively to their (trans) male identity, the results suggest that their feelings of ‘difference’ may have been exacerbated by the fact that their ASC was not identified until they had entered adolescence, and mostly only *after* they had been referred to gender services. Therefore, the majority of participants had no framework for understanding their neurodiversity prior to then. Once they had received a diagnosis, all participants felt that an ASC diagnosis went some way to explain their past experiences. While there is currently limited research exploring the impact of delayed diagnosis of people with ASC, a study exploring the experience of late-diagnosed young women with autism participants stated that their lives would have been easier had they received their diagnosis earlier in life, and might have helped them to understand why they were different from others, especially during school years when they felt acutely different from their peers (Bargiela, Steward & Mandy, 2016: 3291). Further, accurate diagnosis of females with ASC may enhance their access to early and

ongoing intervention and support to maximise their development and wellbeing (Head, McGillivray & Stokes, 2014). It is also possible that the absence of a diagnosis of ASC at an earlier stage may increase the likelihood of young people with ASC seeking alternative explanations for their perceived difference to others (Parkinson, 2014). This is consistent with the suggestion that “long-standing feeling of being different and an outsider among peers could play a role in children with ASC developing gender dysphoria in adolescence” (Kaltiala-Heino et al., 2015: 7).

All participants described experiencing gender-variant feelings or displaying non-conformist behaviour in relation to their gender from an early age. This was manifest in general preferences for stereotypically male toys, clothing, and activities with many identifying as ‘tomboys’. This suggests that ASC may predispose birth-assigned females towards holding more narrow, fixed and stereotyped views about what it means to be ‘male’ or ‘female’ (Holt et al., 2014), and interpreting any gender nonconformity that they display as indicative that they are transgender (de Vries et al. 2010; Jacobs, Rachlin, Erickson-Schroth & Janssen, 2014). It also raises important questions related to whether ASC may predispose birth-assigned females with ASC to more ‘masculine’ ways of self-expression and relating to others. For instance, participants showed a general preference for interacting with male peers since they perceived them to have less complicated social rituals, and ways of relating that were seen as “*more straight-forward*” (P08), which are perhaps more consistent with an ‘autistic-style’ of interaction. This is consistent with findings that women with ASC can experience a conflict between a feminine and autistic identity, and often find it harder to interact with women (Bargiela, Steward & Mandy, 2016). The results do not substantiate theories that gender variance can only be a reaction to difficult same-sex peer relations (Tateno, Tateno & Saito, 2008). While the participants had a general preference for male friendship, most reported challenging peer relationships with both sexes.

The onset of puberty was a critical time for all participants; all reported experiencing significant distress and an intensification of gender dysphoric feeling. Participants expressed this in terms of the increased felt incongruence between their birth-assigned sex and experienced gender. This is consistent with evidence showing that puberty can present a particular challenge for gender dysphoric young people due to the significant physical changes young people undergo during this time (Devor, 2004; Hewitt et al., 2012). It may also be important to set these findings in a broader context, given that adolescence is a period of life typically characterised by significant uncertainty, upheaval and confusion, as young people adjust to major changes associated with puberty (Churcher Clarke & Spiliadis, 2019). The findings also accord with research showing puberty is a particularly challenging experience for young women (Roen, 2016), and for young people with ASC (Gillberg, 1984). For these reasons, that it has been suggested that “during puberty and adolescent development, there may be some overlap between normative testing of sexuality and gender roles in the one end, and gender dysphoria as a disorder in the other end of the spectrum” (Kaltiala-Heino et al., 2015: 7).

While there is no set age at which puberty commences and the age of onset differs from child to child pubertal onset commonly occurs between the ages of 8–14 years in girls (NHS Choices, 2012). Most participants reported entering puberty while still in primary school, and some perceived this to be early relative to peers. This is consistent with research showing early pubertal timing is common among adolescent female-to-male ‘sex reassignment applicants’ (Sumia et al., 2016). This may be of significance given that early pubertal timing is associated with adverse biological and psychosocial outcomes (Kaltiala-Heino, Marttunen, Rantanen, & Rimpelä, 2003; Mendle, Turkheimer & Emery, 2007). One of the hallmarks of puberty is its variation, which can “lead to further distress when individuals see themselves as ‘different’ to their peers, a factor influenced by the differences in timing of onset and the speed at which

developments occur” (Perry, 2012: 275). Young people with ASC often struggle to adjust to major life changes, which may explain why it can be harder for them to transition through puberty compared to neuro-typical young people (Gillberg, 1984). It is evident that puberty is a complex period of adjustment for all young people. More focused research is required to elaborate the particular experiences of gender dysphoric young people with ASC of puberty, and to test the hypothesis that early puberty may be associated with gender dysphoria in birth-assigned females with ASC.

Alongside the advent of puberty, the participants perceived shifting social norms, which tended to coincide with the transition to secondary school. These experiences may be best understood in relation to the gender intensification hypothesis (Hill & Lynch, 1983). Hill and Lynch (1983) suggest that young people experience increased pressure to conform to culturally-sanctioned gender roles during adolescence. While young people with ASC may be more likely than neuro-typical young people to resist pressure to conform to certain gender norms, this did not mean that the participants were unaware of these social strictures. Young females with ASC have been shown to face particular challenges transitioning to and coping with secondary school (Adreon & Stella, 2001; Cridland, Jones, Caputi & Magee, 2013). As they entered adolescence, the participants became increasingly aware that certain behaviour was no longer tolerated or seen as socially acceptable, and therefore they faced further restrictions or exclusion from certain social spheres. This tended to exacerbate their distress in relation to their experienced gender identity. Pressure to conform to gender norms contributes to internalising problems commonly found in young females (Keenan & Shaw, 1997).

Sexuality is understood to be integral to adolescent identity formation (Tolman & McClelland, 2011). Most participants reported same birth-assigned sex attracted at some point, but over time developed a range of sexual identities, including lesbian, bisexual, pansexual,

gay male etc. This is consistent with wider research showing that there is a high level of same birth-assigned sex attraction among gender variant adolescents and adults (Cerwenka et al., 2014; de Vries et al., 2011). These findings could be understood in the context of concerns about ‘lesbian eradication’ (Moraga, 2011), which highlight that lesbians may be becoming more denigrated over time and in different contexts, making being lesbian more challenging and less socially preferable to young women. However, it is important to note that some participants reported that they saw no link between their gender and sexuality, and for some their sexuality was subject to a degree of fluidity in direct contrast to their (trans) male identity, which was experienced as more defined and unchangeable. This perhaps only partly substantiates the suggestion that young people with a comorbid diagnosis of gender dysphoria may hold more rigid views of what it means to be male or female given the comparative flexibility of thinking in relation to their sexuality (Holt et al., 2014). ASC traits are associated with minority sexual orientation, and perhaps with uncertain self-identification and/or a defiance of traditional ways of categorizing sexual identity (Rudolph, Lundin, Åhs, Dalman & Kosidou, 2018). People with ASC are also likely to consider a romantic partner on the basis of personal characteristics rather than sex, and are therefore more flexible in their sexual orientation (Lai et al. 2011; Mandy, Chilvers, Chowdhury, Salter, Seigal & Skuse, 2012). The present study perhaps serves to highlight the challenge of examining the relationship between gender, sexuality and ASC. Further research is needed to explore this relationship in more depth specifically among gender variant young people with ASC.

It is clear that social media played an important role in enabling participants to understand their perceived difference, as it aided a process of exploration online. This may be connected to broader social and cultural factors related to participants being members of ‘Generation Z’ (also known as ‘Post-millennials’) characterised by being technologically savvy, questioning of gender norms, espousing individuality and choice, and frequently

reinventing themselves online (Doster, 2013). It may also be facilitated by transgender people being increasingly depicted in both offline and online media since these representations can have a significant impact on gender variant young peoples' identity development and lived experiences (McInroy & Craig, 2015).

Exposure to trans people online and hearing about others' experiences helped participants to make sense of some of their earlier experiences in life. When participants alighted on the term 'transgender', they experienced this as a "*lightbulb*" moment where they could begin to "*make sense*" of past experiences and begin to understand themselves in a more coherent way. This 'realisation' of their (trans) male identity was associated with greater self-assurance, which may relate to them feeling a sense of belonging. This finding is similar to research showing the experience of a late diagnosis of ASC among women, where participants stated that having a diagnosis had fostered a sense of belonging in a group of like-minded people and that this promoted a more positive sense of self (Bargiela, Steward & Mandy, 2016).

The conviction and apparent surety of their (trans) male identity was manifest in participants' desire for and pursuit of medical intervention (and for some a rejection of the 'trans' label altogether). Zucker et al. (2012) observed that young people referred to GID services can express certainty about medical interventions being the only solution to their gender dysphoria. The inflexible thinking and restricted interests in clients with gender dysphoria has been considered as a possible manifestation of the cognitive rigidity characteristic of ASC (Galluci, Hackerman, & Schmidt, 2005; Landén and Rasmussen, 1997). It may also be necessary to situate these findings within a developmental framework. For example, Marcia (1966), expanding on Erikson's Stages of Psychosocial Development (Erikson, 1959), identified four statuses that characterise adolescence identity development. The first of these statuses, 'foreclosure', is when a commitment is made without exploring alternatives, and defensively maintained by denying or distorting disconfirming information

(Marcia, 1966).

An inherent tension in the research is the finding that, while participants appeared to subscribe to quite narrow and stereotyped views about what it means to be ‘male’ or ‘female’, the results also suggest that gender variant, young birth-assigned females with ASC may present to services more readily than neuro-typical young people because they are less socially conformist and more questioning about gender norms. Social norms are implicit or explicit rules that promote conformity by defining expectations of appropriate behaviour within a society (Christensen, Rothgerber, Wood & Matz, 2004). These include gender stereotypes, which are often founded upon neuro-typical norms; for instance, young females have been found to be more socially precocious than young males (Lutchmaya & Baron-Cohen, 2002). The results also suggest that participants may also be subject to less direct peer influence due to their relative social isolation. A potential consequence may be that they become more exposed to indirect peer influence online (e.g. through the YouTube videos of transgender blogger, Alex Bertie, who has over 300,000 subscribers). As explored above, social media played a significant role in enabling participants to “make sense” of their gender identity, as they alighted on transgender-related content online.

Among the participants, gender variance provided a specific, culturally-sanctioned means by which they could “*make sense*” of and manage their physical, psychological and social discomfort and unease. Some participants noted that their own feelings of social isolation meant that they were able to align more readily with individuals and groups that resisted social pressures to conform, particularly to gendered expectations. Almost all participants had contact with these individuals and groups online. This contact with an online transgender community, perhaps coupled with a desire to understand why they felt different to others from an early age, had the consequence of participants considering their own gender identity in more depth and forming a more concrete view of their own gender identity. This exploration tended to come at

a time when participants were experiencing puberty, which all participants found distressing, and adapting to shifting social norms and expectations.

The finding that young birth-assigned females with ASC may be more questioning about gender norms is aligned with research showing that children with autistic traits are less likely to conform to a social majority on a line judgment task compared to neuro-typical children (Yafai, Verrier & Reidy, 2014). This is taken as indication of the resistance of children with ASC to social pressure (Ibid., 2014). By contrast, neuro-typical adolescents are suggestible and more prone to submit to group pressure to gain acceptance (Gardner & Sternberg, 2005). The results also substantiate research showing that birth-assigned females with ASC are more resistant cognitively to social conditioning and, therefore, more likely to adopt trans or non-binary identities (Walsh, Krabbendam, Dewinter, & Begeer, 2018). These findings are also consistent with research showing that autistic individuals' tendency to disregard social norms reduces the likelihood that cisgenderism and transphobia will inhibit them from sharing their identities (Ansara and Hegarty, 2011). The results further corroborate research showing that young women with ASC often find it hard to maintain reciprocal friendships, and can therefore experience social exclusion (Cridland et al., 2014; Gould & Ashton-Smith, 2011). Social isolation has also been shown to be extremely common among gender dysphoric young people seeking sex reassignment, meaning that they are less exposed to peer influence that is important in adolescent development (Kaltiala-Heino et al., 2015). As mentioned above, a potential consequence may be that they become more exposed to and influenced by indirect peer influence online.

Methodological Limitations

Methodological limitations were linked to the study design. Due to the relatively small sample size, it is unlikely that all the categories reached theoretical saturation (Charmaz, 2006). This might have been possible had the researcher been able to identify and interview new

participants who have additional information about the categories, or re-interview participants to elaborate the existing categories emerging from the analysis (Ibid., 2006); however, it was not possible to recruit additional participants within the timeframe or to request that participants give up further time since the majority were preparing for national exams at the time of interview. Many potential participants were still awaiting or undergoing ASC assessment at the time of recruitment. Due to these limiting factors, the study cannot be held to present a comprehensive account of gender identity development within this population. However, it has been acknowledged that “fully fledged theory does not always result from a [Grounded Theory] study and that conceptual development and construction of a framework that pertain to “what is going on here” can suffice” (Timonen, Foley & Conlon, 2018: 8).

The study may also have been affected by self-selection bias. All of the participants identified as (trans) male, rather than non-binary or gender fluid. Gender dysphoric young people may view GID services as gateways to physical intervention. Physical interventions may be more likely to be pursued by those who identify on the gender binary (i.e. as male or female), rather than adopt a more fluid gender identity. This is corroborated by recent research showing that the majority (56.9%) of young people referred to a GID service in the UK identified as trans, 29.3% identified as a binary gender (male or female), 11% identified as non-binary and 1.2% as agender (Twist & de Graaf, 2019).

It is also the case that participants were selected for inclusion in the study on the basis of having positive presence of particular characteristic, namely gender variant identity and ASC. The researcher anticipated a link between the gender dysphoria and ASC based on the extensive extant research showing the association between these two phenomena. This may be considered incompatible with a grounded theory methodology, which in its purest form holds on to idea of the researcher as ‘naïve’. However, this position was difficult to maintain as prior knowledge is necessary when devising a research study. It could also be held that because the

researcher anticipated a link between gender dysphoria and ASC that little attention was paid to evidence that refuted the relationship between neurodiversity and gender dysphoria. In reality, the link between ASC and gender dysphoria was co-constructed between the researcher and participants, even though a number of participants did not consider there to be link between the two conditions.

Of the 25 invited to participate in the research, all ten participants who chose to take part identified as White British. While this is consistent with UK studies which show that between 90-94% of referrals to GID services are White (Arcelus, Claes, Witcomb, Marshall, & Bouman, 2016; de Graaf et al., 2019; Holt et al., 2016; Skagerberg et al., 2015), it is possible that gender clinics may be less accessible to young people from Black, Asian and Minority Ethnic (BAME) backgrounds. Gender may be conceptualised differently cross-culturally, which may be harder for gender diverse young people coming from BAME backgrounds to “label their identity” (de Graaf, Manjra, Hames, & Zitz, 2019: 8). Further research is required to investigate the under-representation of young people from BAME backgrounds being referred to GID services (de Graaf et al., 2019).

In addition, clinicians advised against inviting a number of young people, who fitted the inclusion criteria, to participate as they were either at a critical stage of their engagement with the GID service (i.e. making important decisions relating to medical intervention), or had recently experienced a significant deterioration in their mental health. Furthermore, all participants would be considered as having high functioning ASC, since they did not have a learning disability (LD) in addition to their ASC diagnosis, and have language and cognitive abilities outside of the LD range (Sanders, 2009). This means that the young people who agreed to take may not fully reflect the broad spectrum of experiences within this population.

It is important to consider that all participants were recalling events that had happened to them at different points in their lives, and might have been affected by recall difficulties,

especially when talking about difficult past experiences which may have given rise to anxiety. People with elevated levels of state anxiety have been shown to perform poorly on retrospective memory tests (Harris & Cumming, 2003). In some cases, young people may also believe that reporting a longstanding history of gender dysphoria and expressions of certainty with regards to their gender identity may improve their chances of accessing desired treatment, especially in the context of recent somewhat controversial research related to ‘rapid onset gender dysphoria’ (Littman, 2018). Future studies adopting a more critical realist stance would benefit from obtaining qualitative data from parents and clinicians, which would afford a comprehensive perspective on how a young person’s gender identity has developed over time. The triangulation of current findings could confirm which processes and influences might contribute to birth-assigned females forging a (trans) male identity. In contrast to a constructivist stance, which holds that theories are not discovered but rather constructed between the researcher and participants, critical realism holds that theoretical explanations can be made regarding phenomena in the world.

Four participants asked to be interviewed in the presence of a parent. The difference in interview method may have impacted the topics the interviewees were comfortable or willing to discuss with the researcher, and this could have influenced the categories generated from the collective analysis. For instance, participants may have been less willing to share their reflections, especially in relation to sexuality and relationships. Sexuality was not explored in sufficient depth with participants in the study. For instance, the study did not explore with participants the extent and meaning of their sexual experiences. As an initial, exploratory study it was necessarily broad in scope, but this also meant that certain important topics were not explored to the degree necessary to formulate specific ideas or theories. As mentioned above, further research is needed that examines the relationship between gender, sexuality and ASC.

A further limitation could be how few explicit links participants made between their ASC and gender dysphoria when recounting their experience of gender identity development. This may be a limitation of the interview schedule, which may not have invited participants to reflect sufficiently on the relationship between the two conditions (Appendix G). However, this could also be considered a significant finding in itself, as it suggests that most participants did not consider their diagnosis of ASC as having a bearing on their gender identity development. The dilemma in analysing the data centred around how much to interpret and make inferences based on the data. This necessitated a systematic approach to data analysis to ensure that all categories were grounded in the data.

Another possible limitation of the study was the highly structured nature of the interview schedule (Appendix G), and how the core category of “Journey Towards Understanding” mirrors to some extent the interview schedule’s progression from exploring participants’ experiences during early childhood through to later adolescence. In reality, interviews with participants were not conducted in such a linear fashion and the schedule merely served as a guide for interview.

Clinical implications

This study offers insights into why gender variant birth-assigned females with ASC are presenting in such significant numbers to specialist gender identity services worldwide. It also demonstrates the complex interaction between gender variance and ASC, reinforcing suggestions that neuro-diverse young people progress through gender identity development along differing timelines or frameworks compared to their neuro-typical peers (Van Schalkwyk, Klingensmith & Volkmar, 2015). This underscores the importance of the initial clinical consensus guidelines for gender variant young people with ASC, which recommend an extended diagnostic period and that clinical decisions proceed more slowly due to the

myriad “social, adaptive, self-awareness, communication and executive function complexities” of this population (Churcher Clarke, & Spiliadis, 2019; Strang et al., 2018, 107).

Participants offered important reflections on their experienced of assessment within the GID service, and how they had feared that having a diagnosis of ASC could prevent them from accessing desired medical interventions. This offers clinicians working in these services valuable insight into how young people with ASC may experience clinical assessment, and how having a diagnosis of ASC may have a bearing on a young person’s level of engagement/disclosure during the process.

Similar to previous research (Bargiela, Steward & Mandy, 2016; Cridland et al., 2013, Kabot, Masi & Segal, 2003), this study highlights the importance of identifying ASC in females at an earlier stage. There is further need to improve GPs and other professionals’ recognition of signs of ASC in females to facilitate diagnosis and access to support at an earlier stage. In addition, it is important that clinicians working with young people with ASC are aware of gender-diversity in this population, and have the knowledge and skills to explore gender and sexuality in their work. This would ensure clinical teams that are providing comprehensive therapeutic support young people with ASC, with the aim of reducing gender-related distress, and increasing understanding of these experiences.

Research recommendations

As this was an initial, exploratory study with a previously understudied population, further investigations with larger samples of birth-assigned females with ASC (including those referred to gender clinics around the world) would provide valuable comparative data, and elaborate upon the categories identified in this study. Further studies exploring the experiences of birth-assigned males with ASC of gender identity development, as well as comparative studies between birth-assigned females and males with ASC, are also needed. Research into

the experiences of those whose gender identity falls outside of the gender binary (i.e. non-binary, gender fluid etc.), which may involve recruiting non-clinical samples, is also required.

Further studies are required to test the hypothesis that later diagnosis of ASC may have a negative impact on individuals' well-being since this is one of a limited number of studies reporting such a finding (e.g. Bargiela, Steward & Mandy, 2016; Cridland et al., 2013, Kabot, Masi & Segal, 2003). It has been proposed that this could be achieved through quantitative research that investigates the relationship between age of diagnosis, functional impairment and well-being in a representative sample of males and females with ASC (Bargiela, Steward & Mandy, 2016); however, an additional focus should be on exploring the link between delayed diagnosis and gender-related distress.

The study also raised the question as to whether females with ASC are predisposed to a stereotypically 'masculine' way of self-expression and relating to others. Young females are typically seen to possess stronger verbal and communicative skills compared to young males, but "these are domains that are saliently affected in ASD, and this might explain why autistic females may experience GD symptoms to a greater extent than their male peers" (George & Stokes, 2018: 978). This hypothesis would need exploring further.

In addition to a general need for more studies examining the relationship between gender, sexuality and ASC, it would be useful to explore how young people with ASC's construction of the relationship between gender and sexuality differs with regards to the need for coherence and categorisation (i.e. there is a need to explore why young people with ASC are perhaps more likely to adopt a more defined, binary gender identity in contrast to a more changeable sexual identity). This is because, for some participants, their sexuality was subject to a degree of fluidity in direct contrast to their (trans) male identity, which was experienced as more fixed and unchangeable.

Puberty is a complex period of adjustment for all young people, but perhaps especially challenging for females with ASC, who may experience sensory sensitivity connected to menstruation (Churcher Clarke & Spiliadis, 2019). More focused research is required to elaborate the particular experiences of gender dysphoric young people with ASC of puberty, and particularly of birth-assigned females. A useful study would be to compare how young people with ASC – with and without gender dysphoria - experienced puberty and relate to their post-pubertal body.

It would be interesting to understand whether the levels of exposure to and use of social media differs between gender variant young people with and without ASC. It is also not understood how online social influence and culture impacts body image and gender identity. It is necessary to find ways of measuring this, and lessons could be learned from other disciplines. For instance, there is a body of quantitative research emerging from within communications research, examining the impact of social media on women's perceptions of their bodies (e.g. Eckler, Kalyango, & Paasch, 2017).

Longitudinal studies with this population are also required. Conducting follow-up interviews over the course of several years would help illuminate how gender identity development among gender variant birth-assigned females with ASC develops into early adulthood and beyond. It would also help ascertain whether psychological and/or physical intervention improves psychological functioning in this cohort.

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Part 3: Critical appraisal

Introduction

This critical appraisal outlines the political, sociocultural and clinical context for the research and considers how this influenced the researcher's position. It also reflects on the conceptual and practical challenges faced by the researcher in designing and conducting qualitative research with gender variant young people with Autism Spectrum Conditions (ASC). It considers how specific methodological challenges arising during four phases of the research process were (or could have been) addressed: study design; recruitment; interviews with participants, and transcription and data analysis. Further implications for future research and clinical services are also considered.

Political, sociocultural and clinical context for the research

One of the advantages of adopting a Constructivist Grounded Theory (CGT) approach for the study was that it is “suitable for studying individual processes, interpersonal relations and the reciprocal effects between individuals and larger social processes” (Charmaz, 1995: 28). It also provides tools that help the researcher locate individual action within wider social and political contexts (Oliver, 2011). This is necessary since individual behaviour is socially and contextually embedded (Charmaz and Henwood, 2008), and the world “consists of multiple individual realities influenced by context” (Mills, Bonner, & Francis, 2006: 26). This was particularly important for this study since there were a wide range of political, sociocultural and clinical influences shaping the research context. It is also important to acknowledge some of the challenges and inherent contradictions that exist with CGT. For instance, it started as a more realist-informed methodology, but has evolved into a constructivist methodology over time. Therefore, CGT occupies at times an uncomfortable middle ground.

While the majority of discussions related to clinical decision-making are conducted within academic and professional circles, debates related to the care and treatment of

transgender children and adolescents are being played out in the public sphere. During the period that the research was being conducted, the British Broadcasting Corporation (BBC) aired a Panorama TV programme entitled “Trans Kids: Why Medicine Matters”, which questioned the level of evidence underpinning physical interventions that intervene in puberty. In addition, numerous newspaper articles reported findings from an internal review of the Gender Identity Development (GID) service, where the research was being conducted. There was also a legal case going to the High Court, reported on widely in the media, involving a researcher, who was challenging a university’s decision to prevent him from researching gender de-transition.

It is clear that attitudes towards the clinical care and treatment of children and adolescents with gender dysphoria have become highly polarised. There are broadly two seemingly incompatible positions held to strongly by particular interest-groups. So-called ‘affirmative’ parents’ groups, such as Mermaids, adopt a more rights-based approach and have expressed concern about the length of the assessment process before medical interventions can be offered to young people. By contrast, some so-called ‘gender critical’ parents’ groups, such as Transgender Trend, have expressed concern about children and adolescents being ‘fast-tracked’ through GID services without possible underlying social and psychological factors being explored in sufficient depth. It was against this background that the researcher embarked on the research.

There is a common misconception that to use the CGT research method, the researcher has to be a “blank sheet devoid of experience or knowledge” (Suddaby, 2006: 634). Instead, the research method invites the researcher to consider his/her role in interpreting the data, and acknowledges that he/she are not an objective witness to a social reality, but are instead actively involved in the construction of a particular understanding of a studied phenomenon. In other words, theory is not ‘discovered’, but rather shaped by the researcher's decisions, questions,

application of method and worldview and, therefore, recognised as one tentative, hypothetical reading of the data (Willig, 2008). CGT helpfully encourages researchers to be aware of their presuppositions and considering how these may affect the research (Charmaz, 2006), as well as to consider how participants construct their experiences as influenced by the cultural and discursive resources available (Willig, 2008).

At times during the research process, I felt that I confronted a false binary. On the one hand, I was very conscious of risking being on the wrong side of history, such as the psychoanalysts who viewed a homosexual orientation as “evidence of pathology or arrested development” (Newbigin, 2015: 1), by enquiring into the association between ASC and gender dysphoria. On the other hand, I was concerned that my efforts to avoid being perceived as “transphobic” may lead me towards not being sufficiently curious about ASC as an underlying factor, especially in a context where clinical decisions have major consequences since “young people, their families and clinicians, are facing complex decisions around possible medical interventions in physically healthy and developing bodies” (Churcher Clarke & Spiliadis, 2019: 2). As stated positions become even more entrenched and reactionary, maintaining a position of curiosity and ‘not knowing’ can be hard to maintain. I imagine that this is a dilemma that all researchers, especially those that are new to working in the sphere of gender identity development, need to navigate.

As discussed in the empirical paper, participants also did not make a lot of explicit links between their ASC and gender dysphoria when recounting their experience of gender identity development. This may be a significant finding in itself since it appeared that most participants did not consider that their diagnosis of ASC had a bearing on how they experienced their gender identity. A couple even explicitly resisted exploring the association between gender dysphoria and ASC with me during the interview (e.g. *“It’s just a coincidence”* P03 and *“Personally I don’t think there is [a link]”* P05). The dilemma in analysing the data centred around how

much to interpret and make inferences based on the data. With support from my supervisors, I aimed to take a systematic approach to data analysis and ensure that all of the categories were thoroughly grounded in the data. In the interest of transparency, I shared the results with the participants and invited their feedback.

Research process: Methodological challenges

The political, sociocultural and clinical background to the research provided important context to the research process and how it shaped my thinking at various stages of the research process. This section addresses in turn specific challenges that were addressed during four phases of the research process: study design; recruitment; interviews with participants, and transcription and data analysis.

Study design

From the outset, careful attention was paid to the use of language to ensure that all written materials (e.g. information sheet, consent forms etc.) used during the study were appropriate for the intended audience. With guidance from my supervisors, the decision was made early on to refer to ASC, rather than Autism Spectrum Disorders (ASD). This was indicative of a strengths-based view of ASC, which holds that ASC is reflective of difference, rather than is indicative of disorder. I opted to use the term birth-assigned (rather than natal, physical, biological or birth sex), when referring to participants' sex. This is because language has evolved significantly in recent years. It is my understanding that birth-assigned sex is the generally preferred language among the trans community, as it is perceived to make room for gender identity to be the basis of a person's sex. I appreciate though that it is a controversial term, which is perceived by some to deny the biological differences between males and females, such as genital and chromosomal differences. Throughout the results sections of the empirical paper, I have put the word trans in brackets to reflect the fact that a number of the participants did not consider themselves to be trans male, but simply male. Two participants

mentioned in their post-interview feedback that the use of the terms birth-assigned sex and ASC in the research materials informed their decision to participate in the study. This indicates the importance of careful use of language when working with this clinical population, and how it can impact their willingness to engage in research.

ASC is a lifelong neurodevelopmental condition partly characterised by impaired social communication. Therefore, I was cognisant of the need to use clear and precise language, avoiding the use of metaphor unless employed by participants in all written and verbal communications. A challenge in developing an interview schedule for the young people involved in this study was balancing the importance of asking non-leading questions to avoid influencing participants' answers (Legard, Keegan, & Ward, 2003) with an awareness that abstract, open-ended questions can be particularly challenging for interviewees with ASC to answer. The interview schedule included a number of clarifying prompts in case the meaning of the questions was lost (see Appendix G).

The interview schedule was devised with reference to the "Genderbread Person" (Killermann, 2017), which is a useful tool used by GID services to help young people explore different dimensions of gender (see Appendix M). These include gender identity (how gender is experienced and/or defined based on how much a person aligns with what they understand the options for gender to be, including interests, roles, expectations etc.); gender expression (how gender is presented through actions, clothing, demeanour etc.); attraction (how a person is drawn or not drawn to another person, sexually or romantically), and anatomical sex (the physical traits that a person is born with). Attempt was made to involve a project consultant with ASC and to gain input from a GID service user group in the development of the interview schedule and other research materials, but neither was possible due to their lack of availability. Therefore, I was reliant on significant input from my supervisors, with their relevant expertise, knowledge and experience in ASC and gender dysphoria.

Recruitment

All participants were recruited from a large, national NHS GID service. As there was no way to record a formal diagnosis of ASC on the patient record system, the GID service's research team could only identify potential participants by ascertaining if they had a moderate to high score on the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2005). The SRS measures the social ability of children from 4 years to 18 years old. It is used primarily with individuals with ASC, family members of individuals with ASC, and others who have social impairments. It is, however, not a formal diagnostic tool.

The use of SRS scores to identify potential participants raised important questions as to whether it serves a useful proxy for a formal ASC diagnosis. The impression was that there was poor correlation between whether a young person scored highly on the SRS, and had a formal ASC diagnosis. This is because clinicians identified and approached young people on their caseload with a formal diagnosis of ASC, but who did not score highly on the SRS. The spreadsheet also identified a significant number of birth-assigned females with moderate to high scores who did not have a diagnosis of ASC. This is consistent with studies showing that some autism screeners used in studies exploring the link between gender dysphoria and ASC have poor specificity (e.g. Turban and van Schalkwyk, 2018). It would be useful, therefore, if the record systems used by specialist clinical services could find ways of recording formal diagnoses, including ASC, to aid future research.

With the exception of two participants who emailed me directly to confirm that they wanted to participate in the study, the majority of participants confirmed their willingness to take part through their parents. This raises some important ethical questions regarding the degree of consent displayed by the young people, and whether there could have been any parental coercion. It was not my impression though that any of the participants took part involuntarily.

Interviews with participants

The interview schedule was devised so that participants were initially asked questions about their interests to enable them to begin by answering questions that they felt most able and comfortable to answer (Jacob & Furgerson, 2012) (see Appendix G). I also adopted a flexible approach by adapting my interview style, pacing and order of questions to meet the needs of the participants.

It is also necessary to consider whether the setting of the interview might have had a bearing on the participants' level of candour and disclosure. Of the ten participants who took part in the study, four were seen for face-to-face interview at the GID service; three were interviewed face-to-face in their own home; one face-to-face at a location in London, and two via Skype. Elwood and Martin (2010) suggest that people take on different identities in different physical locations. It is possible that those interviewed at the GIDs service may have been more likely to view themselves as 'patients desiring medical intervention', and consciously or unconsciously have shaped their narratives accordingly. By contrast, those being interviewed in their own homes may have been more likely to view me as someone 'outside' of the system. This may have contributed to a flattening of the power dynamic and heightened a sense of confidentiality; although one participant interviewed at the GIDs service stated that they felt more comfortable talking to me than GIDs clinicians because of my status as a researcher (e.g. *"you do research so that's fine I can talk more openly."* P01). Conducting interviews in a familiar environment can be particularly important for young people with ASC to facilitate interaction, as they typically value order and predictability, as this can help them manage the uncertainties of daily life.

It is recommended that researchers consider the participants' stake and interest in participating in the study (Potter & Hepburn, 2005), as well as consider how social processes operate in selecting memories to be discussed within interviews (Thomsen & Brinkmann,

2009). This is because participants construct their experiences as influenced by the cultural and discursive resources available (Willig, 2008). For instance, it is possible young people presenting to GID services may believe that reporting a longstanding history of gender dysphoria may improve their chances of accessing desired treatment. For instance, one participant shared a story about a (trans) male friend who had been denied treatment by a GID service:

“My friend that I mentioned before that looks so feminine he wants...he likes long hair because he feels short hair makes his face look weird cos he doesn't he thinks short hair makes you look more masculine...he likes the feminine kind of things. And he wants to give birth to a child so they don't believe him as male. They don't view him as male so he's actually been told to go away.” (P01)

Therefore, specific autobiographical memories recalled in interviews are not necessarily an accurate record of what happened in the past (Thomsen & Brinkmann, 2009). The triangulation of the findings with clinician and parent reports could confirm which processes and influences might contribute to birth-assigned females forging a (trans) male identity. A number of the parents of the participants expressed interest in taking in part in research, and therefore I do not anticipate that such studies would encounter major difficulties with recruitment.

In addition, it is also important to consider that all participants were recalling events that had happened to them at different stages of life, and might have been affected by recall difficulties. Furthermore, one participant in the study struggled to recall early memories, indicating that it felt painful to think about himself as a ‘girl’ and that he preferred not to recall earlier periods in his life. Another expressed concern that their social communication difficulties, linked to ASC, may impact on the ability of specialist GID services to assess them fully, and to get sufficient information from them to make an informed decision related to their care. Two participants were evidently nervous during the interview process. One reported after the interview was concluded that he felt it had been achievement to be able to remain in a room

with me and to talk about his experiences. Emotional arousal can inhibit hippocampal functioning, impeding the formation of memory (Madan, Fujiwara, Caplan & Sommer, 2017). This underscores the initial clinical guidelines for gender variant young people with ASC, which recommend an extended diagnostic period and that clinical decisions proceed more slowly (Strang et al., 2018).

A number of participants also expressed concern about how the research would be used, and whether the association between ASC and gender dysphoria would be used to undermine or question their (trans) male identity. This led me to change the way that the statement of the research question was phrased in the interview schedule after I had conducted two of the interviews (see Appendix G). Initially the following question was asked: ‘As I mentioned at the start of the interview, it has been found that young people with autism tend to have more difficulty developing their gender identity. Why do you think this is?’ This was amended to: ‘It has been found that significant numbers of young people with autism come to the attention of Gender Identity Development Services. Why do you think this is?’ I think this amendment facilitated more open reflections on the association of gender dysphoria and ASC among participants, perhaps because the question seemed to present a more positive and less deterministic view of the association between ASC and gender dysphoria.

Interviews that were conducted at the GID service were often constrained by the limited time that a room was available, usually up to 1.5 hours. This meant that certain topics could not necessarily be explored in sufficient depth, which was inevitable given that this was initial, exploratory study with a previously understudied population. This was certainly the case with regards to inquiring into the relationship between sexuality and gender. There seemed to be two broad categories of responses to questions related to their sexuality among participants. Firstly, there were those who were in romantic/sexual relationships who often stated explicitly that they didn’t see how their sexuality had a bearing on their gender identity. Secondly, there

were those who reported having very limited social interaction and/or had no history of romantic/sexual relationships. When discussing relationships and sexuality with these participants, I found myself at times feeling intrusive by exploring with them something that these participants hoped for, but was not currently part of their lived experience. This may have had the effect of shutting down my curiosity, which meant I did not necessarily probe this further. This exemplifies the challenge of teasing apart gender and sexuality in a way that means the links can be explored in the necessary depth.

I also invited participants to complete an experience of interview questionnaire at the end of the interview (Appendix I). The feedback I gained through this process led me to make some necessary changes to the interview process, such as offering participants a break mid-way through interview; however, collecting feedback while I was still present may have prevented the participants from being able to share critical reflections and limited honest disclosure. An alternative means of collecting this information could have been through an anonymous online survey.

Transcription and data analysis

Although it was time intensive, transcribing all the interviews myself meant that I became immersed in the data and developed a proximity to the material that helped to generate initial categories. This informed the lines of enquiry I pursued with later participants. Due to the relatively narrow timeframe for recruitment and scheduling interviews, it was not possible to always maintain methodological purity by adhering to a theoretical sampling approach. This is when data is sought to elaborate and refine the categories which are emerging from the analysis in order for the categories to become ‘saturated.’ This was because I often had to conduct two interviews in the course of a week, which meant that it was not always possible to transcribe and start doing the initial coding before undertaking the next interview. It is recognised that in reality a pragmatic approach is required when undertaking Grounded Theory

qualitative research (Timonen, Foley & Conlon, 2018).

In the interest of transparency and testimonial validity, the researcher sent all participants via email a summary of the results and invited them to provide feedback and their reflections (see Appendix N). It was not possible to include these reflections prior to submission as the researcher was still awaiting responses. Participant feedback could have been facilitated by arranging face-to-face meetings where more detailed verbal feedback could be obtained. While this may have served to strengthen the validity of the results, this would have placed significant additional, possibly unreasonable, demand on the participants.

Implications for future research

There is limited extant qualitative research exploring the experiences of gender variant young people with ASC. This study advances research by Strang et al. (2018), which explored the experiences of gender diverse adolescents with ASC, and it is the first study focusing solely on the experiences of birth-assigned adolescent females with ASC. It also elaborates upon previous ideas advanced in the literature and has generated further hypotheses to be tested; however, it is important to bear in mind that the findings do not represent the experiences of all birth-assigned females with ASC. Instead, the results were co-constructed between the researcher and the participants. Due to the relatively small sample size, the categories presented in the empirical paper are unlikely to have reached theoretical saturation (Charmaz, 2006).

For these reasons, it is important that the study is replicated with larger samples, and that future research includes the experiences of birth-assigned males, and those whose gender identity falls outside of the gender binary (e.g. non-binary, gender fluid etc.), which may involve recruiting non-clinical samples. This would generate valuable insights into the experiences of gender identity development among non-referred, gender variant young people with ASC compared to clinical populations. As discussed in the empirical paper, longitudinal studies are also required. Conducting follow-up interviews over the course several years would

illuminate how gender identity development among gender variant birth-assigned females with ASC develops into early adulthood and beyond.

Additional research is required to elaborate why females are diagnosed with ASC later than males or misdiagnosed, and how clinical services could improve for young females with ASC. This is consistent with existing studies. For instance, a paper exploring the concerns of professionals, women and parents of females with ASC suggests that more research is focused on understanding why females can often ‘slip through the net’ with regards to an ASC diagnosis, as well as the best approaches for working with young females with ASC (Pellicano, Dinsome & Charman, 2014). Given that all participants in the study identified as White British, research is also required into assessing whether there are barriers to engagement with services and/or in clinical research among young people from Black, Asian and Minority Ethnic (BAME) backgrounds.

Implications for clinical services

This section considers how the findings reflect on current service provision for birth assigned females with ASC, and how clinical care may be improved in future. As mentioned in the empirical paper, one participant, reflecting on their experience with the GID service, recalled that he had been cautious in clinical sessions about discussing his ASC diagnosis. This was because he was concerned that his ASC may be viewed by his assessing clinicians as a determining factor in his gender dysphoria, and that this may prevent him from accessing physical interventions, such as testosterone. It is, therefore, important that all professionals working with gender variant young people with ASC are aware that this can be a worry for some young people, and that this might impact the work and young person’s level of engagement/disclosure.

Another participant explained that it could be a challenge for him to express himself clearly to GID clinicians, which he attributed to his social communication difficulties

associated with ASC. This led him to worry about whether he would be “*believed*” by clinicians, and therefore be able access the support that he felt he needed from the service. His social communication difficulties may, in turn, have impacted on the GID clinicians’ ability to undertake a comprehensive assessment, and to get sufficient information to make an informed decision related to the young person’s care. This underscores the importance of an extended diagnostic period for neuro-diverse young people, as discussed in the empirical paper. Young people with ASC could also benefit from extended sessions with clinicians in specialist gender services, and from being offered alternative means of relaying their thoughts (e.g. through drawing etc.) to facilitate their engagement.

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Appendices

Appendix A: Letter of Approval from National Research Ethics Service Committee

Appendix B: Sample Information Sheets – Young Person

Appendix C: Sample Information Sheets – Parent/Guardian

Appendix D: Sample Informed Consent Form – Young Person

Appendix E: Sample Informed Consent Form – Parent/Guardian

Appendix F: Sample Informed Assent Form – Young Person (Under 16)

Appendix G: Interview Schedule

Appendix H: Strengths and Difficulties Questionnaire (SDQ) with Impact Supplement

Appendix I: Sample Feedback Form

Appendix J: Gender Terminology

Appendix K: Example of Initial and Focused Coding

Appendix L: Diagram of Core Category, Major Categories and Sub-Categories

Appendix M: Genderbread Person

Appendix N: Summary of Results for Participants

Appendix A: Letter of Approval from National Research Ethics Service Committee



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



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22 August 2018

Dear Dr Mandy

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	Understanding gender identity development in gender variant adolescent natal females with autistic spectrum conditions (ASC)
IRAS project ID:	220314
Protocol number:	17/0204
REC reference:	17/LO/1957
Sponsor	University College London

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?

You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

IRAS project ID	220314
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It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Misha Ladva

Tel: [REDACTED]

Email: [REDACTED]

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **220314**. Please quote this on all correspondence.

IRAS project ID	220314
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Yours sincerely

Miss Lauren Allen
Senior Assessor

Email: hra.approval@nhs.net

Copy to: Ms Misha Ladvá, Joint Research Office, UCL

IRAS project ID	220314
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List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Covering letter on headed paper [Cover Letter - REC Committee]		28 June 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Confirmation]		26 September 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Certificate 2017-18]		24 July 2018
HRA Schedule of Events	1.0	13 July 2018
HRA Statement of Activities	1.0	13 July 2018
Interview schedules or topic guides for participants [Interview schedule]	4	20 August 2017
IRAS Application Form [IRAS_Form_25102017]		25 October 2017
IRAS Application Form XML file [IRAS_Form_25102017]		25 October 2017
IRAS Checklist XML [Checklist_31102017]		31 October 2017
Participant consent form [Informed Consent Form - Parent or Guardian - 170204]	5	13 July 2018
Participant consent form [Informed Consent Form - Young Person - 170204]	5	13 July 2018
Participant consent form [Assent Form - Young Person - 170204]	2	13 July 2018
Participant information sheet (PIS) [Information Sheet Parent 170204]	5	13 July 2018
Participant information sheet (PIS) [Information Sheet Young Person - Final]	5	13 July 2018
Research protocol or project proposal	5	13 July 2018
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator]	1	27 September 2017
Summary CV for student [Summary CV for student]		25 September 2017
Summary CV for supervisor (student research) [Summary CV for supervisor]		25 September 2017

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards?	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	A minor change was made to the Protocol following REC favourable opinion to remove reference to the site in Leeds, as this site will not be participating in the research.
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Statement of Activities and Schedule of Events will act as the agreement between the sponsor and site.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No funding will be provided to the site.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No identifiable data will be recorded on questionnaires.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments

IRAS project ID	220314
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Section	HRA Assessment Criteria	Compliant with Standards?	Comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type. A member of the clinical team at the site will identify potential participants and provide the study information sheet. Consent, questionnaires and interviews will be conducted by the research team and may take place at the site or in participants' homes.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

IRAS project ID	220314
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Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A key contact should be identified at the site to identify potential participants and send study information on behalf of the research team.

A Local Collaborator will only need to be identified where the external research team requires access arrangements to conduct study activity at the site.

GCP training is not a generic training expectation, in line with the [HRA/HCRW/MHRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

It is expected that study activity will be conducted by the student research who holds an Honorary Research Contract with the site therefore no additional access arrangements are expected.

If study activity conducted at the site is undertaken by external staff (e.g. University) who do not have an existing contract with the site then these staff will be expected to obtain a Letter of Access. This should confirm Disclosure and Barring Service (DBS) and Occupational Health Checks. Enhanced DBS checks should be confirmed where the study activity involves participants younger than 16 years.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix B: Sample Information Sheets – Young Person



Research Study Information Sheet: Young Person

Title of study: Understanding gender identity development in gender variant birth-assigned female young people, with autistic spectrum conditions (ASC)

Researcher Details

Emily Hard, Trainee Clinical Psychologist
Research Department of Clinical, Educational and Health Psychology, UCL, 4th Floor, 1-19 Torrington Place, London, WC1E 7HB
E: emily.hard.15@ucl.ac.uk
T: XXXXXXXXXXXXXXXX

What is all this about?

The Gender Identity Development Service (GIDS) is a clinic for young people experiencing difficulties with their gender identity. We are always looking to learn more about the strengths and difficulties of the young people who come to our clinic, so that we can learn new ways to help. One way that we continue to learn (and help other professionals continue to learn) from the work that we do is by doing research with particular young people/families/organisations. This is known as a 'research study'.

If you are reading this it is because you are being asked whether you would like to take part in a research study. It is about the gender identity of young people who have autism.

Why are we doing this research?

The reason for doing this study is because previous research has shown that young people with autism tend to identify in gender diverse ways (e.g. as transgender, non-binary, gender fluid etc.) and can have more difficulties with developing their gender identity. There are also many young people assigned female at birth accessing gender identity development services. Little is understood about why this is the case.

What are the aims of the research?

By talking to you, and other young people, I aim to better understand how birth-assigned female young people with a diagnosis of autism experience their gender identity development. We also want to understand how services can provide better support.

Who is doing the research?

I am a Trainee Clinical Psychologist from University College London. I am working within the GIDS team on this research study with support from clinicians.

What would I be asked to do if I decide to take part?

I would ask you (or your parent/guardian if you are under 16) to sign a consent form to show that you are happy to take part in the research. I would send this to you in the post for you to sign and return to me in an envelope that I will have stamped and addressed for you.

I would then invite you to meet me in person (or talk to me via Skype if you would prefer).

To start, I would ask you to complete a couple of short, written questionnaires. These would not take more than five minutes for you to complete. They include questions about your strengths, as well as any areas where you feel you have a bit more difficulty. You would also be asked about the type of school that you attend.

I would then ask you some questions about your experiences at different stages of life. Your answers to these questions would be audio recorded and kept very carefully, so no one outside the research team could ever hear them. In the interview you can say as much or as little as you want – you choose whether there are topics you do not want to talk about

At the end of the meeting there would be time for you to talk with me about the study, and share any concerns you may have. The meeting would last between 1 and 1.5 hours

Where would the research study take place?

The research study would take place wherever you would feel most comfortable. You could choose to meet with me either at the GIDS clinic, or in your own home/another place of your choosing. It could even be arranged for you to speak to me via Skype if you would prefer.

When is the research study take place?

I will be meeting with a number of young people, like you, between December 2018 and May 2019.

Would I get anything in return for participating?

Yes. You would be given a £10 voucher for Amazon if you chose to participate in the research study. This would be my way of thanking you for taking the time to be an important part of the study.

Would this study protect my privacy and the privacy of my family?

Research studies are set out in a way that maintains confidentiality (in other words, no one would be able to identify you in the study). Any information (e.g. names) that could be used to identify you, your family or anyone else involved would be removed or changed. I would also use codes, rather than names, to identify you and the other participants. I would save all the information that I have collected in an electronic database using the code only. A separate document linking your name to your study code will be kept securely and separately from the collected study information.

Once the recording of your conversation with me has been typed up and stored safely on a computer, the recording would be deleted.

The only time I would need to discuss with another person what we had spoken about would be if you were to tell me something that suggested you or others were at risk of harm.

Would I get to see the results of the study?

Yes. If you were interested in seeing the results of the study, I would send you a summary of the overall findings (based on all the interviews that I have carried out rather than just yours), and invite you to complete a brief on-line survey to help you feedback your thoughts. This way you could let me know whether you thought the results reflect your point of view. If you were not happy with what was written, you would be able to tell me and ask me to change it or take it out.

What would happen if I don't want to carry on with the study?

If you decided at any time that you no longer wish to take part in this study, you could let me know by email (emily.hard.15@ucl.ac.uk) and I would withdraw your answers immediately. None of your direct quotes would be used if you withdraw from the study.

What happens next?

If you would like to take part in the research or if you have any questions at all – get in touch with us! You can contact me either via email at emily.hard.15@ucl.ac.uk or via phone on XXXXXXXXXX. If I do not answer the phone, please leave a voice message and I will give you a call back as soon as I can.

Thank you for taking the time to read this!

Best wishes,

Emily Hard, Trainee Clinical Psychologist

Appendix C: Sample Information Sheets – Parent/Guardian



Research Study Information Sheet: Parent/Guardian

Title of study: Understanding gender identity development in gender variant assigned female young people, with autistic spectrum conditions (ASC)

Researcher Details

Emily Hard, Trainee Clinical Psychologist
Research Department of Clinical, Educational and Health Psychology, UCL, 4th Floor, 1-19 Torrington Place, London, WC1E 7HB
E: emily.hard.15@ucl.ac.uk
T: XXXXXXXXXXXXX

Chief Investigator

William Mandy, Senior Lecturer
Research Department of Clinical, Educational and Health Psychology, UCL, 4th Floor, 1-19 Torrington Place, London, WC1E 7HB
E: w.mandy@ucl.ac.uk
T: 0207 679 1897

What is all this about?

The Gender Identity Development Service (GIDS) is a clinic for young people presenting with difficulties with their gender identity. We are always looking to learn more about the strengths and difficulties of the young people who come to our clinic, so that we can learn new ways to help. One way that we continue to learn (and help other professionals continue to learn) from the work that we do is by doing research with particular young people/families/organisations. This is known as a 'research study', and in this instance it is being undertaken as part of an educational project.

If you are reading this it is because you are being asked whether you would be willing for your child to take part in a research study. It is about the gender identity of young people who have autism.

Why are we doing this research?

The reason for doing this study is because previous research has shown that young people with autism tend to identify in gender diverse ways and can have more difficulties with developing their gender identity. There are also many young people assigned female at birth accessing gender identity development services. Little is understood about why this is the case.

What are the aims of the research?

By talking to your child, and other young people, I aim to better understand how assigned female young people with a diagnosis of autism experience their gender identity development. We also want to learn how services can provide better support.

Who is doing the research?

I am a Trainee Clinical Psychologist from University College London. I am working within the GIDS team on this research study with support from clinicians.

What would your child be asked to do if they decide to take part?

I would ask your child (or you if your child is under 16) to sign a consent form to show that they are happy to take part in the research. I would send this to you in the post for you or your child to sign, and return to me in an envelope that I will have stamped and addressed for you.

Your child would then be invited to meet me individually in person (or talk to me via Skype if your child would prefer).

To start, I would ask your child to complete a couple of short, written questionnaires. These would not take more than five minutes for them to complete. They include questions about your child's strengths, as well as any areas where your child feels that they may have a bit more difficulty. Your child would also be asked about the type of school that they attend.

Next, I would ask your child some questions about their experiences at different stages of life. Your child's answers to these questions would be audio recorded and kept very carefully, so no one outside the research team could ever hear them. In the interview, your child can say as much or as little as they want – they can choose whether there are topics they do not want to talk about.

At the end of the meeting there would be time for your child to talk about the study, and to share any concerns they may have. The meeting would last between 1 and 1.5 hours.

Where would the research study take place?

The research study would take place wherever your child feels most comfortable. They can choose to meet with me either at the GIDS clinic, or at home/another place of their choosing. It can even be arranged from them to speak to me via Skype if they would prefer.

When is the research study taking place?

I will be meeting with a number of young people, like your child, between December 2018 and May 2019.

Would your child get anything in return for participating?

Yes. Your child would be given a £10 voucher for Amazon if they choose to participate in the research study. This would be our way of thanking them for their time.

Would this study protect my child's and my family's privacy?

Research studies are set out in a way that maintains confidentiality (in other words, no one would be able to identify your child or your family in the study). Any information (e.g. names) that could be used to identify your child, your family or anyone else involved would be removed or changed. I would also use a code, rather than your child's name, to identify your child and the other participants. I would save all the information that I have collected in an electronic database using the code only. A separate document linking your child's name to their study code will be kept securely and separately from the collected study information.

Once the recording of your child's conversation with me has been typed up and stored safely on a computer, the recording would be deleted.

The only time I would need to discuss with another professional what I had spoken about with your child would be if they were to tell me something that suggested they, or others, were at risk of harm.

Would my child and I get to see the results of the study?

Yes. If you and your child were interested in seeing the results of the study, I would send you and your child a summary of the overall findings via email (based on all the interviews that I have carried out rather than just your child's) and invite your child to complete a brief on-line survey to help them feedback their thoughts. This way they would be able to let us know whether they think the results reflect their point of view or not. If they are not happy with what is written, they can tell me and ask me to change it or take it out.

What would happen if my child didn't want to carry on with the study?

If you or your child decided at any time that you no longer wished to take part in this study, you would be able to let me know by email (emily.hard.15@ucl.ac.uk) and I would withdraw your child's answers immediately. None of your child's direct quotes would be used if your child withdraws from the study.

What happens next?

If you would like your child to take part in the research or if you have any questions at all – get in touch with us! You can contact me either via email at emily.hard.15@ucl.ac.uk or via phone on XXXXXXXXXX. If I do not answer the phone, please leave a voice message and I will give you a call back as soon as I can.

Thank you for taking the time to read this!

Best wishes,

Emily Hard
Trainee Clinical Psychologist

Appendix D: Sample Informed Consent Form – Young Person



Informed Consent Form – Young Person

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: Understanding gender identity development in gender variant assigned female young people, with autistic spectrum conditions (ASC)

Thank you for your interest in taking part in this research. Before you agree to take part, I need to explain the project to you.

If you have any questions after having read the information sheet, please ask me (Emily Hard, the researcher) before you decide whether you want to take part in the study.

Participant's Statement

If you sign this consent form it indicates that you know that (please initial each box next to each statement that you have read and understand):

.....I consent to take part in this study and that, if I do not want to, this will not affect my care/treatment.

.....I have read the Information Sheet and I understand what the study involves.

.....I understand that if I decide at any time that I no longer wish to take part in this project, I can let the researcher know by email (emily.hard.15@ucl.ac.uk) and she will withdraw my answers immediately.

.....I consent to my answers and personal information being used for the purposes of this research study only.

.....I understand that the researcher will be treating my information as strictly confidential and it will be handled in accordance with the Data Protection Act 2018.

.....I agree that the researcher has clearly explained the research project named above to me and that I agree to take part in this study.

.....I understand that my answers to the interview will be audio taped and I consent to the research using my answers as part of the study.

.....I understand that, if I wish to receive it, the researcher will send me a summary of the findings and invite me to complete a brief on-line survey to facilitate feedback. If I am not happy with what is written, I know I can tell the researcher and ask them to change it or take it out.

.....I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

.....I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from University College London, from regulatory authorities or from the Tavistock and Portman NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

Signature:

Name Printed:

Dated:

Signature of Person Obtaining Consent:

Name Printed:Emily Hard.....

Dated:

Appendix E: Sample Informed Consent Form – Parent/Guardian



Informed Consent Form – Parent/Guardian

Title of Project: Understanding gender identity development in gender variant assigned female young people, with autistic spectrum conditions (ASC)

Thank you for your interest in enabling your child to take part in this research. Before you agree on your child's behalf to take part, I need to explain the project to you and your child.

If you have any questions after having read the information sheet, please ask me (Emily Hard, the researcher) before you decide whether you want your child to take part in the study.

Parent/Guardian's Statement

If you sign this consent form it indicates that you know that (please initial each box next to each statement that you have read and understand):

.....I consent for my child to take part in this study and understand that, that if I do not want to give consent, this will not affect my child's care/treatment.

.....I have read the Information Sheet and I understand what the study involves.

.....I understand that if my child or I decide at any time that we no longer wish to take part in this study, I can let the researcher know by email (emily.hard.15@ucl.ac.uk) and she will withdraw my child's answers immediately.

.....I consent to my child's answers and personal information being used for the purposes of this research study only.

.....I understand that the researcher will be treating my child's information as strictly confidential and it will be handled in accordance with the Data Protection Act 1998.

.....I agree that the researcher has clearly explained the research project named above to me and that I agree, on behalf of my child, for them to take part in this study.

.....I understand that my child's answers to the interview questions will be audio taped and I consent to the researcher using my child's answers as part of the study.

.....I understand that, if my child or I wish to receive it, the researcher will send me a summary of the findings and invite my child to complete a brief on-line survey to facilitate feedback. If my child is not happy with what is written, I know that they can tell the researcher and ask them to change it or take it out.

.....I understand that confidentiality and anonymity will be maintained and it will not be possible to identify my child or family from any publications.

.....I understand that relevant sections of my child's medical notes and data collected during the study, may be looked at by individuals from University College London, from regulatory authorities or from the Tavistock and Portman NHS Trust, where it is relevant to my child taking part in this research. I give permission for these individuals to have access to my child's records.

Name of child:

Date of birth of child:

Name of parent:

Signature:.....

Date:

Name of person taking consent: Emily Hard

Signature:.....

Date:

Appendix F: Sample Informed Assent Form – Young Person (Under 16)



Assent Form – Young Person

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: Understanding gender identity development in gender variant assigned female young people, with autistic spectrum conditions (ASC)

Thank you for your interest in taking part in this research. Before you agree to take part, I need to explain the project to you.

If you have any questions after having read the information sheet, please ask me (Emily Hard, the researcher) before you decide whether you want to take part in the study.

Participant's Statement

If you sign this assent form it indicates that you know that (please initial each box next to each statement that you have read and understand):

.....I consent to take part in this study and that, if I do not want to, this will not affect my care/treatment.

.....I have read the Information Sheet and I understand what the study involves.

.....I understand that if I decide at any time that I no longer wish to take part in this project, I can let the researcher know by email (emily.hard.15@ucl.ac.uk) and she will withdraw my answers immediately.

.....I consent to my answers and personal information being used for the purposes of this research study only.

.....I understand that the researcher will be treating my information as strictly confidential and it will be handled in accordance with the Data Protection Act 2018.

.....I agree that the researcher has clearly explained the research project named above to me and that I agree to take part in this study.

.....I understand that my answers to the interview will be audio taped and I consent to the research using my answers as part of the study.

.....I understand that, if I wish to receive it, the researcher will send me a summary of the findings and invite me to complete a brief on-line survey to facilitate feedback. If I am not happy with what is written, I know I can tell the researcher and ask them to change it or take it out.

.....I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

.....I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from University College London, from regulatory authorities or from the Tavistock and Portman NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

Signature:

Name Printed:

Dated:

Signature of Person Obtaining Consent:

Name Printed:Emily Hard.....

Dated:

Appendix G: Interview Schedule

Interview Schedule

Nb: text in square brackets indicates possible follow-up questions or alternative ways of stating a question.

Introduction

- Check what participant wants to be called
- Check if they are comfortable with the setting that we are in, and ask if there is anything I could do to help them feel more comfortable
- Go through consent form and practical information
- Introduction to the purpose of the research

We are meeting today because you have chosen to be a part of this research study. Thank you so much for agreeing to take part. I am hoping that by talking to you and other young people I will start to build a better picture of how assigned female young people with a diagnosis of autism experience their gender identity development, and how services can better support them.

I am going to ask you about different phases of life in terms of your gender feelings, your relationships with your family and friends, your feelings about your body, your sexuality etc. Some of these things can feel quite personal to talk about. It is important for you to know that you don't need to answer any questions that you don't feel comfortable with and that there are no right or wrong answers, only your answers.

I am also aware that as a non-transgender/cis-gender woman, I might not be able to get things right or use the right language. If at any stage you don't like the language I am using or the way I've put things, please let me know and I will do my best to adapt what I say.

- Do you have any specific questions about this study? [Allow for questions/follow-up].
- Discuss any questions or concerns the participant may have

Engaging participant

Just to help me build up a picture of you in general, can you tell me a little about what you would be doing if you weren't here with me now? [e.g. what are your interests/hobbies?]

Relationship with autism diagnosis

How did you end up receiving a diagnosis of autism?

At what point in your life did you receive a diagnosis of autism?

What did you think about diagnosis? Did you agree with it? What does it mean to you to be

autistic? What impact, if any, did this diagnosis have on you?

What do you think about your diagnosis now?

Exploring family tree

I would like to find out a little bit about your family. A good starting point can often be drawing a family tree in which we identify the significant people in your family – shall we do that together? There is a tradition that women/girls are represented by circles and men/boys are represented by squares, however of course that does not work for everyone and some people identify outside the gender binary [i.e. identify as neither male or female]. How would you like to be drawn on your family tree?

[Alternative question, if young person prefers not to complete family tree]: You said you prefer to be known as X, is this the name that you have had since birth? [Possible follow-up question if not: How did you come up with this name? Who knows you by this name? Who does not? How come?]

What do you think are the differences are in your family between boys and girls/men and women? [Possible follow-up question: How did you become aware of these differences?]

Exploring early childhood/pre-school years (age approx. 0-4)

Can you tell me a bit more about what was your childhood was like before you went to school? [Possible follow-up questions, if required: What are some of your earliest memories? How did you see yourself at that time?]

What was it like growing up as ‘a girl’ [I will take the participant’s lead regarding language at that point in their life e.g. trans boy?] at that point in your life? [Follow up question if required: How aware were you of your gender at that time?]

Did you feel that like people expected you to behave like ‘a girl’? [Possible follow-up questions: If so, how were you required to behave? What was this like for you? Where and when did you feel that most/least; where and when did gender seem to matter most/least; what other things seemed less/more important; why/how do you make sense of that now?]

How did you express your gender during this period of your life? [Possible follow-up information, if required: So what did that mean in terms of how you lived your gender in your day-to-day life? For example, did you express your gender through your choice of clothes/fashion; how you wore your hair; interests; body language; choice of friends etc.? If so, how? What led you/why did you choose to express your gender in this way?]

How did you get on with children your own age? [Possible follow-up question, if required: How did they respond or react to you? How did you respond or react to them? What did you think about the way people responded/reacted to you? How did they the way people responded/reacted to you make you feel?]

Exploring later childhood/primary school years (age approx. 5-11)

What was it like for you starting primary school [Possible follow-up questions, if required: Do

you have any specific memories of starting primary school? How did you see yourself at that time?]

What was it like being at primary school? [Possible follow-up question, if required: How did you get on with your classmates? Explore peers' perceptions regarding the young person's gender and the young person's experience of this, as above].

Did you feel that there was any expectation to behave in any particular way as 'a girl' at this point in your life? [Possible follow-up questions, if required: If so, how were you required to act or behave? What was this like for you? Where and when did you feel that most/least; where and when did gender seem to matter most/least; what other things seemed less/more important; why/how do you make sense of that now?]

What was it like growing up as 'a girl' [I will take the participant's lead regarding language at that point in their life e.g. trans boy?] at that point in your life? [Follow up question if required: How aware were you of your gender at that time?]

How did you express your gender during this period of your life? [Possible follow-up questions, if required: So what did that mean in terms of how you lived your gender in your day-to-day life? For example, did you express your gender through your choice of clothes/fashion; how you wore your hair; interests; body language; choice of friends etc.? If so, how? What led you/why did you choose to express your gender in this way?]

How did the people closest to you (your parents, siblings or significant others) tend to respond or react to you during this time in your life? [Possible follow-up questions: What did you think about the way they responded/reacted to you?]

Did you do anything or did any happen to you good or bad (e.g. have any key experiences; conversations, relationships, see anything in the media etc.) during that time that helped you to make sense of your developing identity as a 'trans boy'? [I will take the participant's lead regarding language at that point in their life]. If so, how did this help you?

Exploring early adolescence/secondary school years (age approx. 12-14)

What was it like for you moving from primary to secondary school? [If not in mainstream school, ask: What was it like for you as you entered your early teens?] [Possible follow-up questions, if required: Do you have any specific memories from that time in your life? How did you see yourself at that time?]

What were your relationships like with your classmates and other teenagers? [Possible follow-up question, if required: Explore peers' perceptions regarding the young person's gender and the young person's experience of this, as above].

Did you feel that there was any expectation to behave in any particular way particular way as 'a girl' at this point in your life? [Possible follow-up questions: If so, how were you required to behave? What was this like for you? Where and when did you feel that most/least; where and when did gender seem to matter most/least; what other things seemed less/more important; why/how do you make sense of that now.]

Often the move to secondary school happens at the same time as start of puberty. Of course the

timing of puberty can vary a lot – some people start experiencing puberty much younger, others later. I'd be interested in hearing what going through puberty was like for you? [Possible following up questions: When did puberty start for you? What did you notice? What did you think and feel about those changes (e.g. breast growth, periods etc.)?]

What was it like growing up as 'a girl' [I will take the participant's lead regarding language at that point in their life e.g. trans boy?] at that point in your life? [Possible follow-up question if required: How aware were you of your gender at that time?]

How did you express your gender during this period of your life? [Possible follow-up information, if required: So what did that mean in terms of how you lived your gender in your day-to-day life? For example, did you express your gender through your choice of clothes/fashion; how you wore your hair; interests; body language; choice of friends etc.? If so, how? What led you/why did you choose to express your gender in this way?]

How did the people closest to you (your parents, siblings or significant others) tend to respond to you during that time in your life? [Possible follow-up questions: What did you think about the way they responded to you? How did the way they responded to you make you feel?]

Our early teens are also a significant time in life in that it is often the stage at which we start to become more aware of sexuality and/or explore this in new ways. I'd be interested in hearing about how you would talk about your sense of yourself in terms of sexuality and/or romantic attractions. [Possible following up questions: Who were you attracted to in your early teens? What were your experiences of intimate or sexual relationships? How did you describe yourself e.g. homosexual, heterosexual, bisexual etc.?]

Did you do anything, or did any happen to you, good or bad (e.g. have any experiences; conversations, relationships, see anything in the media etc.), during that time that helped you to make sense of your developing identity as a 'trans boy' [I will take the participant's lead regarding language at that point in their life] If so, how did this help you?

Exploring later adolescence/secondary school years or college (age approx. 15-18)

Thinking about where you are now in life, how would you say life is like for you now?

What are your relationships like with your classmates [if relevant] and other teenagers? [Possible follow-up question, if required: Explore peers' perceptions regarding the young person's gender and the young person's experience of this, as above].

Do you feel that there is any expectation to behave in any particular way 'as a girl' at this point in your life? [Possible follow-up questions: If so, how are you required to behave? What was this like for you? Where and when do you feel that most/least; where and when does gender seem to matter most/least; what other things seem less/more important; why/how do you make sense of that.]

How do you express your gender at this point in your life? [Possible follow-up questions, if required: So what does this mean in terms of how you lived your gender in your day-to-day life? For example, do you express your gender through your choice of clothes/fashion; how you wear your hair; interests; body language; choice of friends etc.? If so, how? What leads you/why do you choose to express your gender in this way?]

How do you think and feel about your body now? [Possible follow-up questions, if required: What did you think and feel about those changes (e.g. breast growth, periods etc.) that your body has been through.]

How would you describe your gender identity today? You may feel that one or two words describe you best, or that a number of different terms apply to you. You may feel that a term you have heard about applies to you, or you may have a unique term or phrase that is individual to you. [Possible follow-up question: Can you please tell us a bit about what this word/these words mean to you?]

How do the people closest to you (your parents, siblings or significant others) tend to respond to you now? [Possible follow-up questions: What do you think about the way they respond or react to you? How does the way they respond or react to you make you feel?]

How would you describe your sexuality now? [Possible follow-up questions: Who are you attracted to? Who do you have relationships with? What are your experiences of intimate or sexual relationships? How do you describe yourself – homosexual; heterosexual, bisexual etc.?].

Are you doing anything at this point in time to help you to try to make sense of your developing identity as a 'trans boy' [I will take the participant's lead regarding language at that point in their life] (e.g. belonging to any groups of like-minded people; internet research, reading books etc.)? If so, how would you say that this helps you? Have you had any experiences in this area, which have been unhelpful?

Looking back on the journey you've been on up to now, how would you describe yourself now compared to the person you were in childhood?

Exploring the future (age approx. 15-18+)

What are your hopes for the future in relation to your gender?

What challenges do you feel that you may face?

Prompts:

- 1) Your expression of your gender [Alternative way of phrasing question: In an ideal world, how would you like to be able express (or show) your gender to others? What do you think needs to happen to make that possible? Is there anything you would like to do to enable to feel more comfortable in your gender identity?]
- 2) Your body [Alternative way of phrasing question: Is there anything that you feel that you need/would like to change about yourself physically?]
- 3) Your gender role [Alternative way of phrasing question: How would you like to be able to act or behave in relation to your experienced/expressed gender? What difference would this make to you?]
- 4) Your sexuality and relationships [Alternative way of phrasing question: In an ideal world, what types of relationships would you like to have with others (e.g. intimate/sexual relationships, friendships etc.) How do you think these relationships might develop in the future?]

Statement of the research question

As I mentioned at the start of the interview, it has been found that young people with autism tend to have more difficulty developing their gender identity. Why do you think that is?

Any other questions

Anything else you would like to say about your experiences or anything we've discussed today?

Appendix H: Strengths and Difficulties Questionnaire (SDQ) with Impact Supplement

Strengths and Difficulties Questionnaire

S 11-17

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

Your Name

Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am restless, I cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually share with others (food, games, pens etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get very angry and often lose my temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am usually on my own. I generally play alone or keep to myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually do as I am told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have one good friend or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I fight a lot. I can make other people do what I want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other people my age generally like me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am easily distracted, I find it difficult to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am nervous in new situations. I easily lose confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often accused of lying or cheating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other children or young people pick on me or bully me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often volunteer to help others (parents, teachers, children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think before I do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take things that are not mine from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get on better with adults than with people my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have many fears, I am easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I finish the work I'm doing. My attention is good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Overall, do you think that you have difficulties in one or more of the following areas:
emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Do the difficulties upset or distress you?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Do the difficulties interfere with your everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Do the difficulties make it harder for those around you (family, friends, teachers, etc.)?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your Signature

Today's Date

Thank you very much for your help

© Robert Goodman, 2005

Appendix I: Sample Feedback Form

Understanding gender identity interview feedback form

What was your experience of being interviewed? (put a cross on the line)

Easy to engage in

Challenging to engage in

I felt relaxed
anxious

I felt

I felt listened to

I felt I was not listened to

Overall, I felt (tick appropriate face) about the interview process



I would change...

Something I would keep the same...

Appendix J: Gender Terminology

Birth-assigned female/male: The assignment and classification of people as male or female at birth often based on physical anatomy.

Bottom surgery: Genital surgeries such as vaginoplasty, phalloplasty, or metoidioplasty.

Cis(gender): A term for people whose gender identity matches the sex that they were assigned at birth.

Gender: A set of cultural constructs describing characteristics that may historically be related to femininity, masculinity, women, men, non-binary people, or social norms.

Gender expression: The physical manifestation of one's gender identity through clothing, hairstyle, voice, body shape, etc. (typically referred to as masculine or feminine).

Gender identity: A person's internal sense of being male, female, neither of these, both, or other gender(s).

Gender diverse/variant/non-conforming: Umbrella terms used to describe some people whose gender identity and/or expression is different from conventional expectations (norms/stereotypes) of gender.

Gender dysphoria: Anxiety and/or distress related to a person's sex assigned at birth.

Gender fluid: A changeable or "fluid" gender identity.

Non-binary: An umbrella term for all genders other than female/male or woman/man.

Pansexual: Being attracted to many/any gender(s).

Sex: A set of characteristics associated with reproduction and biology that generally assign individuals into categories of "male" and "female."

Sexual orientation: A person's sexual, romantic, emotional, aesthetic, and/or other form of attraction to others.

Stealth: To not be openly transgender in all or almost all social situations.

Top surgery: Chest surgery such as double mastectomy, breast augmentation, or periareolar (keyhole) surgeries.

Transphobia: Systemic violence against trans people, associated with attitudes such as fear, discomfort, distrust, or disdain.

Transgender: An umbrella term for people whose gender identity differs from the sex they were birth-assigned.

Transition: A person's process of developing and assuming a gender expression to match their gender identity.

Source of definitions: <http://www.transstudent.org/definitions/> (Retrieved 28th May 2019)

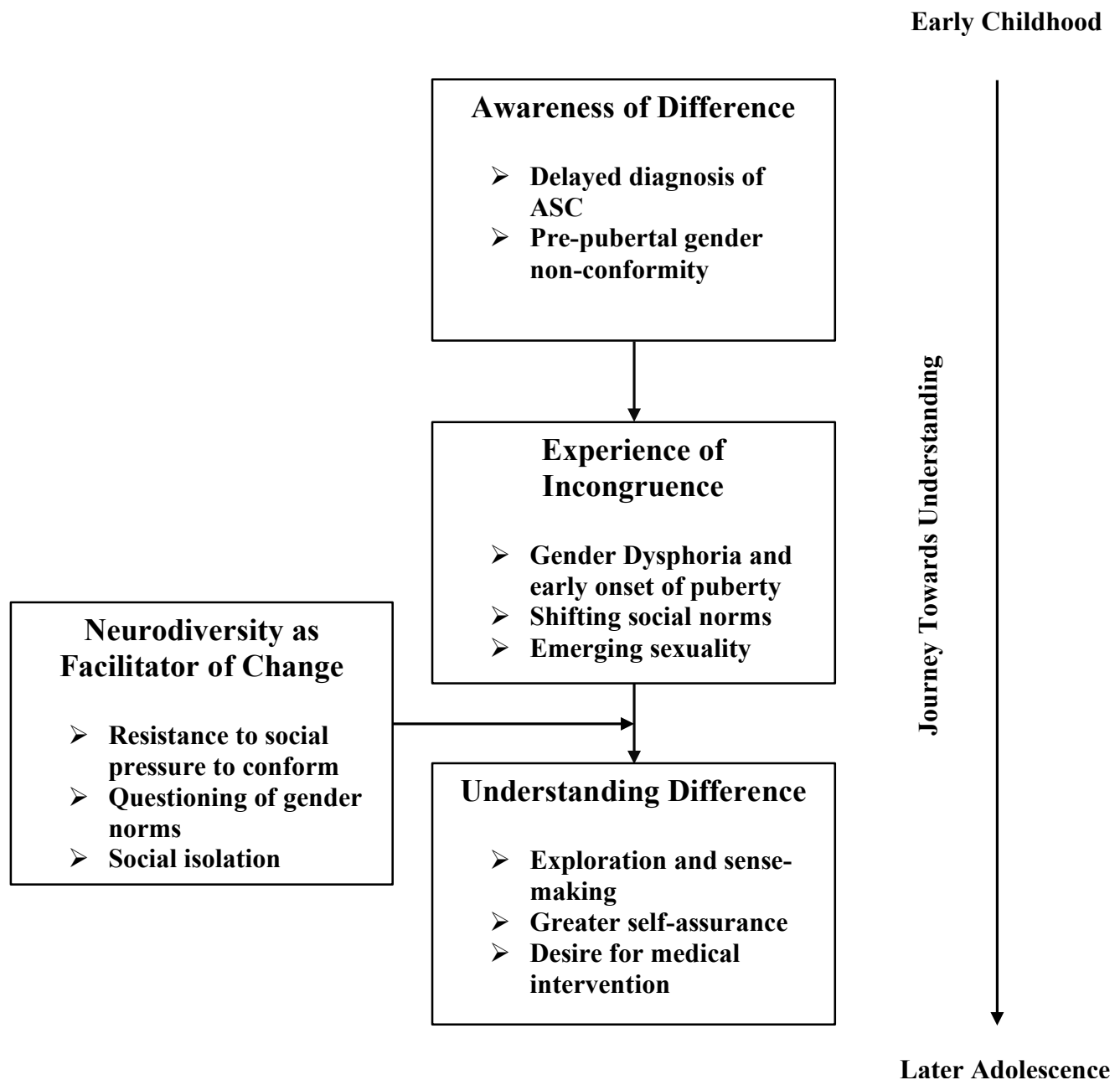
Appendix K: Example of Initial and Focused Coding

Start Time	End Time	Transcript	Initial Coding	Focused Coding
00:26:21.6	00:26:30.5	In terms of your relationship with gender, did that change at all during secondary school?		
00:26:30.6	00:27:01.6	Err. I <u>wanted to wear trousers</u> in year 7 but because of the growth spurt...mum was like you've grown so much I grew out of an entire pair of trousers in a few months. Then I got <u>hopeful I'd be tall</u> , but that didn't happen. But then because id grown so much I wore the skirt for the entire year 8 I think, but then I <u>went back to trousers</u> in year 9 I think...that's when the <u>main gender complete...I was like oh my god I feel male.</u>	<p><i>Preference for what is considered to be 'masculine' attire</i></p> <p><i>Height possibly perceived as a 'male' attribute?</i></p> <p><i>Preference for what is considered to be 'masculine' attire</i></p> <p><i>Awareness of gender identity – experienced as clear/definite/sense of 'process of discovery complete'</i></p>	<p>'Masculine' gender expression - clothing</p> <p>'Masculine' gender expression - clothing</p> <p>Awareness of gender identity</p> <p>Surety of male identity</p>
00:27:01.6	00:27:06.6	So those two years when you had to wear skirts, what was that like for you?		
00:27:06.6	00:27:29.2	I had my first panic attack in the October of year 8. I didn't know what was going on. I can't remember why but yeah. So <u>it was just a very uncomfortable time</u> . Year 7 was still just <u>in my own world</u> . Year 8 I kind of <u>woke up</u> , I guess you could say.	<p><i>Implicit linking of anxiety to wearing 'feminine' attire?</i></p> <p><i>Discomforting time (early adolescence)</i></p> <p><i>Socially isolated from peers</i></p> <p><i>Awareness of male gender identity experienced as an 'awakening'</i></p>	<p>Anxiety</p> <p>Discomfort</p> <p>Social isolation</p> <p>Awareness of gender identity</p>
00:27:30.2	00:27:30.8	What was that experience like of waking up?		
00:27:30.8	00:27:47.4	The mental health problems started. <u>I became anxious</u> and stuff. That's when I was like properly anxious.	<i>Mental health difficulties - gender dysphoria?</i>	Anxiety
00:27:48.9	00:27:51.7	Did you like the anxiety in your mind to gender?		
00:27:51.7	00:27:57.5	No...not until year 9, so 13.	<i>Connection of MH difficulties to gender not made initially</i>	
00:27:58.9	00:27:59.0	So these were like the early warning signs that something...		
00:27:58.9	00:27:59.0	Yeah.		

00:28:05.6	00:28:09.1	And then what happened in year 9 that...		
00:28:09.1	00:28:31.1	I <u>got my hair cut very short</u> finally after being bob, long, bob. It was short, staying short. I wore trousers and <u>told my mum that I felt like a boy</u> . And then nothing happened for a year and then I told my mum <u>I wanted a binder</u> and then lots of stuff happened.	<i>Decision to express themselves in more 'masculine' ways</i> <i>'Coming out' as male to mother</i> <i>Desire to hide secondary sex characteristics</i>	'Masculine' gender expression – hair Telling others Unwanted physical changes - breasts
00:28:31.6	00:28:48.5	In terms of this transition to year 9...		
00:28:48.5	00:29:18.1	<u>It was kind of like a puzzle piece</u> I guess that what people say. It like I've got the <u>whole picture seen</u> but that <u>make sense</u> because you can see the picture before all the puzzle pieces are in. So the puzzle piece doesn't really work because say <u>you were missing a pieces you could still see the picture</u> . It's not going to change even with one piece difference even if it was a big part of the picture, but that was like when I was like ' <u>I feel like a male</u> ' rather than just feeling uncomfortable, I feel male.	<i>Awareness of male gender identity experienced as a puzzle piece fitting – now makes sense/can be seen</i> <i>Even though the full picture incomplete, sense that it was male identity true for them all along</i> <i>Male gender identity as explanation for previous discomfort.</i> <i>Sense of surety in male gender identity</i>	Making sense of past experiences Surety of male identity
00:29:18.1	00:29:21.3	Can you say a little bit more about what it felt to be male?		
00:29:21.3	00:29:49.9	<u>That's why I felt like the way in primary</u> ...it wasn't just a thing that...just <u>that's how I felt the whole time</u> . It wasn't just a thing of 'I feel different'. That's what I'd been feeling making sense. That's why when I was younger I didn't like my name, that's why I did the chanting, <u>that's why I wanted to try and fit in with the boys</u> , but then ended up not because I was too scared and young and dah dah dah.	<i>Male gender identity provides an explanation for past feelings of difference</i> <i>Makes sense of past feelings</i> <i>Male gender identity as an explanation for previous gender non-conformity – preference of male companionship</i>	Making sense of past experiences
00:29:49.9	00:30:16.3	And you mentioned about binding, and this takes us back to the experience of puberty and that for you that felt quite uncomfortable, and I wondered what it was like for you to experience those physical changes?		
00:30:16.3	00:30:50.0	Err...year 7 I didn't think about it. Year 8 I didn't understand why I felt anxious. You know. I feel uncomfortable although you	<i>Retrospective understanding of why felt anxious – implicitly linked to</i>	Making sense of past experiences

		know even <u>when the menstrual bit started I felt very uncomfortable</u> with it all, but didn't know why. I struggled to say I need this but I didn't know why. <u>I felt the uncomfortableness but I didn't understand why</u> , by year 9 I understood why.	<i>gender/development of female secondary sexual characteristics?</i> <i>Discomfort linked to menstruation</i> <i>Previous lack of understanding of why he felt discomfort</i>	Unwanted physical changes - menstruation
00:30:50.0	00:30:52.0	What was it like once you had that knowledge?		
00:30:52.0	00:31:05.9	I started getting <u>more confident</u> . The <u>more male I was able to be perceived as looking, the more confident I got</u> . Even mum noticed that and other people.	<i>Growing confidence – enhanced by male gender identity</i> <i>Observable to others</i>	Growth in confidence
00:31:06.9	00:31:08.6	What did they notice?		
00:31:08.6	00:31:28.7	That I was kind of...I think the word that people described it is as <u>coming out of your shell</u> . That I more like starting to <u>get friends</u> and doing things with friends rather than only being invited to parties that was just the entire class, it was <u>actually having friends</u> .	<i>Growing confidence in social settings</i> <i>Decreased social isolation</i> <i>Development of peer friendships</i>	Growth in confidence Peer friendships
00:31:29.4	00:31:40.2	So it was a significant shift for you compared to how things were before, now you had more confidence in yourself. What was it you think that gave you that confidence?		
00:31:40.2	00:31:57.6	<u>Understanding the reason that I felt weird</u> . It was like a <u>fitting in</u> , so it didn't feel as weird because it <u>made sense</u> I guess. It was like 'oh I feel male' that's what I've been feeling. Oh I can be happy now I <u>don't have to worry</u> about feeling uncomfortable I guess.	<i>Gender making sense of existing feelings of difference/'oddness'</i> <i>Sense of belonging</i> <i>Male identity experienced as clear/defined?</i> <i>Reduced discomfort/worry</i>	Making sense of past experiences Experience of belonging
00:31:57.6	00:32:07.3	It sounds like that led to a different way of being around other people at school. What happened in the relationships?		
00:32:07.3	00:32:14.0	I started to <u>get friends</u> .	<i>Decreased social isolation/Development of peer friendships</i>	Peer friendships
00:32:14.0	00:32:14.1	What enabled you to get friends?		
00:32:14.0	00:32:26.1	I had the <u>confidence</u> to go up and talk to people rather than just reading a book. I go up and say 'oh hi'.	<i>Growing confidence in social settings</i> <i>Decreased social isolation</i>	Growth in confidence

Appendix L: Diagram of Major Category, Core Categories and Sub-Categories

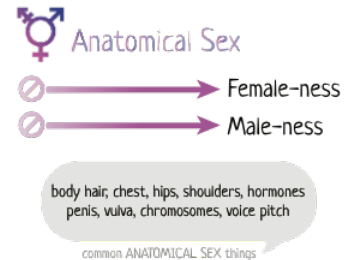
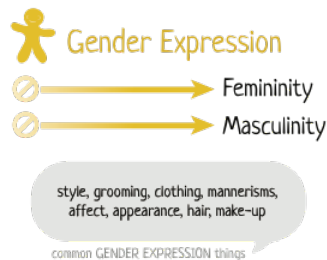
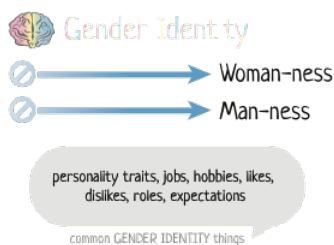
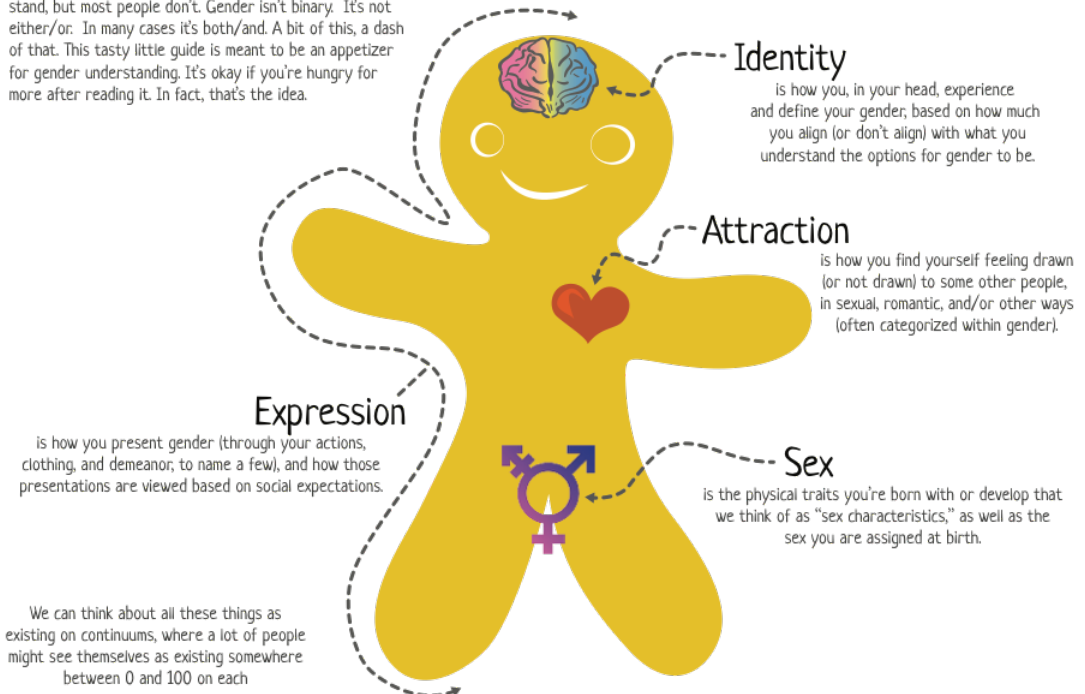


Appendix M: Genderbread person

The Genderbread Person

by its pronounced **METROsexual**.com

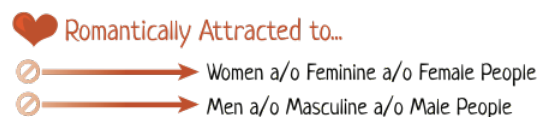
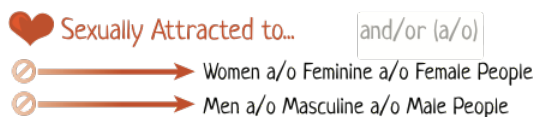
Gender is one of those things everyone thinks they understand, but most people don't. Gender isn't binary. It's not either/or. In many cases it's both/and. A bit of this, a dash of that. This tasty little guide is meant to be an appetizer for gender understanding. It's okay if you're hungry for more after reading it. In fact, that's the idea.



Identity ≠ Expression ≠ Sex
Gender ≠ Sexual Orientation

Sex Assigned At Birth
☐ Female ☐ Intersex ☐ Male

Typically based solely on external genitalia present at birth (ignoring internal anatomy, biology, and change throughout life), Sex Assigned At Birth (SAAB) is key for distinguishing between the terms "cisgender" (when SAAB aligns with gender identity) and "transgender" (when it doesn't).



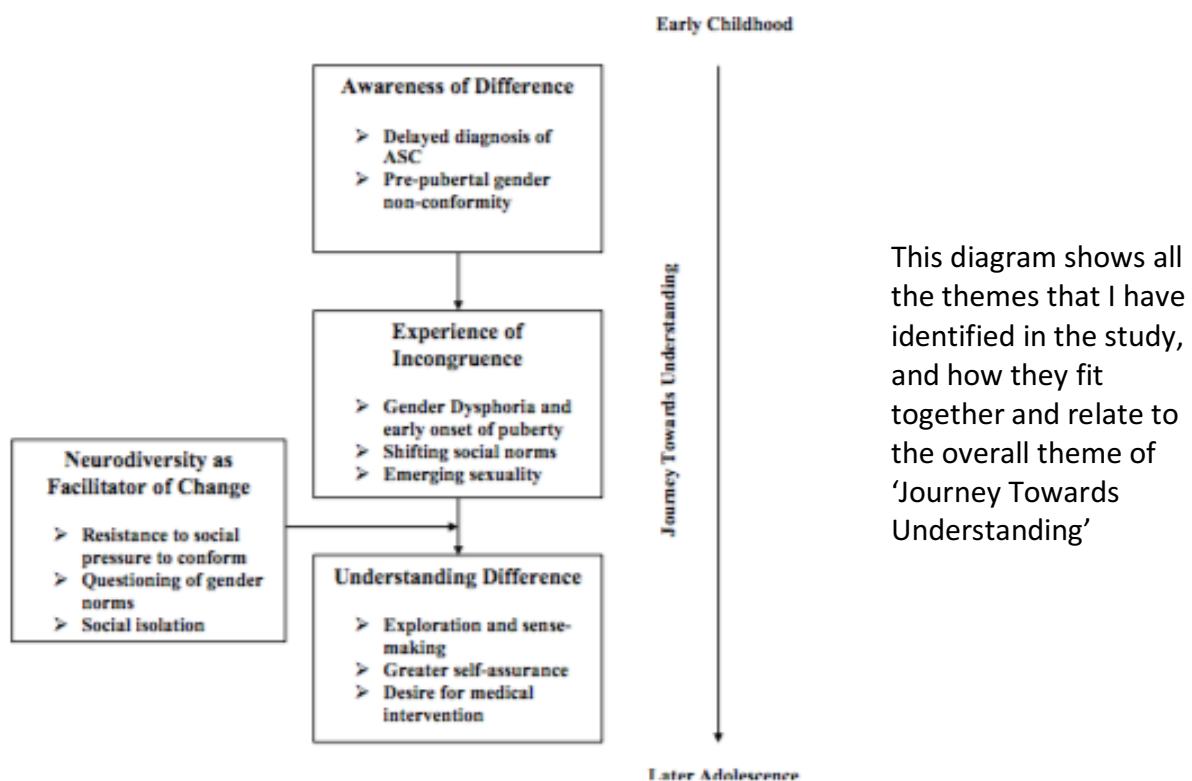
Genderbread Person Version 4 created and uncopyrighted 2017 by Sam Killermann

For a bigger bite, read more at www.genderbread.org

Appendix N: Summary of Results for Participants

Overall Theme: Journey Towards Understanding

The theme of 'Journey Towards Understanding' reflects the fact that overall the young people I spoke to about their gender identity development gave me the impression of a sense of progression from a time where they felt that they were aware of their 'difference' to others towards understanding this 'difference' as connected to their gender identity (in other words, that they came to understand feelings of difference in childhood as connected to understanding themselves to be [trans] male). My sense was that this 'journey' broadly followed the transition from early childhood to early and then later adolescence.



Theme 1: Awareness of Difference.

The first main theme reflects the idea that overall participants suggested in their accounts that they had experienced and understood themselves to be "different" in comparison to peers or family members from an early age, but that they could not account for why they experienced this to be the case when they were young. I gained the impression that it was only later on that they started to make sense of this in directly in connection to their gender. I suggest that there were two main reasons that the young people I interviewed may have experienced this period of not knowing/understanding, which I outline below:

- Delayed diagnosis of ASC

Most of the young people I spoke to were not diagnosed with ASC until they entered adolescence (average age 13.3), and often only received a diagnosis after they had been

referred to gender services. This meant that a number of participants felt that they had little explanation for their perceived “difference” prior to then:

“I was just weird and didn’t mind just being on my own, and just kind of very different to how most children are and they just didn’t want me around and yeah I did struggle with that in primary school.”

My understanding is that once most participants had a diagnosis of ASC they were able to make some sense of these feelings of ‘difference’.

“It’s just confirmation and it makes me feel more secure in myself cos I know why I am the way I am and it’s not because I’m wrong or broken and need to be fixed, it’s just me and being autistic just means this is how my brain is wired. This is how my brain works and it might be harder to do these things, and easier to do these things and you know, but it’s just fun.”

- Pre-pubertal gender non-conformity

In general, participants gave me the strong impression that they had experienced a degree of gender non-conformity from an early age. This included:

- Preference for performing traditionally ‘masculine’ roles (e.g. a prince or father) or resisting playing ostensibly ‘feminine’ roles (e.g. a mother).
- Preference for ‘masculine’ modes of expression, specifically in relation to their choice of clothing.
- Preferences for traditionally ‘masculine’ interests

The sense I got was that on reflection participants in general saw this gender non-conformity as early evidence of their (trans) male identity:

“I was really into a lot of fantasy type stuff I remember and I remember a few years later I spent hundreds of pounds on like a war hammer um yeah I was really into that. And I was really into lord of the Rings and like Star Wars and all that type stuff, which is man-type stuff.”

A number of the young people I spoke to felt that they “*clicked more with boys*”, resulting in a general preference for male companionship. This was because some of them felt that “*they didn’t have any complicated social groups*” or “*were generally a bit more relaxed*” and/or were perceived to do more “interesting” activities, such as football, tree-climbing and video games. The majority of the people I spoke to identified as “tomboys” in primary school.

My impression was that this gender non-conformity at times also reinforced the sense of feeling ‘different’:

“I knew there was something different. I didn’t know because I hadn’t been told that [transgender] was even a thing. I just sort of brushed it off”

Theme 2: Experience of Incongruence

This second major category relates to the idea that in general participants described going through a period of deepening incongruence between their experienced male gender and birth-assigned female sex. It has three sub-categories: 'Gender dysphoria and the onset of puberty', 'Shifting social norms' and 'Emerging sexuality'

The first two sub-categories link to the idea that, as I understand it, participants' sense of incongruence in relation to their gender was generally made worse by the onset of puberty, and the experience of shifting gender-related social norms.

- Gender dysphoria and the onset of puberty

Many of the young people I spoke to reported relatively early onset of puberty, with the majority of participants beginning to notice physical changes in early primary school. Most experienced distress/intensification of gender dysphoric feeling in relation to the start of puberty and expressed a wish to *"halt it"*:

"I know it was really, really crap and I felt really crap about it but at that time I didn't know why. It was just something isn't quite right here. And it pissed me off a lot. And you know there were the girls in the group who were like 'this is a big thing' and they were excited about starting, and I was like "I want this to go away right now."

A couple of participants thought that level of distress associated with these physical changes may have been heightened by their ASC:

"I started going through puberty when I was about 9 which could have a lot to do with my depression at the time. And things were changing and I didn't like change. That's a classic autistic thing. My body was changing, and I don't know how different my mind was, my mind has always been different so sometimes you can't quite tell when things aren't right, but I'm sure it definitely influenced a lot of my thinking."

- Shifting social norms

A number of the young people I spoke to reported that it was easier for them during the earlier years of school to express themselves in a more 'masculine' way among their peers:

"People started going 'tomboy' and I'd be like 'that's me'. I play football, and love motorbikes and stuff like that. And that's not like what everyone else is into at this stage. I was just kind of un-phased by it cos I was like 10 or 11 at most and it didn't really matter."

Some felt this started to change as they entered adolescence and they experienced shifts in the ways that the sexes related to each other:

"It wasn't until puberty hit that it was a thing...because everyone sort of accepted me and allowed me to be one of the lads and it wasn't something...even the girls they didn't really

see me as a girl or anything. I was always just one of the lads. It wasn't an issue until secondary school when puberty hit and I became 'the weirdo' because I was like the girl who wants to be a boy."

- Emerging sexuality

Some participants did not see their gender and sexuality as linked in any way (e.g. *"I don't see the link between who you are and who you like"*). Most reported being attracted to others of the same birth-assigned sex at some point, although none identified as lesbian (e.g. *"I knew I was a boy so I wasn't a lesbian."*)

It was clear that participants had a range of ways of describing their sexuality: *"I just like girls"*, *"gay boy"*, asexual, bisexual and pansexual (e.g. *"I don't see a difference with gender. I find any gender attractive if I like the person's personality."*)

While for some sexuality was experienced as something that was fixed and unchangeable, for others sexuality was subject to greater fluidity (e.g. *"there's no point stressing over it and trying to find a label, as I know it's likely to change"*)

Theme 3: Understanding Difference

This major category addresses how participants in general began to make sense of their experience of feeling 'different' to others, and the effect of this 'sense-making' process. It has three sub-categories: 'Exploration and sense-making', 'Greater self-assurance' and 'Desire for medical intervention'.

- Exploration and sense-making

Overall participants suggested to me that they went through a process of exploring their gender identity, which for most young people was facilitated online by social media (e.g. YouTube, Facebook etc.).

I was given the impression that this played an important role in giving participants a shared language around their experience of incongruence in relation to their gender, and helping them to feel as if they were not alone:

"I was on Facebook and George Takei had shared a link to a YouTube video of a family where their young son was trans female to male, and I watched that and went 'oh that's actually a thing.' And then I think I went onto YouTube and just searched the word transgender like never heard it before and I found the YouTuber Alex Bertie and watched all of his videos and like went 'yeah, that's a thing'. That wasn't even a big surprising thing. Just 'yeah, that makes a lot of sense actually.' Now I have a word that fitted."

As a result of this process of exploration largely online, many of the young people I spoke to described experiencing something akin to an awakening (e.g. *"Sort of like a lightbulb moment in a sense."*)

The impression I got was that in general participants felt they understood their (trans) male gender identity as an explanation for their previous childhood experience of feeling 'different' and 'uncomfortable'. Most participants experienced their (trans) male gender identity as something *"real"* or *"solid"* that could explain these past feelings and was characterised by a significant degree of certainty.

Greater self-assurance

Overall participants helped me to understand that the experience of making sense of their gender identity was associated with feeling more confident (e.g. *"I'm more confident in what I do. I'm more confident in doing the right thing."*) and comfortable (e.g. *"I'm more comfortable and I can explain things better"*).

For some participants, this opened up new opportunities for friendship and/or self-expression or self-knowledge:

"I think the word that people described it is as coming out of your shell. That I more like starting to get friends and doing things with friends rather than only being invited to parties that was just the entire class, it was actually having friends."

Desire for medical intervention

The sense I got from speaking to the participants that in general the only viable way for most to consolidate their (trans) male identity was to pursue medical interventions that would halt menstruation and enable them to develop a more masculine physique.

All the young people I spoke to expressed a desire to access testosterone, and undergo surgery:

"[I want to change] everything... even just little things like your facial structure and the shape of your jaw"

The desired interventions were pursued with apparent determination and optimism:

"If I get rid of what makes me unhappy then surely that leaves me with more space to be happier"

Some participants expressed concern about whether their ASC diagnosis may prevent them from accessing physical interventions:

"I'm being asked questions and I'm like 'I don't know how to respond' to them and so sometimes that will stress me out cos I will think 'my future is going to be in jeopardy' cos I can't get how I feel across enough"

"I worried about...people not taking me so seriously, especially if I went to [the GID service] and explained how you know I feel like I'm transgender and I worry that maybe they'll see that I'm diagnosed with Asperger's and then go 'we can probably just explain this away by

the fact that he's autistic and he's probably just confused and going through that time or whatever." in primary school."

Theme 4: Neurodiversity as a Facilitator of Change

This final major category relates to the idea that some participants suggested that their ASC/neurodiversity may have facilitated the process of them socially transitioning to being (trans) male. It has three sub-categories: 'Resistance to social pressure to conform', 'Questioning of gender norms' and 'Social isolation'.

Many of the young people I spoke to reported having experiences, and ways of viewing and relating to the social world, that they felt may differ to neuro-typical young people. These include:

- Resistance to social pressure to conform

A number of participants said that they experienced times when they felt the need to adhere to certain social expectations and sensed that at times they were falling short. However, the sense I got was that this was held in tension with some participants' tendency to display a degree of resistance towards or disregard social pressures to conform to gendered expectations, particularly as they entered adolescence:

"People with autism are more kind of blunt and more likely to not care what people think about what they are doing because it doesn't occur that things aren't appropriate or socially acceptable and there is an understanding that something not being right and will just go 'yeah this is how it is' and so whether it's actually that more autistic people are trans or trans people are autistic, it's more that people who are autistic will explore that without a second thought or will express it."

- Questioning of social norms

Some of the young people I spoke to suggested that, because of their ASC, they feel that they are more questioning of gender norms. This ability to *"question things"* enabled some participants to be less bound by the strictures of social expectations related to gender.

"[People with ASC] have a different understanding of things. If you don't understand why we gender things, why society genders things then you would be more questioning about things. If you understand the world slightly differently to everyone else. Everyone else would sort of just see something that we gender in society and just sort be 'well that's the way it is' but someone who thinks of the world differently might ask why would we gender something like that."

- Social isolation

Most of the young people I spoke to recounted times in life when they experienced some form of exclusion or bullying by peers. This led a number of participants to feel socially isolated or to align themselves with others they also considered to be "different",

“outsiders” or *“who also felt a bit weird.”*

This relative social isolation freed up some participants to express their experienced gender because it did not matter because people *“didn’t like me already and...I didn’t need to worry about them liking me less”*

Other perceived themselves to be less exposed to pressures to conform to social norms (e.g. *“you don’t have...these social gender stereotypes shoved at you because you’re distanced from it”*)