Transgender experiences: Exploring social support and the perceptions and experiences of adults who identify as trans with and without intellectual disabilities

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Table of Contents

Introductory Chapter: Thesis Overview	1
References	
Chapter 1: Literature Review	
Abstract	
Introduction	8
Social support	11
Social support definition	12
Previous systematic reviews	13
Aims of the review	13
Method	15
Study eligibility	15
Data analysis	23
Study characteristics	23
Methodological characteristics	24
Social support measurements	25
Assessments of depression and anxiety	25
Risk of bias	26
Main findings	30
Discussion	42
Methodological strengths limitations and implications for research	44
Clinical and research implications	46
Conclusion	47
References	48
Chapter 2: Empirical Paper	57
Abstract	58
Introduction	60
Method	64
Design	64
Rationale	64
Researcher's Epistemological Position	65
Participant characteristics	67
Ethics	67

Recr	uitment	68
Info	med consent	70
Inter	views	70
Parti	cipant wellbeing	71
Refle	exivity	71
Data	analysis	71
Qual	ity assurance	72
Results	ş	73
Ther	nes	73
1.0	Superordinate Theme 1: Formation of self-concept	75
2.0	Superordinate Theme 2: Social stigma	82
3.0	Superordinate Theme 3: Support and knowledge	
4.0	Superordinate Theme 4: Barriers	92
5.0	Superordinate Theme 5: Hope, resilience and positive action	94
Discus	sion	97
Strei	ngths and limitations	102
Rese	arch and clinical implications	106
Cond	clusion	107
Refere	nces	108
List of T	ables	
Chapter 1	: Literature Review	
Table 1:	Inclusion and exclusion criteria applied to the systematic search	16
Table 2:	Characteristics of included studies	19
Table 3: 1	Risk of bias assessment	28
Table 4:	Association between depression and social support across studies	31
Table 5:	Association between anxiety and social support across studies	38
Chapter 2	2: Empirical Paper	
Table 6: 1	Participant demographics	67
	Inclusion and exclusion criteria	
	Quality assurance demonstrated in the current research	
	Super-ordinate and constituent sub-themes	
	-	

List of Figures

Chapter 1: Literature Review	
Figure 1: Flow chart of included studies	18
Appendices	121
Appendix A: Author Guidelines for the International Journal of Transgenderism	122
Appendix B: Systematic Review Protocol	123
Appendix C: Adapted Risk of Bias Assessment Tool	128
Appendix D: Author guidelines for Journal of Applied Research in Intellectual Disa	abilities
	131
Appendix G: NHS Ethics Approval	133
Appendix H: Recruitment Poster	137
Appendix I: Participant Information Sheet	138
Appendix J: Participant Information Summary Sheet	162
Appendix K: Consent Form	165
Appendix L: Interview Schedule	174
Appendix M: Debriefing Form	178
Appendix N: Reflective Diary Excerpt	185
Appendix O: Annotated Transcript Sample for 'Kirsty'	186
Appendix P: Example of List of Emergent Themes for 'Kirsty'	189
Appendix Q: Table of Themes and Representation of Participants within Themes	
Appendix R: Explanation of Audit Trail	193

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Introductory Chapter: Thesis Overview

It is important to understand a range of factors experienced by adults who identify as transgender to gain a better understanding to help to guide future interventions. These factors include, lived experiences, discrimination and the role of social support. Therefore, the focus of this thesis was to explore the experiences of gender identity, the stigma and discrimination faced, and the impact of social support in adults who identify as transgender. This was achieved through: 1) a systematic review of the literature to explore the relationship between social support and depression and anxiety in adults who identify as transgender. A review of the quantitative literature was chosen to ensure a thorough, robust systematic approach due to the diversity in the current transgender research literature; 2) an empirical study to explore the perceptions and experiences of adults with intellectual disabilities (ID) who identify as transgender.

There has been increasing interest and attention paid to the needs of transgender and gender non-conforming people. Gender identity refers to a person's subjective personal sense of one's own gender (Eliason, 2007). For some, this sense of gender is congruent with the gender category that they have been socially assigned. However, this isn't necessarily the same for all individuals. 'Transgender' is as an umbrella term used to define individuals whose gender identity or expression differs from the social construction of gender associated with sex (male or female) (Davidson, 2007).

Those who identify as transgender often encounter societal stigmatisation and discrimination (Lev, 2004) known as transphobia (Yarhouse & Carr, 2012). Transgender individuals face an incredible burden of stigma and discrimination in almost every aspect of their lives. Social isolation, rejection, and lack of overall support are commonly reported within the transgender literature (Factor & Rothblum, 2007; Gapka & Raj, 2003).

Transgender individuals who report experiences of transphobia report a higher prevalence of depression and anxiety compared to cisgender¹ counterparts (Clements-Nolle, Marx, & Katz, 2006). However, less is known about the role of perceived levels of social support and anxiety and depression in adults who identify as transgender. The first chapter within this thesis, therefore, aimed to explore the associations between social support and depression and anxiety in adults who identify as transgender by systematically reviewing quantitative literature.

The minority stress model (Meyer, 2003) suggests that the stress associated with stigma, prejudice, and discrimination increases rates of psychological distress in minority populations such as those who identify as transgender. This particularly relates to people with intellectual disabilities (ID) who identify as transgender, who are a minority within a minority (Abbott & Howarth 2005). Little is known about how people with ID currently develop and experience their gender identities and what exists is largely descriptive and based on single case studies. Therefore, the voices of people with ID who identify as transgender are left unheard. Consequently, the second chapter aimed to explore the perceptions and experiences of adults with ID who identify as transgender. Seven people were interviewed, and data were analysed using Interpretative Phenomenological Analysis methodology.

The experiences of gender identity, the stigma and discrimination faced, and the impact of social support in adults who identify as transgender lies at the heart of this thesis. The two chapters together will broaden understandings of transgender experiences, exploring social support and the perceptions and experiences of adults who identify as trans with and without ID. Research and clinical implications are discussed.

¹Note on terms: 'Cisgender' is used throughout this review as it is the internationally preferred term in research literature. It is defined by the Oxford English Dictionary as "Designating a person whose sense of personal identity and gender corresponds to his or her sex at birth; of or relating to such persons. Contrasted with *transgender*." (Oxford English Dictionaries, n.d.).

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5 6	Chapter 1: Literature Review
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9	An examination of the relationship between depression, anxiety and social support in adults
10	who identify as trans: A systematic review ²
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 $^{^2}$ Article prepared for submission to the International Journal of Transgenderism for peer review. Please see Appendix A for author guidelines.

1 Abstract

2

3 **Background/Aims:** There has been increasing interest and attention paid to the needs of transgender and gender non-conforming people. Transgender individuals who experience 4 transphobia report a higher prevalence of depression and anxiety compared to cisgender 5 counterparts. Furthermore, a lack of social support is associated with higher rates of anxiety 6 7 and depression. This aim of this review was therefore, to provide a systematic review of the relationships between depression and anxiety and social support in adults who identify as 8 transgender. 9 Method: Electronic databases (PsycINFO, PsycArticles, Web of Science, CINAHL, Scopus 10 11 and Medline) were systematically searched. Included studies were critically assessed utilising a risk of bias assessment tool and a transparent and rigorous narrative synthesis of the results 12 13 were conducted. **Results:** Eleven studies were identified and included in the review. Of these, ten studies 14 15 examined depression and social support, seven examined anxiety and social support and one study combined overall relationship between 'psychological distress' and social support. 16 Several methodological issues were identified. The included studies indicated that depression 17 18 was negatively associated with social support. The reviewed studies also suggested a weak negative association between anxiety and social support, however, the associations were 19 found to be small across the studies. Furthermore, when the relationship between anxiety and 20 social support was examined at a multivariate level, overall, the significant relationship was 21 22 inconsistent across studies. 23 **Discussion:** The results of this review extend the literature exploring the role of social support in depression and anxiety in adults who identify as transgender. The review found 24 25 that poorer perceived social support is associated with higher levels of depression. The results

- 1 suggested that the association between anxiety and social support is inconsistent. Clinically,
- 2 the data suggest the importance of identifying the social support needs of people who identify
- 3 as trans in relation to depression.

5

4 **Keywords:** Depression, anxiety, social support, transgender, systematic review.

Introduction

'Transgender' is as an umbrella term used to define individuals whose gender identity or expression differs from the social construction of gender associated with sex (male or female) (Davidson, 2007). Transgender individuals express their gender in a variety of ways, including doing nothing to change the physical manifestation of their gender, changing clothing, using hormone treatments, and choosing sex and/or gender reassignment surgery (Korell & Lorah, 2007). Examples of such identities include transman (female-to-male), transwoman (male-to-female), bigender, agender, genderqueer, gender fluid, and other identities. Gender nonconforming individuals include those who identify as neither a man nor a woman, as both man and woman, or as fluid between genders (Bouman & Arcelus, 2017). Gender queer persons identify as a different gender or as somewhere between male and female (Beemyn & Rankin, 2011). Terms such as transgender, trans, gender-variant or gender-nonconforming are often used interchangeably to describe the diversity within this community.

Conversely, 'cisgender' is defined as "designating a person whose sense of personal identity and gender corresponds to his or her sex at birth; of or relating to such persons.

Contrasted with *transgender*." (Oxford English Dictionaries, n.d.). The term cisgender differentiates gender and sexuality and can be viewed as a way to normalise and include transgender non-conforming labels and provide categorical labelling equality (Ansara & Hegarty, 2012). However, although the term cisgender aims to draw upon gender differences and highlights disadvantages, the term has also been viewed critically. Some have argued that the term cisgender is limiting and divisive because it describes an identity as being the opposite of trans and could seem to affirm gender normativity and represent an assumption that trans is not normal (Enke 2013).

Research on transgender identities frequently categorises gender-nonconforming under transgender umbrella terms such as transgender and non-conforming gender identities (TGNC) (Matsuno & Budge, 2017). Research often uses labels in order to capture large samples of TGNC individuals. However, these terms may suggest gender as static and binary and do not explore intersexuality. The terms may also fail to capture all gender identities and individuals who do not position themselves within a gender label.

There are a number of constraints when conducting systematic reviews in the trans population because it is difficult to capture specific search terms for each individual's subjective experience of gender. Therefore, in order to capture the terminology utilised in the current research literature for a systematic review, the researcher elected to include the broad umbrella terms of transgender and non-conforming gender identities (TGNC). Conversely it is not intended that the use of TGNC terms within the review will, position TGNC as something that is binary, stable, or separated away from normative expressions of gender. It is also acknowledged that each individual's gender is relational and an internal subjective feeling.

In recent years, there have been significant legislative developments over the inclusion of gender identity diversity, including the 'Employment Non-Discrimination Act' (ENDA) and the 'Gender Recognition Act' (2004). With an increase in information, awareness, visibility and biomedical advances, overall the number of people identifying as transgender and accessing services has increased significantly (Witcomb, 2017). Considering these developments over the years, there has been increasing interest and attention paid to the needs of transgender and gender non-conforming people. Early studies of mental health outcomes among transgender persons considered gender-variance and gender dysphoria to be representative of underlying pathology (Haraldsen & Dahl, 2000). Over the past twenty years or so, this view has shifted from that of gender pathology and medicalisation to a focus on the

- social construction of gender identity and non-binary identities (Dean et al., 2000). This
- 2 review will, therefore, exclude terms that imply underlying gender pathology such as gender
- 3 dysphoria.

- 4 Individuals who identify with a gender identity that does not coincide with their
- 5 biological birth sex do not necessarily adhere to western society's views of binary genders.
- 6 Those who identify as transgender often encounter societal stigmatisation and discrimination
- 7 (Lev, 2004) known as transphobia (Yarhouse & Carr, 2012). Social isolation, rejection, and
- 8 lack of overall support are commonly reported within the transgender literature (Factor &
- 9 Rothblum, 2007; Gapka & Raj, 2003; Maguen, Shipherd, & Harris, 2005).

It was historically assumed that discomfort or distress associated with one's gender identity contributed to levels of emotional distress (Lev, 2004). However, research now suggests that emotional distress experienced among individuals who identify as transgender is associated with oppressive societies and environments (Nuttbrock et al., 2013). Meyer (2003) proposed the minority stress model as an explanation. The model suggests that the stress associated with stigma, prejudice, and discrimination increases rates of psychological distress in minority populations such as the transgender population (Abbott & Howarth 2005). The hypervigilance that comes from being discriminated against results in internalised stigma. The minority stress model suggests that mental health differences between cisgender and TGNC individuals may be understood from the stress associated with gender minority stigma. For instance, transgender individuals who report experiences of transphobia report a higher prevalence of depression and anxiety compared to cisgender counterparts (Clements-Nolle, Marx, & Katz, 2006; Moody & Smith, 2013; Rotondi et al., 2011).

Depression and Anxiety

Historically, there have been many biological and psychological explanatory theories
of depression and anxiety. The biomedical models posits that depression and anxiety are
caused by biological factors and chemical imbalances that can be treated with
pharmacological treatments which target the posited imbalances. Two main classification
systems are currently utilised based on the biomedical model, the Diagnostic and Statistical
Manual of Mental Disorders (DSM-IV) and the International Statistical Classification of
Diseases and Related Health Problems (ICD 10). Categorical diagnosis, including anxiety
and depression, can provide a shared language, providing a description of shared
characteristics and experiences and advancements in understanding and intervention.
Furthermore, categorical diagnoses are also widely used in research.

Limitations of the biomedical model have been highlighted. For example, there are no scientific links between aetiological processes and the diagnostic categories, such as depression and anxiety. Furthermore, the psychological constructs and psychological distress are difficult to classify and measure due to the heterogeneity of diagnostic categories and overlap of symptoms identified (Fried, 2015). It is also argued that diagnostic thresholds are arbitrary (Bebbington, 2015) and research suggest that reliability, validity and utility of diagnosis are uniformly poor (Freedman et al., 2013). Furthermore, as the biomedical model positions the causes outside of a person's control, this may prevent individuals from exploring and understanding the complexities of biopsychosocial explanations and drawing upon personal resources to address difficulties (Johnson et al., 2018).

Social support

Empirical studies on social support (Davis, Saltzburg & Locke, 2009; Kostova, Caiata-Zufferey, & Schulz, 2014; Schmidt, Miles, & Welsh, 2011) have primarily focused on

the experiences of cisgender individuals. However, a focus on the levels and types of distress

2 experienced by individuals who identify as transgender has become of increased interest to

researchers. Recent studies have outlined the impact of a lack of social support (Riley, Wong

& Sitharthan, 2011; Israel, Gorcheva, Burnes, & Walter, 2008). Studies suggest that a lack of

support is associated with higher rates of anxiety and depression (Budge, Adelson & Howard

6 2013).

7 Conversely, research suggests higher levels of perceived social support are associated

with positive factors such as a reduction in the risk of mental health difficulties (Thoits,

1995), higher quality of life ratings (Eisenberg, 2017) and may help to reduce the risk of

physical health symptoms (Uchino, Cacioppo & Kiecolt-Glaser, 1996).

As there are reported higher levels of depression and anxiety within the transgender population (Clements-Nolle, Marx, & Katz, 2006; Moody & Smith, 2013; Rotondi et al., 2011), it is important to understand the relationship between depression and anxiety and social support in order to develop appropriate and relevant support mechanisms.

Social support definition

Within the research literature, social support has been defined in a number of different ways. Thoits' (2010) defines social support as "emotional or practical assistance from significant others within an individual's network, such as friends, family members or coworkers; support may be received from others or simply perceived to be available when needed" (Thoits, 2010: 46). Thoits conception of social support does not include networks outside of an individuals' network, such as social integration (Nurullah, 2012). Therefore, this review will explore social support as emotional, informational, or practical assistance from significant others.

Research suggests that there are key cultural differences in how people hold different models of the self and their relationships with others (Adams, 2005). It is suggested that western and North American cultures hold individualistic models of themselves as independent and are motivated by personal beliefs and goals (Triandis, 1994). Social support and relationships are viewed as freewill by each individual and social support may be drawn to meet individual needs (Clark & Mills, 1993). Whereas other cultures, such as those in some parts of Asia, hold more collectivist models of the self, in which individuals are relational and are interdependent of each other. Social norms and group solidarity are prioritised over self-oriented goals (Kim, Sherman, & Taylor, 2006). Social support can, therefore, take on different meanings and roles in different cultures.

Previous systematic reviews

To date, research focusing on the experiences of people who identify as transgender has tended to focus on young people and lesbian, gay, bisexual, transgender and questioning (LGBTQ) communities rather than adults within transgender communities. To the researcher's knowledge, one systematic review has explored the relationship between social support and mental health in LGBTQ adolescents (McDonald, 2018). The review suggested that low levels of social support were associated with higher levels of depression and anxiety, along with lower levels of positive self-esteem.

Additionally, Valentine and Shipherd (2018) systematically reviewed 77 studies, exploring social stress (including stigma, discrimination, and bias events) and mental health among transgender and gender non-conforming people in the United States. It was suggested that coping and social support were negatively associated with mental health difficulties in individuals who identify as transgender.

Aims of the review

 To the researcher's knowledge, there are no reviews to date exploring the relationship

2 between depression and anxiety and social support in adults who identify as transgender.

3 Since the association between anxiety and depression and social support is likely to be culture

dependent, the review will be limited to studies conducted in 'Western' countries, including

5 the USA, Canada and Europe (EU and member states of the European Free Trade

6 Association), Australia and New Zealand. However, it is also acknowledged that this is a

holistic view of models of social support within Western countries. Diversity of cultural

subgroups across the countries are aggregated and, therefore, this approach does not account

for individual differences.

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This systematic review aims to advance the current understanding of social support within the adult transgender population by examining the relationship between social support and depression and anxiety.

In order to establish a robust review and validity, the systematic review aims to include research employing quantitative measures of social support along with a measurement of depression and/or anxiety in order to provide a quantitative measure of association. Therefore, the review includes original quantitative research rather than qualitative papers, involving adults who identify as transgender, published in peer-reviewed journals. Using Thoits' (2010) definition of social support, studies of social networks were included if they explicitly explored the provision of emotional, informational or practical support within from informal social (non-professional) 'significant others'.

The overall objectives of the review are to examine:

1) The associations between social support and depression and anxiety in adults who identify as transgender.

2) The methodological characteristics of studies focusing on social support, depression and anxiety in adults who identify as transgender.

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4 Method

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- 6 The following methodology was guided by the Preferred Reporting Items for Systematic
- 7 Reviews and Meta-Analyses guidelines (PRISMA; Moher, Liberati, Tetzlaff, & Altman,
- 8 2009). The guidelines provide an evidence-based approach to the content of systematic
- 9 reviews to ensure rigour. A protocol was developed (see Appendix B) to guide the review
- process. The paper outlines a systematic review of quantitative evidence.

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Study eligibility

- A systematic search for research papers was conducted on 13.03.2019, PsycINFO,
- 15 PsycArticles, Web of Science, CINAHL, Scopus and Medline databases were searched. Only
- 16 peer-reviewed articles were included. Grey literature was not included to maintain a robust
- 17 review. Search terms selected for this review included: (a) transgender; transgender* OR
- transsex* OR gender non-conform* OR gender minority OR gender varian* OR genderqueer
- OR gender diverse OR bigender OR agender OR two-spirit OR genderfluid OR gender
- 20 neutral and (b) social support; social support OR perceived social support OR social
- 21 connectedness OR social network and (c) anxiety and depression; mental health OR
- 22 depression OR psych* OR anxiety. Search terms were combined using the Boolean operator
- 23 "AND".
- Inclusion and exclusion criteria were applied to the search (Table 1). The researcher
- 25 screened the titles and abstracts and papers that did not meet the selected inclusion criteria

- 1 were rejected. Reference lists and bibliographies of the articles collected were also searched,
- 2 and Google Scholar was used to search papers that cited the selected studies.
- 3 Table 1
- 4 Inclusion and exclusion criteria applied to the systematic search

Inclusion Criteria

- Quantitative design
- Limited to Western countries, including the USA, Canada and Europe (EU and member states of the European Free Trade Association), Australia and New Zealand.
- Adults aged ≥ 18 years
- Studies that include participants who identify themselves as transgender or as gender variant from their natal sex.
- Must examine social support from human beings as a primary variable/theory of interest, empirical methods (i.e., not policy and theoretical analyses)
- Must include a quantitative measure of social support, to provide a quantitative measure of association.
- Must compare social support with a measurement of depression and/or anxiety
- Any observational study, in adults that assessed the relationship between social support and depression or anxiety.
- Studies published in peer-reviewed journals in English.
- No restrictions in dates

Exclusion Criteria

- Qualitative designs will not be included as the focus of this review is solely on quantifiable measures of social support and anxiety and depression.
- Lesbian, gay, bisexual and transgender (LGBT) community where results of the transgender population are not analysed separately
- Cisgender sexual minorities; men who have sex with men (MSM); healthcare providers (HCPs); co-occurring conditions (i.e., trans with other physical health issues)
- Non-western countries
- Studies that focus on specific subgroups to maintain a homogenous population (e.g., military, older adults).
- Lack of direct measurement of depression and/or anxiety for transgender participants
- Absence of measures of anxiety and/or depression
- Full text unavailable in English
- Non-peer reviewed
- Case studies
- Reviews and systematic reviews
- Studies that are primarily focused on substance and alcohol use, surgery reassignment physical health outcomes and focus (e.g. HIV and cancer, and older adults).
- Concepts based on objective ratings of the size and functioning of social networks, such as social isolation and social network size.

To avoid researcher selection bias, a second reviewer (SC) examined 10% of the

2 initial abstracts identified in the search criteria. Full texts were then explored to assess the

eligibility of the inclusion criteria. Papers that did not fulfil the criteria were excluded. The

researcher and the second reviewer discussed discrepancies identified in two of the potential

studies that were excluded. Following this discussion, 100% agreement was met.

6 Using PRISMA guidelines (Moher, Liberati, Tetzlaff & Altman, 2009), eleven

articles were identified as eligible for review (Fig. 1). The search strategy identified 1613

papers, from which 11 publications were identified for inclusion (Boza & Nicholson Perry,

2014; Budge, Adelson, & Howard, 2013; Budge, Rossman, & Howard, 2014; Fuller & Riggs,

2018; McLemore, 2018; Meier, Pardo, Labuski, & Babcock, 2013; Meier, Sharp, Michonski,

Babcock, & Fitzgerald, 2013; Pflum, Testa, Balsam, Goldblum, & Bongar, 2015; Scandurra,

Amodeo, Valerio, Bochicchio, & Frost, 2017; Trujillo, Perrin, Sutter, Tabaac, & Benotsch,

13 2017; Witcomb et al., 2018).

Data extraction

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Data extraction for this review was conducted. This included extracting, relevant

sample characteristics, study designs and main research findings (Table 2). To minimise

researcher selection bias, the second reviewer examined five studies to ensure consistency in

the data extraction process.

Assessment of quality and risk of bias

An assessment of quality and risk of bias for each study was undertaken, which is

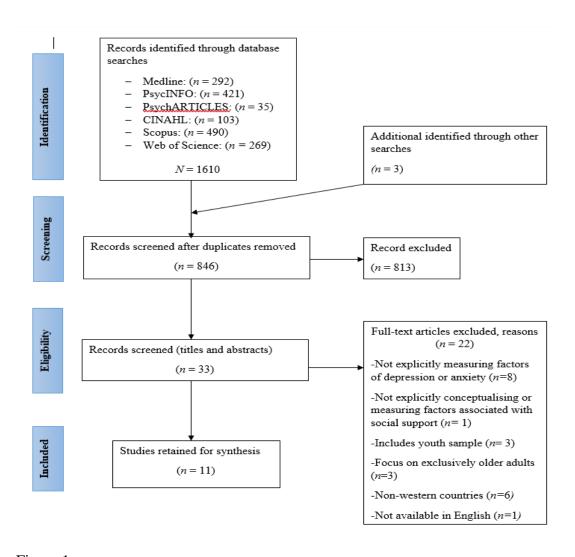
essential when conducting a systematic review (Sanderson, Tatt & Higgins, 2007). A large

variety of tools and checklists are available, but there is currently no 'gold-standard' tool for

quality assessment (Sanderson, Tatt & Higgins, 2007). Given this, the adapted version of the

Agency for Healthcare Research and Quality tool (AHRQ; Williams, Plassman, Burke,

- 1 Holsinger & Benjamin, 2010) was identified as an appropriate tool, based on a published
- 2 systematic review of quality assessments (Sanderson, Tatt & Higgins, 2007) (Appendix C).
- 3 Each area was scored using the ratings of 'yes', 'no', 'partial', 'cannot tell', or 'not applicable
- 4 indicated within the assessment tool. To address subjectivity, a second reviewer also
- 5 evaluated the selected papers utilising the AHRQ and any discrepancies in scores were
- 6 reviewed and resolved. An example of a discrepancy included whether Budge et al. (2014)
- 7 included an adequate description of the cohort, it was, therefore, agreed the paper only
- 8 included a 'partial' description.



10 Figure 1

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11 Flow chart of included studies

Table 2
Characteristics of included studies

Reference	Location Study N at Sample characteristics of Study recruitment			of Study recruitment group characteristic	•		•		-	Design	Social Support measure	Depression measure	Anxiety measure
Boza and Perry (2014)	Australia	N=243;	Female (n=100); Male (n=47); Transgender (n=16); Transsexual (n=16); Gender Queer (n=19); Bigender (n=4); Cross Gender (n=13); Other (n=16); <i>M</i> age (SD)= 37.89 (13.65)		Cross sectional	MSPSS	CES-D	-					
Budge et al. (2013)	USA	N=64	Gender queer (n=64); <i>M</i> age (SD)= 30.3 (11.3)		Cross sectional	MSPSS	CES-D	BAI¹					
Budge et al. (2014)	USA	N=351;	Transgender Women (n=226); Transgender Men (n=125) M age (SD)=40.28 (12.85)		Cross sectional	MSPSS	CES-D	BAI					

Fuller and Riggs (2018)	North America	N=345;	Male; (n=109); Non- binary (n=87); Female (n=85); Another gender (non- Cis) (n=45); Agender (n=17) <i>M</i> age (SD)= 27 (-)	Cross- sectional	MSPSS	K10	K10
McLemore (2018)	USA	N=410	Transgender (n=28); Transgender Man (n=38); Transgender Woman (n=90); FtM (n=38); MtF (n= 58); Female (n=78); Male (n=44); Genderqueer (n=27); Other (n=9); M age (SD)= 30.27 (12.40)	Cross sectional	Social Support Questionnaire.	CEDS-10	STAI-6
Meier et al. (2013)a	USA and 18 other countries; Europe, Canada, Mexico, Australia	N=503	FtM (n=503); <i>M</i> age (SD)= 27 (8.0)	Cross sectional	MSPSS	DASS	DASS
Meier et al. (2013)b	USA & Europe	N=593	FtM (n=593); <i>M</i> age (SD)= 27 (8.03)	Cross sectional	MSPSS	DASS	DASS

al. (2015) Canada queer (SD) 2 woma age (SW) 2 woma age (SW) TMS(queer (SD) 2 Trans M (SI		TFS (n=427); Gender queer (n=158); <i>M</i> age (SD) 24.5 (7.1); Trans woman; (n=163) <i>M</i> age (SD) 37.2 (14.9); Woman (n=106); <i>M</i> age (SD) 39.2 (16.2); TMS(n=438): Gender queer (n=34); <i>M</i> age (SD) 34.6 (13.9); Trans man (n=259); <i>M</i> (SD) 30.9 (11.3); Man (n=145); <i>M</i> age	Cross sectional	BSSS	CES-D	GAD-7	
Scandurra et al. (2017)	Italy	<i>N</i> =149	(SD) 31.9 (11.0) M age (SD)= 33.18 (10.96); MtF (n=75); M age (SD)= 37.21 (12.24); FtM (n=74); M age (SD)= 29.22 (7.77)	Cross sectional	MSPSS	CES-D Italian adaption	BAI ²
Trujillo et al. (2017)	USA	<i>N</i> =78	M age (SD) 29.6 (10.46); trans man (n=26); trans woman (n=29); other (n=23)	Cross sectional	MSPSS	HSCL-25	HSCL-25
Witcomb et al. (2018)	UK	N=913	M age (SD)= 30.4 (13.9); Transgender males (n=331);	Cross sectional	MSPSS	HADS	-

Transgender Females (n=582)

BAI¹= Burns Anxiety Inventory(Burns, 1998); BAI²= Beck Anxiety Inventory (Beck, Epstein, Brown & Steer, 1988); BSSS= Berlin Social Support Scales (Schulz & Schwarzer 2003); CED-D=Center for Epidemiologic Studies Depression Scale (Radloff, 1977); DASS= Depression, Anxiety Stress Scale (Lovibond & Lovibond, 1995); GAD=Generalized anxiety symptoms (Spitzer, Kroenke, Williams & Löwe, 2006); HADS= Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983); HSCL-25= Hopkins Symptoms Checklist 25 (Derogatis, Lipman, Rickels, Uhlenhuth & Covi, 1974); K10=Kessler 10 (Kessler et al, 1994); MSPSS= Multidimensional Scale of Perceived Social Support (Dahlem, Zimet & Waljer, 1991); STAI-6= State Trait Anxiety Inventory (Marteau & Bekker, 1992)

1 Results

Data a	anal	vsis
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Due to the heterogeneity of the methodology and measures of social support, depression and anxiety, a meta-analysis was not deemed appropriate. Therefore, the results were synthesised narratively.

Study characteristics

Depression, anxiety and social support were not the main focus of some of the included papers and only sample sizes, measures, data and outcomes relevant to this review are reported. The main characteristics of the included studies are displayed in Table 2. The aims of each study varied. The eleven studies were published between 2013 and 2018. The studies were conducted in western countries, including the USA, Europe, Canada and Australia. Two studies (Meier, Pardo, Labuski, & Babcock, 2013; Meier, Sharp, Michonski, Babcock, & Fitzgerald, 2013) included a small sample of participants from non-western countries; including Mexico and Asia. However, as the non-western countries represented less than 5% of the sample size, both studies were included in the analysis.

The age of the participants ranged from 18 to 79 years. The sample sizes of the 11 studies included in this review constituted a range of 64 to 913, totalling 4514 participants across the studies. Two studies (Meier, Pardo, Labuski, & Babcock, 2013; Meier, Sharp, Michonski, Babcock, & Fitzgerald, 2013) included the same sample of participants (4011 participants excluding the same sample of the two studies). However, the research question, number of participants and analysis were different, for example, Meier, Sharp, Michonski, Babcock, & Fitzgerald, (2013), analysed the data using multivariate analysis, exploring confounding variables. Therefore, both studies were included in the review.

All the studies provided demographic data. Gender identity was reported in all studies through self-identification of the participants. Gender identity labels across studies the studies varied. Labels included: gender queer only, transwomen and transmen only, any transgender non-conforming (TGNC) identity and treatment-seeking TGNC clients.

This review found an inherent methodological difficulty in studying a trans population. Some of the studies narrowed gender identities into categories. Two studies utilised categories to identify a range of gender identities to allow for the analysis of characteristics within these subcategories. These included participants who identified as 'trans female spectrum' and 'trans male spectrum' (Pflum, Testa, Balsam, Goldblum, & Bongar, 2015) and transwomen and transmen (Budge, Adelson, & Howard, 2013), However, reducing the wide range of gender identities in the research unintentionally narrows the perspective on this diverse population.

Nine studies provided race/ethnicity analysis, which ranged from two to seven ethnic groups per study. Ethnic minority samples represented between 2% to 24% across the selected studies. However, two studies did not include data on the ethnicity of the participants within the studies (Witcomb et al., 2018; Budge, Rossman, & Howard, 2014).

Methodological characteristics

All of the reviewed studies included utilised convenience or non-probability sampling methodology. One study recruited participants who had specifically accessed specialised gender services (Witcomb et al., 2018).

Nine of the studies employed a cross-sectional design, and two were case-control studies. Eight of the included studies recruited from lesbian, gay bisexual, transgender and questioning (LGBTQ) support groups utilising adverts and posters. Due to the purposive method utilised to recruit participants, there may have been an increased risk of selection bias

- within the selected studies. Furthermore, self-report measures were used to explore the
- 2 associations of depression, anxiety and social support, therefore increasing the risk of self-
- 3 reporting bias across all studies.

Social support measurements

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- 6 All studies considered social support. This was measured using a variety of tools such
- 7 as the Multidimensional Scale of Perceived Social Support (MSPSS; Dahlem, Zimet &
- 8 Walker, 1991) for perceived social support (e.g. Boza, & Perry, 2014; Fuller & Riggs, 2018);
- 9 the Berlin Social Support Scales (BSSS; Schulz & Schwarzer, 2003) (Pflum, Testa, Balsam,
- Goldblum, & Bongar, 2015) and the Social Support Questionnaire (McLemore, 2018). Eight
- of the studies in this review used the MSPSS tool. The mean total and subscale scores ranged
- from 1 to 7, in which a higher score indicated greater perceived social support. The tool
- highlights that "a mean score of 1 to 2.9 could be considered low support; a mean score of 3
- to 5 could be considered moderate support, and a mean score from 5.1 to 7 could be
- considered high support" (Dahlem, Zimet & Walker, 1991.

Assessments of depression and anxiety

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Depression

- All of the reviewed studies measured depression. The main tool used to measure
- 20 depression was the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff,
- 21 1977). Other tools used were the Depression, Anxiety Stress Scales (DASS; Lovibond &
- Lovibond, 1995), the Hospital Anxiety and Depression Scale (HADS) (Zigmund & Snaith,
- 23 1983) and the Kessler 10 (K10) (Kessler et al., 1994).

Anxiety

- 25 The selected studies used a range of tools to measure anxiety including the Burns
- Anxiety Inventory (BAI; Burns & Eidelson, 1998), The Beck Anxiety Inventory (BAI; Beck,

- 1 Epstein, Brown, & Steer, 1988); the Depression, Anxiety Stress Scales (DASS; Lovibond &
- 2 Lovibond, 1995), the Counseling Center Assessment of Psychological Symptoms (CCAPS)
- 3 which is a standardised, multidimensional assessment of psychological symptoms (Locke et
- 4 al., 2012) and the Kessler 10 (K10) (Kessler et al., 1994). Two studies did not include
- 5 measures of anxiety (Boza & Nicholson Perry, 2014; Witcomb et al., 2018).

Risk of bias

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- 8 The risk of bias quality assessment rating, utilising the AHRQ are presented in Table
- 9 3. The assessment highlighted methodological issues of the selected studies identified
- including, limitations in study design, analysis of missing data, a lack power analyses,
- 11 limitations in the consideration of confounding variables, and the assessment of depression,
- anxiety and social support. Biases in the selection of samples were indicated across a number
- of the studies included. All the studies utilised convenience and self-selecting sampling
- methods, therefore, the findings of the studies cannot be generalised across populations.
- None of the studies reported a power calculation. Without the power analysis, it is
- difficult to determine whether the analyses of each of the studies were appropriate. The
- 17 results should, therefore, be viewed with caution.
- All the studies included in this review utilised a cross-sectional design. Therefore,
- 19 causality could not be inferred. While most of the studies attempted to control for
- 20 confounding variables (k = 9), it is difficult to determine whether any relationships suggested
- are a result of anxiety and/or depression or other confounding variables. Only two studies
- 22 (Boza & Perry, 2014; Budge, Rossman, & Howard, 2014) controlled for demographic and
- 23 confounding variables.
- Three studies (Budge, Rossman, & Howard, 2014; Pflum, Testa, Balsam, Goldblum,
- & Bongar, 2015; Trujillo, Perrin, Sutter, Tabaac, & Benotsch, 2017) did not report on any

- 1 missing data or how it was addressed within analysis which may indicate areas of bias within
- 2 the studies. Within the studies that reported missing data, all studies suggested levels below
- 3 20%.
- The main strengths of the studies were identified. The majority (k = 8) provided
- 5 adequate descriptions of the cohort, including the minimum information pertaining to
- 6 participant demographic information, such as, age and gender identity categories. A further
- 7 strength was that all the included studies utilised social support measures that suggested good
- 8 validity and reliability. Ten studies utilised measures of depression, and eight studies utilised
- 9 measure of anxiety that also suggested good validity and reliability. One study, however,
- 10 (Fuller & Riggs, 2018) provided a combination of depression and anxiety scores, so
- depression and anxiety could not be identified as individual relationships.

1 Table 3

2 Risk of bias assessment

Authors	Unbiased selection of cohort	Selection minimises baseline	Sample size calculated/ justified	Adequate description of cohort	Valid method to explore depression	Valid method to explore anxiety	Valid method to explore social support	Missing data minimal	Control of confounders	Analysis appropriate
Boza and Perry (2014)	Partial	N/A	No	Yes	Yes	N/A	Yes	Yes	Yes	Cannot tell
Budge et al. (2013)	Partial	N/A	No	Yes	Yes	Yes	Yes	Cannot tell	Partial	Cannot tell
Budge et al. (2014)	Partial	N/A	No	Partial	Yes	Yes	Yes	Yes	Yes	Cannot tell
Fuller and Riggs (2018)	Partial	N/A	No	Yes	No	No	Yes	Yes	Partial	Cannot tell
McLemore (2018)	Partial	N/A	No	Partial	Yes	Yes	Yes	Yes	Partial	Cannot tell
Meier et al. (2013)a	Partial	N/A	No	Yes	Yes	Yes	Yes	Yes	Partial	Cannot tell
Meier et al. (2013)b	Partial	N/A	No	Yes	Yes	Yes	Yes	Yes	Partial	Cannot tell

Pflum et al. (2015)	Partial	N/A	No	Yes	Yes	Yes	Yes	No	Partial	Cannot tell
Scandurra et al. (2017)	Partial	N/A	No	Yes	Yes	Yes	Yes	Yes	Partial	Cannot tell
Trujillo et al. (2017)	Partial	N/A	No	Yes	Yes	Yes	Yes	Cannot tell	Partial	Cannot tell
Witcomb et al. (2018)	Partial	Yes	No	Partial	Yes	N/A	Yes	Yes	Partial	Cannot tell

Main findings

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Association between social support and depression

Ten of the eleven reviewed studies examined the relationship between depression and 4 social support. Of these studies, seven (Boza & Perry, 2014; Budge, Adelson, & Howard, 5 2013; Budge, Rossman, & Howard, 2014; McLemore, 2018; Meier, Pardo, Labuski, & 6 7 Babcock, 2013; Meier, Sharp, Michonski, Babcock, & Fitzgerald, 2013; Pflum et al., 2015) 8 investigated the association between depression and social support utilising bivariate 9 analysis. All seven studies found significant small to medium negative associations between depression and social support between r=.25 to r=.45. That is, higher ratings of depression 10 were associated with lower levels of perceived social support when utilising bivariate 11 12 analysis. One of the studies (Pflum, Testa, Balsam, Goldblum, & Bongar), did not report the size of the correlation. Three studies (Scandurra, Amodeo, Valerio, Bochicchio, & Frost, 13 2017; Trujillo, Perrin, Sutter, Tabaac, & Benotsch, 2017; Witcomb et al., 2018) did not report 14 15 the correlational association when utilising bivariate anlysis. 16 Eight studies utilised multivariate analysis to investigate the association between depression and social support. Four of the studies (Boza & Perry, 2014, Meier, Sharp, 17 Michonski, Babcock, and Fitzgerald, 2013, Pflum, Testa, Balsam, Goldblum, & Bongar, 18 2015; Witcomb et al, 2018) found significant associations when controlling for other selected 19 20 variables (e.g. age, assigned sex, education and employment). Budge, Adelson, and Howard, (2013) observed significant relationships using multivariate analysis between depression and 21 22 social support in the transwomen sample but a significant relationship was not found in the 23 transmen sample. Important non-significant predictors for each study are highlighted in Table 4. 24

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Table 4
 Association between depression and social support across studies

Study	Social Support Variable Perceived social support	Depression Variable Depression symptoms	Analysis Multiple regression	Bivariate Association Significant negative correlation r=45, p<.001	Multivariate Results			
					Significant Predictors	Non-significant predictors		
Boza and Perry (2014)					 Education Employment Alcohol problems Suicide attempt Hormone therapy Surgery MSPSS 	Assigned sexRelationship		
Budge et al. (2013)	Social support	Depression symptoms	Correlation SEM analysis	Significant negative correlation r=41, p<.01	Trans women • Avoidant coping • Social support	Trans women Facilitative coping Transition status Loss Family history Age Income		
					Trans men • Facilitative coping • Avoidant coping • Family history • Income	Trans men Transition status Loss Family history Age Social support		

Budge et al. (2014)	Social support	Depression symptoms	Multiple regression	Significant negative correlation r=342, p<.01	Avoidant coping	 Age Income Social support Facilitative coping Facilitative coping x social support Avoidant coping x social support
Fuller and Riggs (2018)	Social Support	Psychologic al distress (depression + anxiety)	Correlation	Significant negative correlation r=-0.24, p<.01	Not measured	Not measured
McLemor e (2018)	Social support	Depression symptoms	Correlation	Significant negative correlation r=45, p<.001	Not measured	Not measured
Meier et al. (2013)a	Perceived social support	Depression symptoms	Correlation	Significant negative correlation r=-0.33, p<0.001	Not measured	Not measured
Meier et al. (2013)b	Partner social support	Depression symptoms	Correlation Hierarchical regression	Significant negative correlation r=-0.25, p<0.001	Social supportRelationship status x social support	• Relationship status

Pflum et al. (2015)	General social support	Depression	Multiple regression	TFS: Significant negative correlation (size unreported)	TFS:	Social support Trans community connectedness Age (controlled for)	TFS: No non-significant predictors identified
				TMS: Significant negative correlation (size unreported)	TMS:	Social support Age (controlled for)	TMS: • Trans community connectedness
Scandurra et al. (2017)	Perceived social support	Depressive symptoms	Logistic regressions	Not reported	•	Everyday discrimination Pride Alienation Resilience MSPSS family Everyday discrimination x resilience	 Age Education Income Marital status Community Religious education Prejudice events Perceived stigma Shame Passing MSPSS friends MSPSS significant others
Trujillo et al. (2017)	Perceived social support	Depressive symptoms	Multiple Regression	Not reported	Model •	1: HHRDS-HR	Model 1: • MSPSS Family • HHRDS-HR x MSPSS Family

					Model 2:	Model 2	:
					• HHRDS-HR	• N	MSPSS Friends
							HHRDS-HR x MSPSS Friends
					Model 3:	Model 3	:
					HHRDS-HRMSPSS significant other		HHRDS-HR x MSPSS significant other
Witcomb et al. (2018)	Perceived social support	Presence/ absence of depression	Linear regression	Not reported	MSPSSSelf esteemInterpersonal proble	ms • A	Age Assigned gender Cross sex hormones pre assessment Fransphobia

HHRDS-HR= Heterosexist Harassment, Rejection and Discrimination Scale (Szymznski, 2006); MSPSS= Multidimensional Scale of Perceived

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Social Support (Dahlem, Zimet & Waljer, 1991); TFS= Trans Female Spectrum; TMS= Trans Male Spectrum

- 1 Two studies divided social support into subsets (family, friends and significant other).
- 2 One study (Scandurra, Amodeo, Valerio, Bochicchio, & Frost, 2017) did not report findings
- 3 when utilising bivariate analysis, but observed significant relationships utilising multivariate
- 4 analysis, in the family source of support subset only: friends and significant other were not
- 5 significant when utilising multivariate analysis. One study (Trujillo, Perrin, Sutter, Tabaac;
- 6 Benotsch, 2017) did not report findings utilising bivariate analysis, but observed significant
- 7 associations utilising multivariate analysis, only in the significant 'other source of support'
- 8 subset: friends and family were not significant when utilising multivariate analysis.
- 9 One study (Budge, Rossman; Howard, 2014) found significant associations utilising
- bivariate analysis; however, when selected variables were controlled utilising multivariate
- analysis, significant associations were not found. Two studies (McLemore, 2018; Meier,
- 12 Pardo, Labuski, & Babcock, 2013) did not report multivariate results.

Association between social support and anxiety

- Seven studies examined the relationship between anxiety and social support. Six of
- the studies (Budge, Adelson, & Howard, 2013; Budge, Rossman, & Howard, 2014;
- McLemore, 2018; Meier, Pardo, Labuski, & Babcock, 2013; Meier, Sharp, Michonski,
- Babcock, & Fitzgerald, 2013; Pflum et al., 2015) investigated the association between anxiety
- and social support utilising bivariate analysis. All six studies found significant small negative
- associations between anxiety and social support between r=.14 to r=.29. That is, higher
- 20 ratings of anxiety were associated with lower levels of perceived social support. However,
- 21 this association was weak across all studies. One of the studies (Pflum et al., 2015), did not
- report on the size of the correlation. One study (Scandurra, Amodeo, Valerio, Bochicchio, &
- 23 Frost, 2017) did not report the correlational association utilising bivariate analysis.

Five studies utilised multivariate analysis to investigate the association between

2 anxiety and social support. When confounding variables were controlled for the results

appeared inconsistent across the studies. Two studies (Meier, Sharp, Michonski, Babcock, &

Fitzgerald, 2013; Pflum et al., 2015) found significant associations when controlling for other

selected variables (e.g. age assigned sex, education and employment). One study (Scandurra,

6 Amodeo, Valerio, Bochicchio, & Frost, 2017) did not report the association utilising bivariate

analysis but reported a significant negative relationship between anxiety and social support

from family when demographics were controlled. However, this study did not find significant

relationships between anxiety and social support from friends and significant others.

Important non-significant predictors for each study are highlighted in Table 5.

One study (Scandurra, Amodeo, Valerio, Bochicchio, & Frost, 2017) did not report findings utilising bivariate analysis, but observed significant relationships utilising multivariate analysis, only in the family source of support subset: friends and significant other were not significant at a multivariate level.

Two studies (Budge, Adelson, & Howard, 2013; Budge, Rossman; Howard, 2014) did not find significant associations when other factors were controlled for using multivariate analysis. Furthermore, two studies (McLemore, 2018; Meier, Pardo, Labuski, & Babcock, 2013) did not report multivariate results.

Psychological distress

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One study (Fuller & Riggs, 2018) explored the relationship between depression and anxiety and social support. However, the authors combined the scores to explore the overall relationship between 'psychological distress' and social support. Significant negative associations between psychological distress and social support were reported with a

- 1 correlation of r=-0.24. However, it is unclear whether there is a relationship observed
- 2 between anxiety and depression and social support individually.

Table 5
Association between anxiety and social support across studies

Study	Social	•	•	Bivariate	Multivariate Results			
	Support variable	variable		Association	Significant Predictors	Non-significant predictors		
Budge et al. (2013)	Social support	Anxiety symptoms	Correlation SEM analysis	Significant negative correlation r=28, p<.01	Trans women	Trans women Facilitative coping Transition status Loss Social support Age Income Trans men Facilitative coping Transition status Loss Social support Age Family history		
Budge et al. (2014)	Social support	Anxiety symptoms	Multiple regression	Significant negative correlation r=299, p<.05	Avoidant copingFacilitative coping x social support	AgeIncomeSocial supportFacilitative coping		

					Avoidant coping x social support	
Fuller and Riggs (2018)	Social Support	Psychologic al distress (depression + anxiety)	Correlation	Significant negative correlation r=-0.24, p<.01	Not measured	Not measured
McLemor e (2018)	Social support	Anxiety symptoms	Correlation	Significant negative correlation r=15, p<.01	Not measured	Not measured
Meier et al. (2013)a	Perceived social support	Anxiety symptoms	Correlation	Significant negative correlation r=-0.23, p<0.001	Not measured	Not measured
Meier et al. (2013)b	Partner social support	Anxiety symptoms	Correlation Hierarchical regression	Significant negative correlation r=-0.14, p<0.01	 Social Support Relationship status x social support 	Relationship status
Pflum et al. (2015)	General social support	Anxiety symptoms	Multiple regression	TFS: Significant negative correlation (size unreported)	TFS:Social supportTrans community connectedness	TFS: Non

					•	Age (controlled for)	
				TMS: Significant negative correlation (size unreported)	TMS:	Social support Age (controlled for)	TMS: • Trans community connectedness
Scandurra et al. (2017)	Perceived social support	Anxiety symptoms	Logistic regressions	Not reported	•	Everyday discrimination Alienation Resilience Shame MSPSS family Everyday discrimination x Family	 Age Education Income Marital status Community Pride Religious education Prejudice events Perceived stigma Passing MSPSS friends MSPSS significant of

HHRDS-HR= Heterosexist Harassment, Rejection and Discrimination Scale (Szymznski, 2006); MSPSS= Multidimensional Scale of Perceived Social Support (Dahlem, Zimet & Waljer, 1991); TFS= Trans Female Spectrum; TMS= Trans Male Spectrum

1 Discussion

The primary objective of this review was to provide an objective systematic review exploring the associations between social support and depression and anxiety in adults who identify as transgender. A total of 11 studies were reviewed, reporting data from a total of 4514 participants. Ten of the studies explored the relationship between depression and social support. Seven examined the relationship between anxiety and social support and one study looked at the relationship between both depression and anxiety, (psychological distress) and social support.

It was predicted that both depression and anxiety would have a significant negative relationship with levels of perceived social support. The systematic review of the included studies found a negative association between depression and social support. Studies also suggested a negative association between anxiety and social support. However, when examined at a multivariate level, overall, the significant associations were inconsistent.

Turning first to depression, the synthesis found clear trends in the research findings. Depression was theorised to be negatively associated with perceived levels of social support (Clements-Nolle, Marx & Katz, 2006). When depression was explored using bivariate analysis, all of the studies found evidence of a negative relationship with social support at a small to medium range. When studies utilised multivariate analysis to explore confounding variables, the association between depression and social support was upheld for the majority of the selected studies. One study (Scandurra, Amodeo, Valerio, Bochicchio, & Frost, 2017) only found a significant negative relationship between depression and social support from family when demographics were controlled.

These findings are especially important, as they demonstrate that low levels of social support may play a role in emotional distress for adults who identify as transgender. The

- 1 importance of adequate social networks and social support should not be underestimated.
- 2 Thus, comprehensive systemic factors should be considered when supporting individuals who
- 3 identify as transgender. For instance, the development of interventions aimed at the families
- 4 of transgender individuals may have beneficial outcomes and supporting individuals to
- 5 enhance their support networks may be effective in reducing distress. A connection to the
- 6 TGNC community may also be an important source of support for individuals (Pflum, Testa,
- 7 Balsam, Goldblum & Bongar, 2015).

or cause of greater levels of depression.

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8 An important consideration in interpreting the findings of this review is that 9 depression appears to make people more likely to appraise their social support as inadequate. Furthermore, low mood may lead to poor interpersonal functioning, which can, therefore, 10 11 lead to limited social networks and social support (Witcomb et al., 2018). One study (Budge & Howard, 2013) also suggested that the less social support a transgender individual has 12 available, the more avoidant coping strategies are used, and in turn, more depressive 13 14 symptoms were reported. The cross-sectional nature of the included studies meant that it was not possible to determine whether lower levels of perceived social support is a consequence 15

The reviewed studies that explored the relationship between anxiety and social support had inconsistent findings. Small negative associations were noted amongst all but one of the studies when anxiety was treated as a uni-dimensional construct. However, these associations were inconsistent at a multivariate level when other factors were controlled. Some associations were found (Meier, Sharp, Michonski, Babcock, & Fitzgerald, 2013, some were not observed, and some found associations with only certain sources of support, such as family. Two studies suggested that those who reported lower social support also reported greater use of avoidant coping and 'thus' experienced greater anxiety (Budge, Adelson, & Howard, 2013; Budge, Rossman, & Howard, 2014). This suggests an interaction between

social support and coping and anxiety rather than social support on its own. This is an area
 requiring further research.

It is possible that focusing too narrowly on depression and anxiety outcomes may serve to over-pathologise a vulnerable population who may be experiencing a normative response to perceived low levels of social support. Consequently, rather than relying solely on the relationship between anxiety and depression and the perceived levels of social support, researchers should investigate the potential positive influences of social support. Future research could focus on exploring ways to quantify and measure social support, looking at frequency and duration of contacts, for example, and using diaries to reduce reporting bias.

Methodological strengths limitations and implications for research

This review was strengthened by following PRISMA guidelines for systematic reviews (Moher, Liberati, Tetzlaff, & Altman, 2009). A second strength was the inclusivity of diverse transgender identities, which provided an opportunity to review studies beyond the LGBTQ community.

Collectively, the data appeared to support the importance of considering levels of perceived social support as potential contributors to levels of depression. However, while the current review provides important evidence and insight into the relationship between social support and anxiety, and depression, consideration of the following limitations should be made. The review identified a number of methodological issues that were apparent in the systematic review.

First, only papers written in English were included in this review, to ensure language translation bias did not occur. This however, may have increased the likelihood of bias.

Furthermore, two studies (Meier, Pardo, Labuski, & Babcock, 2013; Meier, Sharp,

Michonski, Babcock, & Fitzgerald, 2013) included the same sample of participants. Both

- studies were included in the review as the research questions and the number of participants
- 2 and analysis were different. However, the same sample of participants will yield the same
- 3 scores for social support and depression and anxiety. Therefore, the inclusion of the same
- 4 participants means that conclusions should be made with caution.
- 5 In addition, meta-analysis was not possible due to methodological heterogeneity.
- 6 Utilising a more critical and statistical evaluation approach, such as meta-analysis, may have
- 7 yielded a more in-depth review, than the narrative synthesis utilised within this review.
- 8 There are some methodological limitations within the studies selected. First, because
- 9 the review explored studies of a correlational nature, it was not possible to infer causality of
- the associations explored within the review. Furthermore, one study, (Fuller & Riggs, 2018)
- failed to separate depression from anxiety, and instead examined overall levels of
- 12 psychological distress.
- 13 Utilising internet questionnaires introduces an additional source of bias. The use of
- internet measures assumes the participant meets the selected criteria and is able to read and
- make sense of the information. The use of the internet may exclude potential participants and
- reduce the generalisability who do not have the means or access to the internet. The issue of
- social support and depression, therefore, requires more prospective and longitudinal studies
- 18 for the TGNC population.
- Furthermore, the review included only studies that were conducted in western
- societies. Therefore, it is not possible to generalise the results of the study to non-western
- 21 countries and cultures.
- Depression and anxiety were generally measured using self-report questionnaires.
- 23 Although the majority of the scales employed are validated instruments, they are

questionnaire tools and not clinical interviews and, therefore, conclusions from them should
 be interpreted with caution.

This review has focused exclusively on perceived social support using quantitative measures and has not examined social support within the context of social relationships. Reis and Collins (2000) stated that relationships are the "context for the development of social support" (p. 138) and it is relationships that need to be examined in order to understand the role of social support. The interrelationship between the amount, the value placed and the quality of social support available to individuals would also be important. Additional potential contributions such as biological, contextual factors and more subtle considerations of social support (for example, gender specific) must also be considered. Therefore, a more qualitative focus is required to explore the role of support within the context of the relationships for adults who identify as transgender.

Clinical and research implications

The findings of this review extend the current understanding of the relationship between perceived levels of social support and depression in adults who identify as transgender. They provide evidence to suggest that there is a relationship between perceived levels of social support and depression in adults who identify as transgender.

The results highlight that it is important to develop an awareness amongst practitioners working with all TGNC individuals of the importance of social support in order to develop and promote effective social support interventions. Furthermore, working collaboratively with TGNC communities and social care and support agencies to support TGBC individuals to build upon a sense belongingness and connectedness within the community, may support individuals to develop and build appropriate coping strategies (Brennan-Ing Seidel, Larson, & Karpiak, 2014; Johnson & Amella, 2014; Hughes, 2016).

In the UK, third sector services are developing a variety of approaches to social relationships and social participation (Mann et al., 2017). However, increasing opportunities for social contact are not necessarily sufficient for developing new and enduring relationships. Opportunities such as shared activities and enjoyment with others in non-oppressive environments are vital. Given the results of the review, attention should be given to providing more systemic tailored approaches to those who identify as transgender

Future research should attempt to introduce a more interdisciplinary approach, in the research of social support and depression and mental health in the TGNC national population including, service user involvement. An interdisciplinary approach to include diverse disciplines may provide multifaceted layers and a richer viewpoint. This, in turn, may support an increase in knowledge and better communication which would be valuable to research and service development.

Conclusion

The current review extends the literature exploring the role of social support in depression and anxiety in adults who identify as transgender. The review found that poorer perceived social support is associated with higher levels of depression. A number of methodological limitations were highlighted, including the correlational nature of the identified studies. It was therefore not possible to infer causality of the associations explored within the review. Whilst caution must be taken when generalising the findings, the data suggest that the importance of meeting the social support needs of people who identify as TGNC has become increasingly apparent. As such, an interdisciplinary approach to include diverse disciplines may provide multifaceted layers and a richer viewpoint along with working collaboratively with TGNC communities. Further research longitudinal research is needed to better understand the relationship between depression, anxiety and social support.

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6 7	Chapter 2: Empirical Paper
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10	"A bit like trying to understand chaos"
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12	The experiences and perceptions of adults with intellectual disabilities who
13	identify themselves as transgender ³
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³ Article prepared for submission to Journal of Applied Research in Intellectual Disabilities for peer review. Please see Appendix D for author guidelines. The word count for this journal is 7000 words. The American Psychological Association (6th edition) is the required style of referencing. The journal word count is exceeded, and tables and figures included in the main text, for examination purpose only.

1 2 Abstract 3 4 **Background:** Research examining transgender and intellectual disabilities (ID) is scarce, 5 and what exists is largely descriptive and based on single case studies. It is important to 6 explore the interaction between different stigmatising identities. Research exploring the 7 experiences and perspectives of those with ID who identify as transgender is required. 8 9 **Method:** Seven people were interviewed, and data were analysed using Interpretative 10 Phenomenological Analysis methodology. 11 **Results:** Five superordinate themes were developed through exploration of the participants' 12 13 experiences: Formation of Self-Concept', 'Social Stigma', 'Support and Knowledge', 'Barriers' and 'Future Hopes and Perceptions of Possibility'. Subthemes were also 14 15 developed and discussed individually. 16 **Conclusions:** The findings suggested that participants felt encouraged by significant others 17 18 to suppress any expressions of self that were not congruent with their biological sex. All 19 participants had experienced forms of social stigma throughout their lives and indicated a tendency to internalise the views of others. However, participants described feeling 20 21 empowered to act as a source of support and as an advocate for others with ID who identify 22 as transgender due to their own experiences of oppression. Clinical implications include the 23 need for service providers to take a more proactive approach and give people opportunities to 24 explore their identities for themselves. There is also a greater need for education and training 25 in this area for people with ID, their families and carers and practitioners as well as an imperative to address the power imbalances highlighted. 26

1	Keywords: Intellectual disability, transgender, non-binary gender identity, identity,
2	Interpretative Phenomenological Analysis
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20	⁴ Note on terms: 'Intellectual disabilities' ('ID') is used throughout this paper as it is the internationally preferred
21	term in research literature. 'Transgender' and 'Non-binary gender identities are used interchangeably. See
22	Appendix E for the researcher's epistemological position.
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Introduction
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Over the last few decades, there has been a great deal of interest in the interrelated
processes of gender formation, including gender identity development and the interplay with
biological and social factors. Gender identity development is used to understand the
processes through which individuals develop inner understanding of themselves in relation to
gender and the labels associated to them (Bussey & Bandura, 1999).
'Transgender' is as an umbrella term used to define individuals whose gender identity
or expression differs from the social construction of gender associated with sex (male or
female) (Davidson, 2007). The prevalence of gender variance and non-binary gender
identities in adults is presently unknown (Bonifacio & Rosenthal, 2015).
Stigma is seen as a process of "blaming, and shaming" in society that leads to
discrimination that can reproduce social inequalities (Deacon, 2006, p. 418). The Minority
Stress Model (Meyer, 2003) suggests that minority stress stems from the relationship between
minority and dominant values. Minority stress is a result of a conflict within the social
environment experienced by minority individuals (Meyer, 2003). Minority stress is associated
with stigma, prejudice, and discrimination and has been associated with increased rates of
psychological distress in minority populations such as the transgender population (Abbott &
Howarth 2005). Minority stress can consist of actual experiences of rejection or
discrimination (external) and experiences of perceived rejection or discrimination (internal).
This stress can lead to individuals concealing their identity due to fear of discrimination and
stigma.
Stigma and discrimination faced by transgender people have been associated with
increased general life stress, social anxiety and suicidality (De Santis, 2009; Meyer, &
Northridge, 2007). Research has also suggested that transgender people experience even

higher levels of depression and lower levels of peer and family support than individuals who

- 1 identify as gay, lesbian, or bisexual. These factors can be seen from a minority stress
- 2 perspective (Meyer, 2003), in which transgender individuals are exposed to higher levels of
- 3 stress as a result of their stigmatised "other" gender identity status (Testa, Habarth, Peta,
- 4 Balsam, & Bockting, 2015).
- 5 Studies exploring the levels and types of distress faced by the transgender community
- 6 have highlighted the impact of a lack of social support from family, friends and significant
- others (Riley, Wong & Sitharthan, 2011; Israel, Gorcheva, Burnes & Walther, 2008). Due to
- 8 higher levels of psychological and social distress reported, it is important to understand the
- 9 perspectives and experiences of individuals in order to identify and develop appropriate and
- relevant support mechanisms (Riley, Wong & Sitharthan, 2011).
- 11 Qualitative studies of transgender individuals have suggested that involvement in a
- community of peers who share minority stigma and who promote identity pride can act as a
- moderator and a coping mechanism to face the discrimination (Testa, Jimenez, & Rankin,
- 14 2014). Furthermore, family and peer support, have been shown to be negatively associated
- with psychological distress, which may act as protective factors for transgender individuals
- 16 (Fuller & Riggs, 2018). Moreover, research suggests that peer support moderates the
- 17 relationship between stigma and psychological distress in people who identify as transgender,
- thus emerging as a demonstrated factor of resilience in the face of discrimination in society
- 19 (Bockting, Miner, Swinburne Romine, Hamilton, & Coleman, 2013).
- Intellectual disability (ID⁴) is defined as "a significant impairment in intellectual
- 21 functioning and significant impairment in adaptive behaviour (social functioning), with each
- of these impairments beginning prior to adulthood" (British Psychological Society (BPS),
- 23 2015, p. 2). It is estimated that approximately 2% of people in the UK have ID (Krahn,
- 24 Hammond & Turner, 2006).

To date, research examining transgender and ID is scarce, and what exists is largely descriptive and based on single case studies. Knowledge of stigma, mental health, and factors of minority coping remain relatively limited as these factors apply to gender minority populations. This particularly relates to people with ID who identify as transgender, who are a 'minority within a minority' (Abbott & Howarth 2005). It is therefore important to explore the interaction between different stigmatising identities such as ID and transgender and interdependent systems of discrimination or disadvantage. Furthermore, there is a dearth of in-depth qualitative research involving individuals with ID (Beail & Williams, 2014). Consequently, much remains unknown about how individuals with ID experience and

perceive transgender identities.

Wider lesbian, gay, bisexual, transgender and questioning (LGBTQ) studies suggest that people with ID frequently experience difficulties accessing appropriate sexual and gender health care (Greenwood & Wilkinson, 2013). Few opportunities for peer support or dedicated resources have also been highlighted (Galea, Butler, Iacono & Leighton, 2004). Furthermore, it has been reported that people with ID may find it difficult to access non-ID LGBTQ communities and struggle to be fully accepted within this community (Blyth 2010).

Due to societal expectations, talking to family, friends, and significant others about non-binary and transgender identities can often be a frightening process (Lev, 2004).

Furthermore, it has been suggested that support staff lack confidence in supporting LGBT with ID (Abbott and Howarth, 2005; Abbott and Howarth, 2007). Understanding how to best support the development of diverse transgender and gender non-conforming individuals is therefore critical to the provision of culturally sensitive healthcare, education and support services (Drescher & Byne, 2012).

Legislation, such as the Human Rights Act 1998, Mental Capacity Act 2005, and Equality Act 2010, currently protect some of the rights of people with ID and those who identify as LGBTQ. UK Government strategies (Valuing People, DH, 2001; Valuing People Now, DH, 2009) highlight the need for individuals with ID to have the same opportunities as other people in society and to lead fulfilling and valued lives. This includes being able to explore and express gender identity freely. However, low visibility of people with ID who identify as LGBTQ has resulted in double discrimination in the planning and management of learning disability services (Davidson-Paine and Corbett 1995). Furthermore, individuals with ID may be less aware of their rights and are less likely to report abuse against them or infringement of their human rights due to fear that they may not be believed (Joint

In order to understand more about what can be done to support people with ID to develop and express their own gender identities, research exploring the experiences and perspectives of those who identify as transgender is required.

Committee on Human Rights, JCHR, 2008).

Aims

The overarching aim of the current study is to understand how adults with ID who identify themselves as transgender, experience and perceive their own gender nonconforming identities and expressions and whether their experience impacts on their own notions of stigma. It will explore experiences and perceptions by examining accounts elicited directly from adults with ID themselves.

The study aims to explore: 1) an understanding of the experiences of people with ID who identify themselves as transgender 2) how adults with ID have become aware of a transgender identity and how they make sense of their identity as transgender 3) whether

1 adults with ID experience stigma attached to their gender nonconforming identities and

expressions 4) the support needs of adults with ID who identify themselves as transgender.

4 Method

Design

An interpretative qualitative study explored the experiences of a sample of adults with

ID who identify as transgender using semi-structured interviews. Interview data were

explored and analysed utilising Interpretative Phenomenological Analysis (IPA; Smith, 1996;

Smith & Osborn, 2008; Smith, Flowers, & Larkin, 2009).

Rationale

IPA is used to explore the unique lived experiences of a particular phenomenon and does not seek objectivity. The aim of the research is to explore the experiences of adults with ID who identify as transgender.

IPA requires small, homogenous samples which enable detailed exploration. This study utilises a small sample of adults with ID who identify as transgender. Therefore it was felt that this constituted an appropriate homogeneous sample size for the analysis chosen.

IPA views the phenomenon from the perspectives of the participants in an attempt to understand and describe their experiences whilst attempting to understand how people make sense of their experiences (Eatough & Smith, 2008). Thus IPA was determined to be suitable for this study as it attempts to explore the perspectives of adults with ID who identify as transgender whilst also attempting to describe how they make sense of their experiences throughout their lives. The study aims to explore each participant's experience, whilst also

exploring the dataset as a whole to creating new understandings. IPA proposes that we cannot understand the parts of something without looking at the whole, and we cannot understand

the whole without understanding its parts (Smith et al., 2009).

The rationale for the use of IPA methodology in this study was based on the consideration of a range of qualitative methods. Although the use of grounded theory was considered, it was felt that this approach was not appropriate as theory development was not the aim of this research. It was felt that thematic analysis is primarily a descriptive analysis, and that a more interpretative approach was appropriate in order to try to understand the experiences and meaning making of the participants.

Researcher's Epistemological Position

Each experience, perspective and internalisation are unique and can be interpreted in different ways. However, within psychological research qualitative methodologies can focus on discovery orientated approaches thinking about knowledge and how it may be applied. Phenomenological approaches (Husserl, 1970) aim to develop knowledge about people's lived experience and use of language and meaning making whilst attempting to take into considerations the researcher's values. A reflective journal was therefore kept throughout the research process, which aimed to develop my reflexivity. This encouraged consideration of my own beliefs, assumptions and preconceptions as well as the participants within the study.

The hermeneutic position considers shared linguistic meaning, how it is acquired and makes sense of emotional and interpersonal experience. These are informed by our culture and values (Schwandt, 1999). Therefore, analysis includes alternating between exploring from the outside and then from within, the accounts of the participants. Furthermore, IPA

- 1 employs a double hermeneutic (Smith & Osborn, 2008) enabling the researcher to make
- 2 sense of each participant making sense of their own experiences.

my reflexive position upon data collection and analysis.

- I am a 32-year-old White British cisgender woman without a disability. My main clinical interests are working with people with ID and Autism Spectrum Disorder (ASD). Prior to conducting this research, I have had many years of experience supporting people with ID in support worker and assistant psychologist roles. My interest in this study developed from my reflections on my epistemological stance and being aware of the lack of service provision in supporting people with ID to express their own sexuality and gender identities, including trans and non-binary gender identities. I embrace diversity while having a passion to understand and confront social injustice and discrimination, and I have a desire to empower participants to take part in research, particularly for people with ID. I remained attuned to these beliefs throughout this research study and was alert to the potential impact of
 - ID has been defined as "substantial limitations in present functioning (IQ<70), existing concurrently with related limitations in two or more adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work," occurring "before age 18", (Luckasson et al, 1992, p.5). The term ID conveys a sense of difficulties of "intellect" whereas 'learning disability' can appear to describe a more narrow set of deficits in learning. The terms are socially constructed by the value judgements in given social, historical contexts and linguistic diversity (Hatton, 2001). However, diagnosis may be important for access to services, including psychiatry and psychology provision. Furthermore, there have been difficulties classifying this population (Fryer, 1993). The term 'learning disability' may be misleading, as it suggests that individuals may are not able to learn new skills. Therefore, for the purpose of

this study, Intellectual disabilities' ('ID') is used throughout this paper. It is also the

2 internationally preferred term in the research literature.

3 Queer Theory and Feminist Theory suggests that gender identities are socially

constructed (Rich, 2007). People assign meaning and labels to particular groups of

behaviours and roles within society (Butler, 1999). However, these can be interpreted

differently depending on social context and identities are formed and performed through our

interactions and through social rules (Butler, 1999). In this study, I am interested in the

experiences and perceptions of those who identify as transgender and their experiences within

society. I also recognised the importance of using participants' labels of their own gender

identity within the research.

Participant characteristics

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To maintain confidentiality pseudonyms were chosen by the participants and used throughout the research analysis. Seven participants, six who identified as trans female and one trans male, were recruited from services and support groups across the UK, including an LGBTQ support group for adults with ID (N=4), third sector supported living (N=2) and an

NHS service for adults with ID (N=1).

All participants lived in the community. All the participants identified as white

British, and self-reported that they had an ID and those who supported them also confirmed

this. Table 6 presents the demographics for each participant with their pseudonyms.

Procedure

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Ethics

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25 NHS ethical approval was sought and granted before the research began (Appendix G).

1 Table 6

Participant demographics

Pseudonym	Race/Ethnicity	Gender Identity	Length of interview in minutes
Sarah	White/Caucasian	Trans female	81
Kirsty	White/Caucasian	Trans female	64
Charlie	White/Caucasian	Trans female	62
Grace	White/Caucasian	Trans female	80
Peter	White/Caucasian	Trans male	48
Isla	White/Caucasian	Trans female	66
Luna	White/Caucasian	Trans female	40

Recruitment

Seven participants were purposively recruited, they were selected on the basis that they were aged 18 years or over, whose gender identity or expression differs from their assigned sex at birth, had an ID and were able to provide informed consent to participate and had expressive language abilities sufficient enough to allow them to participate (see inclusion and exclusion criteria, Table 7). Expressive language ability was assessed using the British Picture Vocabulary Scale BPVS-II (Dunn, Dunn, Whetton & Burley, 1997), which has been widely used in research with people with ID. Vocabulary tests are believed to be a good predictor of general cognitive ability (Wechsler, 1974), and the BPVS-II correlates well with other tests of general cognitive ability (e.g. the British Ability Scales). A language comprehension ability equivalent of 4 years 5 months cut-off score was used. This was based on previous research suggesting individuals demonstrate substantial verbal comprehension skills for receptive language at 4 years 5 months age equivalence as assessed by the BPVS-11(Reed and Clements, 1989).

1 Table 7

2 Inclusion and exclusion criteria

Inclusion Criteria

- Aged 18 years or over
- Have an intellectual disability (confirmed by professional, support workers or individual).
- Participants whose gender identity or expression differs from their assigned sex at birth
- English speaking
- Able to provide informed consent to participate.
- Expressive language abilities sufficient to allow them to participate in the interview process (assessed by BPVS).
- Participant must be in contact with professionals who are skilled in assessing capacity to consent

Exclusion Criteria

- Aged under 18 years,
- Do not have an intellectual disability
- Non-English speaking
- Does not have the capacity to consent to participate
- Does not have expressive language abilities.

- Potential participants were identified by members of specialist NHS gender
- 5 services and community NHS ID psychology teams across the UK. These individuals were
- 6 contacted by a member of the team via telephone and provided with a brief overview of what
- 7 the research entailed. The researcher was not involved in the initial contact process to
- 8 minimise researcher bias or breaching confidentiality. The study was also advertised in third
- 9 sector support groups such as LGBT groups via posters (Appendix H) and the researcher also
- visited groups to speak about the research.
- Once interest in participating in this study was indicated, the researcher organised an
- initial meeting with each potential participant to provide them with the participant
- information sheet (PIS), a summary PIS (Appendix I & J) and to explain the processes that
- were involved in the research. Meetings were either in the participant's home or at University
- 15 facilities.

Informed consent

To ensure potential participants were provided with information to enable them to make an informed choice to participate, an accessible PIS (Appendix I & J) and consent form (Appendix K) were developed. Department of Health and National Research Ethics Service guidance was followed (DH, 2010; NRES, 2011) and advice was sought from a speech and language therapist (specialising in working with adults with ID), and experts by experience with ID. Twelve potential participants were approached. One did not meet the criteria, and one did not wish to take part. Support staff did not provide contact details of the final three potential participants, which provided a barrier to accessing the study. Seven people met with the researcher and were provided with the PIS. The researcher read through the PIS with each participant and answered questions throughout this process. As explained in the PIS, the researcher explained that audio recording equipment would be used in the interviews and the equipment was demonstrated to each participant. Those who wished to take part took home the PIS and were invited to a second meeting to provide consent and signed the consent form provided.

Interviews

Following the initial meeting, as described above, a second meeting was offered to conduct the interviews. The interviews were all carried out by the researcher. Three participants chose to have a support worker with them during the interview. Interviews took place in the participant's home or at University facilities. These environments were chosen to enable the participant to feel as comfortable as possible during the interview and at the choice of the participant. The BPVS was administered before the interview. All participants met the BPVS age equivalent cut off score of four years five months.

An interview schedule based on a review of the current literature was used to guide a semi-structured interview process (Appendix L). The schedule was piloted by the first participant and reviewed by the research supervisors prior to the subsequent interviews.

Interviews ranged between 40 and 81 minutes in duration, lasting until the areas of guided enquiry were covered, and when participants had nothing left to add to the interview. When the interview ended, all participants were given a debriefing form (Appendix M), and this was read through with the participants. The initial three interviews were transcribed verbatim by the researcher. The final four interviews were transcribed verbatim by a university approved transcriber and the researcher listened to the recordings and thoroughly checked the transcripts following completion. All recordings were deleted once transcripts were finalised. All participants' transcripts were saved onto a password protected USB stick and kept in a locked cabinet at the University of Liverpool for five years, in accordance with the British Psychological Society (BPS) guidelines (2014).

Participant wellbeing

There are several challenges when conducting research with individuals with ID which were considered and addressed in detail. It was important to ensure that participants fully understood what the study involved while maintaining their rights and dignity (Iacono & Johnson, 2004). A sensitive interview approach was adopted throughout the data collection period. A debrief form including a list of contact details for appropriate support services (Appendix M) was provided at the end of each interview.

Reflexivity

Reflexivity is an important process of IPA throughout the research as the researchers' personal experiences, expectations and reflections influence the analysis process (Smith & Osborn, 2008). To maintain reflexivity, my experiences and beliefs were explored in research

- supervision, throughout the research process. I also kept a reflective diary (Appendix N) to
- 2 explore my beliefs, expectations, personal views and emerging ideas and reflections
- 3 throughout the research process.

Data analysis

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- Research data analysis was informed by Smith and Osborn (2008) and Smith,
- 8 Flowers, and Larkin, (2009). The interviews with participants were recorded and transcribed
- 9 verbatim. Transcripts were read by the researcher and and the audio recording of each
- transcript listened to simultaneously. Transcripts were line-numbered and unfocused notes,
- including ideas, thoughts and associations were noted in the left-hand margin. Descriptive,
- 12 linguistic, and conceptual themes were highlighted throughout each transcript (see Appendix
- O for a sample). Emergent themes were noted and themes were labelled, which aimed to
- "capture something about the essential quality of what is represented in the text" (Willig,
- 2001, p.55). Related themes were then grouped into superordinate themes. A table of
- superordinate themes along with corresponding quotes were created for each participant
- 17 (Appendix P). The remaining transcripts were then subject to the same process before themes
- tables were considered together as well as evidence of new emergent themes, and connections
- and differences. A list of master themes was produced, and redundant themes were removed
- 20 (Appendix Q).

Quality assurance

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- Quality assurance was considered throughout the research (Elliott, Fischer & Rennie,
- 24 1999). Table 8 and appendix R detail the quality assurance procedures evaluated, along with
- 25 an audit trail (Yin, 1989).

Table 8

Quality assurance process

Quality assurance process	Examples
Considering researchers perspective ¹	Reflexivity of the researcher's position was considered throughout the process including in supervision.
Embedding the sample ¹	Participant demographics and contextual information provided regarding recruitment.
Grounding in examples ^{1,}	Each theme was demonstrated using quotes ¹
Themes ¹	Analysis was considered throughout the process with supervisors
Participant validation ^{1, 3}	A pilot study was completed at the beginning of the research ¹ . The double hermeneutic process within IPA means that the results were analysed utilising the researcher's interpretations of the participants interviews ³ Participant validation of the themes were not sought as this was not included as part of the ethics procedure. Limitations regarding this are explored within this paper's discussion section.
Evidence of themes ⁴	Results were documented utilising tables and annotated transcripts. 4

¹Elliott, Fischer & Rennie, (1999); ²Smith (2011); ³Smith, Flowers, & Larkin (2009); ⁴Yin (1989)

Results

Themes

Individual experiences were considered along with connections and differences for

each participant and five super-ordinate themes emerged (Table 9).

1 Table 9

2 Super-ordinate and constituent sub-themes

Super-ordinate Themes		Constituent Sub-themes	
1.	Formation of	1.1. "I knew I was different": Trying to make sense	
	self-concept	1.2. "She threatened to get me sectioned": Childhood	
		1.3. "I feel happy when I'm wearing women's clothes": Gender expression	
		1.4. "I had to come out like forcefully": Early experiences of 'coming out'	
2.	Social stigma	2.1. "Oh, that's not a boy that's a girl": Society's gender binary views	
		2.2. "They will probably make fun of me, calling me a poofter": Fear of reactions	
		2.3. "It's just a phase": Powerful others	
		2.4. "I was going to get called names like a pervert": The hidden self	
3.	X X	3.1. "We're here to support you": The role of others	
	knowledge	3.2. "I go on the internet 24/7": Sources of information and knowledge	
		3.3. "I want people to be supportive of me": Desire for knowledge, support and acceptance	
4.	Barriers	4.1. "You never know, something might happen": Social challenges	
		4.2. "I am on the waiting list, about 900 on the list": Service barriers	
5.	Future hopes and perceptions of possibility	5.1. "Being happy in the body I was meant to have": Future	
		5.2. "I am who I am; I know who I want to be": Developing pride in who I am	
		5.3. "I would like to be able to help": Desire to empower others	

- 4 The similarities and differences between each of the seven participants are considered
- 5 in relation to five super-ordinate that can be drawn from the analysis: Formation of Self-
- 6 concept', 'Social Stigma', 'Support and Knowledge', 'Barriers', 'Future Hopes and
- 7 Perceptions of Possibility'. Subthemes were also developed and will be discussed
- 8 individually. Themes are illustrated by pseudo-anonymised quotes shown in *italics*.

1.0 Superordinate Theme 1: Formation of self-concept

The first superordinate theme reflects the participants' ability to know, perceive and feel. This theme describes their awareness of their gender identity and key influencers. The initial period of questioning related to one's assigned gender, which led to themes of confusion and uncertainty, incongruence, experimentation and acceptance.

1.1 "I knew I was different": Trying to make sense

All participants spoke about times in their lives that they were trying to make sense of their identities. Many initially talked about being unaware of alternative gender identities and transgender identities in childhood. As children, differences in gender identity or expressions were not discussed and explored with participant's parents and carers. Furthermore participants reported a lack of education around gender diversity and non-conformity within school settings. For many, a limited awareness, dialogue and education prevented them from exploring and considering any differences and feelings in gender identity. Grace describes her experience of feeling "different" early in childhood but reports that she was not told of alternative identities throughout her childhood:

"Even though I've been feeling like wanting to be a woman since I was five, nobody's told me."

All participants articulated how the process of identity evolution started in childhood. Many struggled to find the words that accurately portrayed their own gender identities, experiences and concepts. However, such a construction cannot happen in seclusion, with the sense of self emerging from many forms of language exchanges with others (Burr, 2003). The opportunities for experiences of language exchanges in childhood appeared limited for the participants.

- Finding the words and information came sometime after childhood, for many in
- 2 adulthood. Awareness was often accompanied by doubt, confusion or emotional upheaval
- 3 during the period of questioning. Some participants struggled to articulate an awareness of
- 4 their gender identity and differences. Grace described an internal feeling rather than a
- 5 cognitive awareness:
- 6 *"There was a horrible tickly feeling inside me."* (Grace)
- 7 Some described becoming aware that something was 'different' at a young age:
- 8 "I knew I was different from when I was about six years old because when I went to
- 9 school, I knew I was different from other kids." (Charlie)
- "I knew I was different from when I was six. Or I didn't know what I was." (Peter)
- "There's a question mark is the best way to describe it. A bit like trying to
- 12 understand chaos" (Luna)
- There was a sense of participants experiencing meaning making overtime. For many,
- this journey and sense-making appeared to build over time:
- "Like start off small but building...bit like it over a longer time span" (Luna).
- However, the participants presented disjointed and unclear accounts of their identity,
- perhaps due to lack of opportunity to explore their gender identities for themselves during
- 18 childhood and adolescence. The analysis suggests that being asked about identity in
- 19 childhood was a rare occurrence for these individuals:
- 20 "Because back then it was frowned upon and I wasn't allowed to do it..it just meant
- 21 that I weren't allowed to talk about it and I had to keep it hush hush" (Kirsty).

- 1 Discovering additional external evidence in adulthood around transgender identities,
- 2 allowed some participants to go through a process of further self-examination that provided a
- 3 strong identification with their feelings and identity:
- 4 "It was like an epiphany" (Luna).
- 5 "When I was growing up I didn't know much about it...in 2006 and I was researching
- 6 because I was cross-dressing and gender and I was like yeah that's me, I don't like having a
- 7 penis, I don't like being a man" (Kirsty).
- 8 However, the experience of finding a label or words to encompass all that is an
- 9 individual's transgender identity is complex. A number of participants felt that the concept of
- transgender applies to individuals in the middle of the transition process who have not yet
- undergone surgery, yet once people underwent surgery they wanted to be identified as male
- or female and not transgender:
- "For now, transgender but when I have had the operation I don't want to be called a
- trans woman...I want to be called a woman...because I've been through the process and I've
- done it and I am now a woman" (Kirsty).
- "I usually prefer transgender, but it's best to say transition or that someone has been
- 17 transitioned because it's like being in a process of it" (Grace).
- Participants struggled with the explicit topic of ID. Most did not mention ID when
- 19 asked to describe themselves or their identity. Only Kirsty talked about her ID, however, it
- appeared important for her to highlight that "I only have a mild learning difficulty" but
- 21 recognised vulnerabilities associated with ID "I have realised who does take advantage".
- This theme of vulnerability in relation to ID is woven through participants' accounts
- rather than naming ID itself:

- 1 "I don't feel safe being out later than the usual time...no because I'm a vulnerable
- 2 person because of my learning disability and that" (Peter).
- 3 "Back then erm I weren't allowed to go out and my auntie kept me in because of my
- 4 *vulnerability*" (Kirsty)

1.2 "She threatened to get me sectioned": Childhood

- 6 There was a predominance of disrupted or challenging childhood experiences
- 7 described by participants that were often deemed instrumental in directing an individual's
- 8 journey of self-discovery. Many participants described their childhood as a time wrought
- 9 with confusion, with stereotyped gender roles views imposed by families.
- When participants described their feelings about talking to their families about their
- gender identity, they used words such as "frightened, scared, worry, anxious and nervous".
- 12 These all described negative feelings that appeared to have a great impact on them in
- childhood. This was particularly salient for Kirsty:
- "She threatened to get me sectioned and stuff like that because it was frowned upon
- and she thought it was something to do with my own mental health and it was a phase and I
- 16 was going to grow out of it".
- Other participants also described their negative experiences in telling their families:
- "I came out to my parents when I was 14. It didn't turn out the way I wanted it to...
- 19 they disowned me for being trans... I told my dad and my dad didn't understand a word that
- 20 trans...my mother, she didn't understand it she said I can't have my son being trans...I was
- 21 expecting them to accept me as being a female". (Charlie).

1	"I'm frightened of my dad. Just in case he loses his temper or might with his fist I
2	don't know if he will accept me as a woman or not. So that's the that's the million-dollar
3	question I kept it to myself. Till I was old enough, to tell the truth." (Isla).
4	"The first foster family, said 'you don't want to be a woman I don't think you want
5	to go into the details'." (Grace).
6	The participants' accounts express a complex combination of emotions which
7	appeared to contribute towards a sense of underlying helplessness and powerlessness. The
8	struggle to develop and define oneself within a context where that unique identity is not
9	accepted can place additional strain and stress on individuals when they are most vulnerable.
10	Furthermore, participants' feelings of alienation were embedded in their attempts to fit in and
11	try to live up to the gender stereotypical expectations of their families as described, for
12	example, by Kirsty:
13	"Going out with girls when you know I didn't want to go out with girls" (Kirsty).
14	This raises important questions about how the meaning of such experiences is
15	developed and processed and the subsequent impact of this on the sense of self for
16	individuals with ID.
17 18	1.3 "I feel happy when I'm wearing women's clothes": Gender expression
19	Participants described characteristics of themselves that are associated with presenting
20	as either female or male. Gender expression and gender authenticity appeared to be signified
21	by wearing clothes by all participants:
22	"I wear girls' underwearlike with a t-shirt and then when people knock on the
23	door yeah, I take them off and put boys' stuff back on" (Sarah).

- 1 "I feel happy when I'm wearing women's clothes, but then when I wear these
- 2 (pointing to clothes), I feel sad" (Isla).
- 3 Masculine characteristics included affiliation with sports activities such as "football",
- 4 "boxing" and "wrestling". Feminine characteristics included, emotionality, speaking in a soft
- tone of voice, a "different walk", and "girly" interests such as "baking" and "knitting".
- For Isla, there was a vast contrast describing female characteristics: "looks nice,
- 7 beautiful, personality". And male characteristics: "always getting in trouble. They like
- 8 showing off in their cars...like drunk and disorderly, or they could go around and rape. Or
- 9 use them for sex or whatever".
- This theme appears to be associated with extreme gender stereotypes asserted in
- childhood and throughout society. These may be the roles and standards that the participants
- feel they have to fulfil in order to find a valued place within society. It was suggested that the
- individuals were expected to conform even more closely to gender stereotypes than cisgender
- peers. This has important implications because it might make it even more difficult for them
- to adopt alternative identities.
- All participants implied feeling that their families and society expected them to
- conform to gender binary roles and gender stereotypes:
- "My Dad and my Uncle like you are spending too much time with the girls you
- 19 should be doing more laddish things. It was a more male industry back then, you know it was
- 20 more you know more supported to men play football and be a coach and play boxing and
- 21 play wrestling and do a bit of fighting and muck about." (Kirsty).
- "I knew I liked boys' toys more than girls'...even though I wasn't allowed to... my
- 23 *Mum used to take them off me.*" (Peter).

1	It seems the participants adopted the dominant family and society's definitions of
2	gender, expressions and gender roles from others, rather than developing their individual
3	definitions. If individuals are supported to explore and create their own meanings of their
4	individual gender identity, individuals with ID may be empowered to and embrace and
5	express their gender
6	1.4 "I had to come out like forcefully": Early experiences 'coming out'
7	Participants described how they experienced 'coming out' in relation to acceptance
8	from others. Kirsty described her early experience of feeling forced to "come out" initially,
9	which seemed to leave her feeling powerless:
10	"Then I had to come out like forcefully by the old bill".
11	When Kirsty felt ready to tell her friends, she was left feeling invalidated and
12	rejected:
13	"Two years ago, a couple of my friends when I came out, I came out as bisexual first
14	and they were fine with that and then as soon as I came out as trans none of them wanted to
15	know".
16	For Luna: "It took me a while to talk to (support worker)I'm a bit of a pessimist
17	reallyI don't know but I didn't want to take that chance it's a bit like, bit like playing
18	Russian roulette it's like having five chocolate bars and one was made of marmite and I
19	would not take the risk".
20	Luna also described telling some close friends at college she explained: "I told them
21	to treat it like it's a nuclear launch code basically, so they wouldn't tell". However, she
22	chose to withhold it from certain people, when asked why she felt this was: "Probably fear.

1 probably shit hitting the fan. I'd rather not think about it to be honest. It's a bit like, I

2 imagine the weeping angels".

Peter also stated that "I only tell certain people" and recognised that gay venues
might be a source of support for other trans people, but not for him. "I don't go to all these
gay clubs because I don't want to be targeted…it kind of scares me".

Participants conveyed a sense of it feeling difficult to tell others. Participants developed unique coping strategies for doing so avoiding face to face communication, which included: (1) asking others to tell people on their behalf, "Got someone in the family to phone up my Aunt and tell my dad's side, Whatsapped my mum, got my support worker to tell other support workers": (Luna). (2) Texting others: "I first sent a text to (support staff)…because it was easier to send a text message…because it is quicker, in case she thought it was just me being silly" (Sarah) (3) Using the phone "Because it was the right time to tell her, to be honest, but I spoke to her on the phone, but I didn't confess face-to-face": Isla. The use of the word "confess" for Isla, implied a sense of feelings of guilt when telling her mother.

2.0 Superordinate Theme 2: Social stigma

The second superordinate theme captures experiences of discrimination, disapproval and felt and internalised stigma experienced within their social networks from all participants. These experiences appeared to influence beliefs around expectations of gender identities within society, which in turn appeared to shape internalised belief around their own identities and expressions.

2.1 "Oh, that's not a boy that's a girl": Society's gender binary views

This theme emerged from participants' accounts of encounters and ways of being that were commonly dismissed or ridiculed by others. Participants described having experienced

- 1 prejudice, discrimination, verbal taunts and/or violence. They also provided many accounts of
- bullying, including verbal and physical harassment, particularly in the school and college
- 3 environment.
- 4 "I got bullied for being me... and got attacked on my way home...I got pushed down
- 5 the stairs and ended up in hospital. I had a bad childhood...it's because I identified as a
- 6 female...they went oh that's not a boy that's a girl, half man half woman... my mum told all
- 7 the school that I was half man half woman and it went round the school" (Charlie).
- 8 Charlie's comments highlighted a stoicism also found in other participants' accounts,
- 9 who also appeared to tolerate bullying and violence with little or no support. Throughout
- their journey's participants also described many experiences of invalidation when exploring
- and developing gender identities, for example, Peter:
- 12 "My problem was I left home because of the abuse...because it's like I went through
- a phase of wearing shorts for bed, like jeans, shorts, and they caught me, and they cut them
- 14 *up* " (Peter).
- The negative attitudes toward transgender identity that the participants experienced
- gave rise to feelings of insecurity and internal questioning. They appeared to have
- internalised these views as their narratives were dominated by these assumptions of others.
- 18 This culminated in a self-identity that appeared to be co-constructed by society and
- 19 significant others. However, some participants tended to minimise the emotional impact of
- 20 their experiences, for example, Grace:
- 21 "I just focus on what (support workers) think, just don't think about what anybody
- 22 else thinks".

2.2 "They will probably make fun of me, calling me a poofter": Fear of reactions

- 1 Felt stigma captures the fear of experiencing some form of enacted stigma and is
- 2 another form of stigma that characterised participants' experienced in their communities.
- 3 Participants consistently reported believing that they would be viewed negatively by others
- 4 and often feared society's reactions:
- 5 "I was nervous about what other people would think" (Grace).
- 6 "If I wore women's clothes every day, they will probably make fun of me, calling me a
- 7 poofter...they're probably ask me for sex, because I don't want, that's what worried me
- 8 because I don't want." (Isla).
- 9 The felt stigma appears to exacerbate the participants' feelings of vulnerability,
- isolation and helplessness. Many participants also feared questions from others, feeling as
- though they could not answer the questions:
- "When I meet someone else...I don't get changed, I don't wear women's clothes...just
- in case, if, they might say something nasty, or they might laugh at me or start asking me
- 14 questions which I don't know the answer" (Isla).
- "Why is he doing it? He was born male" (Sarah)
- However, it appears that some participants in this study partly held these apparent
- 17 unresolved questions themselves, such as Sarah:
- "Why do I want to change my gender Is it good for me? Is family going to be happy?
- 19 Err erm will I get stared at? Erm when I go through it, will I regret it?" (Sarah).

20 2.3 "It's just a phase": Powerful others

- 21 Throughout their lives, all the participants were brought into contact with "powerful
- others" for example, family members, support workers and medical professionals, who they
- 23 felt had the power to judge their experiences and capacity about their gender identities. Many

- 1 participants experienced unhelpful invalidating responses from significant others. They
- 2 seemed to be reluctant to challenge this due to being silenced by others and not taken
- 3 seriously by others: "it's just a phase". It appeared that participants felt unheard by the
- 4 operation of aspects power within the networks around them, reinforcing their oppression:
- 5 "A family friend, I spoke to her about I wanted to change my gender and she says that
- 6 something that I was going through, that I was going through a phase...and that put me off"
- 7 (Sarah).
- 8 "No because it wasn't heard of back then. My Mum and Dad probably thought I was
- 9 going through a phase" (Peter).
- Others conveyed experiences of feeling invalidated and condescended to by
- professionals, feeling that because they had an ID, their feelings were not taken seriously by
- those who were supposed to be supporting them. This was particularly salient for Grace who
- experienced people around her as disapproving and attempted to inhibit such expressions of
- 14 her identity:
- "This carer told me, you're going against god's wishes...and you're never going to be
- Grace...it was a shock to me really... It wouldn't bother me if it was from somebody I didn't
- know but because it was somebody who's really supported and helped me in the past, it was
- 18 *just really difficult at the time.*"
- When Grace raised her concerns with her care management, she was again left
- 20 feeling dismissed and invalidated:
- 21 "I spoke to my boss about it but unfortunately because she's now left as a carer, I
- 22 can't really put a complaint in because she's just an individual now. It was just a shock, I
- 23 was almost in tears, I didn't know whether to like her or hate her".

Due to their experiences, the participants in this study found themselves part of marginalised groups facing discrimination regardless of individual capacity or right. Some also found that decisions were often made on their behalf:

"When I was growing up... the doctors were like 'are you sure it's not just your learning difficulty telling you want to be a woman' and I was like no I'm sure I know what I want. I was put onto male hormones before female hormones to not make me have these thoughts about being a woman...but I stopped, not by the doctors stopping by myself stopping because I didn't want those hormones" (Kirsty).

This suggests some participants, particularly Kirsty, experienced disempowering care. This experience may also serve to perpetuate a stereotype of people with ID as 'eternal children' resulting in them being regarded and treated differently. This raises questions around adherence to government policies (Valuing People Now, DH, 2009) and the impact of the organisational culture of services in relation to people with ID. There was no indication that this study's participants would (or perhaps could) challenge this and obtain this knowledge for themselves. This highlights the importance of listening to the voices from individuals with ID themselves.

2.4 "I was going to get called names like a pervert": The hidden self

The stigmatised stereotypes employed by participants when describing how 'the world' perceived transgender people ("pervert, weirdo and transgender freak") influenced how most negotiated their identity with others. The participants reported hiding their true feelings about gender and trying to adapt to the expected role of their birth sex for fear of reactions from others. Specifically, participants described how they concealed their gender identity often out of fear or worry that others would respond negatively:

1	Thad a perspective I was if I did it privately no one would know and if someone did
2	find out I was going to get called names like 'pervert, weirdo' because it was frowned upon"
3	(Kirsty).
4	Participants reported how concealing gender identity was a frequent source of stress.
5	Some chose to hide their gender identities from those with whom they did not feel safe. This
6	theme of hiding from others is woven through all participants' accounts:
7	"When people knock on the door yeah, I take them off and put boys' stuff back on"
8	(Sarah).
9	For Sarah, being private provided her with greater freedom to express her identity:
LO	"And when I am on my own, that's when I come out of myself a bit more. Because I
l1	feel more like when I'm on my own, I feel like that's my own space. I feel more female".
L2	Participants identified fears linked to rejection and victimisation from others, with the
L3	only logical conclusion being "you have to hide" and the feeling the need to "build
L4	confidence" to be their true selves within society.
L5 L6	3.0 Superordinate Theme 3: Support and knowledge
L7	The third superordinate theme reflects the importance placed on the need and
L8	desire for support and acceptance by the participants.
L9	3.1 "We're here to support you": The role of others
20	This theme describes how this study's participants' support networks, family and
21	friends facilitated the courage to explore their gender identities with. This sub-theme
22	described moderators of acceptance; which included the role of others, reframing and valuing

positive experiences. Responses from other people could both facilitate and hinder

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acceptance.

- Affirming language and positive social support tended to help bolster participants'
- 2 self-esteem. Acknowledgement and understanding from others appeared to facilitate
- 3 participants' understanding of their identities and validated their experiences. Participants
- 4 who reported positive understanding and experiences reported feeling accepted and having
- 5 their gender identity respected by support staff and others:
- 6 "When I explained to them, they said 'if you want to wear women's clothes, we're
- 7 here to support you. No matter what happens, we'll be here for you, 24/7, if you want to go
- 8 shopping to buy women's clothes, we'll come with you'" (Isla).
- 9 Charlie spoke of her experience in finding supportive support workers, where, after
- years of ostracism and harassment both at home and at school, she found people who did not
- judge her based on her gender expression. Furthermore, the support she received promoted
- self-acceptance and encouragement, which helped her to navigate social situations:
- "People go 'oh that's a man dressed as a woman', but (support worker) goes 'just
- ignore them and walk'...well, it can make you upset, but I just try and walk away. I talk to
- 15 (support worker), he is one of the best."
- Participants highlighted the value of others understanding and communicating with
- them about their experiences, which seemed to validate participants feelings. This feeling of
- validation from others appeared to enable participants to develop positive self-esteem and
- self-identity despite experiencing social stigma and discrimination from others:
- 20 "My support workers. They were supporting me every way...I felt like I could talk to
- 21 *them more*" (Peter).
- 22 Contact with other LGBT people seemed important to participants. They valued
- 23 spending time together, sharing advice and experiences:

1 "That's the first person I've met who is trans... I got talking and then we

connected...she goes I wouldn't mind coming meeting you one day and trying clothes on. I 2

said we can do that...she said we will support each other" (Charlie). 3

"To go to an LGBTO group...and go yeah it is accepted, we are here, we are doing it 4

but it's a very small community at the moment but we are trying to get it into a larger

community" (Kirsty).

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7 However, although Grace attended an LGBTQ group, she felt that she could not 8 connect with the members due to age differences and changes in services for transgender individuals:

"I'm not very keen on that...it's tricky because some of the people might have been transgender, which is fine, but a lot of things have changed since they've been transgendered. I can't really learn much from them really and now."

In addition to communication, understanding and acceptance, participants also valued practical support received from others. Practical support gave them opportunities to express their gender identities and build their confidence. Participants also suggested their ability to access help was made slightly easier by the support they had in place. The presence of support was important to maintain a safe environment and to create and maintain a culture of acceptance:

"The hardest thing was getting ladies clothes because when I went with another support worker in, Primark, they were saying "Is he waiting with you?" and (support worker) was like telling them at their faces 'No she's just getting changed', the shop said 'go downstairs' (support worker) said 'he is a she'...because if it was just me, I couldn't be doing this" (Grace).

1	"Taking me out to eventsgoing to clubsyou talk about things that are worrying
2	you about you know transitioning and coming out as gay very helpfulthe fact you're not
3	isolated indoors and you're not dealing with the thoughts on your own and you can sit there
4	and chat with someone and get some advice" (Kirsty).

However, when asked for their thoughts on whether there is a difference in support for individuals with ID who identify as transgender and those without ID, there was a difference in opinion. Some thought individuals with ID required more support, such as Kirsty:

"People without a learning disability would know more than a person with a learning disability because they might not know how to use the internet, they might not know how to go on the computer and do research like I did."

Whereas Charlie thought that individuals with ID might have access to more support than those without ID:

"I think people with a learning disability coming out as trans may have support but people without a learning disability coming out as trans may find it hard because they have got nobody to support them".

3.2 "I go on the internet 24/7": Sources of information and knowledge

The participants highlighted that "TV, newspapers and the internet" enabled them to explore information and validate their experiences:

"They showed me how they do your nose as a female, they move your lips, they take your Adam's apple out, I watched it all. That's prepared me. I go on the internet 24/7. I used to watch YouTube. That's been helpful" (Charlie).

1	"Internet there were some good stories about it that made me feel a lot better and
2	everythingYoutubeand, you can read some of them on the website as well" (Grace).
3	"I was just searching on some sites and that about how to make your chest look flat,
4	and it came up with some chest bands" (Peter).
5	Some participants in this study were also told about and directed to information by
6	their support staff, family members and friends, suggesting a potentially valuable information
7	source. However, for Peter, negative portrayals in the media appeared to impact on his
8	confidence to access the community at night:
9	"I read stories in the newspaperabout LGBT, but I feel sad when it's like people
10	coming out of clubs getting targeted, and that's probably why I don't go to all these gay clubs
11	because I don't want to be targetedit kind of scares me."
12	3.3 "I want people to be supportive of me": Desire for knowledge, support and
13	acceptance
14	Participants expressed a desire for acceptance and a greater need for knowledge:
15	"I'm always putting information out there and telling people about me so I am
16	accepted" (Kirsty).
17	"I want people to be supportive of me well, someone to go on and explain to me
18	dad, that hopefully so he'll understand," (Isla).
19	"They should have booklets where it says like trans and then when people come out.
20	Yeah in case their kids come out as transgender" (Charlie).
21	The suggestions from the participants show a sophisticated awareness of the danger of
22	ignorance in families and society whilst demonstrating great empathy for other transgender
23	people.

4.0 Superordinate	Theme 4:	Barriers
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The fourth superordinate theme embodies the barriers faced by the participants in navigating their own identity and gender expression within a gender binary society.

4.1 "You never know, something might happen": Social challenges

The participants in this study were very consistent when citing specific areas of challenge for transgender people in the community. Public toilets and changing rooms were identified as tangible examples of such challenges. Most participants described navigating public toilets and changing rooms as a particular source of stress. They shared examples of developing strategies to maintain safety and a personal sense of security, such as Grace:

"I've been going to disabled toilets...I was in a ladies toilet and like walking slowly and getting prepared in case any women came and said owt to me...it's like if I go in men's, something might happen". (Grace).

"In the swimming baths I use the female ones but, in the toilets, and that I use the disabled ones because I don't feel comfortable using the ladies ones anymore. I have been in the male ones but felt a bit weary in case someone said something. I'd like to use the male ones and be more confident using the male ones" (Peter).

Participants spoke about their desire to have gender-neutral toilets and changing rooms available:

"Yeah, when I need the toilet, I go to the boys' toilet, but I would prefer to go to the girls' toilet. There could be a unisex toilet and male and female" (Charlie).

"I feel like they should have toilets that are a bit unisex. Like male and like cross-gender can use it" (Sarah).

1 Some also felt that finances and social care were a barrier for them. A combin
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- 2 a lack of finances and lack of control over the little money they had appeared to have a
- 3 considerable effect in preventing many from meeting people and expressing their identities.
- 4 This reduced their opportunities for them to express their identities in a way they desired:
- 5 "I can't do anything about it because of my budgeting situation because of my money.
- 6 *I can't go out and get my hair cut like other people can*" (Kirsty).
- 7 "It is not going to happen overnight, it's going to take time. It costs a lot of money to
- 8 go through what I want to happen" (Sarah).
- 9 "You need somebody to maybe go with them somewhere, to these like clothes shops
- 10 with you, I still don't know my way around because I don't really live there. I couldn't make
- 11 my way around because it's just not familiar" (Grace).

4.2 "I am on the waiting list, about 900 on the list": Service barriers

- The process of medical transitioning is long and complex. The practicalities of
- accessing this specialised healthcare come with challenges and complexities for transgender
- individuals, particularly for those with ID. This was captured by Kirsty's experience:
- "I came out when I was 24, I had to go through psychiatric testing...so there has been
- a lot of psych doctors you know saying 'are you sure this, is what you really want?' and stuff
- 19 *like that...* then being put on a load of tablets because you're depressed and you've tried
- 20 killing yourself because you're not looking like you want to be" (Kirsty).
- 21 The wait to access services was identified as being problematic for many of the
- 22 participants:

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1	"I've been to the gender identity clinic. I am on the waiting list, about 900 on the list,
2	and it hasn't gone down yet" (Charlie).
3	Living life before surgery was also a concern for many participants, mainly facing
4	society, such as Kirsty:
5	"You have to be portrayed as a woman before you get the hormones, that's not
6	helpful that's when the name call starts like 'cock in a frock' and stuff like that because
7	your looking more male than you do female and I'd rather be put on the hormones first then
8	wear the dress because I would look more feminine than male and no one would call me a
9	cock in a frock and certain names".
10	However, this did not appear to be a concern for Peter:
11	"I've got to be seen to be living as a male which I've been doing for years anyway
12	since I was 16".
13 14	5.0 Superordinate Theme 5: Hope, resilience and positive action
15	The final superordinate theme reflects the hope, resilience and positive action
16	expressed by all participants, despite the struggles and conflict described.
17	5.1 "Being happy in the body I was meant to have": Future
18	Participants spoke about their hopes and desires to change their gender physically in
19	the future:
20	"I want to change me body, I want to have women's breasts and a woman's
21	vaginamy future would be as a woman" (Isla).
22	"Being happy in the body I was meant to have, a male top surgery and eventually
23	bottom surgery as well. I'd definitely get a hysterectomy as well." (Peter).

1	"I don't want to be me. I don't want to be male. I want to be female moving on. I
2	would have girl parts" (Sarah).
3	Charlie felt that surgery would change his life:
4	"It will change my life, the way I have wanted it to have been since I was born".
5	Furthermore, Kirsty and Luna appeared to have ideas of perceptions of future
6	possibilities for their physical selves:
7	"I've even contemplated getting a womb implant, I know that can be done in a few
8	years' time in Switzerland because they are moving forward then have my first period and
9	be able to get pregnant from it" (Kirsty).
10	"The more that technology advances erm to the point that you can grow your own
11	uterus from stem cells or something" (Luna).
12	5.2 "I am who I am, I know who I want to be": Developing pride in who I am
13	Participants described a process of finding, understanding and managing the self. This
14	individuality may in part represent the different stages of acceptance that participants had
15	reached. The sense of a journey of exploration being personal continues into participants'
16	present lives:
17	"But in myself, I want to be happy for who I am, and for what I am I want to be
18	happy in myselfI want to be proud of myself" (Isla).
19	"I do feel trapped in the wrong body I just want to know what my next step isjust
20	like thinking I wish it could just happen" (Sarah).

- Over time, some participants described feeling less concerned about the perceptions
- 2 of others. Most described a transitional process of self-acceptance and becoming more
- 3 comfortable and confident with who they were as individuals:
- 4 "I look perfect. It's something what has changed. It's because who I am, I like going
- 5 *out as Charlie... I become Charlie and I looked more as myself*" (Charlie)
- 6 "I have accepted who I am, I am who I am, I know who I want to be" (Kirsty).
- 7 Overtime, Peter also felt able to challenge and correct the use of pronouns others used. This
- 8 appeared important to him:
- 9 "Getting the pronouns right as well. Some people slip up, and I always correct them
- 10 politely...I just say I'm a trans male or transguy trapped in a female body and I like to be
- 11 referred as a he".

5.3 "I would like to be able to help": Desire to empower others

- Participants expressed feeling empowered to support and advocate for others as a result of their own experience and adversities:
- "If people with learning disabilities don't know how to come out I would like to be
- able to help and send them to places...and go yeah it is accepted, we are here, we are doing it
- but it's a very small community at the moment but we are trying to get it into a larger
- 18 *community*" (Kirsty).
- "I just want people's parents to just accept them for who they are then they won't get
- 20 bullied for who they want to be. I didn't have a good experience, but I want people to come
- out and have a good experience...talk more often, understand it might take a while and then
- 22 *will know exactly what to do support them and show their love"* (Charlie).

Grace was able to recognise that she struggled to "stand up for herself", but it felt easier to support and empower others:

"I was not right good at standing up for myself. It's quite odd that I'm more better for other people. I'm not sure why that it's... when it's for somebody else, it's more easier because they don't want other people getting involved".

7 Discussion

This study aimed to understand the experiences and perceptions of adults with ID who identify themselves as transgender. This has hitherto been a neglected area of research. Seven participants were interviewed, and their transcripts analysed using IPA. This analysis yielded five super-ordinate themes: Formation of Self-Concept', 'Social Stigma', 'Support and Knowledge', 'Barriers' and 'Future Hopes and Perceptions of Possibility' and 16 subthemes within the super-ordinate themes.

All participants had some awareness of their "differences" in gender identity in childhood or early teens. Children are often guided by parents/carers and usually conform to their gender roles and expectations, therefore acceptance of differences in gender identities may have been difficult in childhood for participants. Throughout their lives, the participants in this study were subjected to representations of binary gender roles, representing how their gender was understood, viewed and the manner in which they were expected to behave. The dominant view in society sees gender as binary, rigid and fixed. Many of the participants described feeling strongly encouraged by significant others to suppress any expressions of self that did not conform to society's representations of with their biological sex. It, therefore, appeared there were external controls over the autonomy of their own gender presentations

- 1 and expressions. This may lead to internal conflicts for participants when developing a sense
- of gender identity or negative sense of gender identity (Erikson, 1968),

expectations and explore 'alternative' identities.

- When gender is not viewed as multidimensional in society and is conceptualised as
- 4 binary, any divergence from this view may be silenced or ignored, which may inhibit a
- 5 person's identity (Sampson, Potter, Bragg & Langill 2014). People with ID may be well able
- 6 to see what is expected of them by the views placed on them by significant others in a
- 7 dominant gender binary society but may fail to understand why these demands are made
- 8 (Withers, 1997).

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- The findings of this study suggest that people with ID who identify as transgender
 have to ignore the social and family expectations to explore and accept their identity. Only
 when the participants in this study were in their adulthood did they begin to disregard these
 - Participants defined gender by presenting as either female or male which appeared to stem from the gender stereotypes held by others. All participants appeared to identify binary conceptualisation, adopting socially constructed norms in opposition to their biological sex. Gender expression and gender authenticity appeared to be signified by wearing clothes by all participants. Clothing is often the embodiment of gender and can be crucial for trans people and, indeed, for everyone. This mirrors the historical identity movement described by Dvorsky and Huges (2008) who suggested within a first wave, individuals embodied socially constructed binary gender norms opposite to their biological sex, to the extreme. The participants within this study appear to adopt a gender binary models. However, it is suggested that, more recently, a second wave has conceptualised gender as more fluid rather than adopting rigid binary identities (Bilodeau, 2005). This second wave of gender fluidity conceptualisation did not emerge within this study's participants' experiences

they tended to talk about their vulnerabilities related to their ID. One participant (Kirsty)
mentioned her ID. However, it appeared important for her to highlight that she "only has a
mild learning difficulty". This is consistent with the findings of previous research with
individuals with ID who identify as LGBT, which reported that most participants did not
describe having an ID when exploring their identity within the research (Dinwoodie,

Most participants did not identify having an ID throughout the interviews. Instead,

Greenhill and Cookson, 2016). Research also suggests that having ID is associated with

stigma, and it affects most other social identities that the individual may have (Hughes, 1945,

as cited in Davies & Jenkins, 1997). Furthermore, it is suggested that some people avoid

using ID labels in LGBT environments to reduce the likelihood of hostility from others

(Thompson 2002; Abbott & Howarth 2005).

All of the participants in this study experienced forms of social stigma throughout their lives related to their gender identities and gender expressions. All the participants gave accounts of being bullied in relation to their gender expression, in school, in their local communities, from family, friends and some support staff. They described incidents of verbal abuse, physical assault, and they all experienced felt stigma in some form. Previous research has found similar accounts of bullying or abuse related to ID (Bennett & Coyle, 2007) or sexuality (Abbott & Howarth 2005; Stoffelen, Kok, Hospers & Curfs, 2013).

It is suggested that people with ID appear to strive for a 'normal' identity and tend to internalise the views of others (Wilkinson, Theodore, & Raczka, 2015). The participants in this study indicated a tendency to internalise the views of others and identified as individuals who are perceived as unaccepted and unvalued by society because of their identity. These experiences of social discrimination can lead to internalised stigma, internal feelings of shame, inadequacy and difference (Goffman, 1963). Furthermore, participants reported that their gender identity and gender expressions were often ignored by service-providers

- 1 resulting in them being made to feel the 'need to hide' their gender expression and identity.
- 2 This mirrors previous findings in relation to gay identities held by people with ID (Stauffer-
- 3 Kruse, 2007; Stoffelen, Kok, Hospers & Curfs, 2013).
- In order for people to accept an opposite gender identity to their biological birth sex, it
- 5 is necessary to find a way to cope with widely held negative views about non-binary gender
- 6 identities. Questioning and challenging these views may be potential strategies, but this study
- 7 suggests that some participants were unable to do this because they believed that the
- 8 information given to them by other people was true. Participants were left feeling powerless,
- 9 silenced and in fear of abuse, rejection and isolation.
- In the face of societal negative binary gender beliefs, it is unsurprising that it led the
- participants in this study to feel the need to hide their true identities and to believe that such
- identities could be considered shameful. This mirrors previous findings that adults with ID
- commonly do not come out in all contexts when they anticipate LGBT related hostility
- 14 (Withers 1997). Furthermore, concealment of gender and sexual identity has been linked to
- an increased stress levels and a negative effect on health outcomes (Brotman, Ryan, Jalbert &
- 16 Rowe, 2002).
- Participants described increased self-acceptance of their gender identity over time.
- 18 This supports previous research in adults with ID in the LGBT community, who also
- described increased self-acceptance overtime (Dinwoodie, Greenhill & Cookson 2016). Some
- of this study's participants had come out to some people in their lives based on needing to
- 21 feel accepted and supported. They also employed a number of strategies to tell people, which
- were viewed as the safest, non-threatening, options in some circumstances.
- The subtheme "It is just a phase" powerful others', highlights that individuals felt
- 24 that their perspective was not as valued by some professionals and support workers. This

- suggests a power imbalance between the individual and 'powerful others. Adults with ID may
- 2 be less aware of their rights and are reluctant to challenge the infringement of their human
- 3 rights due to fear of not being heard and being silenced by others. The study, therefore,
- 4 highlights the need to address the power imbalance and adherence to government policies
- 5 (Valuing People Now, DH, 2009).

- Research has suggested that many support workers hold negative discourses around
 the sexuality of people with ID and feel underprepared to support people with ID in this area
 of their lives (Grieve, McLaren, Lindsay, & Culling, 2009). Previous research has also found
 that carers/staff may lack confidence and training in talking to people with ID about
 relationships and sexual preferences (Emamiannaeini & Ferry, 2010; Evans, McGuire, Healy,
 & Carley, 2009). This study suggests that this may also extend to conversations around
 identity and gender expression.
 - Some participants in this study were told about, and directed to, information by their support staff, family members and friends, suggesting a potentially valuable information source. Participants also found media and online resources to be the main sources of information regarding non-binary identities and described developing self-awareness and self-expression by comparing and contrasting themselves with the media portrayals and information provided. The presence of this information from the media appears to make it easier for people with ID to access and encourage exploration and self-awareness. Studies have shown that persons with ID, similarly, can gain many benefits from the use of media and the internet (Molin, Sorbring & Löfgren-Martenson, 2015; Shpigelman, 2018). However, as one of the participants in this study, Kirsty, highlighted not all of those with ID are able to access and use the internet. Lee et al. (2004) argue that computers are 'cognitively inaccessible' for many individuals with ID. It would appear, then, internet accessibility may act as a barrier for individuals accessing information and support

This study's participants felt they had unmet needs as they often felt isolated and unsupported in navigating society and services. Participants also reflected that there were few opportunities for peer support or dedicated resources. Many were economically disadvantaged, and so financial difficulties were a barrier for some participants to access services and express their identities. For example, some feared that they would not have sufficient money to pay for new birth certificates. This, therefore, becomes an issue of social 7 justice, with these two factors (economic disadvantage and barriers to information access) interacting to exacerbate oppression.

It is suggested that individuals generally lack access to positive transgender role models with ID (Abbott & Howarth 2005), leaving media as providing the only role models with whom to identify. However, some participants described feeling empowered to act as a source of support and as an advocate for others due to their own experiences of oppression, social isolation and lack of role models. It is important to recognise the power of relatable role models, and it has been suggested that having access to accessible role models is protective against mental health problems, such as depression (Eisenberg & Resnick, 2006). It is, therefore, essential to empower individuals ID to take up positions as role models and provide opportunities to inform research and service development.

In summary, there were many similarities in experiences across the seven participants, such as the joint and gradual process of learning about their gender identity, and the impact of social stigma to their sense of self and identity. There were also differences and diversity across their accounts. Further research is indicated, then, to explore whether these adversities are commonly experienced amongst people.

Strengths and limitations

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The main strengths of this study included that it involved interviews with people with ID, a population that has hitherto been neglected with regard to speaking about their experiences of identifying as transgender. There is an increased interest in the experiences and needs of people with an ID identifying as LGBT. However, less is known about the experiences of those who identify as transgender. This study aimed to explore many areas of the participants' lives in considerable detail, giving them a voice. Participants were able to fully engage in this study and discuss their experiences freely. This allows for first-hand experiences, which reduces any bias that may arise when interviewing those who support adults with ID. Therefore, it is accepted that the findings of the study may not be a true representation of the experiences of the larger population of people with ID. The research highlighted the need to explore this more with this population.

Seven participants chose to take part in the study. One potential participant after being provided with information about the study chose not to take part. This illustrated the robustness of the informed consent process of the study and demonstrated that people labelled with ID could be facilitated to make informed choices about taking part in such research, as argued by Rose et al. (2019).

Although no study is completely free from bias, meetings with supervisors along with a discussion of transcripts and themes enabled consideration of multiple perspectives and opportunities for reflection of the researcher's position and interpretations.

The main limitation of this study is that the sample is not entirely homogenous. The sample consisted of seven self-selected White British individuals, mainly from the northwest and the south-east UK. Therefore, the voices do not represent all those with ID who identify as transgender and of different ethnicities, although a small-scale IPA study is not designed to be representative. Therefore, it is not the aim of the study to generalise to the general

1 population. The sample size was modest but consistent with the IPA methodology. The

2 research also contributes to the limited research understanding the experience of adults with

3 ID who identify as transgender.

The concept of multiple perspectives may also include that of the researcher. Using qualitative methodology, particularly IPA, with its emphasis on the interpretative element of the analytic process implicates the researcher as a key part of the process of constructing the accounts of the experience of adults with ID who identify as transgender. A number of aspects of the research design and process meant that the way in which the accounts were elicited and conveyed might have been influenced by the researcher. Furthermore, validation of the themes were not sought as part of the research process, which may, therefore, reflect an emphasis on the researcher's interpretation of the interviews.

Research with individuals with ID often requires some extra considerations.

Adaptations are important to ensure the interview process is understood by the individuals (Walmsley 2001; Beail & Williams 2014). Some participants within this study had limited communication abilities compared to other IPA studies carried out with other populations. However, most participants were able to provide in-depth insights into their experiences, including some striking metaphors. This enabled an in-depth exploration of how the participants made sense of their experiences (Rose et al., 2019).

Other limitations with this study include the use of convenience sampling and the limits of recruiting only those who were able to communicate verbally. The views of individuals with more severe and complex ID were, therefore, missing in the findings, and further consideration should be given to involve those less verbally able. Additional demographic data such as age, were not collected as it was felt that collecting these details could compromise confidentiality. Furthermore, the accessible information leaflet offered

1 participants information on one perspective of the meaning of transgender. Although the

2 information leaflet was designed with speech and language experts and a transgender

researcher was also consulted, using only one perspective of an explanation of transgender

may have influenced participants' views regarding what transgender means to them.

Although the recruitment to this study was conducted across the UK, there were many difficulties accessing potential participants. Firstly, the researcher was dependent on other professionals to initially approach participants about taking part in the research. However, on a number of occasions, the researcher was unable to contact participants even though they had expressed an interest in taking part. The researcher experienced a sense of hostility from some support services, who did not feel individuals should take part in the research even though individuals had expressed an interest to professionals in taking part. It was apparent that some of the services behaved in an authoritative manner towards potential participants. This demonstrated another example of people with ID not being heard, and illustrates that they continue to be impacted by the values of individual caregivers (Craft, 1987). This can be linked to the experiences of the participants within the study within the subtheme 'powerful others'. Furthermore, the reliance on others to access potential participants for this study meant that the researcher could not directly control the recruitment process.

Due to convenience sampling, participants were self-selected, and all experienced some support and opportunities to express their gender identities. Therefore, the experiences and perceptions of those without support were not explored.

Three of the seven participants chose to have a support worker in the room during the interviews. Although all three spoke highly of the support received from the support workers during the interview, the presence of the support workers may have prevented these participants to share particular experiences and perspectives.

Research and clinical implications

Based on the results of the current study, a number of recommendations can be made for future research and clinical implications for services for adults with ID. The findings suggest an agenda for future research using quantitative methodologies with larger sample sizes, which would aid generalisation.

The findings of this study emphasise the need for service providers to explore the attitudes and unconscious bias of support staff around sexuality and gender identity diversities which encourages people with ID to be open and feel safe to express themselves. Service providers and those who work with adults with ID need to take a more proactive approach and give people opportunities to explore their identities for themselves. Furthermore, it is necessary to create opportunities for practitioners to discuss and challenge gender binary assumptions to address the discomfort that maintains stigmatising practise (Kline & Preston-Shoot, 2012).

It is suggested that people with ID lack support from adequate sex education, or it tends to focus on biology (Fitzgerald, & Withers, 2013 & Williams, Scott, & McKechanie, 2014). Zigler (2014) suggests that people with ID often need social and emotional support in educational settings. Therefore, the results highlight the importance of evaluating the effectiveness and impact of education and training for families, staff and professionals involved with adults who identify as transgender.

The research also highlights a necessity to address current policies and legislation when considering the human rights in the context of equality, diversity, empowerment and social inclusion for adults with ID who identify as transgender. This is to ensure that services are taking action to ensure reasonable adjustments are made to meet the social and care needs for people with ID who also identify as transgender (World Health Organization, 2013).

Providing information in an accessible format around gender identity and gender services was highlighted by the participants as a necessity. Furthermore, many reflected on the need for this information to be readily available in public places such as GP surgeries and more widely in public spaces. Access to support, which gives unequivocally positive messages about gender identity is likely to be very important to people with ID.

Conclusion

Seven people with ID who identify as transgender provided rich data about their experiences. This preliminary work highlights the resilience and vulnerability of these individuals with ID who identify as transgender. This study provides an initial insight into these unique experiences. This demonstrates that there is a real need to discuss this topic with this population in more detail, to open up the understanding of the experiences of adults with ID who identify as transgender.

The findings from this study show that people with ID who identify as transgender face significant challenges in terms of their gender identity. The current research highlights a population that could be considered "at risk" in relation to the outcomes associated with struggling to form an identity. More awareness and education about intersectionality is required to uphold the human rights, social inclusion and equalities of individuals with ID who identify as transgender.

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1 Appendix A: Author Guidelines for the International Journal of Transgenderism 2 Review Articles

- Articles should not normally exceed 8,000 words. Tables, figures, illustrations, and
 references are excluded from the word count.
- The remainder of the article should not contain anything, which might identify the
 author(s).
- Should be written with the following elements in the following order: title page;
 abstract; keywords; main text introduction, materials and methods, results, discussion;
 acknowledgments; declaration of interest statement; references; appendices (as
 appropriate); table(s) with caption(s) (on individual pages); figures; figure captions
 (as a list)
 - Should contain a structured abstract of 300 words. Abstract should contain the following headings: Background/Aims(s)/methods/Results/Discussion
- Should contain between 3 and 5 keywords. We encourage authors to adhere to the
 PRISMA guidelines for systematic reviews (see http://www.prisma-statement.org).
 Review articles may have up to 75 relevant references. Authors contemplating the
 submission of a literature review article are welcome to contact the Editor-in-Chief to
 discuss the appropriateness of the topic prior to submission.
 - APA (American Psychological Association) references

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Appendix B: Systematic Review Protocol

2 1.0 Aim

This question aims to explore social support and depression and anxiety among adults who identify as transgender, a systematic review

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1

2.0 Objective

To examine associations between social support and symptoms of anxiety and depression among adults who identify as transgender.

- 1) What are the associations of social support and symptoms of anxiety and depression in adults who identify as transgender?
- 2) What are the definitions of social support used in studies involving adults who identify as transgender?
- 3) What are the methodological characteristics of studies focusing on social support, psychological distress and adults who identify as transgender?

6

7 3.0 Evidence gathering and study selection

- Psychinfo
- Psycharticles
- Web of Science
- Medline
- Cinhal
- Scopus
- Google Scholar by considering cited shortlisted papers

8

9 3.1.1 Searching databases

- 1 The databases in the table below will be searched with a pre-determined strategy. In cases where
- 2 the search results are small in number, search terms will be reduced to maximise the search
- 3 sensitivity.

Population

Transgender* OR

Transsex* OR

gender non-conform* OR

gender minority OR

gender varian* OR

genderqueer OR

gender diverse OR

bigender OR

agender OR

two-spirit OR

genderfluid OR

gender neutral.

AND

Social support

Social support OR

perceived social support OR

social connectedness OR

social network OR

AND

Mental Health

Mental health OR

Depression OR

Psych* OR

Anxiety OR

1 3.1.2 Hand searching

Handsearches will not be done for any specific journals.

The reviewer will scan the bibliographies of the included studies, relevant reviews, government reports and other "grey literature" (see below) for relevant references, a process referred to as "snowballing". Reference lists and bibliographies of the articles collected from those identified will be searched, including include: Google Scholar (advanced).

The search will only include peer reviewed papers.

2

3

3.1.3 Reference searches

- 4 Bibliographies of those papers that match the eligibility criteria below will be searched by hand to
- 5 identify any further, relevant references, which will be subject to the same screening and selection
- 6 process.

3.2 Eligibility criteria

8

7

After gathering the evidence, the following eligibility criteria will be applied to the results and all identified references screened independently by a reviewer using a three-stage approach to reviewing the title, abstract and full text. Full copies of articles identified by the search, and considered to meet the inclusion criteria, based on their title, abstract and subject descriptors, will be obtained for data synthesis. Articles identified through reference list and bibliographic searches will also be considered

for data collection based on their title. Full-text articles of selected abstracts will then be reviewed.

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3.2.1 Types of studies:

Studies must employ a quantitative design to be included in the review. Qualitative designs will not be included because the author chose to focus solely on quantifiable measures of social support and anxiety and depression.

Since this association between anxiety and depression and social support is likely to be culture dependent, the review will be limited to Western countries, including the USA, Canada and Europe (EU and member states of the European Free Trade Association), Australia and New Zealand.

3.2.2 Types of participants:

The participants in this review will include adults aged 18 years identify as transgender. This review will consider studies that include participants who identify themselves as transgender or as gender variant from their natal sex. Studies that included trans* people as a subpopulation of a wider LGBT population were excluded. Only studies that exclusively focused on the trans* population were included.

The search will exclude studies which focus on specific subgroups to maintain a homogenous population (eg military, older adults).

2 3.2.3 Theorised Social support and mental health

The studies must examine social support from human beings as a primary variable/theory of interest, empirical methods (i.e., not policy and theoretical analyses) with a quantitative measure of social support.

The studies must compare social support with a measurement of depression and/or anxiety. Studies will be included if they are compared with a depression and/or anxiety measurement using a validated tool.

Any observational study from the general population, in adults that assessed the association between social support (independent variable) and depression or depressive and or anxiety symptoms (dependent variable).

3

4 3.2.4 Inclusion dates

The studies will include studies published in peer reviewed journals English. There will be no restrictions in dates included.

5

1 3.3 Exclusion criteria

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3

Exclusion will be based on the following criteria: (1) absence of measures of anxiety and/or depression; (2) lack of direct measurement of depression and/or anxiety for transgender participants (3) lesbian, gay, bisexual and transgender (LGBT) community; cisgender sexual minorities; men who have sex with men (MSM); healthcare providers (HCPs); cooccurring conditions (i.e., trans b another health issue). (4) full text unavailable in English; (5) lack of quantitative data analysis (i.e., purely theoretical, editorial, or commentary OR exclusively qualitative studies [without any sample characteristics regarding mental health or psychosocial problems]); (6) non-peer reviewed (legal proceeding, chapters, dissertations, conference proceedings, etc.); (7) abstract only; (9) case studies; (10) studies that measured exposure to violence and discrimination, but did not report mental health or psychosocial correlates of these experiences; (11) Reviews and systematic reviews (12) to gain a homogenous sample articles will be excluded if they are primarily focused on substance and alcohol use, Surgery reassignment physical health outcomes and focus for example HIV and cancer, Self harm/suicide and sex workers, older adults. (13) Since this association between anxiety and depression and social support is likely to be culture dependent, this review is limited to Western countries, including the USA, Canada and Europe (EU and member states of the European Free Trade Association), Australia and New Zealand. Therefore, studies outside of western countries will be excluded.

Concepts based on objective ratings of the size and functioning of social networks, such as social isolation and social network size, were excluded. Social capital was also excluded as it relates to characteristics of society or communities as a whole as well as individuals' appraisal of their relationships.

Editorials, newspaper articles and other forms of popular media will be excluded. Articles will be excluded if they are published as books, abstracts, or conference proceedings, non peer reviewed papers or if they focused on other populations. Failure to meet any one of the above eligibility criteria (section 3.2) will also result in exclusion from the review.

The number of excluded studies (including reasons for exclusion for those excluded following review of the full text) will be recorded at each stage.

1 2	Appendix C: Adapted Risk of Bias Assessment Tool		
3 4	The studies will be assessed using the criteria below. Each criterion will be graded as 'yes', 'no', 'partially' or 'cannot tell'.		
5 6	1. Unbiased recruitment of cohort Factors to consider:		
7	Inclusion/exclusion criteria		
8 9	• Is it clearly described? Recruitment strategy		
10 11 12 13 14 15 16 17	 Is it clearly described? Sample is representative of population of interest Relatively free from bias (selection bias might be introduced e.g. by recruitment via advertisement) 2. Selection minimises baseline differences in demographic factors? (for controlled studies only) Factors to consider: 		
18 19 20	 Was selection of the comparison group appropriate? Consider whether the two sources are likely to differ on factors related to the outcome (other than depression, anxiety and social support). 		
212223	3. Sample size calculated/justifies? Factors to consider:		
24	• Did the authors report conducting a power analysis or describe some other basis for		
25	determining the adequacy of study group sizes for the primary outcome(s) of interest?		
262728	 Did the eventual sample size deviate by ≤ 10% of the sample size suggested by the power calculation? (only applicable if power calculation conducted). 		
29	4. Adequate description of the cohort?		
30	Factors to consider:		
31	• Consider key demographic information such as age, gender and ethnicity.		
32 33	• Information regarding socio-economic characteristics is also important.		
34 35	5. Valid method to explore depression Factors to consider:		

1	•	Was the method used to explore depression clearly described? (Details should be	
2	sufficient to permit replication in new studies.)		
3	•	Do they clearly define what they mean by depression?	
4	•	Was a valid and reliable measure used to explore depression? (standardised measure,	
5		Cronbach's Alpha reported etc, self-report measures tend to have lower reliability and	
6		validity than clinical interview, single items of scales taken form larger measures are	
7		likely to lack content validity and reliability)	
8	•	Were these measures implemented consistently across all study participants?	
9			
LO	<i>6</i> .	Valid method to explore anxiety	
l1	Factor	s to consider:	
L2	•	Was the method used to explore anxiety clearly described? (Details should be	
L3		sufficient to permit replication in new studies.)	
L4	•	Do they clearly define what they mean by anxiety?	
L5	•	Was a valid and reliable measure used to explore anxiety? (standardised measure,	
L6		Cronbach's Alpha reported etc, self-report measures tend to have lower reliability and	
L7		validity than clinical interview, single items of scales taken form larger measures are	
L8		likely to lack content validity and reliability)	
L9	•	Were these measures implemented consistently across all study participants?	
20			
21	<i>7</i> .	Valid method to explore social support	
22	Factor	s to consider:	
23	•	Was the method used to explore social support clearly described? (Details should be	
24		sufficient to permit replication in new studies.)	
25	•	Do they clearly define what they mean by social support?	
26	•	Was a valid and reliable measure used to explore social support? (standardised	
27		measure, Cronbach's Alpha reported etc, self-report measures tend to have lower	
28		reliability and validity than clinical interview, single items of scales taken form larger	
29		measures are likely to lack content validity and reliability)	

31 32

30

8. Adequate handling of missing data/missing data minimal

• Were these measures implemented consistently across all study participants?

33 Factors to consider:

2 handled in the analyses? Did missing data exceed 30%? 3 • Did attrition differ between groups by more than 10% percent? 4 • If missing data is present and substantial, were steps taken to minimize bias (e.g. 5 sensitivity analysis or imputation) 6 7 9. Analysis controls for confounding? 8 9 Factors to consider: • Does the study identify and control for important confounding variables and effect 10 modifiers? 11 12 Did the study control for likely demographic confounders? 13 10. Analytic methods appropriate? 14 • Was the kind of analysis done appropriate for the kind of outcome (categorical, 15 continuous, etc.)? 16 Was the number of variables used in the analysis appropriate for the sample size? 17 (The statistical techniques used must be appropriate to the data and take into 18

account issues such as controlling for small sample size, clustering, rare outcomes,

multiple comparison, and number of covariates for a given sample size).

Are the details of missing data clearly reported, including how missing data was

1

19

20

1 2 3	Appendix D: Author guidelines for Journal of Applied Research in Intellectual Disabilities
4	1. GENERAL
5	The Journal of Applied Research in Intellectual Disabilities is an international, peer-reviewed
6	journal which draws together findings derived from original applied research in intellectual
7	disabilities.
8	All manuscripts submitted to the Journal of Applied Research in Intellectual
9	Disabilities should include:
LO	Cover Page: A cover page should contain only the title, thereby facilitating anonymous
l1	reviewing. The authors' details should be supplied on a separate page and the author for
L2	correspondence should be identified clearly, along with full contact details, including e-mail
L3	address.
L4	Running Title: A short title of not more than fifty characters, including spaces, should be
L5	provided.
L6	Keywords: Up to six key words to aid indexing should also be provided.
L7	Main Text: All papers should have a structured abstract (maximum 150 words) as follows:
L8	Background, Method, Results, and Conclusions. The abstract should provide an outline of the
19	research questions, the design, essential findings and main conclusions of the study. Authors
20	should make use of headings within the main paper as follows: Introduction, Method, Results
21	and Discussion. Subheadings can be used as appropriate. All authors must clearly state their
22	research questions, aims or hypotheses clearly at the end of the Introduction. Figures and
23	Tables should be submitted as a separate file.
24	Style: Manuscripts should be formatted with a wide margin and double spaced. Include all
25	parts of the text of the paper in a single file, but do not embed figures.

MANUSCRIPT TYPES ACCEPTED

- 2 Original Articles, Review Articles, Brief Reports, Book Reviews and Letters to the Articles
- 3 are accepted for publication only at the discretion of the Editor. Articles should not exceed
- 4 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the
- 5 Letters to the Editor section should be no more than 750 words in length. Words in Tables,
- 6 Table captions/legends, Figures and Figure captions/legends are excluded in the limit.
- 7 References

1

- 8 APA American Psychological Association
- 9 References should be prepared according to the Publication Manual of the American
- 10 Psychological Association (6th edition). This means in text citations should follow the
- author-date method whereby the author's last name and the year of publication for the source
- should appear in the text, for example, (Jones, 1998). The complete reference list should
- appear alphabetically by name at the end of the paper.



North West - Greater Manchester South Research Ethics Committee

3rd Floor, Barlow House 4 Minshull Street Manchester M1 3DZ

Telephone: 0207 104 8002

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

10 April 2017

Dr Laura Golding Doctorate in Clinical Psychology The Whelan Building, The Quadrangle Brownlow Hill, Liverpool L69 3GB

Dear Dr Golding

Study title: The experiences and perceptions of adults with

intellectual disabilities who identify themselves as

transgender.

 REC reference:
 17/NW/0159

 Protocol number:
 UoL001264

 IRAS project ID:
 217887

Thank you for submitting your response on 05 April 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair and Mr Robert Bedford.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact nra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start

A Research Ethics Committee established by the Health Research Authority



Dr Laura Golding Doctorate in Clinical Psychology The Whelan Building, The Quadrangle Brownlow Hill, Liverpool L69 3GB

Email: hra.approval@nhs.net

10 April 2017

Dear Dr Golding

Letter of HRA Approval

Study title: The experiences and perceptions of adults with intellectual

disabilities who identify themselves as transgender.

 IRAS project ID:
 217887

 Protocol number:
 UoL001264

 REC reference:
 17/NW/0159

Sponsor University of Liverpool

I am pleased to confirm that <u>HRA Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read Appendix B carefully, in particular the following sections:

- Participating NHS organisations in England this clarifies the types of participating
 organisations in the study and whether or not all organisations will be undertaking the same
 activities
- Confirmation of capacity and capability this confirms whether or not each type of participating
 NHS organisation in England is expected to give formal confirmation of capacity and capability.
 Where formal confirmation is not expected, the section also provides details on the time limit
 given to participating organisations to opt out of the study, or request additional time, before
 their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

Page 1 of 8

IRAS project ID 217887

It is critical 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 and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A List of documents reviewed during HRA assessment
- B Summary of HRA assessment

After HRA Approval

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.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as
 detailed in the After Ethical Review document. Non-substantial amendments should be
 submitted for review by the HRA using the form provided on the HRA website, and emailed to
 hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation
 of continued HRA Approval. Further details can be found on the <u>HRA website</u>.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

Page 2 of 8

IRAS project ID	217887
in a to project in	2

procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is 217887. Please quote this on all correspondence.

Yours sincerely

Dr Claire Cole Senior Assessor

Email: hra.approval@nhs.net

Copy to: Mr Alex Astor

Ms Karen Bruce, Mersey Care NHS Trust

Participants Needed

To take part in research on "The experiences of adults with learning disabilities who identify themselves as transgender."



Who? We want to speak to who identify as transgender and have a learning disability.



What? You will have an interview to talk about your experiences of identifying as transgender.







The interview will last about 1 hour.



How? If you would like to take part please phone Michaela Chapman on 07721354340. For more information.



The University of Liverpool is organising this research.

Participant Poster; Version 1, 5th February 2017, IRAS Project ID: 217887

2

The experiences and perceptions of adults with intellectual disabilities who identify themselves as transgender.



This leaflet is about some research.

Research happens when we want to understand something better.

Research is how we find out answers to questions.



A researcher does research.

A researcher asks people questions to understand something better.

Then they can tell other people about it.

This helps more people to understand it.

Page **1** of **24**

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887



This research is called

The experiences and perceptions of adults with intellectual disabilities who identify themselves as transgender.



This leaflet tells you about our research.

It will tell you why we are doing our research.

It will tell you how to join in if you want to.

Page 2 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



Please do not make up your mind now.

Think about it before you say yes or no.

Your support worker, your carer or a member of your family can help you decide.

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

People doing the research



This is Michaela Chapman.

She is the researcher.



Michaela goes to the University of Liverpool.

She is a **Trainee Clinical Psychologist**.

This means she is training to be a Clinical Psychologist.

Clinical Psychologists help people.

They talk to them when they have a problem.

Page 4 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



Clinical Psychologists also do research. This helps them understand how to help people.

This research will help Michaela to become a Clinical Psychologist.



This is Laura Golding.

She is in charge of the research.

She is a Clinical Psychologist.



Laura works at the University of Liverpool.

Laura checks what Michaela does.

She makes sure she does the research right.

Page 5 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



If you want to ask Laura any questions you can telephone her.

Her telephone number is 0151 794 5530.



Before any research is allowed to happen, it has to be checked by a group of people.

The group of people is called a Research Ethics Committee.

The Research Ethics Committee makes sure the research is fair.

This research has been checked by the Research Ethics Committee.



They said it is ok for Michaela to do this research.

Page 6 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1

If you are unhappy about the research, you can tell Laura Golding.



You do not have to tell Laura, you can tell **PALS** instead if you want to.

PALS is the Patient Advice and Liaison Service.

They help people who are unhappy about research.



PALS telephone number is 0800 073 1106.

Page 7 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1

What is transgender?



When we think of ourselves as male or female, it's called gender identity.



Everyone has a gender identity, a sense of being man or woman.

Most people's gender identities are the same as their bodies on the outside.



But those who are transgender feel different from their bodies on the outside.



When people who are transgender they feel their gender are different from their bodies.

Page 8 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1

What we want to understand better



We want to speak to people with intellectual disabilities about people's experiences of identifying as transgender or who are questioning their gender.



We want to ask how people with intellectual disabilities talk to other people about being transgender.



We want to know if other people talk to you about being transgender.



We also want to talk about whether you have any support from others.

Page 9 of 24

Why we want to know



People with intellectual disabilities sometimes do not get to talk about feeling transgender.

People with intellectual disabilities sometimes don't get asked to be in research.

This means we do not know how it is best to help people.

We hope our research will tell us the best help to offer.



Who can join in

Anyone with an intellectual disability who identifies themselves as transgender.

Page 10 of 24



10

We want about 10 people to join in.

How you can join in if you want to





If you want to join in, we will ask for your consent.

Consent means you can say yes or no to join in the research.



If you want to join in, we will ask you to sign a consent form.

Page **11** of **24**



You do not have to join in the research.

You can say no if you do not want to join in.



It is ok to say no.



Please keep this leaflet and think about it for a while.

It will help you say **yes** or **no** to joining in.

Staff or family can help you to choose to say **yes** or **no**



Even if you say yes, it is ok to change your mind and then say no.

It is ok to change your mind at any time.

It is ok to change your mind for any reason.

Page 12 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1

What might help you say yes or no to join in

Michaela will visit you to tell you more about the research if you want.



Michaela will try to answer questions you have.

You do not have to meet Michaela if you do not want to.



Staff or family can help you to make a decision if you do not want to talk to Michaela.

Page **13** of **24**

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1

If you say yes to join in, this will happen:



Michaela will meet you to make sure you want to join in.



Michaela will ask you some questions using a pictures and questions called the British Picture Vocabulary Scale.



This will be used to see if we think you will be able to answer the questions in the interview.

After you have finished the questionnaire, Michaela will either:

Page 14 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



Ask you to take part in an interview.

Or



 Ask you <u>not</u> to take part in the interview. This is because you might not be able to answer the questions.



If you are asked to take part, you will have an **interview** with Michaela.

Michaela will talk to you and ask you some questions.

She will ask about your experiences of identifying as transgender.







The interview will last about 1 hour.

Page 15 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1

1

You will only have 1 interview.



You can stop the interview any time you want to.





You can also stop the interview at any time, to take a break and then continue.



Michaela will record what you say.

This is so Michaela can remember what you said.



After the interview Michaela will listen to it again.

Page 16 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



Everything you say will be written down.

Michaela will write about this in her work.

Michaela will not use your name when she writes about you.



You will have a made up name.

If you wish, you can choose your made up name

This means other people will not know what you say.



Other people will read Michaela's work.

This will help others learn from the research.

Page 17 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



You do not have to tell anyone what you say to Michaela if you do not want to.



Your interview will be at your home,



Or at the University of Liverpool



It will be in a quiet room where it is private.

This means only you and Michaela will be in the room.

Page 18 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1

To keep you and other people safe:



If you say someone hurt you, Michaela might have to tell someone.

Michaela will tell you if she has to do this.



If you say you might hurt yourself or someone else, Michaela might have to tell someone.

Michaela will tell you if she has to do this.



If you feel really upset, Michaela might have to tell someone.

This is to check you are ok.

Page 19 of 24



If you do not agree with this, you will not be able to join in.



It is ok if you do not agree with this.

It is ok if you do not join in.

What will happen after the interview



When Michaela has interviewed everyone who wants to join in, she will go away and think about what everyone said.



She will write her ideas down and show people who work at the University of Liverpool.

If they think her ideas are good enough she will be able to tell other people about the research.

Page 20 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



This will help other people learn from the research.

This might help them think of better ways to help people with relationships.

There are different ways to tell people about the research.



Michaela wants to write about the research in a **journal**.

Writing in journals is a good way to tell other people about research.



Journals are in libraries



Journals are on the internet

S

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



When Michaela tells other people about the research, she will say some things that people said in their interview.

But she will not say who said it.



This means she might say the words you said, but she will not say your name.

People can learn from what you said but they will not know that you said it.

It is free to join in this research



The University of Liverpool is organising this research.

They pay for the research to happen.

Page 22 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1



You do not pay any money to join in the research.

We will not give you money to join in the research.



We can pay for a bus, train or taxi for you to go to the interview.

We can only pay for this if you keep the bus or train ticket or your taxi receipt.



We cannot pay for your bus, train or taxi if you have a travel pass.



If you would like to take part in the study and to meet with Michaela for more information, please complete the form below.

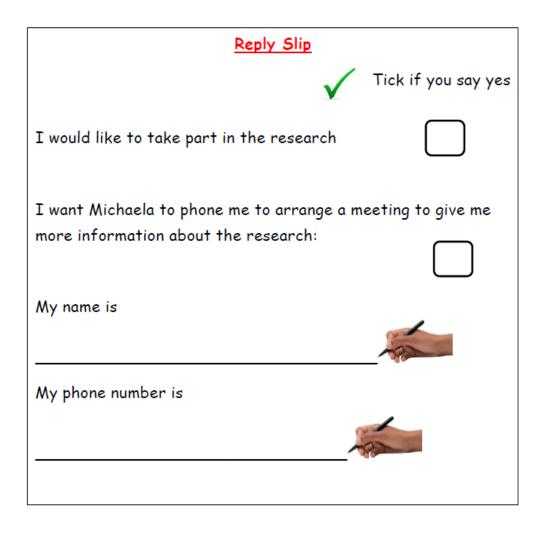


Michaela will phone you to meet with you.

Page 23 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1





Please put the completed reply slip in the envelope provided.

You do not need to put a stamp or address on, it is already on the envelope.



Please post the letter in the letter box.

Page 24 of 24

Participant Information Sheet; Version 2, 24th March 2017, IRAS Project ID: 217887

1

The experiences and perceptions of adults with intellectual disabilities who identify themselves as transgender.

Information summary sheet

What will I have to do?



You will have an interview with Michaela.







The interview will last about 1 hour.



What happens if I say no?

You do not have to join in the research.

Page 1 of 3

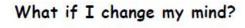
Participant Information Summary Sheet; Version 1, 5th February 2017, IRAS Project ID: 217887

2



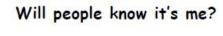
It is ok to say no.

If you say no Michaela will not meet with you.





It is ok to change your mind at any time.





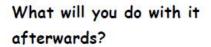
Michaela will not use your name when she writes about you.

Page 2 of 3
Participant Information Summary Sheet; Version 1, 5th February 2017, IRAS Project ID: 217887

1



This means other people will not know what you say.





Michaela will write her ideas down and show people who work at the University of Liverpool.



Michaela wants to write about the research in a journal.



When Michaela tells other people about the research, she will say some things that people said in their interview.

But she will not say who said it.

Page 3 of 3
Participant Information Summary Sheet; Version 1, 5th February 2017, IRAS Project ID: 217887

1

The experiences and perceptions of adults with intellectual disabilities who identify themselves as transgender.

Consent form





Consent means you can say yes or no to join in the research.



If you say yes, tick the boxes on pages 3, 4, 5, 6 and 7, to show you say yes.



Then write your name on page 8, to show you say yes.

Page 1 of 9
Consent Form; Version 1, 5 February 2017, IRAS Project ID: 217887

2



It is ok to say no if you want to.

Please do not say yes if you really want to say no.



Do not tick the boxes if you want to say no.



Even if you say yes now, it is ok to change your mind and then say no.

It is ok to change your mind at any time.

It is ok to change your mind for any reason.

Page 2 of 9 Consent Form; Version 1, 5 February 2017, IRAS Project ID: 217887

Consent

Tick if you say yes





This leaflet is about some research.

Research happens when we want to understand something better.

Research is how we find out answers



A researcher does research.

A researcher asks people questions to understand something better.

Then they can tell other people about it



This research is called Talking to staff about sex. I have the leaflet called The experiences and perceptions of adults with intellectual disabilities who identify themselves as transgender.



I read the leaflet or someone helped me read it.



Page 3 of 9
Consent Form; Version 1, 5 February 2017, IRAS Project ID: 217887

?	I asked the questions I wanted.	
?	Michaela answered all my questions.	
	I know what the research is about.	
Consent	I can say no if I do not want to join in.	



I want to join in the research.





Michaela will ask me questions in an interview.





Michaela will record what I say.

I can ask Michaela to stop the recording. I can ask for words to be changed.

Page 5 of 9 Consent Form; Version 1, 5 February 2017, IRAS Project ID: 217887



After the interview, Michaela will listen to it again. She will write down things that I said.





She will write about this in her work.





Michaela will not use my name when she writes about me. She will use a made up name.



This means other people will not know what I said.

Page 6 of 9 Consent Form; Version 1, 5 February 2017, IRAS Project ID: 217887



If I say someone is hurting me or has hurt me, Michaela might have to tell someone.

Michaela will tell me if she has to do this.



If I say I might hurt myself or someone else, Michaela might have to tell someone.

Michaela will tell me if she has to do this.





I want to read what Michaela writes in her report.





I want Michaela to explain this report to me on my own.

-1
- 1

My name is	
My signature	
The date today is	

Page 8 of 9 Consent Form; Version 1, 5 February 2017, IRAS Project ID: 217887

Michaela Chapman is the researcher.	
Michaela's signature	
The date today is	

This research is organised by the University of Liverpool



Appendix L: Interview Schedule

Interview schedule

Interview

1

· You know what the research is about, why do you think I have met with you today?

Self-Perceptions

What is important to know about you?

Possible prompts

· Can you tell me five important things about yourself?

How do you see yourself?

Possible prompts

- · How do you define yourself?
- · Do you think you are different to others?
- · What do you think other people think about you?

As you know the research is about people with learning disabilities, what does this mean to you?

Possible prompts

· How do you think this has affected your life?

Transgender

What does the term transsexual mean to you?

Possible prompts

- · Can you say what transgender means?
- · Could you describe to me what you think transgender is?
- What do you think it means to be a transsexual?

Do you see yourself as transgender?

How long have you known you are transgender?

Interview Schedule; Version 2, 24th March 2017, IRAS Project ID: 217887

2

What can you remember from this time, e.g. how did it make you feel?

Possible prompts

- Is it a term you identify with? (why/why not?)
- · Is it a term you have, or would use to represent yourself?
- · When? In what situations?
- · Are there any situations in which you would prefer NOT to identify as transgender?
- (why?)
- Do you think to identify as a transsexual gives a full enough representation of yourself?
- · Do you remember when you first became aware of your assigned gender?

When you look at yourself in the mirror, what is your impression of what you see?

Possible prompts

- · How do you show masculinity, femininity, or both?
- · Tell me the good things about being transgender?
- · Tell me the bad/ difficult things about being transgender?

Do you think carers think it is ok for you to be transgender?

Do you think having a learning disability has made a difference to you as transgender?

Possible prompts:

· Have you faced any challenges being transgender

Support

Do you feel able to talk about your gender identity with your family, friends and carers?

Possible prompts:

- Do you feel that your family, friends or carers treat you the way you want to be treated in terms of your identity?
- Do you have staff that work with you? Do they know about you identifying as transgender? What have their response been?

Interview Schedule; Version 2, 24th March 2017, IRAS Project ID: 217887

1

Possible prompts:

- Can you tell me something about the care/support groups that you are or have been involved in?
- · Have you had negative experiences of the LGBT community?
- Can you give me any examples of when the support/help you have been given has been good?
- Can you give me example of when support/ help has been bad?
- -what kind of support would have been most helpful?

Where do you feel safest in your current identity? And most threatened?

What has been your experience with the LGBT community? For example, do you feel supported and validated by other LGBT individuals?

Possible prompts:

- What has been your experience with other people in the community? For example, do
 you feel supported by the community?
- Have you had negative experiences in the community?
- · Are there any individuals of your identity that you look to as role models?

What resources were available to you?

Possible prompts:

- · Have you meet or know anyone you could identify with?
- · Can you tell me about your experiences of support with you gender identity?
- · Do you think that trans people in general have any specific care needs?
- What sort of support would you like from your carer / service provider?
- · Have you ever accessed gender services?
- Have you had access to any information on support services. Could you understand
 the information provided. Would it help if it was in a different format, more
 accessible?
- · Do you think there should be more information?

Do you feel you have the same rights as people without learning disabilities who identify as transgender? What do you think needs to happen in order for your rights to be acknowledged?

Possible prompts:

- Have you met anyone with a learning disability who identifies as transgender?
- Has your experience changed over time?

Can you tell me about how you see your life in the future? Possible prompts:

Relationships, family life, social life, work life...

General open question to end

 I've been asking you a lot of questions – is there anything else about Identifying as transgender you would like to tell me?

Thanks. Debrief

(Check out how the person has found the interview, what feelings did they have while we were talking and how do they feel now).

What happens next

(Explain how the research process will proceed, reiterate what happens with their information and how they will find out about what conclusions I've drawn from the research as a whole).

N.B- This is an interview guide rather than a strict interview schedule. This means that although the topics and general framework will remain similar the structure of the questions will be flexible.

Interview Schedule; Version 2, 24th March 2017, IRAS Project ID: 217887

The experiences and perceptions of adults with intellectual disabilities who identify themselves as transgender.



thank you

Thank you for taking part in this research.



This research was about The experiences and perceptions of adults with intellectual disabilities who identify themselves as transgender.



What is transgender?

When we think of ourselves as male or female, it's called gender identity.

Page 1 of 7

Debriefing Sheet; Version 1, 5th February 2017, IRAS Project ID: 217887

2

3



Everyone has a gender identity, a sense of being man or woman.

Most people's gender identities are the same as their bodies on the outside.



But those who are transgender feel different from their bodies on the outside.



What did we wanted to understand better?

We wanted to speak to people with intellectual disabilities about people's experiences of identifying as transgender or who are questioning their gender.



We wanted to ask how people with intellectual disabilities talk to other people about being transgender.

Page 2 of 7

Debriefing Sheet; Version 1, 5th February 2017, IRAS Project ID: 217887



We wanted to know if other people talk to you about being transgender

We also wanted to talk about whether you have any support from others.

Why we wanted to know



People with intellectual disabilities sometimes do not get to talk about feeling they identify as transgender.

People with intellectual disabilities sometimes don't get asked to be in research.

This means we do not know how it is best to help people.

We hope our research will tell us the best help to offer.

Page 3 of 7

Debriefing Sheet; Version 1, 5th February 2017, IRAS Project ID: 217887



What if I have a question?

If you have questions now about the research, please ask.



If you have questions later, please phone Michaela on 07721 954940.

Who can I contact if I need to talk to someone about what I spoke about in the interview?



If you feel really upset about what you talked about after the interview please tell your carer or a family member about how you are feeling.

Page 4 of 7

Debriefing Sheet; Version 1, 5th February 2017, IRAS Project ID: 217887

1 2



If you need to talk to a professional about how you are feeling please phone the Samaritans on 116 123.



You can also find support on the internet on:

www.mencap.org.uk/advice-andsupport/relationships-and-sex

www.themix.org.uk/sex-andrelationships/having-sex/disabilityand-sexual-confidence-4684.html

www.bild.org.uk/information/help/

Page 5 of 7

What happens after the interview?



When Michaela has interviewed everyone who wants to join in, she will go away and think about what everyone said.



She will write her ideas down and show people who work at the University of Liverpool.



If they think her ideas are good enough she will be able to tell other people about the research.

This will help other people learn from the research.

Page 6 of 7

Debriefing Sheet; Version 1, 5th February 2017, IRAS Project ID: 217887



If you would like a copy of the research when it is finished, please tell Michaela



or phone Michaela on 07721954340 to ask for a copy.



thank you

Thank you for taking part in the research.

Appendix N: Reflective Diary Excerpt

Interview One:

As this was my first interview, I was feeling quite nervous. As I identify as a cisgender female, I was worried about ensuring I use the correct terminology, I also wanted to make sure that I asked all the right questions. I had been informed that the first participant was anxious about taking part, as this was her first experience talking to someone outside of her support team about her experiences. I was keen to ensure that this person felt comfortable with meeting me as a new person, whilst also ensuring that I was able to ask the questions in an accessible way for her. However, she chose to have her support worker in the room when completing the consent form but appeared to feel comfortable enough to choose to continue with the interview on her own. I noticed that the participant was nervous at the beginning of the interview and often struggled to finish her sentences, finishing with "yeah" on some occasions. I considered whether I did not leave enough gaps between the questions to give her an opportunity to expend, utilising the prompts quickly, due to my own feelings of discomfort. Note to self to allow participants longer to answer.

Overall, the interview went well, her account and experiences varied between being heart-breaking and being filled with optimism. It was interesting that she used only activities that she engaged in to describe herself: this seems to be a common finding in LD research. Perhaps explicitly ask questions about personal qualities e.g. what sort of person do you think you are? Tell me some good things about you and your personality? Next time.

She also spoke quite a lot of material about wearing non-birth gender's clothing in private. Might be interesting to explore why in other interviews. This participant used "cross gender" where the idea for this came from?

This participant expressed concerns about 'being rude' on a number of occasions. It felt as though she had been infantilised in the past. Was she not allowed to talk about her body "its rude"?

Emerging Themes	Original Transcript	Codes/Comments			
	interviewer: do you think that is a good				
	word to use or do you identify with a				
	different word?				
Identity and labels	Kirsty: Erm for now I will find it ok to use	Find transgender "OK" but only in			
'Meaning and	as transgender because I am transitioning	period of time of transitioning			
Description of gender					
identity'	T				
D (C	Interviewer: Ok	0 10 1 11 17			
Perceptions of	Kirsty: so for now yeah transgender but when I've changed transitioned or when I	Concept of transgender identity applies to transitioning only			
possibility. Identity and labels	have had the operation I don't want to be	applies to transitioning only			
'Meaning and	called a trans woman				
Description of gender	canco a trans woman				
identity'					
rocinity					
	Interviewer: right				
Identity and labels	Kirsty: I want to be called A woman	Appears important to be identified			
'Meaning and		as 'woman' but after her			
Description of gender		perception of transition and the			
identity'		physical aspects of having an			
Perceptions of		operation.			
possibility.					
	Interviewer: Ok yeah				
	Support worker mmm				
	Kirsty: because I've been through the	"process" transgender appears to			
	process and I've done it and I am now a woman	represent a period of transitioning for Kirsty.			
	Interviewer: mmhmm	for Klisty.			
Perceptions of	Kirsty: I am not transitioning	When had operation feels not a			
possibility.	Kirsty. I am not transitioning	time of transitioning and trans			
possionny.		woman?			
	Interviewer: right				
	Interviewer: So do you not identify as a				
	woman now				
'Meaning and	Kirsty: Er I still feel like a woman now	still feel like a woman now woman			
Description of gender		and not transgender why is this,			
identity'		other people's views, societies			
		labels?			
26	Interviewer: yeah	71 (6 10 10			
'Meaning and	Kirsty: erm and I still identify as a woman	Identify different to above			
Description of gender		comment, identify and feel a			
identity'		woman, feelings inside and labels,			
		feel and identify represent different concepts for Kirsty			
	Interviewer: yeah	concepts for Kirsty			
Social	Kirsty: but erm because a lot of people	Identifies as a woman but feels the			
acceptability/social	don't accept that I am a woman still I	term "transgender" is easier for			
stigma	prefer to be known as a transgender person	others to accept?			
-0	because then I can sit down and explain it	Conforming to society			
	to them	expectations, feels like a woman			
		but others do not accept this due to			
		perceptions of transitioning,			
	Interviewer: right				

Nogotisting and	Vicetry and just say look I'm trans. Law	I'm tugue using tugue wathou than		
Negotiating and	Kirsty: and just say look I'm trans, I am	I'm trans using trans rather than		
Verifying Identity	changing from male to female and that's	female to explain to others.		
	why I still sound more male then I do	Feels the need to explain herself to		
	female	others to understand?		
	Interviewer: right			
	Kirsty: so they understand.	Does she feel others do not		
		understand unless she explains and		
		uses_"trans" label?		
	Interviewer: So it sounds like it's because			
	of other people rather than yourself.			
Social acceptance/	Kirsty: Yeah yeah it's just other people it's	A process of others understanding		
social stigma/ social	not me because I have accepted who I am	and accepting		
perception				
	Interviewer: yeah			
Own identity	Kirsty: I am who I am, I know who I want	Accepting own identity		
(confidence)	to be	Confidence in own identity?		
	Interviewer: of course			
Social acceptance/	Kirsty: erm its just letting other people	Process of others accepting		
social stigma / social	accept it	identity		
perception	•	Desire for acceptance and		
		affirmation from others?		
	Interviewer: right			
	Kirsty: around me			
	Interviewer: mmm.			
	Interviewer: And what is your experience			
	about how other people have been around			
	vou?			
Social acceptance/	Kirsty: Erm two years ago a couple of my	Friends accepting sexuality but not		
social stigma/ social	friends when I came out, I came out as	gender identity "non of them		
perception	bisexual first and they were fine with that	wanted to know"		
perception	and then as soon as I came out as trans	wanted to know		
Visibility and	none of them wanted to know. Erm the	She experienced worse rejection		
'outness'	boyfriend that I had said yeah he would	for being trans than for being		
Outhess	support me but then it kind of went a little	bisexual		
	bit sour because he lived in (place) and I	<u>oisexuai</u>		
	lived down here so			
	Interviewer: mmhmm	A bit too much. What was a bit too		
	Kirsty: it was a bit too much and we just			
	went our own separate ways and ended it.	much for her or for her boyfriend?		
	Erm or otherwise I would of you know if	Was she rejected by her boyfriend?		
	I'd of moved up there I would of moved up			
	there with him and yeah I would of stayed			
	with him			
	Interviewer: yeah			
	Kirsty: and carried it on.			
	Interviewer: So what do you think it is			
	about people feeling it is OK to accept you			
	as bisexual but not accepting you as			
	transgender?			
Own identity.	Kirsty: Erm I honestly don't know. I don't	Identifying and understanding as		
Medicalisation	think they fully understand what body	"body dysphoria" and impact on		
	dysphoria is and what it implicates on	own mental health		
	people's mental health.			
		Refers spontaneously to		
	-			

		dysphoria/mental health issues — recognises the psychological impact of being oppressed into not transitioning
Social acceptance/ social stigma/ social perception	Interviewer: Mmhmm Kirsty: Because they think oh it's just because your sitting there trying to change like if your bisexual or gay	They others in society? Them and me?
Social acceptance/ social stigma/social perception	Interviewer: yeah Kirsty: instead of just sitting there and you know changing your gender from male to female they think it's just one you've woken up one morning and gone oh your female	Thoughts that others perceive it is a decision made quickly "just woken up one morning" Has she experienced this reaction from others, just a quick decision?
Social acceptance/ social stigma/social perception	Interviewer: mmhmm Kirsty: and they want to be a female it's not that it's been there for years	Thoughts that others perceive it is a decision made quickly "just woken up one morning" perception of a whim decision
	Interviewer: yeah yeah. Interviewer: And what's your understanding of gender dysphoria and transgender?	
Developing/ constructing own identity Knowledge/support	Kirsty: Er when I was growing up I didn't know much about it weren't until I moved out erm in 2006 and I was researching because I was crossdressing anyway and I was researching gender and stuff like that and I was like yeah that's me, I don't like having a penis, I don't like erm you know being a man	Little knowledge in childhood. Own research when cross dressing I don't like erm you know being a man no labels or anything to identify with as a child? Just knows she didn't like being a man
Visibility and 'outness' Powerful others	Interviewer: mmhmm Kirsty: so like yeah then I had to come out like forcefully by the old bill	experience of exploring one's identity while relying on information from other sources Forced to "come out" not on own terms and in own way.

Themes	Indicators quotes
Identity formation Something different	when I was growing up at school er hanging around with the girls more than the boys wanting to talk about boy bands than football
	Er when I was growing up I didn't know much about it weren't until I moved out erm in 2006
Labels: trans	"Erm for now I will find it ok to use as transgender because I am transitioning"
	"so for now yeah transgender but when I've changed transitioned or when I have had the operation I don't want to be called a trans womanI want to be called a woman"
	"because I've been through the process and I've done it and I am now a woman I am not transitioning"
	"Er I still feel like a woman now"
	"erm and I still identify as a woman"
	"but erm because a lot of people don't accept that I am a woman still I prefer to be known as a transgender person because then I can sit down and explain it to them"
	"and just say look I'm trans, I am changing from male to female and that's why I still sound more male then I do femaleso they understand"
Labels: gender	gender to me just means anyone and anything so anyone could be making the clothing anyone could wear it and so it shouldn't be identified as female it should just be identified as clothing Er but because people identify as female and male and stuff like that it should be accepted as a universal gender
Sense of self	I am who I am, I know who I want to be
	it was the fact that I recognised how much more comfortable I was.
Negotiating and verifying	Erm I would saw is was about 22 21 I would buy women's clothes at
identity	peacocks and wear them I moved in to where I am now
	yeah it was also like I said when I was 15 16 I though I would have been you know year 9 so.
	er and I do know why its called female and male clothing now er and obviously because I am experiencing the transitioning and going through the changes and everything but er wearing the underwear and wearing the clothing and feeling more comfortable in women's clothing

	than male clothing that was the most confident that I got when I did came out
	Now I know that both genders can like football. You know men and women you know.
	now its like all genders that can do it.
	like I am realising you know why did they go so mad, its normal, its common you know there are people out there now and in the 21st century and they are still like coming out so.
	a lot of people don't have to do what we have to do and that is you know, sit there and go oh by the way I'm changing from male to female, I am having voice training to sound like a girl but because I'm not on the hormones yet it's still not working properly. And I have given up smoking as well and yeah trying to get acceptance
Gender expression	
Forced outness	so like yeah then I had to come out like forcefully by the old bill
	but for a certain story I had to come out about being trans and I was forced so it weren't of my own accord.
	but that's what forced me into coming out to the old bill because my house got raided and they found underwear and that and I had to sit there and go oh its coz I you know want to be a woman (sigh) so yeah.
	she caught me one day doing it in the kitchen and she went mad erm and that's when I came out to her.
	one day they did they caught me and my brother went mad and she went mad so it was yeah.
	they did catch me one time in the kitchen and also in the bathroom wearing make up and wearing my swimming costume.
Telling others family	Erm I came out when I was 16 to my Auntie but she didn't like it so I had to live a lie until I was 24 and pretend I was a boy and done boy stuff and done boy things.
	she caught me one day doing it in the kitchen and she went mad erm and that's when I came out to her.
	erm and once when I did say I was gay they said oh there's a guy up the road that may fancy you shall I go and get him?
Telling friends	when I did buy a pair of female slippers and I put them on and I forgot to take them off before he came round he saw them and he just laughed and when he laughed it made me feel upset and angry at him because he was laughing at me
Coping: Not telling others	Er but then I realised I'm not giggling coz I've seen him you know wearing women's clothes I'm giggling because that's my feelings inside but I couldn't tell him that

Coping: withdrawing

I just told him to do one I said look I don't want to be your friend no more I said if your not going to accept me for who I am then don't bother coming round any more. And I sent it over a text and he was like oh you knobhead and crying down the phone... Erm we are not friends any more no and he did continue sending me messages erm and he turned round and said er I was only laughing because at first I just thought it was funny I do you know think that and your weren't transgender or nothing and I was like no it weren't funny and it hurt my feelings. But he was like OK fine I'm sorry do you still want to talk to me and I went no I said if your not going to accept it then you know we will go our own separate ways.

and they went sir and I go no I'm a female and then put the phone down because I don't want to talk to them so.

like I said those ones I got rid of but

Yeah that's way of managing that if they are not supportive I tell them to just do one. Erm and if they are supportive then they can come round and yeah.

I used to come to the (name) but I stopped for a while because I had a friend who was being abusive to me down the phone and they used to come here and it stopped me from coming.

Coping: Hiding/secrecy

yeah because when I was wearing her underwear secretly and doing things in it that you shouldn't be doing yeah I couldn't be honest and I couldn't be upfront with them and if I did say I was bisexual they would've took the piss

er I was doing it secretly I weren't doing it publicly I was doing it secretly in my in my flat and when someone came around I had to get changed quickly back into my boys clothes

Because I had a perspective and the vision that I was if I did it privately no one would know and if someone did find out I was going to get called names like a pervert a wierdo because it was frowned upon when I was living at my aunties so I didn't want to be called those sort of names like pervert, wiedro, freak.

sitting in the bathroom putting make up on my aunties make up on you know then washing it off before they found out you know yeah.

Erm it was the unknown of the reaction that I was going to get ok if it was going to be a good reaction or a bad reaction and I think that was what the buzz was... Yeah, yeah a part of me wanted for them to catch me and so I didn't have to come out

Yeah because I again because I'm hiding it and my feeling weren't male feelings it was more both I wanted to be female and male but because I was getting stressed about life as a male and stuff like that and growing up with my auntie as well was very stressful being beaten by both of them it weren't just my auntie it was my uncle as well

 $Appendix\ Q:$ Table of Themes and Representation of Participants within Themes.

Theme	Participants					
	Sarah	Kirsty	Charlie	Grace	Peter	Isla
Formation of self-concept:	+	+	+	+	+	+
Trying to make sense	+	+	+	+	+	+
Childhood	+	+	+	+	+	+
Gender expression	+	+	+	+	+	+
Early experiences of "coming out"	+	+	+	+	+	+
Social Stigma:	+	+	+	+	+	+
Society's gender binary views	+	+	+	+	+	+
Fear of reactions	+	+	+	+	+	+
Powerful others	+	+	+	+	+	+
The hidden self	+	+	+	+	+	+
Support and knowledge:	+	+	+	+	+	+
The role of others	+	+	+	+	+	+
Sources of information and knowledge	+	+	+	+	+	+
Barriers:	+	+	+	+	+	+
Social challenges	+	+	+	+	+	+
Service barriers	+	+	+	+	-	+
Desire for knowledge, support and	+	+	+	+	+	+
acceptance						
Hope, resilience and positive action:	+	+	+	+	+	+
Future	+	+	+	+	+	+
Developing pride in who I am	+	+	+	+	+	-
Desire to empower others	+	+	+	+	-	-
Key: Superordinate theme; Sub-theme. Partic	ipant represer	ted within	theme: +/-			

Appendix R: Explanation of Audit Trail

The audit trail through this research was facilitated by accurate record keeping and consisted of:

- Supervision notes
- Research proposal
- Interview schedule
- Audio-recorded interviews
- Reflective diary
- Annotated transcripts
- Lists of emerging themes
- Groupings of emerging themes/refining themes
- Tables of themes for participants linking themes to quotes
- Draft reports
- Final report.

All data are stored on the data CD held by the data custodian and are available upon request.