Lived Experiences of Autism with a Specific Focus on Gender Dysphoria

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Declaration

This work has not been submitted for any other degree or to any other institution.

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Overall abstract

This thesis aims to enhance understanding of the lived experience of autism from individuals' perspectives, voices typically marginalised within research, just as their needs have been marginalised within society. The research comprises: a systematic review and an empirical study.

The literature review synthesises and critically evaluates 14 qualitative studies on the experience of autism in adulthood. Six themes representing core features of experience were identified: identity and self-perception; interpersonal relationships; sensory experiences; dating and sexual experiences; institutional experiences; employment. The findings highlight the balance required between targeting remediation of autism-related difficulties, and efforts to make society, its services, public spaces, and institutions more autism-aware and inclusive. Future research directions are highlighted including a need for qualitative research exploration of sexuality, gender identity and related support needs.

In response to this review and the small but growing body of research describing the co-occurrence of gender dysphoria in people with autism, a qualitative study was undertaken investigating the impact of autism on the experience of gender dysphoria. A theoretical framework was developed of common processes involved in understanding and addressing GD, the influence of autism and the social environment. The overall experience is captured in the core category *conflict versus congruence*. Individuals achieve greater personal congruence and wellbeing upon social and physical transition. However, conflicts remain related to fear of hostility and an enduring sense of difference. Services facilitating increased social support and proactively addressing gender and sexual issues are recommended.

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Part One

Literature Review

The Lived Experience of Autism in Adulthood: A Thematic Synthesis of the Qualitative Research Base

Abstract

Objectives

This systematic review aimed to identify and critically appraise qualitative research on the experience of autism in adulthood, address gaps in understanding and draw out implications for professional practice and policy.

Method

A systematic search of the literature was undertaken and papers selected according to inclusion criteria. Identified papers' methodological quality was appraised, and a thematic synthesis of the data was carried out.

Results

Fourteen papers using a range of qualitative methodologies were included in the review, all of which were of adequate methodological quality. Synthesis of study's findings led to the identification of three over-arching, general themes regarding the experiences of adults with autism: identity and self-perception; interpersonal relationships; and sensory experience, and three further themes encompassing experiences in specific adult life domains: dating and sexual experiences; institutional experiences; employment.

Conclusions

The findings highlight common challenges adults with autism experience which are not solely the result of the autism-related impairments, but emanate from societal lack of autism awareness, discrimination, abuse and environmental barriers. Balance is required between targeting remediation of difficulties, and efforts to make society, its services, and institutions more autism-aware and inclusive.

Practitioner points

- Autism diagnosis must continue to be a key focus of services to promote individuals' self-understanding, and access to support.
- Adults with autism 'fall between the gaps' in services that don't understand their

needs. Services need to work in partnership with adults with autism to develop services and train staff.

- Supporting adults with autism to develop social connections is vital to reduce isolation and enhance wellbeing.
- A number of the included studies did not specify participants must have a formal autism diagnosis and some participants self-identified as having autism. This limits confidence that the experience represented is of people with autism.
- Participants mostly had Asperger's syndrome diagnoses and the limited information provided about the gender, ethnic and socio-economic backgrounds of participants limits transferability across individuals with autism.

Key words: Autism, ASD, adults, qualitative, review, thematic analysis.

Introduction

Autism spectrum disorder (hence forth referred to as autism) is a neurodevelopmental disorder characterized by impairments in social interaction and communication, as well as the presence of behaviours, activities and interests that are repetitive and restrictive (American Psychiatric Association; APA, 2013).

Historically the focus of policy guidelines on autism has been children. It is only in the last 4-5 years that adults have been given any real attention (The National Autistic Society, 2014). Recent government acts and national strategies recognised that adults with autism are amongst the most excluded and ignored in society, having inadequate access to services and employment (Autism Act, 2009; Department of Health, 2014). The lack of understanding of autism in adulthood among health, social care, justice, education professionals and at a societal level was highlighted in the government's *Fulfilling and Rewarding Lives* (DoH, 2010) autism strategy. Raising awareness and understanding using the perspectives of adults with autism was identified in the strategy as a national priority.

Most research on autism focuses on health professionals', parents' or siblings' accounts of the condition rather than first-hand accounts from individuals with autism, perhaps owing to high prevalence in those with intellectual disability, and its perceived impact on self-awareness and communication (Penway Barnett & Maticke-Tyndale, 2015). However, increasingly adults with autism are providing first-hand accounts of their experiences (DePape & Lindsay, 2016). This study aimed to synthesise this growing body of first-hand accounts.

There is growing recognition of the value of synthesising qualitative research to promote deeper understanding across a number of contexts, potentially informing policy and practice (Thomas & Harden, 2008). Synthesising the qualitative research on the lived experience of autism in adulthood could potentially improve the understanding of professionals and services, enabling them to meet people's needs more effectively.

Only one other review of the qualitative literature on the lived experience of autism has been undertaken to the researcher's knowledge. DePape and Lindsay (2016) aimed to explore the lived experience of individuals with autism from childhood to adulthood. They searched 10 electronic databases, identifying 32 papers highlighting four central themes: perception of self; interactions with others; experiences at school and employment. However, the review was limited in terms of supporting an understanding of autism in adulthood as the onus appeared to be on the experiences of children and adolescents.

An initial scoping search of recent qualitative research on adult experience of autism revealed articles on higher education (HE), gender identity, sexuality, intimate relationships and imprisonment, which were missing from DePape and Lindsay's (2016) review. Other relevant studies have also subsequently been published. Consequently, the aim of this review is to synthesise the qualitative literature to-date and identify the implications of the findings for clinical practice and policy. Specifically, the research objectives are:

1. To systematically identify qualitative research examining the experience of adults with autism.
2. To systematically appraise the quality of the existing research.
3. To thematically synthesise the existing results within the research into overarching descriptive themes summarising the current state of knowledge.
4. To identify gaps in the research base requiring further investigation.

Method

Search strategy

Web of Knowledge, PsychINFO, Medline, Scopus, CINAHL and Google scholar electronic databases were searched from first available dates up to, and inclusive of, December 2016. A search of the literature was undertaken using relevant MeSH terms along with keywords pertaining to autism and qualitative research; the full list of search terms can be seen in Appendix A. To ensure thoroughness, specific qualitative methodologies were incorporated as search terms (Shaw, 2012).

Papers were eligible for inclusion if they were published in English in a peer reviewed journal, used qualitative data collection and data analysis methods (Kidder & Fine, 1997) and participants were adults (age 18+) with a diagnosis of autism. Papers were excluded if they could be identified as a 'topical survey' where findings are restricted to countable or codeable remarks organized by interview question or prevalence of topic category(Sandelowskis & Barroso, 2003, p.908); research analysing the effectiveness of specific interventions; where the research focus is not the lived experience of adults or the participant age wasn't specified; and studies which incorporate others' views such as parents or healthcare staff, in addition to the person with autism.

The titles and abstracts of identified articles were screened against the criteria, with unsuitable articles rejected. Full texts were obtained where suitability was unclear from the title and abstract alone, and screened against the same criteria. Twelve studies were identified. Citation and ancestry searches were conducted with these studies with two further studies identified. Progress through this process is shown in Figure 1.

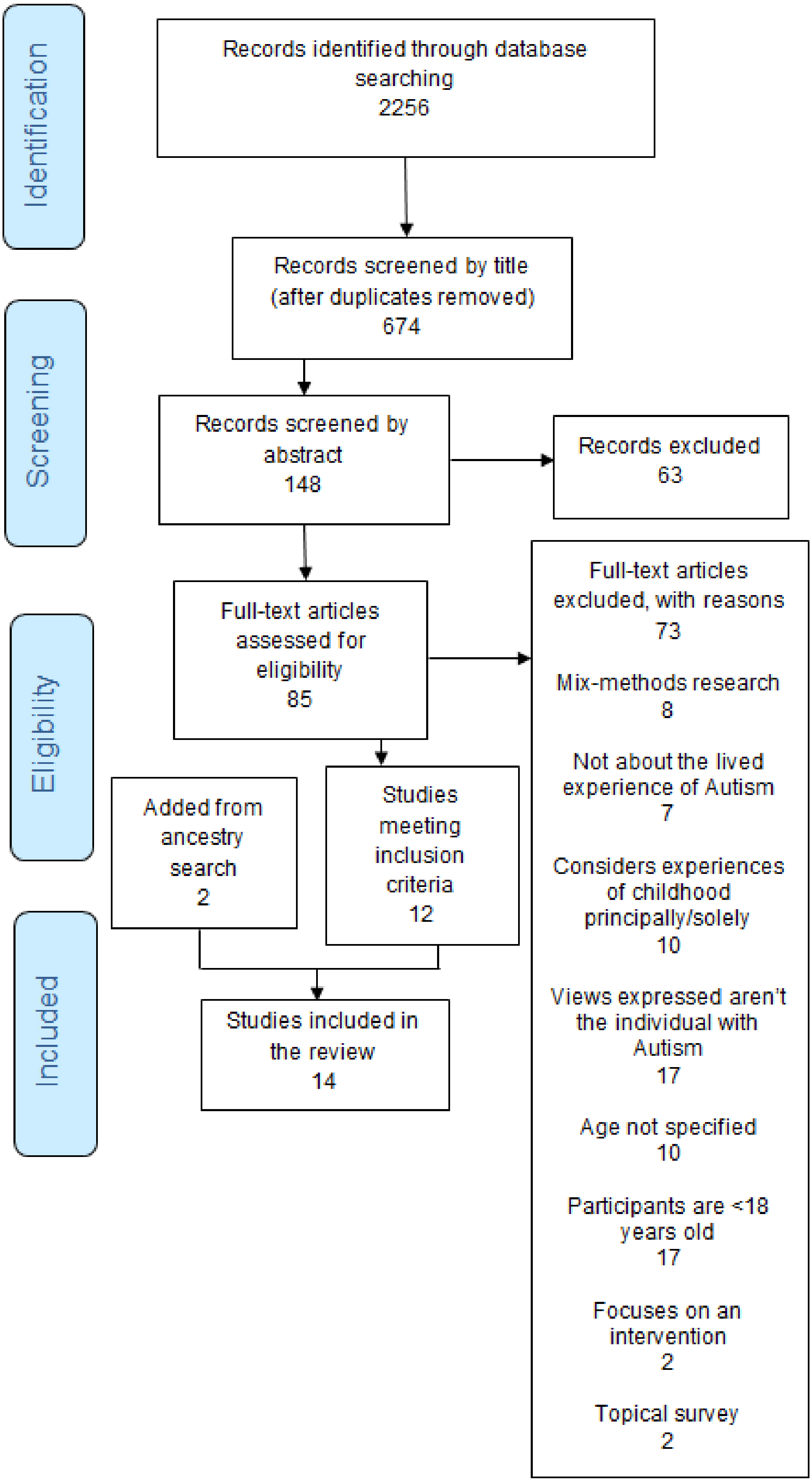

Figure 1. PRISMA diagram of the results of the search strategy

Data extraction

Key data from the 14 studies were detailed in an extraction table based on the Cochrane guidance on qualitative research data extraction by Noyes and Lewin (2011: see Appendix B)

Appraisal of studies

There is no ‘gold standard’ for appraising qualitative research and the present review acknowledges this is a contentious area. This review used a modified version of the Critical Appraisal Skills Programme checklist (CASP, 2013) to appraise quality. This is a widely used tool e.g. in DePape and Lindsay’s (2016) review. The checklist was extended with reference to the Spencer et al. (2003) quality appraisal framework The items are underpinned by the core quality principles of: contribution of the research; the rigour of its conduct; and credibility of its findings. Responses to checklist items were assigned a score (‘yes’ = 2, ‘unsure’= 1, ‘no’= 0) to provide an overall quality score for each study (see Appendix C for the checklist, and D for the detailed quality appraisal of included studies). Possible total quality scores range from 0-24, with higher scores indicating higher quality research. Study’s quality scores were divided into quartiles delineating comparatively ‘low’, ‘moderate’, and ‘high’ quality research. Quality appraisal was undertaken to evaluate and compare studies, rather than exclude papers. An independent researcher selected and assessed three papers at random. Inter-rater reliability was 89% and inconsistencies were discussed to achieve consensus.

Data synthesis

The studies’ findings were synthesised using the thematic synthesis methodology described by Thomas and Harden (2008: see Appendix E), a methodologically neutral synthesis method for the aggregation of research from a range of epistemological positions (Booth et al., 2016), suited to answering questions such as: “what does the data say about the experience of receiving a particular treatment, or living with a particular illness?"

The findings were synthesised across two phases: (1) Line-by-line coding of the primary studies' findings to create a preliminary bank of codes which is added to and modified as initial coding progresses and concepts are translated between studies (resulting in 324 initial codes); (2) Development of descriptive codes through comparison of codes' differences, collapsing them to form a superordinate structure.

Results

Overview of Papers

Fourteen papers (representing 12 studies) published between 2003-2016 were included in the literature review (see Table 1). Eight used a Thematic Analysis approach, four Grounded Theory, one Interpretative Phenomenological Analysis, and one Hermeneutic Phenomenological Analysis.

Demographics. The studies contain interviews with 147 participants and 361 written communications. Semi-structured interviews were used in all but one study (Milton & Sims, 2016) that derived its material from 'Asperger United' magazine. Participants' gender and ethnicity was not provided in some studies but, from the information provided, the majority were Caucasian and male. Most participants had a diagnosis of Asperger's syndrome. The research was conducted predominantly in the USA and England.

Table 1

Summary of Qualitative Studies

Author(s), year (country)	**Method of data collection**	**Participants**	**Method of analysis**	**Themes identified**	**Quality score and rating**
Griffith et al., 2012 (Wales)	Interviews	N = 11, 7 male, 4 female, aged 37-57. 9 had AS diagnoses, 2 seeking diagnosis.	Interpretive phenomenological analysis	Living with AS; employment difficulties; support service experiences; support recommendations.	20 (moderate)
Haertl et al., 2013 (USA)	Interviews and focus groups.	N = 24, Aged 27-55. All had ASD diagnoses.	Thematic analysis	Impact of diagnosis; social isolation; occupational issues; support needs.	18 (moderate)
Hurlburt & Chalmers, 2004 (USA)	Interviews	N = 6, 3 male, 3 female Aged 25-56. All had AS diagnoses.	“	Employment experiences; recommendations for vocational support.	17 (low)
Madriaga, 2010 (England)	Interviews	N = 8. Aged 18-30. All had “label of AS”	Grounded theory	Inaccessibility of university social spaces limiting social engagement.	16 (low)
Madriaga & Goodley, 2010 (England)	Interviews	“	“	H.E academic experiences- the interplay between environmental barriers and ASD-related difficulties.	18 (moderate)
Milton & Sims, 2016 (England)	Written contributions to the magazine ‘Asperger United’	361 written communications. Aged > 18 (not specified). All “on the Autistic spectrum”.	Thematic analysis	Living with an ‘othered’ identity; barriers to social belonging; positive social experiences.	20 (moderate)

Müller et al., 2003 (USA)	Interviews	N = 18 Aged > 18 (not specified). 13 had diagnoses of AS, 2 HF-autism, 1 PDD-NOS.	“	Employment experiences; barriers to employment; vocational support recommendations.	19 (moderate)
Müller et al., 2008 (USA)	Interviews	N = 18 Aged 18-62. Diagnoses as above.	“	Isolation; difficulties in social interactions; efforts to improve social/self-awareness.	19 (moderate)
Newman et al., 2010 (Australia)	Interviews	N = 8, all male. 7 Caucasian, 1 Aboriginal. Aged 21-43. 2 AD, 6 AS diagnoses.	Hermeneutic phenomenological analysis	The unpredictable environment; loss of control; social engagement difficulties.	18 (moderate)
Penwell Barnett & Maticka-Tynedale , 2015 (USA)	Email and Skype, interviews	N = 24, 13 feminine; 6 masculine; 5 genderqueer; 1 androgynous Aged 18-61 Caucasian. All self-identified as on the Autistic spectrum.	Thematic analysis	Dating concerns; sensory dysregulation during sex; inadequacies of sex-education.	20 (moderate)
Punshon et al., 2009 (England)	Interviews	N = 10, 7 males, 3 females Age range = 22-45. All AS diagnoses.	“	Identity formation pre-diagnosis; experiences of services; impacts of diagnosis; societal views of Autism.	20 (moderate)
Robertson & Simmons, 2015 (England)	Focus groups	N = 6, 1 female, 5 males. Aged 24-51. All AS diagnoses.	“	Positive and negative sensory experiences; moderators of sensory experiences; interrelating of emotions/mental states and sensory stimuli; physical	22 (high)

				responses.	
Smith & Sharp, 2012 (England)	Interviews via internet-based instant messaging	N = 9, 6 males, 3 females. 8 Caucasian, 1 Ashkenazi Jewish. Aged 25-49. All AS diagnoses.	Grounded theory	Heightened senses; sensory stress; moderating factors; coping strategies; fascination, and isolation.	22 (high)
Van Hees et al., 2015 (Belgium)	Interviews	N = 34. 17 males, 6 females. Aged 18-25. All AD, AS, or PDD-NOS diagnoses.	“	Managing change; social and academic challenges; ASD-related benefits; support recommendations.	22 (high)

Note. Interviews were face-to-face unless otherwise specified.
Participants’ ethnicity and gender is given where the authors provided this.
ASD= Autism Spectrum Disorder; AS= Asperger’s Syndrome; PD-NOS= Pervasive Developmental Disorder Not Otherwise Specified; HF-Autism= High-functioning Autism; AD= Autistic Disorder.

Methodological quality of the papers. Appendix D provides the detailed appraisal of studies from which the quality score was derived. Quality scores ranged from 16-22 with a mean score of 19.36 (out of a maximum score of 24). Most studies were deemed of ‘moderate’ or ‘high’ quality. Overall, the studies provided detailed accounts of living with autism in adulthood, identified unique themes encapsulating aspects of this experience, and outlined practical and theoretical implications, thereby making valuable contributions to the knowledge base. With regards to the studies’ rigour, all studies use a qualitative design, with methodologies employed appropriate to meet the aims. However, few studies justify why the participants selected were most appropriate, and consideration of reflexivity, and ethical issues is lacking. Regarding the credibility of the findings, all studies provide clear descriptions of their findings with illustrative quotations from the primary data, framing discussions within the context of the wider literature. Most studies provide detailed accounts of a formal comprehensive data analysis process and make use of validity checks. However, the characteristics of participants and details of the research setting are limited in most of the studies. In a minority, the definitiveness of the autism diagnosis is unclear.

Synthesis of Themes

Synthesising the findings across all identified studies led to the identification of six themes (described in detail below) which clustered into two types: *general* experiences of autism; and experiences in *specific* adult life domains. Thus, the first three themes relate to over-arching, broad and general experiences regarding individuals’: 1) *identity and self-perception*; 2) *interpersonal relationships*; and 3) *sensory experiences*. Although outlined as separate themes, each is linked to and influences the other (for instance, *interpersonal experiences* are influenced by *sensory experiences*; and *identity* is shaped by *interpersonal experiences*). The other three themes relate to experiences in specific domains of adult life: 4) *dating and sexual* *experiences*; 5) *institutional environment experiences (higher education and prison)*; and 6) *employment.*

Theme 1: Identity and self-perception.

Identity formation. Issues related to identity and self-perception were central to four studies (Griffith, Totsika, Nash, & Hastings, 2012; Haertl, Callahan, Markovics, Sheppard, 2013; Milton & Sims, 2016; Punshon, Skirrow, & Murphy, 2009) but featured in all studies. The experiences predominantly highlighted challenges associated with living with autism and their impact on their sense of 'self', but also pride in identity and personal development.

As a result of reportedly limited understanding of autism (particularly 'high-functioning' presentations) by GPs and other professionals, most participants did not obtain diagnoses until adulthood. The majority of participants felt "different" (Haertl, et al., 2013, p.32) and "didn't fit in" (Griffith et al., 2012, p. 533; Haertl et al., p.33) from early-life. Many experienced bullying and ostracism (Griffith et al., 2012; Haertl et al., 2013; Milton & Sims, 2016; Punshon et al., 2009) and saw themselves as "defective" and "weird" (Milton & Sims, 2016, p.526), having internalised others' negative views of them. This led to low self-esteem, depression and anxiety.

Many participants saw "perpetual inner conflict" (Griffith et al., 2012, p.537) as central to their sense of self and a defining feature of living with autism. They described the effort required for day-to-day living with autism due to unpredictable mood changes and ever-present anxiety (Griffith et al., 2011; Hurlbutt & Chalmers, 2004).

The impact of diagnosis. Participants' responses to receiving their autism diagnosis and the impact on their identity varied, and sometimes changed over time. Most expressed initial relief, as the diagnosis confirmed a pre-conceived identity of being different, which "exonerated" them from self-blame (Punshon et al., 2009, p.277). For some it led to increased self-understanding, empathy from others and access to support (particularly others with autism), thus improving coping and self-esteem (Griffiths et al., 2012; Haertl et al., 2013; Punshon et al., 2009; Smith & Sharp, 2012).

"I got the letter saying that I had Asperger syndrome, it was…like standing up in court and hearing the jury say 'not guilty'" (Punshon et al., 2009, p.277).

However, for some the diagnosis was devastating as they realised they could not be 'cured' and would "never be normal" (Haertl et al., 2013, p.7). Some did not wish to be defined by autism seeing it as distinct from their 'core' selves (Griffith et al., 2011; Milton & Sims, 2015). However, others described a journey of gradually incorporating autism into their identity, usually via increasing immersion in the autistic community: "*When I first learned about autism, I wanted nothing to do with it. Then, that led to me reluctantly accepting it wasn't going anywhere, and I called myself a person with autism. Now…I think of myself as an autistic person, with a family of other autistic people"* (Milton & Sims, 2015, p.527).

Recognising strengths. Although living with autism presented challenges, many participants highlighted benefits it afforded including: "intellectual liberty from the constraints of normal thinking" (Griffith et al., 2011, p.538), a good memory; loyalty; and fairness in relationships. Abilities were also identified related to heightened senses (see later). Some participants felt the hardships they endured made them more resilient and empathic to others. Recognition of strengths led to self-acceptance and pride for some (Hurlbutt & Chalmers, 2004; Müller Schuler, & Yates, 2008; Smith & Sharp, 2012).

"I am who I am. I have my ups and downs…many caused by not knowing who I was but now I have an understanding…there are many things I can do that others can't" (Smith & Sharp, 2012, p.902).

Coping. Despite experiencing intrapersonal challenges, some described ambivalence about accessing mainstream support services, feeling professionals lacked understanding and could not adequately meet their needs:

"I don't fit mental health, I don't fit learning disability, I just fall through the gaps between departments" (Griffith et al., 2012, p.540).

Many independently developed coping strategies such as increasing self-awareness through researching autism; structuring their lives; avoiding sensory overload; having time alone or being with others who understood; some used alcohol (Hurlbutt & Chalmers, 2002; Punshon et al., 2009; Smith & Sharp, 2012).

Sexual and gender identity. Only two studies consider sexuality and gender identity, both as minor aspects of the study (Penwell Barnett & Maticke-Tyndale, 2015; Milton & Sims, 2016). In Penwell Barnett & Maticke-Tyndale (2015) participants' sexual identity was perceived as being distinct from normative, 'neurotypical'[1] sexuality. Only 11 out of 24 participants identified as heterosexual, three of whom additionally identified as asexual, bicurious, and sapiosexual (attraction to intelligence). Six participants reported being asexual and additionally endorsed identities connected to non-sexual partner preference or relationship style; three identified as gay or lesbian; and four as queer. In Milton and Sims (2016), many contributors to 'Asperger United' magazine identified as lesbian, gay, bisexual or transgender.

There was a high rate of gender identity non-conformity expressed. In Penwell Barnett and Maticke-Tyndale (2015) a quarter of participants identified as having a genderqueer or androgynous identity. Few who identified within the gender binary deemed themselves 'typically' masculine or feminine. One participant suggested:

"A lot of… [people with autism]… perceive gender differently than… [neurotypical] individuals, and perhaps we don't quite identify as solidly with a gender" (Penwell Barnett & Maticke-Tyndale, 2015, p.173)

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[1] a term from the Autistic community, referring to people who don't have Autism.

Theme 2. Interpersonal relationships. Most of the studies considered how autism impacted on interpersonal experiences.

Interpersonal challenges. Participants described social interactions as fraught with difficulties and anxiety, citing a range of communication challenges including: knowing how and when to initiate and conclude conversations; participating in unstructured ‘chit-chat’ requiring an improvised response; drawing social and emotional inferences; and interpreting and using body language and tone of voice. Awareness of their difficulties in social interactions and worrying about being perceived as odd led to attempts to mask difficulties and ‘pass’ as normal. However, attempts at ‘normality’ were often unsuccessful, exhausting and distressing leading some to avoid socialising or using alcohol to quell social anxiety (Müller et al., 2008; Griffith et al., 2012; Punshon et al., 2009).

“I wear this mask when …I have to deal with people…and it’s exhausting” (Griffith et al., 2012, p.538).

Other people’s lack of understanding of autism was perceived to lead to bullying and ostracism, resulting in a lack of trust of others, poor self-esteem and isolation.

“When I’m…with people who are kind and tolerant…then I am as happy as the next person. It is when people tell me I should think, speak or behave differently that I start to feel different, upset, isolated and worthless” (Milton & Sims, 2016, p.527).

Consequent to social challenges many individuals reported difficulties establishing and maintaining close relationships which distressed them:

“[relationships]can more accurately be called acquaintanceships,[they] …stay at that point for many years without progressing.” (Müller et al., 2008, p.178).

Valued social experiences. Despite the challenges of forming relationships, creating close connections was desired and valued by most participants. Close relationships were seen as having a transformative impact on self-esteem and quality of life (Haertl et al., 2013; Milton & Sims, 2016).

"I was teased a lot…And when I met my roommate it made a big difference to my life…I finally found someone like me and that changed my life" (Haertl et al., 2013, p.34).

Groups based on special interests (e.g. chess, playing an instrument, disability/LGBT rights or religious beliefs) were major facilitators of social interaction and friendships. These groups were often structured and created opportunities for thematically focused conversations that were easier to participate in (Haertl et al., 2013; Müller et al., 2008).

One-to-one interactions or small groups were preferable to large group interactions. These smaller groups served as laboratories for learning and testing out social skills. Participants also valued internet-based socialising (Haertl et al., 2013; Müller et al., 2008). Most individuals valued meeting others with autism through support groups or informally, reporting feeling for the first time they belonged (Haertl et al., 2013; Milton & Sims, 2016).

Relationships with family varied but were commonly a crucial source of social support and socialising, and offering a sense of acceptance which improved well-being (Müller et al., 2008; Griffith et al., 2012). However, some reported a lack of family understanding, support and acceptance (Punshon et al., 2009; Smith & Sharp, 2012).

Theme 3. Sensory experiences. Unusual responses to sensory experiences were the primary focus of Robertson and Simmons (2015) and Smith and Sharp (2012), and mentioned in 12 studies.

Participants described having heightened senses; and did not habituate readily to stimuli compared to non-autistic people (Robertson & Simmons, 2015; Smith & Sharp, 2013).

''All of my senses feel like they are over accentuated'' (Smith & Sharp, 2012, p.897).

Sensory experiences could be aversive and a source of stress, but also pleasure, abilities and comfort. The stimuli experienced as stressful or pleasurable were quite idiosyncratic, although high intensity stimuli and multiple inputs were usually aversive, whilst smooth and cold surfaces were commonly pleasurable (Robertson & Simmons, 2015).

Negative sensory experiences. Heightened senses commonly led to adverse sensory experiences causing 'sensory stress' during which participants felt fear, anger, physical pain or nausea (Robertson & Simmons, 2015; Smith & Sharp, 2013). Other people were a common cause. Individuals described feeling overwhelmed by trying to focus on body language, speech and emotional cues simultaneously in personal interactions, or due to the ambient sound of chattering, shouting or moving around in social environments such as open-plan offices and bars. Subsequently some participants avoided social environments, limiting opportunities to connect with others (Griffith et al., 2012; Madriaga, 2010; Smith & Sharp, 2012).

Control over and predictability of exposure to sensory stimuli moderated their impact and increased tolerance; as did feeling calm prior to exposure; whereas an already stressed person was more affected. Awareness of the moderators of sensory stimulation enabled them to be used as coping strategies (Robertson Simmons, 2015; Smith & Sharp, 2013).

"If…I was already…having a pretty bad sensory day, then I wouldn't be able to walk into the place" (Robertson & Simmons, 2015, p.577).

Non-autistic individuals were often unsupportive of sensory sensitivities. Social avoidance and isolation was then, exacerbated by unsupportive others, demonstrating the interaction between themes (Punshon et al., 2009; Robertson & Simmons, 2015; Smith & Sharp, 2013):

"Other PEOPLE …don't understand and can be cruel...if I show I'm afraid of something it always gets thrown at me…it drives me to the point of hiding away from

the world" (Smith & Sharp, p.901).

Diagnosis was important to self-understanding and coping with sensory difficulties, but also obtaining support:

"My wife…used to think I was just being rude or acting weirdly, but now I have a diagnosis she at least understands why it happens'' (Smith & Sharp, 2012, p.901).

Positive sensory experiences. Heightened senses could lead to fascinating, pleasurable or calming experiences which were as powerful as sensory stressors.

"I [stand] in the shop staring at things for about five minutes…it's the kind of structure of the shelves, and repeated things" (Robertson & Simmons, 2015, p.575).

Music, of the person's choosing, was a common source of pleasure and mood management. Participants also described physical contact with some materials such as a soft fabric toy inducing relaxation (Robertson & Simmons, 2015; Smith & Sharp, 2012).

Heightened senses could also give the person abilities others didn't have, which if the person found a practical application for could lead to valued long-term pursuits or jobs. For instance, a fine ear/tongue/eye for details leading to hobbies or jobs such as, in mathematics, mechanics, cookery.

Theme 4. Dating and sexual experiences. Penwell Barnett and Maticke-Penwell (2015) focused on dating and sexual relationships, and Haertl et al. (2013) and Müller et al. (2008) considered it.

Many participants described challenges with flirting and conveying or recognising interest/disinterest due to difficulties interpreting and using nonverbal and oblique verbal communications. Men in particular found expectations of skilful sociality were a major barrier to establishing relationships and sexual encounters.

"It's just like the Justin Timberlake song with the line 'funny how a few words turn into sex'. So true and also why sex is so…awkward and hard for autistic men…dating can be

sooooooooo hard" (Penwell Barnett & Maticke-Tyndale, 2015, p.174).

These issues led to difficulties establishing romantic relationships and later sexual debuts, which caused distress:

*"One of the biggest things I struggled with was not being married at my age or having a significant other…shredded me emotionally" (*Müller et al., 2008, p. 179-180).

Difficulties within sexual encounters were also reported. Sensory dysregulation and differences between each partner's sensory needs were common challenges. During sex, participants commonly experienced sensory overload or found particular sexual sensations unpleasant. Some developed effective strategies including: partners using explicit, direct communication to plan sex and have specific sensory needs met/accommodated; and negotiating alternatives to penetrative sex to avoid sensory over-stimulation.

Inadequate, or non-existent, sex education from parents and/or school was felt to contribute to dating and sexual relationship difficulties by some participants. Those who received sex education reported numerous limitations including: its heteronormativity; unclear communication of material; neglect of social aspects of sexuality including developing and negotiating relationships leading to sex; negotiating competing sexual needs with partners. On entering adulthood, most participants had limited resources to navigate socio-sexual situations.

Theme 5. Institutional Environment Experiences. The experience of Higher Education (HE) was considered in five studies, three of which considered this as their primary focus (Magdriaga, 2010; Madriaga & Goodley, 2010; Van Hees, Moyson, & Roeyers, 2015). One study considered experiences of imprisonment (Newman, Cashin, & Waters, 2010). As with previous themes, experiences predominantly encompassed challenges.

HE. The initial transition to HE brought major simultaneous challenges socially, academically and in people’s living situations. The volume of new information, and unpredictability typical of HE programmes led many to feel anxious, overwhelmed and exhausted:

“First the lesson was supposed to happen, and then it was not…I could not cope with the change…I became so upset by the loss of structure” (Van Hees et al., 2015, p.11).

Some coped through meticulous planning and routines, and/or elected to live at home with parents to limit change (Van Hees et al., 2015).

Academic experiences. Many participants identified their method of processing information as negatively impacting their academic experience. Participants recognised tending to focus on details, and required additional time to apply coherence to information given:

“When I study...it’s difficult to separate essentials from side issues” (Van Hees et al., 2015, p.15).

Participants also had difficulties with planning, time-management, and coursework deadlines. However, some students recognised their information processing style, including precision and detail-orientation, allowed them to excel in specific disciplines.

Assessments, especially unseen exam papers, induced extreme anxiety. Extra time and sitting exams alone was useful for many, but not all. Some disliked segregation as it drew attention to them (Madriaga & Goodley, 2010).

Learning environments were experienced either as inaccessible and overwhelming, or a safe-haven, due to sensory sensitivities. For some, the library offered sanctuary from sensory overload and opportunities to meet and be near others in a measured fashion. However, others found the noise of equipment present induced sensory stress (e.g. photocopiers). Lecture auditoria often caused sensory overload and so were avoided (Madgriaga & Goodley, 2010; Van Hees et al, 2015).

A lack of understanding of the social rules governing group-work often impacted academic tasks. Whilst a few enjoyed group-work, it generally induced anxiety about social performance:

"If it is one-to-one, I am okay. But, if there are a lot of people around, I just get too shy" (Madriaga & Goodley, 2010, p.123).

Socialising. A desire for relationships with fellow students was clear in the studies but many participants, aware of their communication difficulties, felt anxious about social encounters (Van Hees et al., 2015). Many strove hard to 'fit in'. However, the huge effort involved, coupled with anxiety prevented some participants from feeling able to initiate or maintain friendships. However, a minority noted conversations with fellow students were easier than in school due to shared study interests:

"During the first lecture…I sat there, mouth agape… I was surrounded by people just like me…This was absolutely beautiful" (Van Hees et al., 2015, p.14).

Experiences of Freshers' week activities and the Students' Union bar were central to participants' reflections on university social life as they were recognised as key gateways to creating social connections. Some had attended the Freshers' week fair (some with support worker assistance) enabling them to join student societies and develop a social timetable. However, most participants had felt very anxious attending the event due to sensory hypersensitivities and some were unable to attend at all.

"[Freshers' week events] are utterly unsuitable for someone who does not like…crowds. I avoid them like the plague" (Madriaga, 2010, p.43).

Similarly, the Students' Union bar was avoided by many due to the environment causing sensory overload, thus limiting opportunities to connect with other students. However, a minority expressed their fondness for socialising at the bar; and others forced themselves to go to avoid isolation. As a result of these difficulties some participants spent most of their spare time alone (Madriaga, 2010).

Accessing support. Despite challenges inherent to HE, many participants described positive experiences of support including: the provision of planning tools; clear communication and concrete information to set expectations and enable the development of routines. A point of contact for academic and emotional support was valued. Many were also supported to change from a full-time to reduced hours course. Receiving appropriate support relied on institutions having adequate knowledge of autism, which some found lacking (Madriaga, 2010; Van Hees et al., 2015).

Although participants were willing to disclose their diagnosis to the institution's disability office to address specific support needs, many were reluctant to disclose to peers and academic staff. Those that did benefitted in their academic work as they were better understood and supported; and their sense of belonging and wellbeing among peers improved as they felt able to be themselves (Van Hees, 2015).

Imprisonment. As in HE, unpredictability and change were a significant challenge in prison. There were continual changes in cells, cell mates, routines and rules, and movement to other prison facilities. Participants also had difficulty understanding prison rules and routines due to perceived inconsistencies in enforcement between prison officers, causing distress and sometimes resulting in punishment. A sense of stability and predictability was sometimes achieved through undertaking self-imposed routines:

"I clean [my cell] every day… and then I'll change it all around [and] clean it all out" (Newman et al., 2010, p.635).

However, correctional officers' rules and routines often interfered with individuals' attempts to create stability.

A major challenge was negotiating social demands. Some participants were aware of being 'different' to other prisoners and felt this made them a target for abuse:

"I don't do that [socially mix]…that makes you aloof and consequently a victim of

abuse…by being an oddity” (Newman et al., 2015, p.636).

Many participants also described anxiety relating to the prison environment overwhelming their senses, and necessitating unstructured socialising.

“What was scary is you’re chucked in the yard all day with a hundred prisoners, no officers…some of them tried [to talk]… just make general conversation…and I thought, oh what’s going on here?” (Newman et al., 2015, p.636).

Participants often attempted to manage these perceived threats through self-isolation, undertaking activities alone, requesting not to share a cell or placement in a segregation unit which felt like additional punishment.

Theme 6. Employment experiences. Nine of the studies considered employment experiences, two as the primary focus (Hurlbutt & Chalmers, 2002; Müller, Schuler, Burton, & Yates, 2003).

Employment was important to participants, though many described frustrations at being unable to secure jobs in their field, being offered low-skilled, low-paid jobs, and losing jobs. Poor work histories made career enhancement unlikely, led to financial hardship and impacted on self-esteem and wellbeing (Hurlbutt & Chalmers, 2002; Müller et al., 2003).

Participants mostly felt competent in meeting jobs’ technical requirements but identified several autism-related factors which hindered their employability including difficulties imagining what employers wanted and which skills to highlight when applying for jobs and attending interviews. Interviews being complex social interactions, were highly anxiety-provoking, so some felt unable to attend them (Griffith et al., 2012; Müller et al, 2003).

Employers, co-workers and vocational support professionals typically lacked autism knowledge, meaning participants were inadequately supported. Several described difficulties acclimatising to new work environments, routines and tasks, taking longer to learn and ‘get going’, something viewed negatively by employers: *“In…my earlier jobs, my boss was very impatient with me for being…slow to learn physical and manual skills”* (Müller et al., 2003, p.7).

Communication difficulties, including processing rapid spoken instruction, and deciphering inadequately explicit communication, frequently resulted in misunderstanding, and being unable to complete tasks. The main difficulty in the workplace was negotiating relationships with co-workers, employers and customers, which often led to alienation and sometimes dismissal.

Although most participants experienced employment disappointments, some reported successes, usually attributed to finding a career matching their skills and interests and/or social competence was less important (Müller et al., 2003; Smith & Sharp, 2012). Critical to maintaining a job and well-being was an employer (and colleagues) who understood autism and accommodated the individual’s differences, including: allowing extra time to acclimatise to a new role; explicit communication styles; and modifying the environment to suit sensory sensitivities (Hurlbutt & Chalmers, 2002; Müller et al., 2003).

Although some felt disclosure of autism to employers could lead to discrimination in obtaining and maintaining jobs, others felt it was crucial to employment success as they received better support: *“I learned to be honest…about having autism…if I need help, I should ask for help. Get support help when you need it!”* (Hurlbutt & Chalmers, 2002, p.220).

Individuals diagnosed at school-age reported fewer negative work experiences. Their greater autism awareness facilitated identification of potential obstacles in finding and keeping employment, and also recognition of strengths (Müller et al., 2003)

Discussion

The perspectives of adults with autism have been marginalised in research, typically focusing on children. This review is the first to synthesise the growing qualitative research base of adults with autism, aiming to address gaps in understanding and draw-out implications for professional practice and policy.

Synthesis of included study's findings led to the identification of three over-arching, general themes regarding the experiences of adults with autism: *identity and self-perception*; *interpersonal relationships*; and *sensory experiences*. Three further themes encompassing experiences in specific domains of adult life were also delineated: *dating and sexual experiences*; *institutional experiences*; *employment*.

Comparison with other studies

A primary challenge of living with autism was feeling 'different', often exacerbated by a lack of self-understanding due to late diagnosis, and mistreatment by others. The identity formation experiences described, regarding integration of autism into one's identity following diagnosis, are comparable with research concerning individuals with other disabilities and LGBT individuals, where connecting with similar people is highlighted as central to increased self-understanding, belonging, and positive identity formation (Cass, 1972; Davies, 1996). The findings are also consistent with DePape and Lindsey's (2016) theme 'perception of self', although their focus was children's identity development. The current review extends their findings by considering sexual and gender identity, central to a person's identity, but often overlooked in people with autism by professionals and society generally (DoH, 2010). The present review's participants expressed high rates of non-heterosexual identities and gender non-conformity consistent with a recent quantitative research review by Dewinter, Vermieren, Vanweenbeeck & Nieuwehuzen (2013).

Social interactions were challenging and anxiety-inducing due to social communication difficulties and sensory sensitivities, coupled with the perceived societal lack of understanding and mistreatment of people with autism. Connecting with others was greatly valued and when achieved it was experienced to significantly improve wellbeing, although isolation was common. These findings are consistent with the extensive quantitative research documenting the social communication difficulties of people with autism and their relationship with anxiety (Beardon & Edmonds, 2007), difficulties establishing and maintaining relationships, loneliness and lower wellbeing (Mazureck, 2014). Ung et al. (2016) found victimization of people with autism is negatively predicted by their social functioning ability, and positively predicts loneliness, anxiety and depression; though social support can protect against the emotional impact of victimisation (Humphrey & Symes, 2010). The findings are also consistent with DePape and Lindsay's (2016) findings who, focusing on children's experiences similarly found other people are both a source of stress and support. The current review makes explicit this experience permeates adulthood.

Sensory experiences had a significant impact on individuals' lives, being a source of stress, but also pleasure and relaxation, and sometimes unique abilities. Individuals often tried to escape aversive sensory experiences including social environments/interactions leading to isolation. The reviewed studies only consider hypersensitivities, whereas quantitative research evidences hyper- and hypo-sensitivity (Iarocci & McDonald, 2006). This discrepancy is likely due to qualitative studies' small samples not capturing the full spectrum of experience. This theme was a departure from DePape and Lindsay's (2016) review which made little comment on sensory experiences. This was surprising given quantitative research demonstrates the life-long presence of USEs for the majority of people with autism, their impact on daily living (Tomchek & Dunn 2007), and recognition in the DSM diagnostic criteria. This relative absence from DePape and Lindsey's (2016) review may represent differences in subjective interpretation of qualitative data, or indicate sensory experiences have greater salience for adults.

Adults with autism experienced multiple challenges to establishing romantic relationships and satisfying sexual encounters, exacerbated by inadequate sex education. As these experiences were absent from the previous review, this review extends current understanding. The findings are supported by quantitative research indicating that identifying a romantic partner and negotiating the social element of sexual relationships are concerns expressed more often by people with autism than neurotypical peers (Mehzabin & Stokes, 2011). Low rates of marriage and intimate relationships support this (Renty & Royers, 2006).

The transition to HE brought major simultaneous changes which were stressful and exhausting. The academic challenges and difficulties establishing social connections participants experienced were linked to both autism-related impairments and the inaccessibility of learning and social spaces on campus. The findings mirror DePape and Lindsay's (2016) findings regarding childhood and adolescent education challenges linked to cognitive processing issues, teachers' lack of autism understanding, and sensory challenges presented by the educational environment. These findings shed light on data that students with autism are less likely to complete their studies than non-disabled students (25% less, despite matching or exceeding their academic abilities) and students with other disabilities (40% less) (Fabri & Andrews, 2015).

In accounts of imprisonment, participants' distress seemingly largely related to the incompatibility between the prison environment and procedures (including staff behaviours) and autism-related impairments. This aspect of experience was also absent from DePape and Lindsay's (2016) review. The findings are supported by research by Myers (2004) and McAdams (2009) who found UK prison staff reported prisoners with autism did not fit well within services, with staff unable to meet their needs, and were at greater risk of exploitation and abuse.

Individuals valued employment but many experienced under-employment, unemployment and lack of career progression. Positive experiences comprised finding a job which was a good match for individuals’ skills and interests, and having employers and colleagues with a good understanding of autism. These findings were consistent with DePape and Lindsay’s (2016) findings of employment experiences, and the National Autistic Society’s *The Employment Gap* (2016) report that only 32% of adults with autism are employed, compared to 80% of non-disabled and 47% of people with disabilities as a whole. 51% experienced unfair treatment related to having autism. These figures are comparable to US and Australian data (Hedley et al., 2016).

Implications for Professionals and Services

The reviewed study’s findings indicate that the challenges adults with autism experience are not solely the result of autism-related impairments, but also stem from societal lack of autism awareness, discrimination, abuse and environmental barriers. Therefore, it seems, balance is required between targeting remediation of autism-related difficulties (the traditional focus of support, locating the ‘problem’ within the individual -Fabri & Andrews, 2015), and efforts to make society, its services, and institutions more autism-aware and inclusive.

Diagnosis. The findings, in support of the DoH (2014) recommendations, highlight early autism diagnosis as crucial to promote individuals’ self-understanding and reduce self-blame, facilitate access to professional support, wider understanding and support from friends, family, employers and colleagues.

Post-diagnostic support for adults is important to address the potential impact of life-long negative self-appraisals, and help to develop coping strategies. Currently these adults fall between the gaps of services.

Improving services and other environments’ suitability for people with autism. Improved support and diagnosis will require services to better understand the needs of adults with autism. Review participants (Griffith et al., 2011; Haertl, 2013) echo the DoH (2010) recommendations in advising that adults with autism are involved in the development of services and staff training.

More broadly, involving adults with autism in planning social, institutional, and workplace environments, and training staff is likely to help to remove barriers (predominantly their incompatibility with sensory sensitivities and attitudinal barriers i.e. mistreatment and lack of support) which disadvantage, exclude and isolate them. South West Yorkshire Partnership NHS Foundation Trust (2016) produced a checklist for services to improve their environment's suitability for people with autism, and the NAS provide guidance for making public spaces and services 'autism friendly'.

Supporting interpersonal connections. Providing opportunities for adults to connect socially via structured, shared-focus activities is also important. Meeting others with autism, in particular, was highly valued in reducing isolation, but also developing self-understanding and identity pride. Social prescriptions to autism support or activity groups are likely to be effective and resource-efficient means of enhancing individuals' wellbeing.

A central implication of the findings is for policy makers to prioritise ways to enhance societal understanding of autism to reduce ostracism and victimisation. Increasing autism awareness in school children would support this aim as well as mitigating early social stress, impacting wellbeing and self-esteem.

Recognising strengths. Increased societal autism-awareness must encompass recognition of autism-related difficulties but also individual' strengths in order that these may be nurtured, so benefiting individuals' self-worth, academic and occupational success. School's role in supporting the development of individuals' abilities into long-term pursuits and careers was highlighted by Smith and Sharp (2012). The government targeting employers' autism awareness and enhancing their recognition of the value adults with autism can bring to the workplace is important (NAS, 2016).

Review Strengths

The review had a number of strengths including the comprehensive and systematic search method ensuring the capturing of a broad range of the research, and facilitating replication. Although some have asserted synthesising studies with differing qualitative methodologies is questionable (Dixon-Wood et al., 2007), including a broader variety of qualitative methods, synthesised using a methodologically neutral synthesis method, allowed a fuller account of adults' lived experience. The methodological quality of studies was thoroughly and systematically assessed using a modified version of well-established quality assessment tool, underscored by core elements widely acknowledged to constitute good quality research across methodologies. The majority of studies were deemed to be of moderate or high quality which facilitates confidence in the robustness of the review findings. The review extends understanding of the lived experience of adults with autism and the findings suggest ways they may be better supported.

Gaps and Limitations

This review highlighted gaps in the literature, which represent potential avenues for future research. The lack of consideration of experiences of older adulthood, likely an artefact of autism often being seen as a childhood disorder provides an important direction for research to inform appropriate service provision.

Only one study considered the experience of prison and no research was identified considering other aspects of the criminal justice system such as the police, arrest and court proceedings. This requires empirical investigation.

Adults consulted for the DoH (2010) *Adult Autism Strategy* highlighted their sexual and gender identity are not acknowledged by professionals; however research in this area is sparse, limiting understanding of support needs. More research is therefore required on sexuality and gender identity.

Reviewed studies’ samples mostly comprised of those with Asperger’s syndrome/high-functioning autism able to provide verbal accounts of experiences in interviews/focus groups. Future studies need to consider other ways of involving people which suit their abilities and preferences (e.g. internet-based interviews, or using assisted communication) to ensure findings are representative of the broad spectrum of individuals.

Whilst the included paper’s focus on challenges highlights the need for change, future studies looking at effective services, institutions and communities may provide examples of best practice to implement elsewhere.

Researcher reflexivity is not considered in most studies, but is a key aspect of ensuring rigour, and so future qualitative research needs to address this short-coming. A number of the included studies did not specify participants must have a formal autism diagnosis and some participants self-identified as having autism. This limits confidence that the experience represented is of people with autism. Also, limited information was provided about the gender, ethnic and socio-economic backgrounds of participants. More research is needed to explore the impact of these factors.

Finally, excluding research deemed a ‘topical survey’ and non-peer reviewed research, whilst justified in terms of ensuring the quality of qualitative research and capturing a deeper understanding of the meaning of individuals’ experience (Kidder and Fine, 1987), may have meant important studies were missed. Similarly, the decision to exclude research including the perspectives of anyone other than the person with autism was to ensure the voice of adults with autism was prioritised, having been previously subordinated. However, this was likely a factor in excluding studies conducted with people with greater functional impairment who required someone to support communication.

Conclusions

This review is the first to synthesise the qualitative research about the lived experiences of adults with autism, identifying challenges and needs that require addressing. What seems evident from the reviewed studies is we must not assume the difficulties adults with autism experience are primarily the result of impairments. Participants' narratives suggest that, from their perspective, many of the difficulties they experience stem from societal lack of understanding of autism, prejudice and mistreatment. This is apparent in the overtly discriminatory attitudes and behaviours of family, peers, co-workers/employers and professionals, and implicit in services and institutional practices which fail to remove disabling barriers or provide a sense of inclusivity.

A key objective suggested to address the challenges experienced and support these individuals is increasing societal understanding of autism. This will involve services, businesses and institutions acknowledging autism-related difficulties, but also recognising individuals' strengths in order that these are nurtured and utilised allowing contribution to society as equal members. Future research, policy development and implementation must continue to involve people with autism as experts by experience and highlight examples of good practice which may be replicated.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental health disorders: DSM-5* (5th ed.). Washington, DC: Author.

Autism Act. (2009). §.15. Retrieved on 4th September 2016 from: http://www.legislation.gov.uk/ukpga/2009/15/contents

Baker, A. E., Lane, A., Angley, M. T., & Young, R. L. (2008). The relationship between sensory processing patterns and behavioural responsiveness in autistic disorder: A pilot study. *Journal of Autism and Developmental Disorders*, 38, 867-875. doi:10.1007/s10803-007-0459-0

Beardon, L., & Edmonds, G. (2007). *ASPECT consultancy report: A national report on the needs of adults with Asperger syndrome*. Sheffield, England: The Autism Centre, Sheffield Hallam University.

Booth, A., Noyes, J., Flemming, K., Gerhardus, A., Wahlster, P., van der Wilt, G. J., . . . & Rehfuess, E. (2016). *Integrate-HTA: Guidance on choosing qualitative evidence synthesis methods for use in health technology assessments of complex interventions.* Retrieved from http://www.integrate-hta.eu/wp-content/uploads/2016/02/Guidance-on-choosing-qualitative-evidence-synthesis-methods-for-use-in-HTA-of-complex-interventions.pdf

Cass, V.C. (1979). Homosexual identity formation: A theoretical model. *Journal of Homosexuality, 4*, 219-35. Retrieved from http://www.brightfire.com.au/wp-content/uploads/Journal-of-Homosexuality-1979.pdf

Critical Appraisal Skills Programme (2013). Qualitative Research Checklist. Available from: http://www.casp-England.net/wp-content/uploads/2011/11/CASP_Qualitative_Appraisal_Checklist_14oct10.pdf

Davies, D. (1996). Working with young people. In D. Davies & C. Neal (Eds.), *Pink Therapy: A Guide for Counsellors and Therapists Working with Lesbian, Gay* *and Bisexual Clients* (pp. 131-139). Buckingham, England: Open University Press.

DePape, A. M., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities*, 31, 60-71. doi: 10.1177/1088357615587504

Department of Health. (2010). *Fulfilling and rewarding lives: The strategy for adults with autism living in England.* Retrieved from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

Department of Health. (2014). *Think Autism: An update to the government adult autism strategy.* Retrieved from https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy

Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., & Nieuwenhuizen, C. (2013). Autism and normative sexual development: a narrative review. *Journal of Clinical Nursing*, *22*, 3467-3483. doi: 10.1111/jocn.12397

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., . . . Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: A quantitative and qualitative comparison of three methods. *Journal of Health Services Research and Policy, 12*, 42-47. doi: 10.1258/135581907779497486

Fabri, M., & Andrews, P. (2015). *Autism and university: D2.1 literature review report.* Leeds Beckett University. Retrieved from file://stfdata08/home/PC/Pcp14rc/ManWin/My%20Documents/D2.1-AutismUni-Literature-Review-Report.pdf

Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). I just don't fit anywhere: Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism, 16*, 532-546. doi: 10.1177/1362361311405223

Haertl, K., Callahan, D., Markovics, J., & Sheppard, S. S. (2013). Perspectives of adults living with autism spectrum disorder: Psychosocial and occupational implications. *Occupational Therapy in Mental Health*, 29, 27- 41. doi: 10.1080/0164212X.2010.760

Hedley, D., Uljarević, M., Cameron, L., Halder, S., Richdale, A., & Dissanayake, C. (2016). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism*, 1-13 doi: 10.1177/1362361316661855

Humphrey, N., & Symes, W. (2010). Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. *European Journal of Special Needs Education*, *25*, 77-91. doi:10.1080/0885625093450855

Hurlbutt, K., & Chalmers, L. (2002). Adults with autism speak out: Perceptions of their life experiences. *Focus on Autism and Other Developmental Disabilities*, 17, 103-111. doi:10.1177/10883576020170020501

Iarocci, G., & McDonald, J. (2006). Sensory integration and the perceptual experience of persons with autism. *Journal of Autism and Developmental Disorders*, *36*, 77-90. doi: 10.1007/510803-005-0044-3

Kidder, L. H., & Fine, M. (1987). Qualitative and quantitative methods: When stories converge. *New Directions for Program Evaluation*, *35*, 57-75. Retrieved from: https://www.researchgate.net/profile/Michelle_Fine/publication/227662100_Qualitative_and_quantitative_methods_When_stories_converge/links/00b4952161aeda61ab000000.pdf

Madriaga, M. (2010). ‘I avoid pubs and the student union like the plague’: Students with Asperger Syndrome and their negotiation of university spaces. *Children's Geographies*, 8, 39-50. doi:10.1080/14733280903500166

Madriaga, M., & Goodley, D. (2010). Moving beyond the minimum: Socially just pedagogies and Asperger’s syndrome in UK higher education. *International Journal of Inclusive Education, 14,* 115-131. doi: 10.1080/13603110802504168

Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. Autism, *18*, 223-232. doi: 10.1177/1362361312474121

McAdam, P. (2009). Knowledge and understanding of the autism spectrum amongst prison staff. *Good Autism Practice, 10*, 19-25.

Mehzabin, P., & Stokes, M. A. (2011). Self-assessed sexuality in young adults with high-functioning autism. *Research in Autism Spectrum Disorders, 5,* 614-621. doi: 10.106/j.rasd.2010.07.006

Müller, E., Schuler, A., Burton, B. A., & Yates, G. B. (2003). Meeting the vocational support needs of individuals with Asperger syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation*, *18*, 163-175.Retrieved from http://www.autastics.org/JVRpaper.htm

Müller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism*, *12*, 173-190. doi: 10.1177/1362361307086664

Myers, F. (2004). *On the borderline: People with learning disabilities and/or autistic spectrum disorders in secure, forensic and other specialist settings*. Edinburgh, Scotland: Scottish Executive Social Research. Retrieved from http://docs.scie-socialcareonline.org.uk/fulltext/asdsecure.pdf

Newman, C., Cashin, A., & Waters, C. D. (2010). A modified hermeneutic phenomenological approach toward individuals who have autism. *Research in*

Nursing & Health, *33*, 265-271. doi: 10.3109/01612840.2015.1014587

Noyes, J., & Lewin, S. (2011). Extracting qualitative evidence. In J. Noyes, A. Booth, K. Hannes, A. Harden, A. Harris, S. Lewin , C. Lockwood (Eds.), *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*. Cochrane Collaboration Qualitative Methods Group. Retrieved from: http://cqrmg.cochrane.org/supplemental-handbook-guidance

Penway Barnett, J. P., & Maticka-Tyndale, E. (2015). Qualitative exploration of sexual experiences among adults on the autism spectrum: Implications for sex education. *Perspectives on Sexual and Reproductive Health, 47*, 171-179. doi:10.1363/47e5715

Punshon, C., Skirrow, P., & Murphy, G. (2009). The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism, 13*, 265-283. doi:10.1177/136236130910379

Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, *10*, 511-524. doi: 10.1177/1362361306066604

Robertson, A. E., & Simmons, D. R. (2015). The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception, 44*, 569-586.

Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research*, *13*, 905-923. Retrieved from: http://www.stes-apes.med.ulg.ac.be/Documents_electroniques/MET/MET-DON/ELE%20MET-DON%207118.pdf

Shaw, R. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology*, *7*, 233-243. doi: 10.1080/14780880802699092

South West Yorkshire Partnership NHS Foundation Trust. (2016*). Checklist for Autism Friendly Environments*. Retrieved from http://www.southwestyorkshire.nhs.uk/wp-content/uploads/2015/07/autismFriendlyEnvironmentsChecklist.pdf

Smith, R. S., & Sharp, J. (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with Asperger Syndrome. *Journal of Autism and Developmental Disorders, 43*, 891-910. doi:10.1007/s10803-012-1633-6

Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). *Quality in qualitative evaluation: A framework for assessing research evidence*. Retrieved from http://dera.ioe.ac.uk/21069/2/a-quality-framework-tcm6-38740.pdf

The National Autistic Society. (2016). *The autism employment gap: Too much information in the workplace*. Retrieved from file:///U:/ManW7/Downloads/NAS%20TMI%20Employment%20Report%2024pp%20WEB%20(1).pdf

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 45. doi:1-/1186/1471-228-8-45

Tomchek, S. D., & Dunn, W. (2007). Sensory processing in children with and without autism: a comparative study using the short sensory profile. *American Journal of Occupational Therapy*, *61*, 190-200. doi: 10.5014/ajot.61.2.190

Ung, D., McBride, N., Collier, A., Selles, R., Small, B., Phares, V., & Storch, E. (2016). The relationship between peer victimization and the psychological characteristics of youth with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *32*, 70-79. doi: 10.1016/j.rasd.2016.09.002

Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders, 45*, 1673-1688. doi: 10.1007/510803-014-232-4-2

Appendices

Appendix A

List of search terms

Search terms for Autism:

Autism spectrum disorder

Pervasive developmental disorder

Asperger syndrome

Autistic Disorder

Search terms for qualitative research

Qualitative research

Interview

Grounded theory

Interpretative phenomenological analysis

Thematic analysis

Template analysis

Discourse analysis

Narratives

Personal narratives

Phenomenology

Focus group

Lived experience

Appendix B

Example of completed data extraction table

Data extraction field	**Information extracted**
Author and Date	Muller et al. (2008)
Context and participants	Participants were sought by contacting families, teachers, therapists, and autism support groups. All participants received a small payment for participating. The study inclusion criteria were: 18+; self-reported social communication difficulties; formal/informal diagnosis of Asperger syndrome or ASD based on DSM-IV criteria; no intellectual disability. 13 participants had Asperger syndrome diagnoses, two were informally diagnosed with Asperger syndrome, two had formal high-functioning autism diagnoses, and one had a formal PDD-NOS diagnosis.
Study design and methods used	Data was collected from 18 semi-structured individual interviews. Stake-holders were consulted in drafting the interview protocol. Interviews took place in locations of each participant’s choice (e.g. participants’ homes). Analysis took place in two phases. First, four of the most detailed interview transcripts were selected, and research team members independently read the transcripts, identified and labelled statements relating to (a) positive or negative aspects of social experiences, (b)effective social supports and strategies for improving social connections. The team then met to compare findings and agree upon a preliminary coding structure. Next, the first author used QSR NUD*IST 4.0 a qualitative coding software to refine the coding structure and completed the coding process for the remaining interview transcripts. The team checked the coding structure.
Findings	Analysis revealed a number of common experiences including: isolation; difficulty initiating social interactions; communication challenges; longing for relational intimacy; a desire to contribute to society; and efforts to improve social/self-awareness. Recommended social supports included: external supports (e.g. activities based on shared interests, structured activities, and small groups); communication supports (e.g. communication partners using explicit communication, and their being given instruction in interpreting social cues); and self-initiated strategies for handling social anxiety (religious faith, physical activity and time spent alone).

Appendix C

Quality appraisal tool

10 questions to appraise the quality of qualitative research (adjusted)[2]

FOCUS OF THE APPRAISAL

- Relevance: how useful are the findings to my review question?

- Credibility: are the findings well-presented and meaningful? Valid interpretation of the findings?

- Rigour: has a thorough and appropriate approach been applied?

Screening Questions

1. Was there a clear statement of the aims of the research?
Consider:
- The goal of the research?
- Why it was thought important?
- Its relevance?

Yes
No
Unsure

2. Is a qualitative methodology appropriate?
- Does the research seek to illuminate the actions and/or experiences of participants?
- Is qualitative research the right methodology for addressing the aims?

Yes
No
Unsure

Is it worth continuing?
Yes, continue to next section.
No

Detailed questions

3. Was the research design appropriate to address the aims of the research?

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[2] Based on: Spencer, Ritchie, Lewis, & Dillon (2003)

- Has the researcher justified the research design?
- Did the researcher follow through on the design?

Yes
No
Unsure

4. Was the recruitment strategy appropriate to meet the aims?

- Has the researcher explained how the participants were selected?
- Were the participants the most appropriate to provide access to the knowledge sought?
- Were there are any discussions around why some people chose not to take part?
- Is the sample representative?

Yes
No
Unsure

5. Were the data collected in a way that addressed the research issue?

- Is the data collection setting justified?
- Is it clear how data were collected?
- Are the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- Is the form of data clear (e.g. tape recordings, video material, notes etc)?
- Has the researcher discussed saturation of data?

Yes
No
Unsure

6. Has the relationship between researcher and participants been adequately considered?

- Has the researcher examined their influence, bias on data collection and interpretation?

Yes
No
Unsure

6.1 Is the context clearly described?

- Are the characteristics of the participants and settings clearly defined?
- Was context bias considered?

Yes
No
Unsure

6.2 Were the methods reliable?

- Were data collected by more than one method?
- Is there justification for triangulation, or for not triangulating?
- Do the methods do what they claimed to investigate?

Yes
No
Unsure

7. Have ethical issues been taken into consideration?
– Are there sufficient details of how the research was explained to participants ?
– Has the researcher discussed issues raised by the study (e.g. issues around informed consent, confidentiality or adverse effect)?
- Were details of ethic approval given?

Yes
No
Unsure

8. Was the data analysis sufficiently rigorous?
– If there is an in-depth description of the analysis process
– If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
–Has the researcher explained how the data presented were selected from the original sample to demonstrate the analysis process?
– If sufficient data are presented to support the findings
– To what extent is contradictory data taken into account; does the researcher critically examine their own role, potential bias and influence during analysis and selection of data for presentation, themes or categories?

Yes
No
Unsure

8.1 Are the data 'rich'?
- How well are the contexts of the data described?
- Has the diversity of perspective and content been explored?
- How well have the detail and depth been demonstrated?
- Are responses compared and contrasted across groups/sites?

Yes
No
Unsure

9. How does the evidence support the findings?
- Are the findings explicit?
- Coherent reporting?
- Is their adequate discussion of the evidence for and against the researcher's arguments?
- Has the researcher discussed the credibility of their findings (e.g. triangulation, respondent

validation, more than one analyst).
- Are the findings discussed in relation to the original research questions?
- If interpretation was made, was the process explicit?
- Alternative explanations?

Yes
No
Unsure

10. How valuable is the research?
- How do the findings fit with existing knowledge?
- Has the researcher discussed the contribution the study makes to existing knowledge or understanding?
- Do they consider future research directions?
- Do they consider whether the findings can be transferred to other populations, or other ways the research may be used?

Yes
No
Unsure

Appendix D

Study	**1. Statement of aims?**	**2. Qualitative methodology appropriate?**	**3. Design appropriate to address the aims?**	**4. Recruitment strategy appropriate to the aims?**	**5. Data collected in a way that addressed the research issue?**	**6.a Reflexivity?**	**6.b Context clearly described?**	**6.c Methods reliable?**	**7. Consideration of ethical issues?**	**8. Data analysis is sufficiently rigorous**	**9. Does the evidence support the findings?**	**10. Value of research ?**	**Quality score**
Griffith et al., 2012	✓	✓	✓	✓	✓	✘	✓	✓	✘	✓	✓	✓	20
Haertl et al., 2013	✓	✓	✓	?	✓	✘	?	✓	✘	✓	✓	✓	18
Hurlburt & Chalmers, 2004	✓	✓	?	?	?	✘	✓	✓	✘	✓	✓	✓	17
Madriaga, 2010	✓	✓	?	✘	?	✘	✓	✘	✓	✓	✓	✓	16
Madriaga & Goodley, 2010	✓	✓	?	✘	?	✓	✓	✘	✓	✓	✓	✓	18
Milton &	✓	✓	✓	✘	✓	✓	✘	✓	✓	✓	✓	✓	20

Sims, 2016													
Müller, et al., 2003	✓	✓	?	✓	✓	✘	✓	✓	✘	✓	✓	✓	19
Müller, et al., 2008	✓	✓	?	✓	✓	✘	✓	✓	✘	✓	?	✓	19
Newman, et al., 2010	✓	✓	✓	✓	✓	✘	?	✘	?	✓	✓	✓	18
Penwell Barnett & Maticka-Tynedale , 2015	✓	✓	✓	✓	✓	✘	?	?	✓	✓	✓	✓	20
Punshon, et al., 2009	✓	✓	✓	✓	✓	✘	✓	✓	✓	✓	✓	✓	22
Robertson & Simmons, 2015	✓	✓	✓	✓	✓	✘	✓	✓	✓	✓	✓	✓	22
Smith & Sharp, 2012	✓	✓	✓	✓	✓	✘	✓	✓	✓	✓	✓	✓	22

Van Hees, et al., 2015	✓	✓		✓	✓	✗	✓	✓	✓	✓	✓	✓	22

Note: ✓= yes; ✗= no; **?** = unsure

Appendix E

Thematic Synthesis Methodology

Thomas and Harden (2008) describe synthesising data across three phases (1) line by-line coding of the findings of the primary studies, (2) development of descriptive themes, and (3) development of analytical themes. The final stage of conceptual innovation was not undertaken as Thomas and Harden (2008) assert this is only necessary when the primary studies do not directly address the review question.

The studies were imported into NVivo Pro10 (QSR International) a qualitative data analysis software. Next, a study was selected and line-by-line coding of its findings (defined as all text labelled ‘results’ or findings as per Thomas and Hardens’ (2008) suggestion) was undertaken. Codes were created inductively to capture the meaning and content of each sentence. Subsequent articles were analysed and concepts were translated from one study to another. Coding of new studies added to the ‘bank’ of codes, and new codes were developed as necessary. Before completing this stage of the synthesis, all the text apportioned to a particular code was checked for consistency and to see whether additional codes were required. This phase produced 304 initial codes.

Next, similarities and differences between codes were considered in order to group them into an organizational tree structure of three super-ordinate descriptive themes, and three subthemes.

Part Two

Research Report

Gender Dysphoria in Individuals with Autism: A Qualitative Study using Grounded Theory

Abstract

Objectives

A growing body of research describes the co-occurrence of autism spectrum disorder (autism) and gender dysphoria (GD) and a higher prevalence of autism among gender identity clinic patients; however understanding of this is limited. There is a dearth of research into gender identity in people with autism, particularly from the individual's perspective. This qualitative study aimed to understand the experience of GD in people with autism, and the role of interpersonal relationships and the social environment in experiences.

Design and Methods

A social constructivist Grounded Theory approach to data collection and analysis was used with 10 adults with a diagnosis of autism and GD. Participants undertook either face-to-face or video-call semi-structured interviews.

Results

A theoretical framework of common processes involved in understanding and addressing GD was developed comprising: *Feeling Different from an Early Age*; *Concealing and Supressing Gender Feelings, Isolation and Poor Mental Health*; *Percolation of Gender Feelings*; *Reaching a Precipice*; *Achieving Critical Mass*; *Social Transition*; *Wellbeing, Engagement and Witnessing*; *Physical Transition;* and the influence of autism and the social environment. The overall experience is captured in the core category *Conflict versus Congruence*.

Conclusions

Individuals achieve greater personal congruence and wellbeing upon transition. However, conflicts remain as they navigate the social world with an enduring fear of hostility and sense of difference due to having two stigmatised identities.

Practitioner points

- Services require training to enable them to be proactive in addressing gender issues with people with autism.
- Joint working between autism services and gender clinics would enable cost-effective expertise sharing and may enhance gender services' accessibility to people with autism.
- Services might consider supporting transgender peer mentoring programmes, or support groups.
- Caution in interpreting the findings is warranted due to participants fitting the profile of Asperger's syndrome or high-functioning autism, therefore limiting the findings representativeness to people with greater functional impairment.
- Participants were Caucasian and had accessed NHS services, limiting transferability to individuals residing in countries with different notions of gender, or where they must pay for gender-confirming treatment.

Keywords: Autism, ASD, qualitative, grounded theory, gender dysphoria.

Introduction

Autism spectrum disorder (henceforth referred to as autism) and gender dysphoria (GD) are rare conditions. Population prevalence rates are estimated at 1 in 100 (Brugha et al., 2011) for autism, and 1 in 5000 for GD (Reed, Rhodes, Schofield, & Wylie, 2009). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM–5: American Psychiatric Association, 2013) autism is a neurodevelopmental disorder characterised by impaired social interaction and communication, and restricted and repetitive behaviour, interests or activities. GD is characterised by distress that accompanies incongruence between experienced or expressed gender and gender assigned at birth (DSM-5). Many people who experience GD want to change their appearance and/or bodily features to be more congruent with their gender identity. Individuals may undertake a transition process that can encompass a range of steps, from social transitioning, to hormone therapy and gender-affirming surgeries through gender identity services (Reed et al., 2009). Individuals with GD are understood to be transgender[3], although not all transgender people experience GD.

Despite being rare conditions characterised by distinct diagnostic criteria there is a small but growing body of literature describing their co-occurrence and reporting a significantly higher than expected incidence of autism/autistic traits in gender clinic populations compared to the general population prevalence. For instance, De Vries, Noens, Van Berckelaer-Onnes, and Doreleijers (2010) report 6.4 % of children and 9.4 % of adolescents referred for GD had autism. Similarly, Paterski, Gilligan, and Curtis (2014) study of adults with GD found 5.5 % showed clinically significant levels of autistic traits.

A small body of research consisting mainly of case studies offers somewhat controversial perspectives (without empirical support) on the co-occurrence of autism

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[3] individuals whose gender identity differs to their birth-assigned sex

and GD, indicating GD develops as a “sequel to autism” (Kraemer, Delignore, Gundelfinger, Schneider, & Hepp, 2005, p.295), as: an expression of the ‘extreme male brain’ (Baron-Cohen, 2002); deficits in Theory of Mind; a manifestation of cognitive rigidity and intolerance of ambiguity (Jacobs, Rachlin, Erickson-Schroth, & Jannsen, 2014); or ‘cross-gender behaviour’ represents an inherent predisposition toward ‘unusual interests’ characteristic of autism (Williams, Allard, & Sears, 1996). Many of these appear to discredit the authenticity of individuals’ gender identity experiences by assuming they are a symptom of autism. The nature of this research reflects that of the evidence base in the area of sexual and gender identity in people with autism. What research exists is again either case studies, or quantitative, relies on carer/parent report, and focuses on what is viewed as ‘inappropriate sexual behaviour’ and ‘sexual dysfunction’ (for more detail see Dewinter, Vermeiren, Vanwesenbeeck, & Nieuwenhuizen, 2013).

Correspondingly, evidence suggests professionals, services and communities generally fail to “look beyond people’s autism diagnosis” to acknowledge the sexual and gender identity-related needs of individuals with autism (Department of Health[DoH], 2014, p.22). This finding is set within a broader context of governmental reports of adults with autism and their needs continue to be marginalised within services, institutions and the community generally (DoH, 2010; 2014). Individuals with developmental disorders also report difficulty accessing LGBT community spaces (commonly clubs and bars) due to physical, communication or sensory difficulties and being accepted among non-disabled members (Elderton & Jones, 2011).

There is a growing body of research on transgenderism in neurotypical individuals. However, like the autism research, it is predominantly theoretical or quantitative, despite pleas from transgender individuals to be “qualified not quantified” (Sausa, Keatley, & Operario, 2007, p.771). Four Grounded Theory studies of: Ekins

(1997), Devor (2004) Heistand and Levitt (2005) and Levitt and Ippolitto (2014) are exceptions. These studies provided rich accounts of transgender identity development, identified unique themes relating to this experience, and practical and theoretical implications, thereby making valuable contributions to the knowledge base. However, the research mostly comprises of white, middle-class, non-disabled individuals, and is yet to fully interrogate the significance of other intersecting social identities including race, or disability on individuals' gender identity development and expression.

Neurotypical[4] transgender individuals are also similarly marginalised and disadvantaged in access to public services and employment; as well as experiencing transphobic hatred, and aggression (House of Commons Women and Equalities Committee, 2015). They also report marginalisation within LGBT communities (Devor, 2015). Those with ASD and GD therefore face "layered stigma" (McCann, Lee, & Brown, 2016) and 'double discrimination' (Elderton & Jones, 2011).

The emotional wellbeing of individuals with co-occurring GD and autism has not been empirically investigated. However, both autism and GD are associated with an increased risk of mental health disorders, most commonly depression and anxiety. An estimated 15% of people with autism (Balfe & Tantam, 2010) and 32% of transgender people experiencing GD attempt suicide (Clements-Nolle, Marx, & Katz, 2006), exceeding general population prevalence rates. In both populations 'minority stress'- stigma, prejudice, and discrimination related to holding a social minority identity (Meyer, 2003)- is a risk factor for mental health problems and suicide (Rosbrook &Wittingham, 2010; Winter et al., 2016).

The scarcity of qualitative studies in autism has led to calls for more from the

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[4] An abbreviation of neurologically typical i.e. not on the Autistic spectrum originating in the Autistic community.

research community (Bölte, 2014). Furthermore, individuals with autism have reported their dissatisfaction with their lack of involvement in research (Pellicano, Dinsmore, & Charman, 2013).

Aims

The co-occurrence of autism and GD and the high prevalence of autism in gender clinics has been reported, however understanding of this is limited. There is a dearth of research into gender identity and GD in people with autism, and what exists marginalises the individual’s voice. This study sought to address this gap in the evidence base and understand the subjective experience of GD in adults with autism.

Research Questions. ‘Sensitizing concepts’ gained from familiarity with the literature and personal communications with an expert by experience led the researcher to expect that interpersonal relationships and the social environment may impact on the individual’s experience of GD and their gender identity development.

The following research questions were investigated:

- What is the experience of people with autism in coming to understand and address GD?
- What is the role of the social environment in the experience of GD for people with autism?

Method

A qualitative research design was utilised due to its exploratory nature given the dearth of research and theoretical understanding in this area. A range of qualitative approaches were considered, in particular Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) and Grounded Theory (GT). IPA, as an approach, is interested in how individuals subjectively experience the world and make sense of particular issues. This approach would have facilitated capturing detailed, reflective first-hand accounts from people with autism on the lived experience of GD

(Larkin & Thompson, 2012). However, GT was chosen as it similarly positions individuals' actions, experiences and the meaning they attribute to them at its core, whilst seeking to develop a theoretical understanding of these experiences (Charmaz, 2014). Thus, the approach offered the potential of generating a theoretical framework for the relationship between GD and autism, and the influence of interpersonal experiences and the social environment that is empirically grounded in individual experience.

The original conceptualisation of GT by Glaser and Straus (1967) is underscored by a realist epistemology- a 'true' state of the world exists that may be known, characterised and measured. Glaser and Straus (1967) postulate that theory is *discovered* by the researcher maintaining objectivity through avoiding importing prior knowledge or assumptions into data generation and analysis. By contrast, the social constructivist version of GT popularised by Charmaz (2014) asserts social reality is "multiple, processual and constructed" (p.13), and acknowledges researchers' influence on data collection and interpretation which enables construction of theory formed on shared meaning. The present researcher's epistemological stance is aligned with social constructivism.

Furthermore, the social constructivist GT approach's focus on psychosocial processes, and individuals' construction of meaning in relation to their social context (social structures, situations and relationships) (Tweed & Charmaz, 2012) made it an ideal match for the current research question.

Procedure

Recruitment. Opportunity sampling was used to recruit eleven participants from a regional gender identity service (*n* = 5); an Autism and Neurodevelopmental service (*n* = 3); an advertisement on a Facebook page for a local support group for transgender people (*n* = 1) (see Appendix A for the advert); and via the expert by experience (*n* = 2).

The researcher attended both services to present the research to clinicians to gain their support in recruiting service users, and also presented at a service-user meeting to encourage participation. During clinical contacts clinicians discussed the research with service users who met the inclusion criteria, and obtained their consent for the researcher to contact them. They were also given a participant information sheet (Appendix B). The researcher then contacted them and asked basic screening questions to ensure their eligibility to participate before answering any questions they had about the research and arranging an interview.

Participants. Participants met the following inclusion criteria: having formal autism and GD diagnoses according to DSM-5/International Classification of Diseases, tenth edition (ICD-10) criteria and sought gender service medical interventions; aged 18 or over. Individuals at any stage of assessment, treatment or post-treatment for GD were included. Participants were excluded if they: were deemed by clinicians to be ‘high risk’ in terms of suicidal ideation/intent; were non-fluent in English; did not have both GD and autism formal diagnoses.

One of the individuals recruited to participate was unable to undertake an interview (despite several offers of interviews over the data collection period) due to experiencing high levels of social anxiety. Another of the participants (Paula), although able to undertake an interview, was highly anxious during the process. Subsequently the content of her interview was limited and so she is quoted less frequently than other participants within the results section. The demographic characteristics of the final sample (*n* = 10) are displayed in Table1. Although the participants identified as transgender, most endorsed other preferred gender designations. Eight out of 10 participants received their autism diagnosis prior to GD diagnosis. All participants had socially transitioned, and nine had undertaken some level of physical intervention (hormones and/or surgery). Three participants had completed the surgery they desired (maximum three years ago).

Table 1

Demographic and clinical characteristics of the sample

Name (pseudonym)	**Age**	**Preferred gender designation**	**Relationships status**	**Sexual orientation**	**Education level**	**Occupation**	**Age received Autism Diagnosis**	**Age received GD diagnosis**
Alana	34	Woman	Single	Straight	GCSE	Unemployed	14	32
Alex	18	Man	“	Gay	GCSE	Student	16	17
Felix	39	Genderqueer	“	Grey asexual pan-romantic	Masters	Unemployed	34	37
Kate	33	Non-binary transfemine androgynous	“	Queer	Degree	Clerical	32	34
Max	28	Man/agender	“	Bi-sexual	A-level	Student	26	25
Paula	50	Woman	“	Asexual	NVQ	Unemployed	49	45
Rhianna	31	Woman	Complicated	Lesbian/Asexual	NVQ	Unemployed	14	29
Sam	25	Man	Single	Asexual	NVQ	Self-employed	7	22
Wez	65	Man	Married	Straight	PhD	Lecturer/self-employed	35	61
Zain	51	Man	Co-habiting	Straight	NVQ	Quality assurance	40	48

Note: sexual/gender identity terms used were given by participants

Data Collection. Participants completed a semi-structured interview, four of whom consented to second interviews to assist with theoretical sampling and data saturation (see Appendix C interview invitation). Nine interviews were conducted at the autism service; and one via video call (as the person was outside the UK at the time of interview). Interviews commenced with demographic information collection before a series of open-ended questions shown in Table 2 (see Appendix D for full interview schedule). In GT the interview schedule evolves over time to explore emerging themes from concurrent data analysis (see analysis section). Brief feedback on the interview process was obtained at each interview’s conclusion. Interviews were 70-160 minutes duration and audio-recorded.

Table 2

Interview schedule overview

Initial questions about GD

How do you experience your gender?

What does ‘gender dysphoria’ mean to you?

Further questions:

Tell me about when you first got the sense that your gender identity did not match your gender assigned at birth.

What has happened to these feelings over time?

Can you tell me about how you came to use gender services?

Relationship between GD and autism

How do autism and GD interact together?

What impact has having autism had on your experience of GD and addressing it?

Interpersonal/social experiences

What impact have your relationships/experiences with others had on your understanding of GD and your gender identity development?

How has your autism and having GD influenced your relationships with: family/loved ones; services; LGBT community; society in general?

Analysis

Each interview was transcribed verbatim and imported into NVivo 11 qualitative data analysis software (QSR International, 2015). A summary of the GT analytic process is shown in Figure 1.

Interview data was analysed following each interview allowing the researcher to become sensitised to issues and concepts arising to pursue in subsequent interviews. Analysis began with line-by-line coding of the transcripts, giving each line in the data a short label summarising what was happening (see Appendix E for an example). To ensure codes remained grounded in the data, and due to GT's emphasis on analysing processes, gerunds were used where possible.

Focused coding was undertaken in later interviews, selecting the most frequently occurring and/or significant earlier codes to sort and synthesise larger segments of data and develop higher-order codes. This began the process of theoretical integration which progressed over subsequent analytic steps (see Appendix F).

Constant comparison between data, codes and categories was conducted throughout the analytic process to develop increasingly interpretative and abstract conceptual categories. Memo-writing also supported the analytic process by enabling the researcher to capture their analytic decisions, explore ideas and elaborate categories, specify their properties, identify gaps and define relationships between them (see Appendix G for examples). In later memos diagramming was used to assist integrating categories into a theoretical framework (see Appendix H for an example).

Theoretical sampling was undertaken, seeking pertinent data to elaborate and hone emerging categories from concurrent data analysis. This involved modifying the interview schedule over time to include specific questions to develop emerging categories (Charmaz, 2014). For instance, autism as a source of 'conflict' in addressing GD emerged from the first interview as a tentative category. However, in subsequent interviews autism was also identified as offering protection to express ones gender identity freely. The original interview schedule was therefore modified to incorporate questions to explore this and develop the category (e.g. 'are there ways in which having autism helped you in your experience of GD?'). Purposeful ordering of participants for interview also facilitated category elaboration. For example, the first four interviewees were with trans women and they indicated social transition difficulties which related to their masculine physical characteristics. Therefore obtaining trans male individuals' perspectives was subsequently prioritised to compare and contrast experiences.

In later interviews, interviewees were asked to verify the credibility of the emerging categories and conceptual model ('member validation'). Earlier interviewees were also provided with the category properties and an overview of the theoretical model and their feedback was requested. Participants' comments aided the refinement of categories and the final theoretical model. For instance, one participant highlighted the bi-directional relationship between social and physical transition which hitherto had been understood to be uni-directional- social transition leading to physical transition. The model was subsequently amended to reflect this.

In GT researchers generally aim to reach theoretical saturation- the point at which no new properties of the core categories can be identified. Although some have questioned whether obtaining saturation is possible due to potentially limitless new data, and the situation of the research i.e. time limits and access to participants (Dey, 1999; Weiner, 2007). Dey (1999) instead suggests the term 'theoretical sufficiency'- where the researcher claims categories are *suggested* by the data. Due to the limited size of the target population and the sample being heterogenous, theoretical saturation could not be claimed.

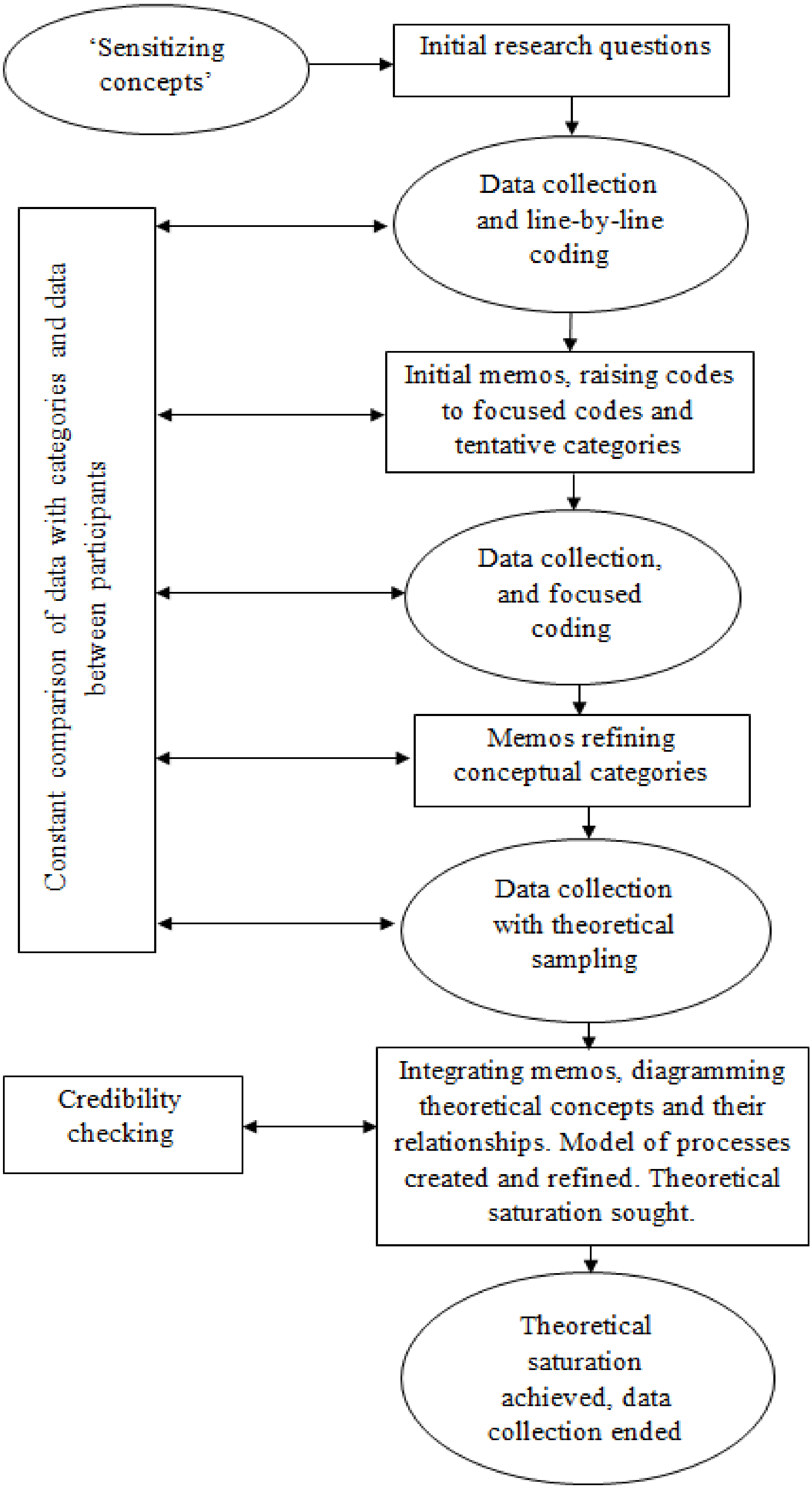

Figure 2. The GT process adapted from Charmaz (2006, p.11)

Ethical Considerations

Ethical approval was obtained from the University of Sheffield Psychology Department Ethics Committee and the NHS Health Research Authority. Governance approval was obtained from the university and NHS Trust prior to contacting participants (see Appendices I, J.K for approval confirmations). Participants' details, encrypted interview audio-recordings, and transcripts made anonymous were stored as password protected documents/files.

Participants were given detailed verbal and written information to ensure they understood the nature of the research and requirements of participation and so were able to provide informed consent (see Appendix L for the consent form). The participant information sheet outlined participants' right to withdraw their consent at any time. This was verbally reiterated prior to beginning each interview.

The researcher acknowledged the interviews may illicit strong emotions or distress for participants. Measures that would be taken in the event of disclosure of risk to self or to others were outlined in the participant information sheet (see Appendix M for more details). No risk issues were disclosed during interviews.

Quality Control

Elliott, Fischer, and Rennie's (1999) quality guidelines were used to ensure the study's quality (outlined in-full with the researcher's actions in Appendix N). Their criteria of 'owning one's perspective' and 'providing credibility checks', in particular, were given careful consideration. 'Owning one's perspective' involved the researcher taking a reflexive approach- identifying her own theoretical positioning and personal anticipations, and acknowledging the impact they may have on the data collection and interpretation (Shaw, 2010). The researcher kept a reflective journal for this purpose and also undertook peer supervision with other qualitative researchers (see Appendix O for a journal excerpt, Appendix P and Q for the reflexivity peer supervision protocol and researcher position statement).

‘Providing credibility checks’ involved sharing and discussing emerging categories and conceptual frameworks with participants, as outlined above. The data analysis process was audited by a fellow qualitative researcher to verify the developing categories were grounded in the data and to interrogate category properties (see Appendix P for the audit protocol). Feedback from these processes was incorporated into the theoretical framework.

Results

The participants’ experiences are described below in terms of categories incorporating illustrative quotations (see Appendix S for additional quotes). Participants’ names are pseudonyms.

The analysis built-up a framework of common processes involved in coming to understand and address GD, embarking upon social and physical transition, and the influence of autism and the social environment. Each element of this process represents a category. The following categories were delineated: *autism as a barrier or protector*; *restrictive and facilitative environments*; *feeling different from an early age*; *concealing ignoring and suppressing gender feelings*; *isolation and poor mental health*; *percolation of gender feelings*; *reaching a precipice*; *achieving critical mass*; *social transition*; *engagement, witnessing and wellbeing*; *physical transition*. The overall experience of GD is captured in the core category *Conflict versus Congruence*. Figure 2 illustrates the relationships between categories.

As the data was derived (largely) from gender clinic patients who seldom have contact with clinics beyond surgery, most participants had embarked upon physical transition, but only three had completed their desired surgeries. Therefore the predominant focus of the transition section is social transition with physical transition reinforcing this.

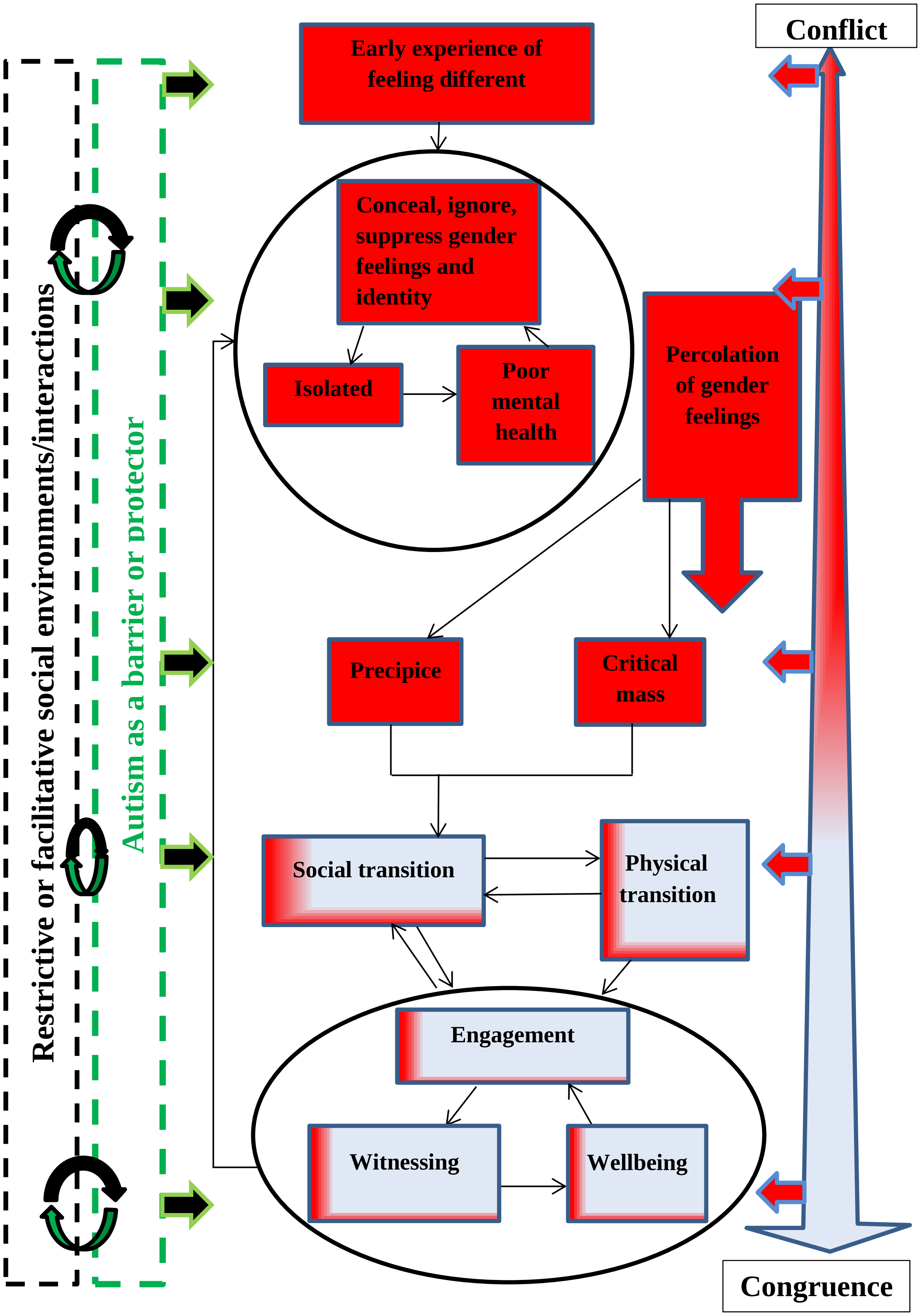

Figure 2. Proposed theoretical framework of the process of understanding and addressing GD in people with autism

Summary

As Figure 2 illustrates, the relationships between categories are complex and bi-directional, so an initial summary is offered below to support readers' understanding.

Core category: Conflict versus Congruence. The core category emerging from the analysis, evident in all participants' narratives, was *conflict versus congruence*. This lies at the heart of the experience of GD in adults with autism who have sought to undertake social and physical transition. It connects all categories, suggesting the experience of GD is one of multi-faceted conflict extending beyond the diagnostic descriptor, comprising conflict with the body; interpersonal conflict with others and society; and psychological or intrapersonal conflict, as Kate explained:

"If I was to give you a definition [of GD], it would be a feeling of conflict…there are lots of . . . different levels of conflict…: social…physical…psychological"

Resolution of conflict and the pursuit of congruence inform experiences of: *'feeling different from an early age'*; *'concealing, ignoring and suppressing gender feelings'* and the *'percolation of gender feelings'* involving the gradual development of language defining and understanding GD and their identity. Some continue suppressing their feelings, leading to an experience described as *reaching a precipice* where only transition may counter the feeling that life is no longer worth living inauthentically, whereas others meticulously plan and build resources *achieving critical mass*. The consequent *social transition,* reinforced by *physical transition* supports movement into *engagement, witnessing and validation,* and *wellbeing*. Generally, individuals move from high body, inter- and intrapersonal conflict and low congruence earlier in life, to lower conflict and higher congruence as understanding develops and transition is undertaken. However, conflict and challenges occur in social transition, into physical transition and beyond, principally in navigating the social world in a new gender role.

Restrictive and facilitative social environments and interactions. The social environment is integral to the sense of conflict and significantly impacts on experiences across the processes. This impact is predominantly *restrictive*, in that it hinders understanding, exploring and expressing gender identity, amplifying or maintaining feelings of conflict underpinned by the dominance of cis-normativity in Western society.

Accessing supportive relationships and environments was instrumental to facilitating understanding and exploration of gender and providing a wider sense of belonging, purpose, and so increasing personal congruence. These relationships create the necessary preconditions for undertaking transition. These "precious" and "rare" facilitative relationships were commonly with LGBT community members.

Autism as barrier or protector. Autism was integral to the sense of conflict in compounding the challenges associated with GD.

Kate: *"Autism complicates things…it's always more complicated with autism".*

Autism impacts significantly upon the phases and exacerbates the impact of the social environment. Autism is a *'barrier'* in the path of understanding and expressing gender-related concerns, accessing facilitative and supportive relationships. Experiencing discrimination due to two stigmatised identities means gender-related concerns are sometimes ignored or invalidated, impacting wellbeing and access to medical interventions. However, for a few participants *'autism as protector'* counteracts fears of negative perceptions, liberating the individual to live authentically according to their gender identity.

The Main Findings

As categories 2-3: *Conflict versus Congruence*; *Restrictive and Facilitative Environments and Interactions* and *Autism as Barrier or Protector* are integral to the overall experience of GD and the common processes identified, they are considered within the detailed exploration of the categories comprising the processes.

Feeling different from an early age. Participants described feeling ‘different’ from their earliest memories of childhood. Although initially lacking the concepts or language to understand and articulate their feelings, they located them in their experience of gender, particularly social roles, and their body. Social environment and autism were central to this experience.

Participants’ accounts of childhood revealed intense multifaceted conflict, incongruence, and so distress, rooted in a collision between their experiential knowledge of their gendered self and others’ treatment and expectations of them, especially regarding behaviour. In particular, family, peers and teachers used pronouns which did not match participants’ experienced gender identification, and expected them to behave in ways considered ‘typical’ of their birth-assigned gender. Participants, given their perspective they were patently not of the gender others saw them as, felt confusion and unease, making social environment integral to their sense of conflict.

Sam: *“I never felt I was a girl and I never…wanted to wear girly clothes or things like that, I always saw myself as being a man…[I thought] everyone else was strange cos they saw me as being a girl.”*

As participants aged they recognised their difference from other girls and boys, so anxiety and distress grew concerning the mismatch between their experienced gender identity and body. That these experiences seemed unintelligible and not shared by anyone else further increased anxiety.

Sam: *“A lot of the boys didn’t want to play with me and a lot of the girls were more take you under your wing, but I didn’t see myself as a girl, so you’re sort of stuck in the middle.”*

Felix: *“[My Body]…never felt right…even when I was too young to have words to describe it I just had the strong feeling…that my body should be more like the boys and* *why wasn't it?!"*

Trans male[5] participants' families permitted some flexibility in childhood about dress and behaviour, allowing *more* congruence with their (male) identity, although these expressions remained within the socially accepted 'female' role of the 'tomboy'. Trans females[6] were denied any flexibility in experimenting with or expressing femininity.

Zain: *"I was always called a tomboy and that was acceptable...because that was someone who was just a sporty female… but if I had known back then about gender dysphoria and raised it, it would have been an absolute no-no".*

Felix: *I'm lucky my parents…were fairly liberal…I was allowed to run around and climb trees and not forced into skirts and things so much, apart from school…but [at] Christmas, I'd ask for Lego and get dolls"*.

School was anxiety-inducing and frustrating as it rigidly enforced traditional gender roles through uniforms, subject selection and the lack of privacy in changing facilities. This magnified participants' sense of gender conflict and difference from others.

Paula: "*I wanted…to do girl things like cookery, but…they tried to stop me. Well, I insisted, and they tried to stop me but they didn't".*

Alex: *"Teachers started separating us when we were getting changed and I was trying to stay with the boys because I felt awkward with the girls. I didn't know where to look because - all the bras and things…I'd…feel a bit weird and…stare at the wall".*

Autism was integral to and compounded participants' early feelings of difference and conflict. One participant explained autism and GD mean one sees the world very differently from neurotypical people, but their experiences were often invalidated.

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[5] Individuals assigned female at birth whose gender identity is male/masculine.

[6] Individuals assigned male at birth whose gender identity is female/feminine.

Zain: "*Your experience is really different so it's always in conflict, in communication I was in the wrong, it was like "I can't be in the wrong", it's really debilitating…Add to that seeing gender differently and WHOAH!…Autistic people can end up with mental illnesses because they're being told their truth doesn't exist and that's really scary".*

Some participants felt they had been discriminated against due to autism, leading them to feel like "second-class citizens".

Rihanna: *"Cos of my Asperger's and erratic behaviour they took me out of school…and put me in a place with other bad kids…druggies, arsonists…And I spent my entire school years there…It's not even a school, it's just a place they get …people out of the way until they are old enough to arrest, pretty much."*

Social communication difficulties, in combination with their different experience of gender were a "double whammy" leading to anxiety around others and rendering friendships difficult, with participants becoming "loners" and targets for bullying.

Sam: "*The boys didn't want to play with me and a lot of the girls…And being autistic as well, it's a double-edge sword…trying to fit in…I don't think either of them helped with friendships".*

Rihanna eloquently summarised the sense of difference, conflicted selfhood and relationship to others resulting from the interaction of GD, autism and a highly restrictive, stigmatising environment:

Rihanna: *"I just didn't feel I fitted in anywhere, not with my sisters, my brother, other people or EVEN with myself, it's like everyone was a stranger and I was the strangest of the lot …I'd think…am I just not supposed to exist?!"*

Concealing and suppressing gender feelings. Participants' accounts illustrated how the restrictions of the social environment and autism led to them to conceal and suppress their gender feelings at great cost to their wellbeing and sense of personal congruence.

Participants outlined how autism-related social communication difficulties including finding the words to express their gender-related feelings and experiences, initiating conversations about them, and predicting others responses, increased their anxiety. Combined with the restrictions of a social environment lacking any transgender discourse and intolerance for difference (gender and neurodevelopmental), most participants felt unable to speak to others of their distress and gender feelings. They felt this delayed their understanding their experiences and gender identity and perpetuated their internal conflict.

Kate: *"[Autism] makes it really difficult to say how I feel…I know lots of trans people who don't have a problem voicing their emotions, and how dysphoria affects them".*

Felix: "*I knew I'm not the gender you say I am…but I also knew I could be defeated by the argument 'this is the state of your genitals so this is what you are' because I didn't know any [counter]arguments, and would find it hard to express, even if I did, because of [autism]".*

Participants, believing their gender experiences were deviant and shameful, felt concealing them from others, presenting in ways socially expected of their birth-assigned gender and suppressing may enable them to "experience some normality" i.e. escape some of the associated conflict and distress. The seeming hopelessness of addressing their difficulties, due to lack of awareness of transition and medical treatment made reducing distress important.

Felix: "*there's big conflicts between how you feel and what other people are saying and how you deal with that…you hide who you really are…you mentally push it away to some extent because it's not good for your mental health to keep banging your head against a brick wall."*

Even those with supportive families concealed experiences, fearing wider societal disapproval and discrimination. Whilst some could ignore GD feelings most of the time, others felt their presence continually "like a dark and ominous cloud looming". One participant felt autism led to perseverative thinking:

Kate: "*I think too much and often…I can think too much about my gender…and [that triggers] a fairly negative spiral"*.

Puberty was an important element of the experience in this phase as the pressure from others to conform to typical gender presentations intensified, even for trans males previously afforded some flexibility.

Felix: "*My mum had to persuade me I wasn't allowed to go around topless in the summer anymore and I was really fed up but felt bound to comply, [due] to gender behaviour expectations again".*

Puberty intensified GD making ignoring it more difficult. The bodily changes were sometimes unexpected - as some participants had assumed or fantasized their body would change to align with identity - and always devastating, as they sharply brought into focus the conflict between gender identity and body.

Alex: *"Things were appearing where they shouldn't be. I didn't like it…I didn't know what was happening. I just thought for some reason it wasn't going to happen to me"*

Most participants described hating their body and not recognising it as their own.

Felix: "*I always had this weird sort of phantom limb thing going on [feeling they had a penis]…In terms of the shape of my genitals…But no matter how many times I would look at how things were my brain was never 100 percent convinced".*

One participant described attacking their body to punish it, feeling it had betrayed them:

Rihanna: *"More than once I attacked it…one time when I was particularly feeling down I scratched…and scratched. I skinned my arm, mum caught me and sent me to doctors".*

Autism was thought to contribute to difficulties as participants recognised change was very challenging for them. Many felt sensory sensitivities made the body a source of distress aside from dysphoria. Autism also presented barriers to successfully enacting expected gender roles through preventing participants from absorbing the requisite cultural norms and schemas:

Alana: *"We're not born with this 'Mundy[7]' encyclopaedia or this psychic network that Mundies seem to know naturally what to do, we don't have that".*

Felix described feeling in a *"double bind of trying to 'pass' as neurotypical…and also trying to act or 'pass' as a woman…I felt like I was in drag."*

During adolescence most of the trans female participants secretly expressed their femininity by cross-dressing, which brought momentary reprieve from the pressure of suppression but also guilt due to internalised transphobia. If discovered they were punished, enhancing their sense of deviancy.

Isolation and poor mental health. Most participants discussed their anger at others regarding their invalidation, mistreatment and discrimination, but also internalised feelings of anger, hatred and self-blame for their difficulty with conforming to cis-normative neurotypical standards:

Rihanna: *"There's a lot of things I hate but…nothing can even compare to how much I hate myself, that is the bottom line".*

Distrust of others coupled with low self-esteem and difficulties "passing as normal" led participants to become increasingly withdrawn, further impacting their mental health. Some had suicidal thoughts. Coping mechanisms typically included devoting themselves to schoolwork or other interests, but three participants used alcohol, drugs and self-harmed. Despite efforts to the contrary, this phase saw participants' sense of conflict intensify.

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[7] Neurotypical people

Percolation of gender feelings. *Percolation of gender feelings* overlaps with *concealing and suppressing gender feeling*. Its subcategories: *reaching a precipice* and *achieving critical mass* represent the outcome of the percolation phase. Despite attempted suppression and the enactment of normative gender, there persisted a strong sense of an alternatively-gendered self which strengthened overtime as participants gained understanding of their gender, which made concealing increasingly problematic. Autism, particularly its diagnosis, affected coming to understand gender experiences and the routes taken towards addressing them.

Participants' accounts suggested a percolation of their gender-related concerns over time. Whilst initially outside of conscious awareness, they slowly began a more conscious exploration of their assigned and experienced gender. Through this they developed self-understanding and a language for their GD and gender identity. Routes to greater understanding were idiosyncratic, but learning about transgenderism was commonly seen as the final part of the puzzle which made sense of all previous experiences. One participant reframed the metaphor of the boiling frog[8] to illustrate this process:

Alana: "*…the frog in cold to hot water...it [knowing you are transgender] doesn't really BANG hit you, it creeps, you grow up with…knowing you're…different…You just don't know until you get to a certain point where you…just know exactly what it is".*

Some participants explored their mandated gender status to better understand it and to find a comfortable way of expressing it.

Felix: *"I did go through a stage of exploring my femininity…and choosing to go out in the evenings in a skirt and seeing how that felt and…it felt a bit like doing drag... I think exploring femininity gave me a better understanding how I felt my gender to be".*

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[8] A metaphor cautioning people to be aware of even gradual change lest they suffer eventual undesirable consequences.

As Felix indicates these experiences had the unintended consequence of confirming their lack of fit to their assigned gender. Similarly, two transmen, in the absence of knowledge of transgenderism, felt their experiences related to their sexuality and adopted "butch lesbian" identities which allowed for a temporarily sufficient, expression of their masculinity.

Some participants described insights gained through others witnessing their experienced gender identity, reinforcing its authenticity. As Zain explained, his lesbian partner witnessed the male identity he had not spoken of:

Zain: *"[NAME-partner] used to call me her little Italian boy and I really liked that…so yes I suppose…quite similar to my autism diagnosis, these little pieces that just…come into, place…which make sense of so much else of the rest of my life".*

Three participants, had heterosexual relationships, but their unsatisfying nature served as further confirmation of their experienced, but still concealed gender identity.

Alana: *"I tried…bits of normality and one of the things I did was, I'm a guy, get a girlfriend…The relationship of course did not work because I wasn't acting as she would have preferred, the relationship fell apart. I'm…glad…as it helped my evolution"*

Most participants felt their autism diagnosis (which for most happened prior to their GD diagnosis) was integral to their understanding their gender identity. This diagnosis was a relief for most participants, confirming one element of their sense of difference, so enabling them to focus on another.

Felix: "*Now I knew what autism was…Although, what that OTHER thing was, was still a bit unclear."*

Diagnosis also gave access to support and helped build coping resources for the later challenges of social and physical transition.

Zain: *"the autism [diagnosis] process…brought answers…to communication…and other health issues…that was…powerful…it allowed me to be in good strong place".*

Two participants also felt diagnosis initially complicated their understanding of GD and gender identity. One felt that receiving the autism diagnosis beforehand led them to conflate the two, distracting them from understanding their gender:

Wez: *"Autism became a coat hanger…I hung everything on…it wasn't until a long time later, when I saw about transitioning I realised these things were clearly about my gender like my breasts…I couldn't abide them, knowing about them, touching them, that wasn't sensory sensitivity…it was very specifically gender".*

The other participant explained the "gender-loaded stereotypes" surrounding autism, e.g. 'the extreme male brain' theory increased her dysphoria (as it implied she had a male brain). Her family used this diagnosis to discredit her transgender identity. They assumed her experiences related to autism symptomatology which caused her extreme distress and sometimes to doubt the validity of her dysphoric feelings.

The reverse could also be problematic. A trans male participant whose autism diagnosis came after being diagnosed with GD described focusing on transgenderism as the source of experiences of difference, emotional, interpersonal and body conflict. He felt in retrospect this may be due to a singular focus cognitive bias in autism. So autism diagnosis was both facilitative and a barrier.

Participants said discovering transgenderism was pivotal, often discovered accidentally in late adolescence or adulthood, through various media. Participants portrayed mixed emotions: relief, as transgenderism enabled understanding of the as-yet-undefined or misattributed aspect of themselves, enhancing personal congruence; and hope their distress could be addressed through transition and medical interventions. Many also felt sadness as they realised transgenderism was a stigmatised identity and living an authentic life would be challenging.

Alex: *"I saw this Jeremy Kyle episode…[a transgender person] was talking about his childhood…and I thought that sounds a bit familiar…this seems like it might be right.*

He just looked like every other man. That's all I wanted to be…I don't think it's what anyone wants to do, go through that, but at least I knew what was wrong".

Participants reflected that increasing public interest in transgenderism and proliferation of material on the topic facilitated their exposure to information.

All participants described researching transgenderism after their initial exposure. A few participants knew transgender people through groups they were part of, and reflecting on their experiences revealed increasing congruency with their own experiences. Further research also revealed treatment options allowing the embodied self to be transformed, which presented dilemmas about whether to continue concealing or undertake transition.

The Precipice. Some participants felt unable to "take on transition", feeling they lacked resilience due to stressors they had already encountered or their circumstances weren't conducive to change. Lacking support at work, in the family home or in society, they continued to conceal and suppress their gender identity.

Felix: "*[transition is] about having the courage to assert yourself, but you reach the point of not being able to not assert yourself anymore…I was already being bullied at work, I was struggling due to my Asperger's…And to do anything that would…make me more open to bullying…I couldn't afford that…I wouldn't have had the confidence to say 'right guys I'm not a woman', I could not have done that!"*

As participants' knowledge of GD and treatment options grew so did their sense of conflict with others who restricted their gender expression, and frustration at themselves for continuing to "live a lie". Over time (from months to 5 years) participants' mental, and in some cases, physical health eroded until they were unable to tolerate suppression and concealment. They reached what Alana described as a "*precipice…where the pressure becomes too much, you have reached the limit of your mental endurance, and you think, yes, I've got to do something..."*

Most participants felt life wasn't worth living in their present state, driving them to feel transition was their only chance of improvement and survival.

Felix: **"***I reached that point…everything went completely to hell, my mental and physical health fell to pieces…I felt like I'd nothing to lose anymore and…it gave me the courage to say " I've hit rock bottom, to hell with trying to fit, I'm gonna decide who I am".*

Autism was felt to compromise participants' tolerance for the distress of GD, both leading to a greater need to seek gender support services, but also to increased suicidal ideation:

Alana: "*I have been thinking about that [suicide]. I can put on a brave face but sometimes it's just a bit much…it [tolerating GD] takes a lot of emotional strength, but I hate the whole emotional thing, I don't handle it well. There's too much emotional pressure and it does actually require a lot of emotional tolerance…mental endurance, and with autism your endurance isn't great".*

Reaching critical mass. By contrast, other participants, upon understanding transition may be a viable option described embarking upon a measured process of planning and building the necessary resources (self-confidence, mental and physical health, further knowledge of GD and treatment options), increasing capacity to manage transition, working towards achieving critical mass[9]. This was based on participants' insight into their preference for preparation and gradual change, which some related to autism.

Sam: "*it was about actually getting yourself to a point where you feel confident enough to be able to do that…knowing the right way to go about it…getting myself healthy…that helps you to feel much more able to take the first step. I was revving myself up…I suppose".*

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[9] The minimum resources required to start or maintain a venture (Oxford English Dictionary)

Participants described an internal conflict, recognising steady preparation was necessary for transition to occur, but feeling frustrated at their inability to move quicker. Here again autism was felt to present a barrier.

Transition. As the focus of the findings is on individuals' coming to understand and address GD, the account of transition focuses on its initiation. Participants' narratives illustrate the continued influence of the social environment and autism in shaping gender expression and the experience of embarking upon post-transition life. Although achieving greater personal congruence, it involves compromises and ongoing conflicts.

Transition involves social and physical elements. The former comprises individuals identifying as their preferred gender identity and presenting and living in greater alignment with it, for example, through dress, personal pronoun use and name. The latter comprises a range of medical interventions, including hormone treatments and surgeries, to align the body and gender identity, easing social transition. All participants decided to make both transitions, undertaking social transition first[10].

Social transition. *Accessing identity affirming relationships and support.* This category differs from those preceding it in that the influence of facilitative relationships and environments came to the foreground in participants' accounts, providing safety and support to explore gender and self-acceptance. This created the preconditions for initiating and maintaining the transition process and buffering from the effects of social restrictions. However, autism affects both access to, and the nature of, these relationships and support.

Paramount in participants' accounts was the importance of connecting with other transgender individuals, with whom transition usually began. Most participants

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[10] a requirement for NHS gender-affirming surgeries (NHS England (2013) *Interim Gender Dysphoria Protocol and Service Guideline*).

sought out transgender and/or LGBT communities as their certainty increased regarding being transgender and wanting to transition. However, as Kate states:

"Autism obviously makes it quite hard to engage in these relationships in the first place"

LGBT events often took place in loud and busy pubs, cafés or restaurants, unsuitable for someone with sensory sensitivities. Many activities focused on face-to-face unstructured dialogue, challenging due to social communication difficulties. Talking in larger groups particularly provoked anxiety:

Kate: *"everyone is talking over drinks and it's a...positive atmosphere, and... welcoming…but I felt that I couldn't engage with it…I get really uncomfortable in that sort of situation…with lots of people having a conversation it's like 'Arg!".*

However, structured activities such as committee meetings and presentations were easier, as were activities where socialising involved 'doing alongside' others (e.g. sports). Due to the above issues some participants preferred to access communities online, for instance through chatrooms and social media.

Despite issues with accessibility, interactions with other transgender people were seen as vital enablers of transition allowing access to practical information and advice on presentation, medical interventions and legal aspects. Participants had the opportunity to compare their feelings and experiences to those who had already transitioned and finding their experiences mirrored provided further certainty of their identity, building confidence to transition. These communities provided role models, relationships, a safe space to experiment with new gender presentations, friendships and, often for the first time, achieve a sense of belonging.

Kate: "*I [made]some friends who were very into being openly feminine, and open about dress and stuff, so that helped like me to experiment with dress and presentation…so accepting friend groups help a lot…through them I was able be the person I wanted to* *be".*

Rihanna: *"what really makes me afraid is…having discovered what friends are, there's this fear of losing them…being alone again".*

Self-blame and internalised transphobia was acknowledged and lessened as they learned through these communities that transphobia is an artefact of gender socialisation and a manifestation of people's fear of difference.

These experiences led many to support and advocate for transgender people by joining their university or local council LGBT committee, offering mentorship, or using social media platforms to educate others on transgender issues. Again, autism impacted on confidence, although their passion to help meant they did all they could. Thus, these communities did much more than facilitate social transition as Sam explained: *"you're meeting new people…for different reasons and that gives you sense of…belonging, and purpose that you might not have had"*

Emboldened, some participants also found other non-LGBT communities offering support and safety to express their gender identity, including poetry groups, voluntary conservation organisations and autism support groups. All had diverse membership, so participants felt "at home".

A commonly mentioned facilitative environment was found online e.g. role-playing games, where participants could experiment with different presentations before trying them in reality. Participants with non-binary identities felt they were the most authentic version of themselves here, free from the restrictions of biology and society. Max: *"there's a game I play…I always make a very masculine character with a beard but I give them a female voice…they'll have female mannerisms so I feel like that, sort of mix, so maybe I want to look male on the outside but still be female a bit*"

Participants desired support to transition which necessitated disclosure to family and loved ones. However, the fear of rejection (even in supportive relationships) and difficulties related to autism made this highly challenging and often delayed it, particularly for those still living with parents due to their additional support and accommodation needs.

Alana: "*In my personal experience…it's always been positive…no fights, no rows…I know X [name], I can tell her anything but I wasn't even sure about that because of the social perception…there was still that fear".*

One participant, whilst confirming the importance of other transgender narratives to their transition, did not identify with transgender identity or see peer support as valuable. He was reliant on family support as mental health problems prevented his desired wider engagement. Responses to disclosure varied, as did their impact on transition. For some with historically discordant family relationships, disclosure resulted in their predicted rejection and, in most cases, autism was used to discredit their gender experiences. This did not alter the decision to transition as their desire for change was greater than the value of the relationships.

Sam: *"I've always enjoyed collecting toys; [my father] said "if you're still playing with toys…you're not mature enough to make these decisions about your gender"…he thinks because of my interests and autism I couldn't know about my gender…when your gender is wrong it's pretty clear!"*

Those with good relationships were ultimately given emotional and, often, practical support, including attending medical appointments and purchasing gender aligned clothing. Disclosure in these cases often increased the closeness of relationships as participants felt accepted for being themselves.

Health services were another crucial facilitative environment/relationship in undertaking transition. However, services and clinicians' attitudes and variable adaptability to autism could compound autism-related difficulties in participants' accessing support. GPs were mostly "accepting" and "helpful" regarding gender issues as an alliance had been built over time which mitigated anxiety. However, two participants felt they were denied treatment from specialist gender services because of their autism.

Rihanna: *"They didn't say directly but I felt because I'd got Asperger's they wouldn't really take me seriously…I spiralled down…and couldn't pick myself up."*

Participants proposed that having autism may increase anxiety about attending gender services beyond what neurotypical people may experience due to the nature of their condition problematizing meeting new people, to undertake an often poorly defined assessment (a complex social interaction). Some attempted to manage their anxiety by extensively researching the assessment process, but would have preferred more guidance from services. For some these issues delayed their first medical appointment.

Alex: "*it's [autism] just made it more a nerve-wracking experience…what's going to happen, what's going to be said, what will happen next?…I nearly didn't go".*

Upon accessing services some participants experienced distress due to a lack of transparency and predictability in the process, and timescales of assessment and treatment. Participants feared being denied treatment due to not being able to give the 'right' or appropriate responses, reflecting communication difficulties.

Kate*: "I get the impression they're looking for very specific comments [about my body] but I just don't know…it's more general for me and difficult to explain".*

While desiring body change, the same change provided a trigger for anxiety which was attributed to autism. Clinicians' allowing time for discussion of concerns and implementing stepped change was helpful:

Zain: "*…he discussed all the reasons I was uncomfortable [with hormone therapy]…all the pros and the cons and spent ages, so in the end I was like "oh okay I'll try the gel"…cos if I got anxious I could wash it off…then I moved onto injections…doing that* *in small increments I was okay".*

The participant who didn't receive his autism diagnosis until after his GD diagnosis felt this hindered the assessment and treatment process as the service wasn't able to adapt to his needs and he wasn't able to anticipate the additional difficulties he may encounter in transition. Specifically, he had not expected to experience a "second puberty" and how profoundly distressing this would be:

Max: "*I did loads of research online and prepared…they'd ask questions like "so you know about the changes that will come with hormones" but I hadn't really processed that meant those things would happen to me...puberty was already a really awful time and I had it again".*

Wellbeing, engagement and witnessing. Most participants spoke of relief moving full-time into social transition, describing it as when their "life properly began". In being more congruent in their gender expression they felt "authentic" which improved their self-confidence and wellbeing. Participants' body conflict also decreased somewhat, and those who identified with the gender binary felt they fitted in more:

Alex: *"I feel like I fit into a group a bit better…I can look in the mirror and I look more like a man, at least with my clothes on".*

Participants' accounts portrayed a positive cycle developing upon social transition as Alana explains:

"Since I've been like this, I've been happier…The more happy I am, the more engaged I am and the more I want to engage…the more I do and…aren't misread, the happier I am".

Participants increased intrapersonal and body congruence meant they felt increasingly confident to engage with others and life, especially when others saw them as they saw themselves, which reinforced wellbeing. However, this virtuous cycle was fragile given the threat of being seen as their birth-assigned gender and abused. One participant had experienced physical abuse; most others verbal abuse, especially transphobic comments. The effect was devastating and could lead to a return to concealment, isolation and poor mental health.

Alex: *"At first your confidence is through the roof…Then it wouldn't take much for it to just crumble…at first I found it a lot easier to make friends, so I had more friends. Then after a while it went away…a few random comments can really get to me, I get really paranoid about it…I don't go out as much".*

Most participants described the great effort they put into planning and executing their presentation (clothing, make-up, binding their breasts) and monitoring their behaviour in order to minimise possible misreading or hostility. This involved presenting as stereotypically masculine or feminine, which suited those who felt this matched their gender identity. However, this could be a source of conflict, particularly for those with a non-binary identity, as such presentations sometimes compromised personal comfort (e.g. transmen wearing binds) and authenticity. For example, Max and Felix did not identify as *men*, although they presented as such in order to live safely and have their masculinity acknowledged in a system which demands certain characteristics from men.

Felix: *"I probably err on the safe side of just not looking weird [presenting outside the gender binary]…it's not worth people being aggressive…I used to get people asking me if I was a boy or a girl…People , they see the world as men and women…that's what you give them to be safe".*

Stereotypical presentations, then, conflicted with some participants' values, being seen as perpetuating the "oppressive gender binary".

Most participants felt autism complicated social transition through their not having an intuitive, neurotypical "encyclopaedia" of presentation making it more likely they were misread. Furthermore, some participants felt less able to 'pass' as neurotypical as they hadn't learned how to "perform that role" in relation to a new gender presentation. Participants' anxiety about being misread made their autistic behaviours more pronounced as Felix explained:

"I don't feel like I'm fully socially transitioned because I am experiencing more autism barriers than I was as a woman…I had thirty odd years to learn how to…pretend to be female…and I'm still trying to come up with new strategies to be consistently read as male because expectations are different…autism makes this slow…I'm also being read more as autistic because I've not learned the disguises for someone now read as male…My confidence is affected…so more autistic behaviour, like stim[ing] creeps out because my anxiety overcomes my energy to…lock down on things like that".

Felix identified practice in interacting with others was important to reinforce social transition but heightened anxiety meant it was often a battle not to withdraw again.

Contrastingly, a number of participants suggested autism may facilitate transition for some, describing people with autism as falling into two types:

Zain: *"…there's us that [are oblivious to] what other people think of us…; and there's those who worry about what everybody's thinking…I fit into the category of I'm not bothered, which is a blessing, so I've not had any negative experiences…or…possibly if there has been something said and done I've missed it".*

For some then, their "obliviousness" to others' perceptions may protect them, to some extent, from the experience of being misread, thus facilitating transition. Furthermore, some felt their unavoidable difference due to autism enabled them to express their authentic gender identity. They had come to accept social rejection and placed little worth on others' opinions.

Zain: *"I'm quite happy with, my shield of 'this is who I am', if I don't actually do the 'right' social male thing tough…I'm used to not fitting in anyway".*

Physical transition. Participants felt their pre-physical transition body presented a barrier to being consistently read as their experienced gender. Trans women felt their masculine size, strong features and voice were barriers to being read as female and made them a target for abuse. Although trans males were less concerned about hostility, as masculine presentations were socially accepted, they were often misread as "butch lesbians" rather than men, which although acknowledging a degree of their masculinity, this was largely invalidating.

Zain: *"I'd always struggled when…called a butch lesbian…I did not feel like a butch woman, I don't know how a butch woman feels to be fair!"*

Therefore, decisions around physical transition were shaped not only by the need to reduce dysphoria by aligning body and gender identity, but also to reduce the likelihood of being misread and the associated threat of discrimination and harm. Kate's comment illustrates the influence of the social environment in decision-making and shaping the embodied self, and how that came into conflict with her values.

Kate: *"I'm hoping transition will alleviate some of the social anxieties around gender roles and expectations…though it leads me back to conflict…transphobia and gender discrimination shouldn't exist…the idea of passing into an oppressive system is really difficult for me, there shouldn't be that oppression in the first place!"*

However, despite such concerns, this was the only option participants felt open which would improve their lives, a "lesser of two evils".

Romantic relationships were a significant source of conflict for participants with partners or who weren't asexual. In the former case, the fear was partners would no longer find them attractive. In the latter case participants expected they would no longer be as desirable as the transitioned body is stigmatised, yet participants felt this was a necessary but costly risk.

Upon embarking upon transition, male-identifying participants reported rapid improvements in dysphoria and social anxiety, as taking hormones and growing facial hair made them feel instantly recognisable as masculine. The trans women felt physical changes were slower to achieve and for some facial masculinisation, in particular, continued to be a source of discomfort with their appearance. Overall, accounts of embarking on physical transition portrayed a reinforcement of social transition as the more congruent participants felt in their body and gender presentation, the more they engaged, providing opportunities for validation of their identity, and so enhancing their wellbeing. Participants' sense of increasing personal congruence is nicely summed-up by Wez: *"The more I've moved into this role as a man ahh I have never felt so whole!"*

All participants reported experiencing personal growth, feeling more self-aware and resilient from overcoming the challenges they experienced and had greater empathy.

Sam: *"I have mixed feelings about being trans…I'm not glad that I was born a girl, but I'm glad it gives me a great understanding of myself and being able to empathise with people,…with trans people…if I was someone looking from the outside I might not be as sympathetic or supportive…I think it makes me a better person for having to work to be the person I am".*

As Sam's quote indicates, although things were much improved for participants, most were keen to impress all is not resolved.

Felix: "*People think you go down a certain path and you're done [physical transition], you live happily ever after but it's a life-long process of navigating your environment"*

Despite progress experienced in terms of personal growth, body-gender identity congruence, interpersonal congruence through 'fitting into a group', finding belonging and safety among trans people and others, participants portrayed an enduring and "ingrained" sense of being 'different' or "fake". The 'fakeness' has a dual nature; relating to their enactment of a new gender role which is compromised by autism-related difficulties and invalidated by others; and their attempted enactment of neurotypicality. The ‘difference’ is an enduring artefact of the double discrimination they have endured and internalised. This limited their sense of identity congruence and self-acceptance, and with that came an expectation of rejection and harm from others:

Kate: “*I find it hard to think of myself as 'authentic' however I present myself. I feel fake. I really hope that will change…but that feeling is quite deeply ingrained. I will probably have to live with it.”*

Alex: “*The whole ‘who I am’. I don't think I'll ever come to terms with that.”*

Discussion

A growing body of research describes the co-occurrence of autism and GD and reports a higher prevalence of autism among gender identity clinic patients; however, understanding of this is limited. There is little research into gender identity in people with autism and that which exists marginalises the individual’s voice. This study aimed to address this gap and is the first to examine the perspectives of adults with autism regarding their experience of GD, addressing the research questions:

- What is the experience of people with autism in coming to understand and address GD?
- What role does the social environment play in the experience of GD for people with autism?

The analysis built-up a framework of common processes involved in coming to understand their gender identity and address GD. It illustrates the role of social environment as a ‘restrictor’ or ‘facilitator’ of the processes, and autism as a ‘barrier’ or ‘protector’.

Participants felt ‘different’ from early childhood. They experienced conflict, incongruence, and distress due to the mismatch between their experienced gender and body, and treatment and expectations of them based on cis-normative ideals. Those assigned male at birth, in particular, were not afforded any flexibility in expressing femininity. Feelings of difference were compounded by having autism- for which they experienced discrimination; and social communication difficulties combined with gender differences made social interactions fraught with anxiety, leading to withdrawal.

Autism-related difficulties with expressing feelings, combined with others' intolerance for 'difference' led participants to believe their gender feelings were deviant and so they suppressed them and attempted to present in ways expected of their birth-assigned gender. However, autism proved a barrier in doing so. Participants' distrust of others, low self-esteem and difficulties "passing as normal" reinforced their social avoidance and isolation, further impacting mental health.

Despite suppression attempts, a strong sense of an alternatively-gendered self persisted and over time participants better understood their gender feelings, making concealing increasingly problematic. For most, autism diagnosis facilitated self-understanding and access to support, aiding transition. Some participants continued to suppress their gender feelings, leading to an emotional precipice; others planned and built resources to achieve critical mass for transition.

Connecting with other transgender people was crucial to initiating transition for most participants, improving self-acceptance and providing a sense of belonging. Family, online environments and health services were also instrumental to transition initiation. Gender services' attitudes to autism and varying accommodation of autism-related difficulties affected their accessibility. Failure to diagnose autism appeared to complicate treatment for one participant as his needs were not fully understood.

Most participants felt relief having socially transitioned which precipitated a positive cycle of: increased gender identity-presentation congruence; enhancing wellbeing and confidence to engage more with others; and others reinforcing their expression of their gender, leading to greater confidence and wellbeing. However, the threat of being misread or harmed necessitated compromises in comfort and gender expression authenticity for some. Autism was a barrier to enacting their new gender role in accordance with societal expectations, increasing social anxiety. However, autism could also protect from the experience and fear of being misread, lowering anxiety. Physical transition decreased social anxiety and reinforced social transition. Although achieving greater intra-inter and body congruence upon transition, some conflicts remained as participants had an enduring fear of harm and sense of 'difference' and being 'fake' resulting from the impact of two intersecting stigmatised identities

Comparison to Other Studies

The findings resonate with the few qualitative studies examining transgender identity development in the neurotypical population, which also use a GT approach: Devor (2004) and Levitt and Ippolito (2014) 14-stage and three-phase frameworks of transgender identity development respectively; Ekins (1997) five phases of trans female identity development; and Heistand and Levitt (2005) five phases of butch identity development. Models share initial periods of gender identity confusion and distress; increasing social pressures to conform to cis/heteronormative ideals; a gradual testing out of gender identities, finding an identity that fits; and highlight the centrality of accessing gender-affirming social groups in facilitating gender exploration and self-acceptance. However, previous models differ in that although the influence of discrimination and threat of harm on gender expression is evident, it plays a less prominent role than in the current study. Furthermore post-transition identity integration and self-acceptance, appears more fully actualised in previous studies. In Heistand and Levitt (2005, p.74) participants' "negative feelings [about their identity] were dispelled and being butch became a prideful identity"; in Devor (2004) participants achieve "serene self-acceptance" and "gender euphoria" (p.63); in Levitt and Ippolito (2014) participants achieve "authenticity" (p.1734) and in Ekins' (1997) identity is ‘consolidated’, although both studies acknowledge presentation involves compromise due to need to manage risk of harm. Whilst the current study’s participants achieved increased congruence and wellbeing, there was an enduring internal conflict as outlined above attributed to having autism in combination with GD. Therefore, study comparison indicates a common identity development process, complicated by autism. Social communication impairments thwart understanding, exploring and presenting gender identity; and the ‘layering of stigma’ (McCann et al., 2016) appears to increase fear of discrimination, ultimately complicating the forming of positive gender identity and self-acceptance. Time elapsed since transition may play a role in identity integration, though previous studies did not record this data.

The findings mirror qualitative research exploring sexual identity development in people with intellectual disabilities (ID). Here again, individuals face the “double disadvantage” of heteronormativity and ableism in forming a positive sexual identity (Wilkinson, Theodore, & Razka, 2015, p.102). ID overshadows their sexual identity which is ignored, invalidated or pathologised by family, services and society generally, limiting opportunities for identity exploration and leading to concealment and shame (Burns & Davies, 2011).

A key finding was the importance of affirming relationships and social support to transition and well-being, something supported by the wider literature on neurotypical transgender individuals. Positive identification with one’s social group (collective self-esteem [Crocker & Luhtanan, 1990]) has been found to be negatively correlated with psychological distress in transgender people (Sánchez & Vilain, 2009). Similarly, family support is associated with higher self-esteem and life satisfaction in transgender people (Erich, Tittsworth, & Kerstein, 2010) and social support, generally, has been found to predict psychological functioning following gender-confirming surgery (Davey, Bouman, Walter, Arcelus, & Meyer, 2014). Social support has also been found to be significant positively related to quality of life in people with autism (Renty & Roeyers, 2006) and can protect against the emotional impact of victimisation (Humphrey & Symes, 2010). However, individuals' with autism difficulty accessing social support due to ostracism, social communication impairments and the inaccessibility of social environments evidenced in the current study finds ample support in the existing literature (e.g. Müller, Schuler, & Yates, 2008; Smith & Sharp, 2012).

Implications for Professionals and Services

The findings highlighted that people with autism, fearing social responses and struggling to understand and express emotions, will conceal their gender concerns often until life becomes unbearable. The toll of concealment, and, therefore, lack of support for GD, is tremendous. Echoing the DoH (2014) recommendations, professionals working with individuals with autism need to proactively address sexuality and gender issues to ensure individuals access the support they need. A number of studies (e.g. Seelman, 2014; House of Commons, 2016) have shown staff (education, health, social care and support professionals) reticence to address these issues commonly relates to a lack of confidence and training. Therefore, staff training for those working with people with autism needs to address sexual and gender issues. Involving experts by experience would enhance the training, with the autism community having made clear they want to be involved in service development (Griffith, Totsika, Nash, & Hastings, 2012). Such training may also help to address prejudice among staff. The importance of addressing gender identity needs should be outlined in service policies.

Accessing affirming relationships was vital but challenging for participants. Access to psychology professionals, particularly for those who are socially isolated, may provide such a relationship to support individuals' gender exploration, cultivate self-acceptance, and adjust to and manage the challenges of post-transition life and minority stress. Working with the family to adjust to transition is likely to be useful given the ongoing reliance on parents for support and accommodation into adulthood for many individuals with autism (Anderson, Shattuck, Cooper, Roux, & Wagner, 2013).

Services may also support access to supportive communities through setting-up transgender peer mentoring programmes, or support groups which are inclusive of those with autism. The current study's participants specified conducive group formats, including structured activities based on a topic rather than unstructured face-to-face dialogue. Online peer support groups may also be a useful avenue for supporting this population given the current study's finding supported by wider growing evidence of its benefits to wellbeing (Griffith, Calear, Banfield, &Tam, 2009).

Lack of exposure to concepts of gender, and the language to describe it, during childhood inhibited understanding. The school curriculum can be used to address this, perhaps within Personal, Social and Health Education, however, the topic is not routinely included (House of Commons, 2016). Routine inclusion of this in the curriculum may also normalise experiences, reducing stigma.

Experiences of gender clinics indicated improvements could be made to enhance accessibility. Some individuals perceived staff prejudice relating to autism, and experienced anxiety due to inadequate information on the assessment and treatment process. This echoes the wider literature on healthcare experiences of people with autism (e.g. DoH, 2010; Nicolaidis et al., 2015). Services have a duty under the Equality Act (2010) to make reasonable adjustments for patients with disabilities. Asking patients about their needs would be a first step in ensuring they are better accommodated. The value of providing additional time to explain assessment and treatment processes and to provide reassurance was indicated in the findings, supported by the National Institute for Health and Care Excellence (2012) recommendations for care delivery. Clinicians' lack of training in autism has been evidenced and is thought to underpin the healthcare issues individuals with autism face (The Westminster Commission on Autism, 2016). Given the high prevalence of autism in gender clinic patients, support for clinicians to meet this populations' needs is crucial. Working in partnership with specialist autism services would support cost-effective knowledge sharing and collaboration opportunities.

Strengths and Limitations

The study has a number of strengths and limitations which must be acknowledged when evaluating the overall findings. The limitations provide direction for future research.

This study makes a unique contribution to the evidence base as the first study to investigate the impact of autism on those experiencing GD. The findings have clinical utility to gender services who describe a high prevalence of autism among clinic patients, and who have a limited evidence base to draw upon in providing support. More generally, the findings have utility to professionals providing services to, or in contact with, people with autism, sensitising them to issues faced in understanding and addressing GD and the support required.

In order to address the potential for the researcher's preconceptions to influence conclusions constant comparison of categories with raw data, a reflexive approach, peer audit, and credibility checks with participants were utilised to ensure the findings were grounded in the data.

Participants were able to provide verbal accounts of experiences in interviews, and would fit the profile of the prior diagnosis of Asperger's syndrome or high-functioning autism. This potentially limits the findings' representativeness to individuals with greater autism-related functional impairments, including co-morbid social anxiety. It seems likely that the challenges presented by autism observed in the present study would be exacerbated in those with greater functional impairment. Future studies may consider other ways of involving people with greater functional impairments which suit their abilities and communication preferences (e.g. internet-based interviews or using assisted communication) to ensure findings are representative of the wider population of people with autism.

Furthermore, the small sample consisting of Caucasian individuals who had accessed NHS services in the UK, limits transferability to individuals residing in countries with different notions of gender, greater acceptance of gender diversity, or where they must pay for gender-confirming treatment. Future studies may investigate the impact of these different factors.

The study charted individual’s experiences up to embarking upon physical transition, dictated by gender services supporting people mainly until surgery and the challenges of accessing participants who have moved beyond physical transition in this very niche population. Future studies may consider experiences beyond this timeframe and the balance of ongoing conflict and congruence as time passes beyond completion of physical transition.

Data saturation was not achieved and the physical transition category, in particular, was comparably less thick and rich (Fusch & Ness, 2015) due to so few of the participants having completed this process. This potentially limits confidence in the robustness of the final conceptual model.

Quantitative investigation of emotional wellbeing in people with autism and GD, and the impact of minority stress and support may substantiate the present findings and further understanding of the experiences of this population.

Conclusion

The findings highlight this population’s vulnerability to stigma, discrimination, isolation, low self-worth and poor mental health as a ‘minority within a minority’.

Transition brings relief from the toll of suppression, increased well-being, greater engagement with others and improved quality of life. However, in the restrictive social environment, living a more authentic life involves compromises for many. Conflicts remain as participants navigate the social world with an enduring fear of hostility and sense of difference and fakeness due to having two stigmatised identities. Services should be proactive in discussing gender issues with people with autism to ensure their needs are addressed sooner. It is crucial that social support is facilitated for this population, particularly connections with other transgender people.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental health disorders: DSM-5* (5th ed.). Washington, DC: Author.

Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism*, *18*, 562-570. doi: 10.1177/1362361313481860

Balfe, M., & Tantam, D. (2010). A descriptive social and health profile of a community sample of adults and adolescents with Asperger syndrome. *BMC Research Notes*, *3*, 300-307. doi: 10.1186/1756-0500-3-300.

Baron-Cohen, S. (2002). The extreme male brain theory of autism. *Trends in Cognitive Sciences*, *6*, 248-254. doi:1.1016/51364-6613(02)0194-6

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, *31*, 5-17. doi: 10.1023/A:1005653411471

Bölte, S. (2014). The power of words: Is qualitative research as important as quantitative research in the study of autism? *Autism*, *18*, 67-68. doi:10.1177/136.2361313517367

Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., . . . Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, *68*, 459-465 doi: 10.1001/archgenpsychiatry.2011.38

Burns, J., & Davies, D. (2011). Same-sex relationships and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *24*, 351-360. doi: 10.1111/j.1468-3148.2010.00609.x

Charmaz, K. (2014).*Constructing Grounded Theory: A practical guide through qualitative analysis* (2nd ed.). London, England: Sage.

Clements-Nolle, K., Marx, R., & Katz, M. (2006). Attempted suicide among transgender persons: The influence of gender-based discrimination and victimization. *Journal of Homosexuality*, *51*, 53-69. doi: 10.1300/J082v51n03_04

Crocker, J., & Luhtanen, R. (1990). Collective self-esteem and in-group bias. *Journal of Personality and Social Psychology*, *58*, 60. doi: 10.1037/0022-3514.58.1.60

Davey, A., Bouman, W. P., Arcelus, J., & Meyer, C. (2014). Social support and psychological well-being in gender dysphoria: A comparison of patients with matched controls. *The Journal of Sexual Medicine*, *11*, 2976-2985. doi: 10.1111/jsm.12681

Department of Health. (2010). *Fulfilling and rewarding lives: The strategy for adults with autism living in England.* Retrieved from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

Department of Health. (2014). *Think autism: Fulfilling and rewarding lives, the strategy for adults with autism in England: An update.* Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., & Nieuwenhuizen, C. (2013). Autism and normative sexual development: a narrative review. *Journal of Clinical Nursing*, *22*, 3467-3483. doi:10.1111/jocn.12397

Devor, A. H. (2004). Witnessing and mirroring: A fourteen stage model of transsexual identity formation. *Journal of Gay & Lesbian Psychotherapy*, *8*, 41-67. doi: 10.1300/J236v08n01_05

Devor, A. H. (Writer/Interviewee). (2015). Transforming Gender. In M. Guerre (Producer). *Doc Zone*. Ottawa, ON: Canadian Broadcasting Corporation. Retrieved from https://youtube/CBxXI0QIbN8

De Vries, A. L., Noens, I. L., Cohen-Kettenis, P. T., van Berckelaer-Onnes, I. A., & Doreleijers, T. A. (2010). Autism spectrum disorders in gender dysphoric children and adolescents. *Journal of Autism and Developmental Disorders*, *40*, 930-936. doi: 10.1007?510803-101-0935-9

Ekins, R. (1997). *A grounded theory approach to cross-dressing and sex-changing: Male femaling.* London, England: Routledge.

Elderton, A., & Jones, C. (2011). Finding a safe place to explore sexual identity. *Learning Disability Practice*, *14*, 14-17. doi:10.7748/ldp2011.06.14.5.14.c8559

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, *38*, 215-229. doi:10.1348/014466599162782

Erich, S., Tittsworth, J., Dykes, J., & Cabuses, C. (2008). Family relationships and their correlations with transsexual well–being. *Journal of GLBT Family Studies*, *4*, 419-432. doi: 10.1080/15504280802126141

Equality Act. (2010). Retrieved from http://www.legislation.gov.uk/ukpga/2009/15/contents

Ness, L. R. (2015). Are We There Yet? Data Saturation in Qualitative Research. *The Qualitative Report*, 20, 1408-1416. Retrieved from: http://nsuworks.nova.edu/tqr/vol20/iss9/3

Glasser, B. G., & Straus, A.L. (1967). *The Discovery of Grounded Theory*. Chicago, IL: Aldine.

Griffith, K. M., Calear, A. L., Banfield, M., & Tam, A. (2009). Systematic review on Internet Support Groups (ISGs) and depression: What is known about depression ISGs? *Journal of Medical Internet Research*, *11*, e41. doi: 10.2196/jmir.1303

Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). I just don't fit anywhere: Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism, 16*, 532-546. doi: 10.1177/1362361311405223

Hiestand, K. R., & Levitt, H. M. (2005). Butch identity development: The formation of an authentic gender. *Feminism & Psychology*, *15*, 61-85. doi:10.1177/0959353505049709

House of Commons Women and Equalities Committee. (2015). *Transgender Equality*. Retrieved from https://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf

Humphrey, N., & Symes, W. (2010). Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. *European Journal of Special Needs Education*, *25,* 77-91. doi: 10.1080/08856250903450855

Jacobs, L. A., Rachlin, K., Erickson-Schroth, L., & Janssen, A. (2014). Gender dysphoria and co-occurring autism spectrum disorders: Review, case examples, and treatment considerations. *LGBT Health*, *1*, 277-282. doi: 10.1089/lgbt.

Jordan, C. J. (2010). Evolution of autism support and understanding via the World Wide Web. *Intellectual and Developmental Disabilities*, *48*, 220-227.doi: 10.1352/1934-9556-48.3.220

Kraemer, B., Delsignore, A., Gundelfinger, R., Schnyder, U., & Hepp, U. (2005). Comorbidity of Asperger syndrome and gender identity disorder. *European Child & Adolescent Psychiatry*, *14*, 292-296. doi:10.1007/500787-005-0469-4

Levitt, H. M., & Ippolito, M. R. (2014). Being transgender navigating minority stressors and developing authentic self-presentation. *Psychology of Women Quarterly*, *38*, 46-64. doi:10.1177/0361684313501644

McCann, E., Lee, R., & Brown, M. (2016). The experiences and support needs of people with intellectual disabilities who identify as LGBT: A review of the literature. *Research in Developmental Disabilities*, *57*, 39-53. doi: 10.1016/j.ridd.2016.06.013

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, *129*, 674-697. doi: 10.1037/0033-2909.129.5.674

Müller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism*, *12*, 173-190. doi: 10.1177/1362361307086664

National Institute for Health and Care Excellence. (2012). *Autism spectrum disorder in adults: Diagnosis and management* (CG142). Retrieved from https://www.nice.org.uk/guidance/CG142/chapter/1-Guidance#organisation-and-delivery-of-care

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., . . . & Boisclair, W. C. (2015). “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism*, *19*, 824-831. doi: 10.1177/1362361315576221

NVivo 11 (QSR International, 2015) [Computer software]. Available from: http://www.qsrinternational.com

Pasterski, V., Gilligan, L., & Curtis, R. (2014). Traits of autism spectrum disorders in adults with gender dysphoria. *Archives of Sexual Behaviour*, *43*, 387-393. doi:10.1007/s10508-013-0154-5

Pellicano, E., Dinsmore, A., & Charman, T. (2013). *A future made together: Shaping autism research in the UK*. London, England: Institute of Education.

Reed, B., Rhodes, S., Schofield, P., & Wylie, K. (2009). *Gender variance in the UK: Prevalence, incidence, growth and geographic distribution*. Retrieved from http://www.gires.org.uk/employment/information-on-prevalence-and-incidence

Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, *10*, 511-524. doi: 10.1177/1362361306066604

Rosbrook, A., & Whittingham, K. (2010). Autistic traits in the general population: What mediates the link with depressive and anxious symptomatology? *Research in Autism Spectrum Disorders*, *4*, 415-424. doi: 10.1016/j.rasd.2009.10.012

Sánchez, F. J., & Vilain, E. (2009). Collective self-esteem as a coping resource for male-to-female transsexuals. *Journal of Counselling Psychology*, *56*, 202. doi: /10.1037/a0014573

Sausa, L. A., Keatley, J., & Operario, D. (2007). Perceived risks and benefits of sex work among transgender women of colour in San Francisco. *Archives of Sexual Behaviour*, *36*, 768-777. doi:10.1007/s10508-07-9210-3

Seelman, K. L. (2014). Transgender individuals’ access to college housing and bathrooms: Findings from the National Transgender Discrimination Survey. *Journal of Gay & Lesbian Social Services*, *26*, 186-206. doi: 10.1080/10538720.2014.891091

Shaw, R. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology*, *7,* 233-243. doi: 10.1080/14780880802699092

Smith, R. S., & Sharp, J. (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with Asperger syndrome. *Journal of Autism and Developmental Disorders, 43,* 891-910. doi:10.1007/s10803-012-1633-6

The Westminster Commission on Autism. (2016). *A spectrum of Obstacles: An enquiry into access to healthcare for autistic people.* Retrieved from https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf

Tweed, A., & Charmaz, K. (2012). Grounded theory methods for mental health practitioners. In D. Harper, & A. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy* (pp. 131-146). Chichester, England: Wiley.

Wilkinson, V. J., Theodore, K., & Raczka, R. (2015). ‘As normal as possible’: Sexual identity development in people with intellectual disabilities transitioning to adulthood. *Sexuality and Disability, 33*, 93-105. doi: 10.1007/s11195-014-9356-6

Williams, P. G., Allard, A. M., & Sears, L. (1996). Case study: Cross-gender preoccupations in two male children with autism. *Journal of Autism and Developmental Disorders*, *26*, 635-642. doi: 10.107/BF02172352

Winter, S., Diamond, M., Green, J., Karasic, D., Reed, T., Whittle, S., & Wylie, K. (2016). Transgender people: Health at the margins of society. *The Lancet*, *388*, 390-400. doi: 10.1016/S0140-6736(16)00683-8

Appendices

Appendix A

Facebook Advertisement

The
University
Of
Sheffield.

Department Of
Psychology.
Clinical
Psychology
Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Would you be interested in participating in a study concerning the experience of gender dysphoria in people with autism?

What does it involve? Participants would undertake one-to-one interviews with the researcher lasting approximately one hour. The interview would consider your experience of gender dysphoria/ being transgender.

Am I eligible to participate? To be eligible to participate you need to have a formal diagnosis of autism spectrum disorder (this can include: Asperger syndrome, pervasive developmental disorder and autism spectrum condition) and gender dysphoria and be age over 18 years old.

What do I need to do to get involved? If you are interested please email rcolemansmith1@sheffield.ac.uk. Alternatively, you can call Amrit Sinha, Research Support Officer at The University of Sheffield on 0114 2226650 and provide him with your preferred method for me to contact you (telephone/ email) to arrange an interview.

Participation is confidential and you are free to withdraw from the research at any time.

Interviews will be concluding in early 2017 so please make contact as soon as possible.

Appendix B

Participant Information sheet

Please note the term ‘Autistic’ was used having consulted experts by experience and service users of the recruitment sites as to their preference. The author acknowledges this is a change from the convention of ‘putting the person first’ in academic writing.

The
University
Of
Sheffield.

Department Of
Psychology.
Clinical
Psychology
Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Gender Dysphoria in Autistic Individuals: A Qualitative Study

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and consider whether or not you wish to take part.

Information

This study is being undertaken by a Trainee Clinical Psychologist from the University of Sheffield. The researcher’s name is Rachel Coleman-Smith and she is interested in interviewing you about your experience of gender dysphoria as someone who is autistic.

The project’s purpose

There are an increasing number of reports describing gender-related concerns in autistic individuals, and higher numbers of autistic people than would be expected, compared to prevalence in the general population, are found to be accessing gender identity clinics. Rachel is interested in understanding how autism and gender dysphoria relate to one another from the perspective of the individual, if indeed they are seen to relate at all. Rachel is also interested in exploring how peoples' relationships with others may relate to autistic individuals' experience of gender dysphoria.

Why have I been chosen to take part?

Rachel is hoping to find between 8 to 20 adults with a diagnosis of autism and gender dysphoria willing to take part in her study. You had indicated to your point of contact at the Sheffield Adult Autism and Neurodevelopmental Service/The Porterbrook Clinic that you would be interested in taking part in the research and signed a consent form allowing Rachel to contact you for such a purpose.

What does taking part involve and what will happen if I choose not to take part?

If you choose to take part you will need to sign and return the attached consent form. Rachel will then contact you to arrange a mutually convenient time and date to interview you face- to –face for around an hour (or less if you would prefer).

Rachel will ask open-ended questions about your gender dysphoria, specifically how you see autism impacting on your experience of gender dysphoria. Rachel will also ask you about your relationships with others and how they may affect your experience of gender dysphoria.

Interviews will take place at either the Sheffield Adult Autism and Neurodevelopmental Service or The Porterbrook Gender Clinic, whichever is your preference. Rachel would like to take audio-recordings during interviews. Rachel may also ask you for a second interview if this is necessary.

It is important that you understand that you can withdraw from the study **at any time.** If you choose to withdraw this will not affect the services you receive. Rachel will not ask you why you have withdrawn, this is your decision and it will be respected. You will be given a copy of the consent form and information sheet to take away with you on the day of the interview.

What will happen with the audio recordings of my interview?

The audio recordings of your interviews will be used only for analysis. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

What are the possible disadvantages and risks of taking part?

Sometimes talking about personal issues can be distressing or uncomfortable. If you become upset during your interview Rachel will ask if you want to continue with the interview. If you choose not to she will ask if you would want any assistance in contacting a friend or family member to support you. If you choose to continue Rachel will allow you some time to compose yourself enough to feel safe to continue. If Rachel becomes concerned about your wellbeing she may advise you to contact your GP or other care provider. You may wish to bring a supportive family member or friend to wait for you whilst you have your interview so that someone is nearby should you become distressed.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the study, some people report finding talking about their experiences helpful. It is hoped that the study's findings will help professionals working with autistic people who have gender dysphoria (for example doctors, psychologists, social workers) to better understand your needs, and so be increasingly effective in meeting them.

What happens if the research study stops earlier than expected?

If due to unforeseen circumstances the study stops earlier than expected and you have consented to taking part you will be contacted by Rachel, or your point of contact at Sheffield Adult Autism and Neurodevelopmental Service/ The Porterbrook Clinic.

What if something goes wrong?

If you are unhappy with, or concerned about something which occurred in the research please contact Rachel and she will do her best to address this. If however your concerns are not satisfactorily dealt with you may contact:

Dr Richard Smith

Sheffield Adult Autism and Neurodevelopmental Service,

Michael Carlisle Centre,

75 Osborne Road, Sheffield,

S11 9BF, **or**

Dr Andrew Thompson

Clinical Psychology Unit,

Department of Psychology,

The University of Sheffield,

Western Bank,

Sheffield,

S10 2TN

Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. Only Rachel will know the names of the people who were interviewed. Your personal details and anonymised interview transcripts will be saved as password protected documents. The audio files of the interviews will be stored in an encrypted folder, with each file password protected. This information will only be viewed by Rachel and her supervisor, Richard Smith, from Sheffield Adult Autism and Neurodevelopmental Service. You will not be able to be identified in any reports or publications.

What will happen to the results of the research project?

Rachel hopes to present her findings to clinicians and service users at the autism service and Porterbrook Clinic. Rachel also aims to publish the findings in the Journal of Autism and Developmental Disorders, an academic journal, as well as presenting the results at conferences. Additionally, Rachel aims to approach the National Autistic Society with her findings in the hope they may publish a synopsis on their website.

Research funding

The research is funded by the University of Sheffield.

Who has ethically reviewed the project?

The project has been reviewed by the University of Sheffield research governance, Sheffield Health and Social Care Trust research governance, and the National Health

Service ethics committee for Yorkshire and Humber.

Contact information

Please contact Rachel Coleman-Smith if you have any questions on: rcolemansmith1@sheffield.ac.uk.

Thank you for taking your time to read this.

Appendix C

Participant Second Interview Letter

The
University
Of
Sheffield.

Department Of
Psychology.
Clinical
Psychology
Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Dear…

Thank you for allowing me to interview you regarding your experience of gender dysphoria. I would like to invite you to be re-interviewed so that I can check whether my understanding of what we discussed accurately represents your experience. This would involve meeting with me again at a mutually convenient time at Sheffield Autism Service or the Porterbrook Gender Clinic.

If you would be willing to be re-interviewed please could you complete the slip below and return it to me as soon as possible.

I……………………………………………………………………………………….
…..confirm that I consent to a second interview with Rachel Coleman-Smith. Please contact me to arrange our second interview by telephone/letter/email (delete as appropriate) on:…………………(date).

Date:…………………………………………………Signature:………………………
……………………………….

Appendix D

Interview Schedule

- How old are you?
- What is your preferred way to identify your gender?
- How would you describe your ethnicity?
- What is your highest level of education achieved?
- Are you employed?
- What is your relationship status?
- What term would you use to describe your sexuality?
- At what age were you when you were diagnosed as being on the autistic spectrum?
- Do you have any medical diagnosis, besides autism and gender dysphoria?
- Are you currently taking any regular medication (aside from those connected to gender transitioning)?
- When did you first attend gender identity services?

Initial open-ended questions about GD

- How do you experience your gender?
- What does 'gender dysphoria' mean to you?

Further questions:

- Tell me about when you first got the sense that your gender identity did not match your gender assigned at birth.
- What happened to these feelings over time?
- Are there any moments or experiences in your life which stand out as important in your experience of GD?

Relationship between GD and autism

- How do autism and GD interact together (if they do at all)?
- What impact has having autism had on your experience of GD?

- What impact has autism had on your addressing your GD?

  Follow up:

  Are there ways in which having autism has helped/protected you in your experience of GD?/ Been a barrier?

Interpersonal relationships and the social environment

- What impact have your relationships/experiences with others had on your understanding of GD and your gender identity development?
- How has your autism and having gender dysphoria influenced your relationships with: a) family/loved ones; b) services; c) LGBT community; d) society in general (neurotypical, cisgender people).

  Further questions:

  Tell me about how other people have responded to your gender dysphoria.

  How have you coped with challenges from others/the environment?

Relationship with body

- How would you describe your relationship with your body?
- Has this changed over time?

Ending questions

- Is there anything else that you think I should know that would help me to understand living with GD as someone with autism?
- How did you find being interviewed? What if anything would have improved your experience?

Appendix E

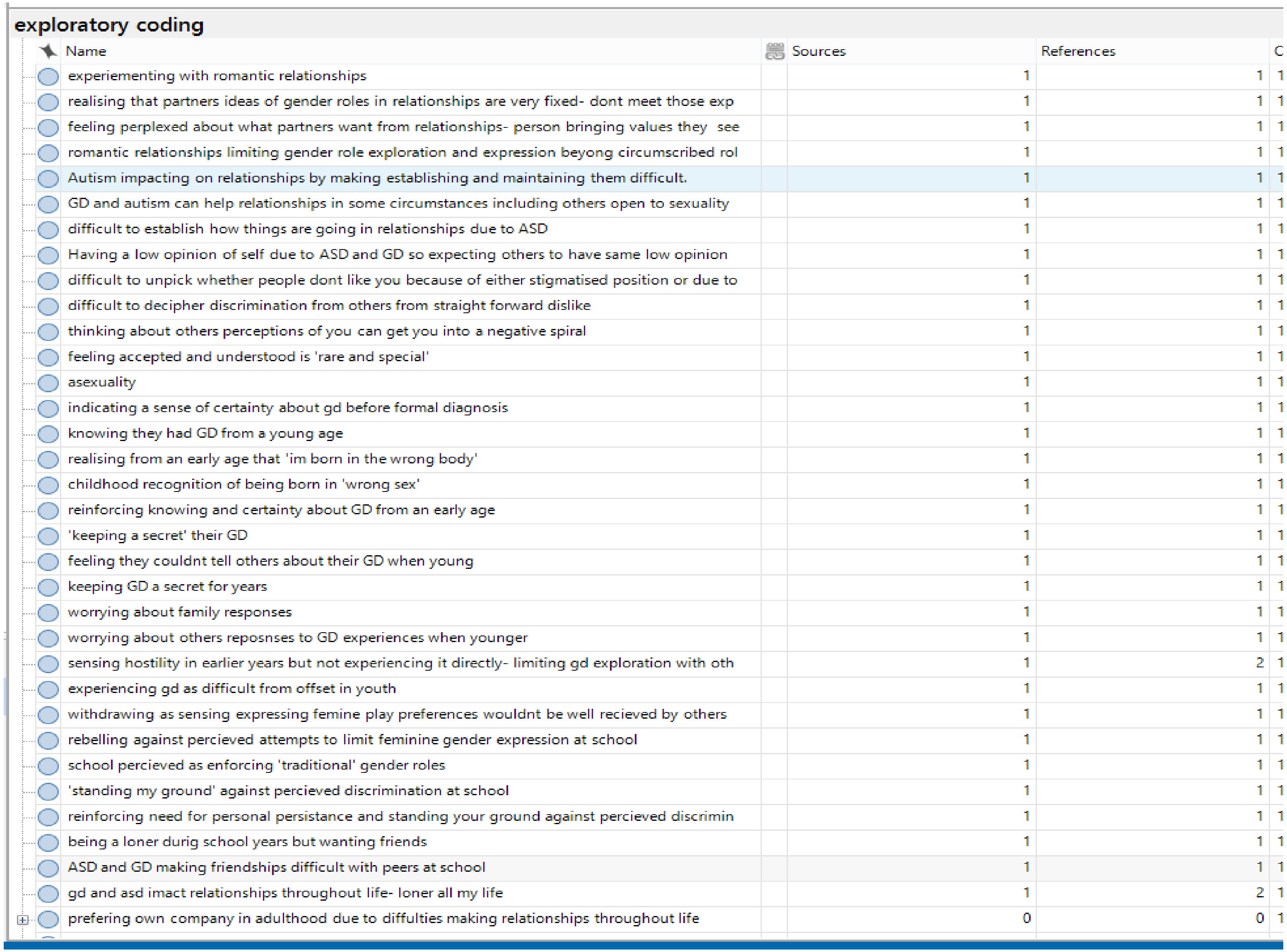
Early Coding Example and Bank of Initial Codes

N-Vivo does not have a facility to see coding alongside the transcript and so below the initial codes created on N-Vivo have been added to a Word version of the transcript. Beneath this is a screenshot from N-Vivo of the bank of line-by-line codes built-up from coding the transcripts.

Interview dialogue	**Coding**
I* Ok, so do you think autism has an impact on the meaning of gender for you?	
P Um… frankly, it makes things complicated. Yes, everything starts off complicated. Ha, I'm told I think too much and often, I'm kind of like in that stage of life, where I can think too much about my gender, which wasn't really like an option for me earlier in life.	Explaining autism complicates gender and more broadly complicates things: Making you think too much-ruminating? Thinking about gender a lot is problematic? Implying there is a stage of thinking but also *not* thinking-ignoring. Implying early-life difficulties restricted thinking about gender. Not feeling gender expression/exploration was an option.
I Can you tell me more about it not being an option?	
P Um, well I grew up in a fairly, pretty difficult quite conflicted household where, um gender expression never really felt like a topic you could, talk about.	Explaining home-life was difficult. Justifying not expressing gender concerns. Gender expression (feminine) forbidden, even *thinking* about it.
I Yes.	
P And I didn't really feel like something I could really take on until I was like in my 20s.	Timing/context not right to 'take on gender'. Suggesting gender is an opponent. Needing to feel ready. Maturity?

I	So you got a sense of well concerns about gender, you were thinking about it but you weren't allowed to explore it?	
P	Um, it feels a lot more like I wasn't allowed to think of it in the situation I was in, there was, you know, there was enough trouble going on.	Clarifying difficulties at home prevented thinking about gender. Implying GD likely to provoke more family trouble! Fearing consequences?
I	Yes. And then you said it was different in your 20s?	
P	Yes, I moved to – I moved from S to L when I was 25, to go to University, and then I started experimenting and being open about, about my gender, when I was living in L.	Moving away from home/conflict enabling experimentation. Being open about gender identity.

*Interviewer
**Participant



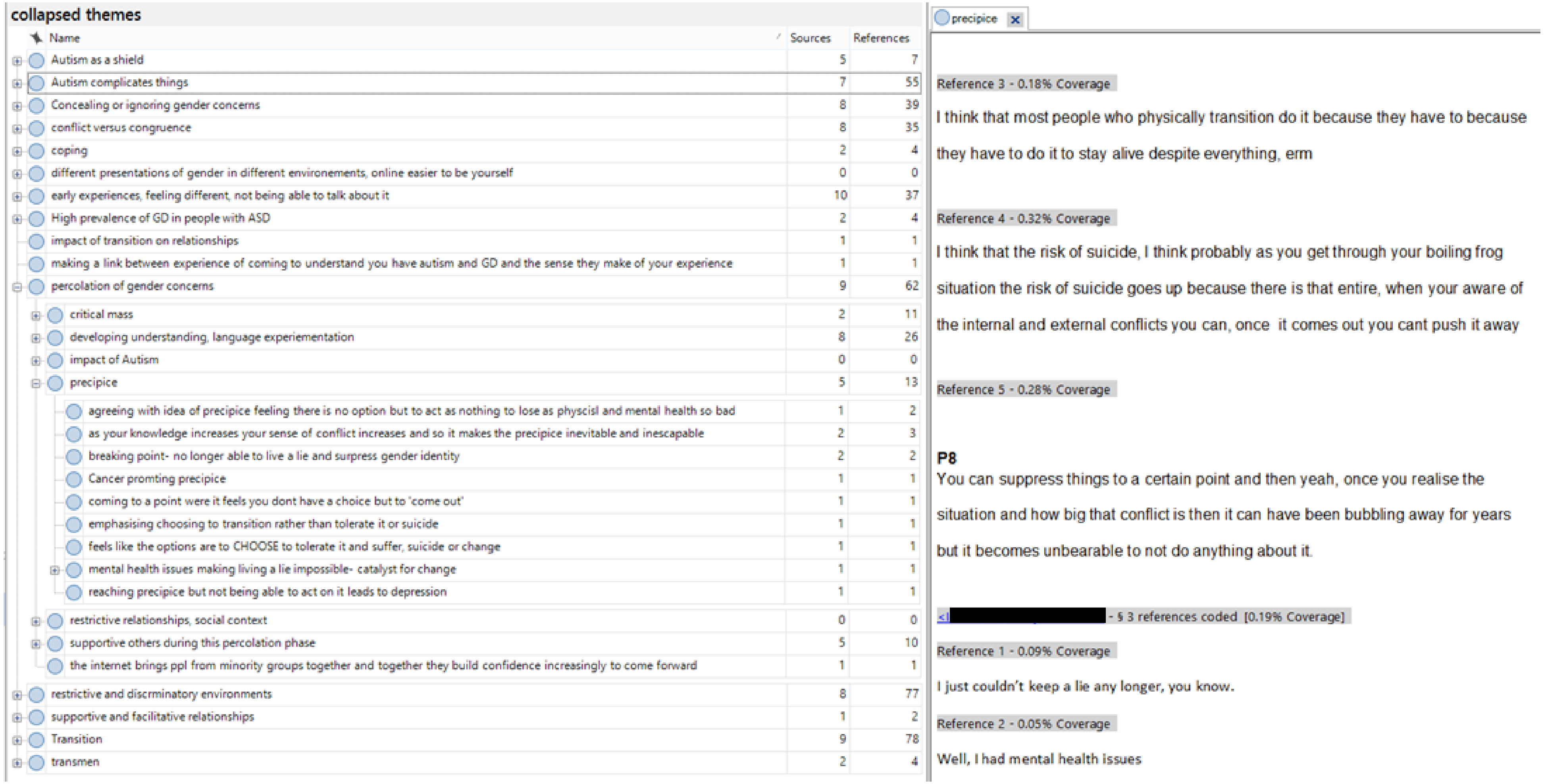
exploratory coding

Name	Sources	References	C
experiementing with romantic relationships	1	1	1
realising that partners ideas of gender roles in relationships are very fixed- dont meet those exp	1	1	1
feeling perplexed about what partners want from relationships- person bringing values they see	1	1	1
romantic relationships limiting gender role exploration and expression beyong circumscribed rol	1	1	1
Autism impacting on relationships by making establishing and maintaining them difficult.	1	1	1
GD and autism can help relationships in some circumstances including others open to sexuality	1	1	1
difficult to establish how things are going in relationships due to ASD	1	1	1
Having a low opinion of self due to ASD and GD so expecting others to have same low opinion	1	1	1
difficult to unpick whether people dont like you because of either stigmatised position or due to	1	1	1
difficult to decipher discrimination from others from straight forward dislike	1	1	1
thinking about others perceptions of you can get you into a negative spiral	1	1	1
feeling accepted and understood is 'rare and special'	1	1	1
asexuality	1	1	1
indicating a sense of certainty about gd before formal diagnosis	1	1	1
knowing they had GD from a young age	1	1	1
realising from an early age that 'im born in the wrong body'	1	1	1
childhood recognition of being born in 'wrong sex'	1	1	1
reinforcing knowing and certainty about GD from an early age	1	1	1
'keeping a secret' their GD	1	1	1
feeling they couldnt tell others about their GD when young	1	1	1
keeping GD a secret for years	1	1	1
worrying about family responses	1	1	1
worrying about others reposnses to GD experiences when younger	1	1	1
sensing hostility in earlier years but not experiencing it directly- limiting gd exploration with oth	1	2	1
experiencing gd as difficult from offset in youth	1	1	1
withdrawing as sensing expressing femine play preferences wouldnt be well recieved by others	1	1	1
rebelling against percieved attempts to limit feminine gender expression at school	1	1	1
school percieved as enforcing 'traditional' gender roles	1	1	1
'standing my ground' against percieved discrimination at school	1	1	1
reinforcing need for personal persistance and standing your ground against percieved discrimin	1	1	1
being a loner durig school years but wanting friends	1	1	1
ASD and GD making friendships difficult with peers at school	1	1	1
gd and asd imact relationships throughout life- loner all my life	1	2	1
prefering own company in adulthood due to diffulties making relationships throughout life	0	0	1

Appendix F

Later Coding

The screenshot beneath shows the final category structure with one category's codes displayed ('reaching a precipice'). The numbers illustrate the number of participants who portrayed the experience of a precipice ('source) and the number of supporting quotes ('references'). The screen to the right shows the quotations comprising the displayed codes.



collapsed themes

Name	Sources	References
Autism as a shield	5	7
Autism complicates things	7	55
Concealing or ignoring gender concerns	8	39
conflict versus congruence	8	35
coping	2	4
different presentations of gender in different environements, online easier to be yourself	0	0
early experiences, feeling different, not being able to talk about it	10	37
High prevalence of GD in people with ASD	2	4
impact of transition on relationships	1	1
making a link between experience of coming to understand you have autism and GD and the sense they make of your experience	1	1
percolation of gender concerns	9	62
critical mass	2	11
developing understanding, language experiementation	8	26
impact of Autism	0	0
precipice	5	13
agreeing with idea of precipice feeling there is no option but to act as nothing to lose as physcisl and mental health so bad	1	2
as your knowledge increases your sense of conflict increases and so it makes the precipice inevitable and inescapable	2	3
breaking point- no longer able to live a lie and surpress gender identity	2	2
Cancer promting precipice	1	1
coming to a point were it feels you dont have a choice but to 'come out'	1	1
emphasising choosing to transition rather than tolerate it or suicide	1	1
feels like the options are to CHOOSE to tolerate it and suffer, suicide or change	1	1
mental health issues making living a lie impossible- catalyst for change	1	1
reaching precipice but not being able to act on it leads to depression	1	1
restrictive relationships, social context	0	0
supportive others during this percolation phase	5	10
the internet brings ppl from minority groups together and together they build confidence increasingly to come forward	1	1
restrictive and discrminatory environments	8	77
supportive and facilitative relationships	1	2
Transition	9	78
transmen	2	4

Reference 3 - 0.18% Coverage

I think that most people who physically transition do it because they have to because they have to do it to stay alive despite everything, erm

Reference 4 - 0.32% Coverage

I think that the risk of suicide, I think probably as you get through your boiling frog situation the risk of suicide goes up because there is that entire, when your aware of the internal and external conflicts you can, once it comes out you cant push it away

Reference 5 - 0.28% Coverage

P8

You can suppress things to a certain point and then yeah, once you realise the situation and how big that conflict is then it can have been bubbling away for years but it becomes unbearable to not do anything about it.

<I[redacted] - § 3 references coded [0.19% Coverage]

Reference 1 - 0.09% Coverage

I just couldn't keep a lie any longer, you know.

Reference 2 - 0.05% Coverage

Well, I had mental health issues

Appendix G

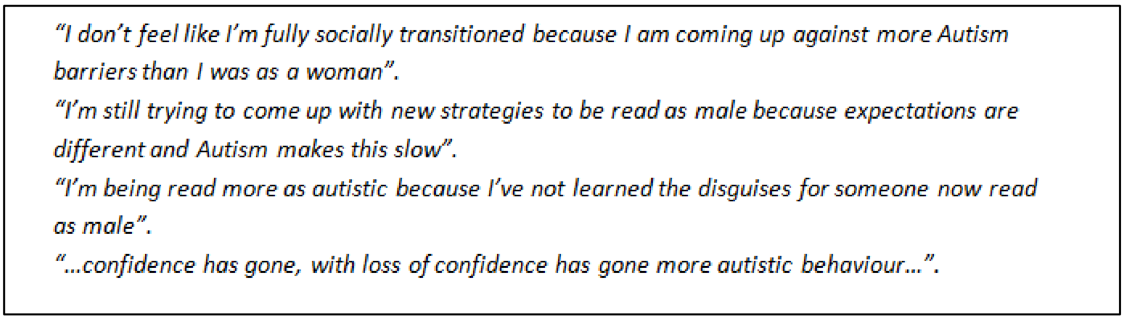
Memo Example

Physical transition and role of autism: Not a fairy-tale ending

24.1. 17

I realised from talking to F and showing him my draft diagram that I had thought of this stage following social transition linearly, and he said that is the medical view too. But actually the two are interrelated. Physical transition is needed to feel able to engage socially. Physical transition allows people to operate more safely in society and have their masculinity or femininity recognised, thus aiding social transition.

F was clear that everything isn't 'all done' when you physically transition- you have ongoing conflicts and challenges in navigating the social environment. Yes, the conflict between body and gender identity has improved, but as you are more consistently read as the 'new' gender, appearance-wise, you are expected to enact the 'typical' gender role. You need to do it convincingly, or there is risk of harm and misreading=dysphoria. This is where the autism creates conflict.



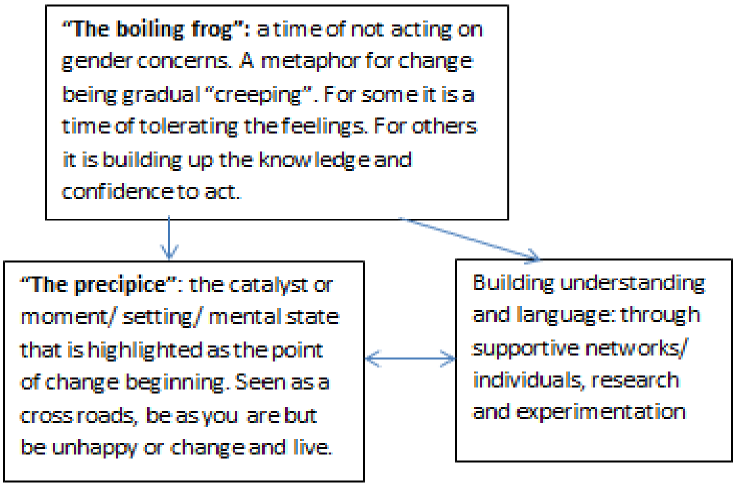
"I don't feel like I'm fully socially transitioned because I am coming up against more Autism barriers than I was as a woman".
"I'm still trying to come up with new strategies to be read as male because expectations are different and Autism makes this slow".
"I'm being read more as autistic because I've not learned the disguises for someone now read as male".
"...confidence has gone, with loss of confidence has gone more autistic behaviour...".

You have spent your life learning how to 'pass' as your birth-assigned gender and as neurotypical. Now you need to learn how to do the same in your new role. This can highlight your autism to others and you. This raises anxiety making your autistic traits more pronounced and so you're 'doing' your gender role less convincingly. A vicious cycle develops which can effect mental health and lead to isolation again.

‘Diagramming’ In Memos

Memo on moving from boiling frog to the precipice i.e. beginning of change 30/1/17

I initially thought that the ‘boiling frog’ phase lead to the precipice and the precipice and understanding were linked in that the precipice led to finding out more and finding out more influenced coming to the precipice.

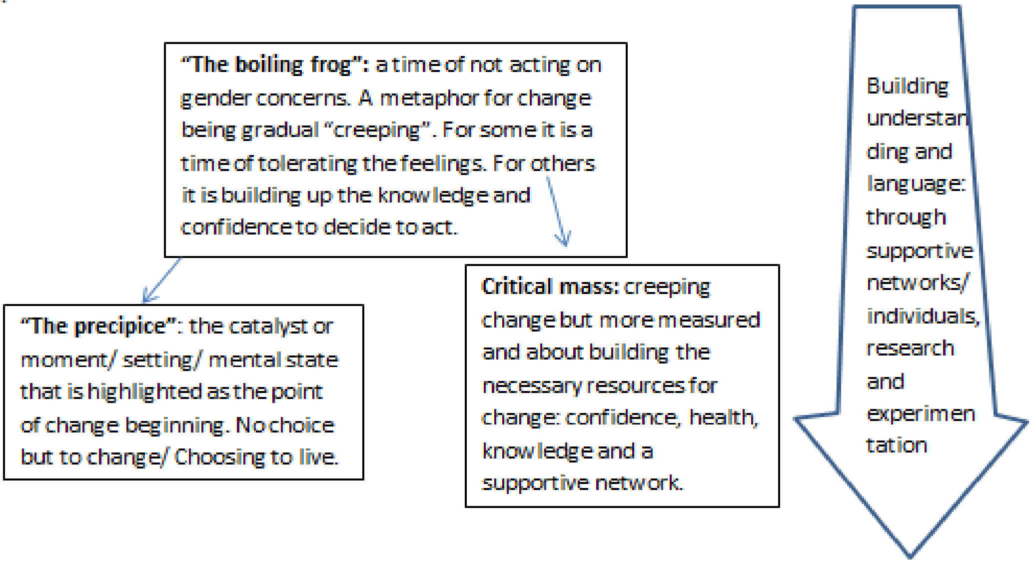


“The boiling frog”: a time of not acting on gender concerns. A metaphor for change being gradual “creeping”. For some it is a time of tolerating the feelings. For others it is building up the knowledge and confidence to act.

“The precipice”: the catalyst or moment/ setting/ mental state that is highlighted as the point of change beginning. Seen as a cross roads, be as you are but be unhappy or change and live.

Building understanding and language: through supportive networks/ individuals, research and experimentation

I’m now wondering if *for some* the boiling frog is about tolerating the GD feelings as long as you can which leads to the precipice in that tolerance has run out, mental health is low and feeling there is no option but to act. Whereas *for others* the boiling frog is also a time of creeping subtle change but more measured and about building the necessary resources for change like confidence, acceptance, knowledge and a supportive network, improving physical health and understanding of autism (like S and Z. This is perhaps more reaching ‘critical mass’ (oxford English dictionary defines as: “The minimum size or amount of resources required to start or maintain a venture”). Then deciding to change now or not. So there are two routes to transition. Autism plays a part: for the former autism “lowers tolerance for mental endurance” (A); for the latter e.g. S and Z they need to go steadily to prepare for change as change is tough. Supportive communities are crucial to the developing knowledge and feeling able to make changes for both those going beyond the precipice and critical mass.

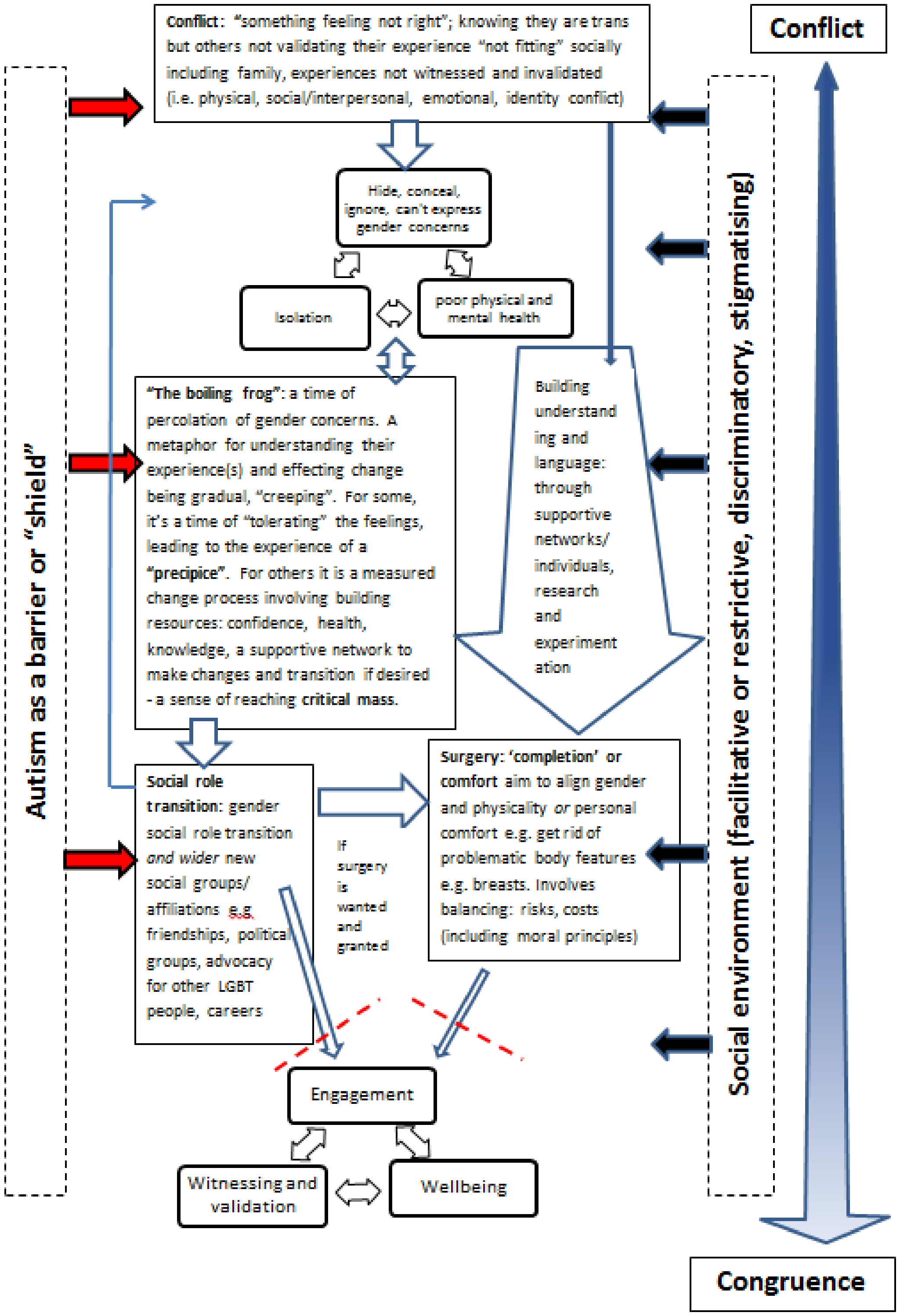


“The boiling frog”: a time of not acting on gender concerns. A metaphor for change being gradual “creeping”. For some it is a time of tolerating the feelings. For others it is building up the knowledge and confidence to decide to act.

“The precipice”: the catalyst or moment/ setting/ mental state that is highlighted as the point of change beginning. No choice but to change/ Choosing to live.

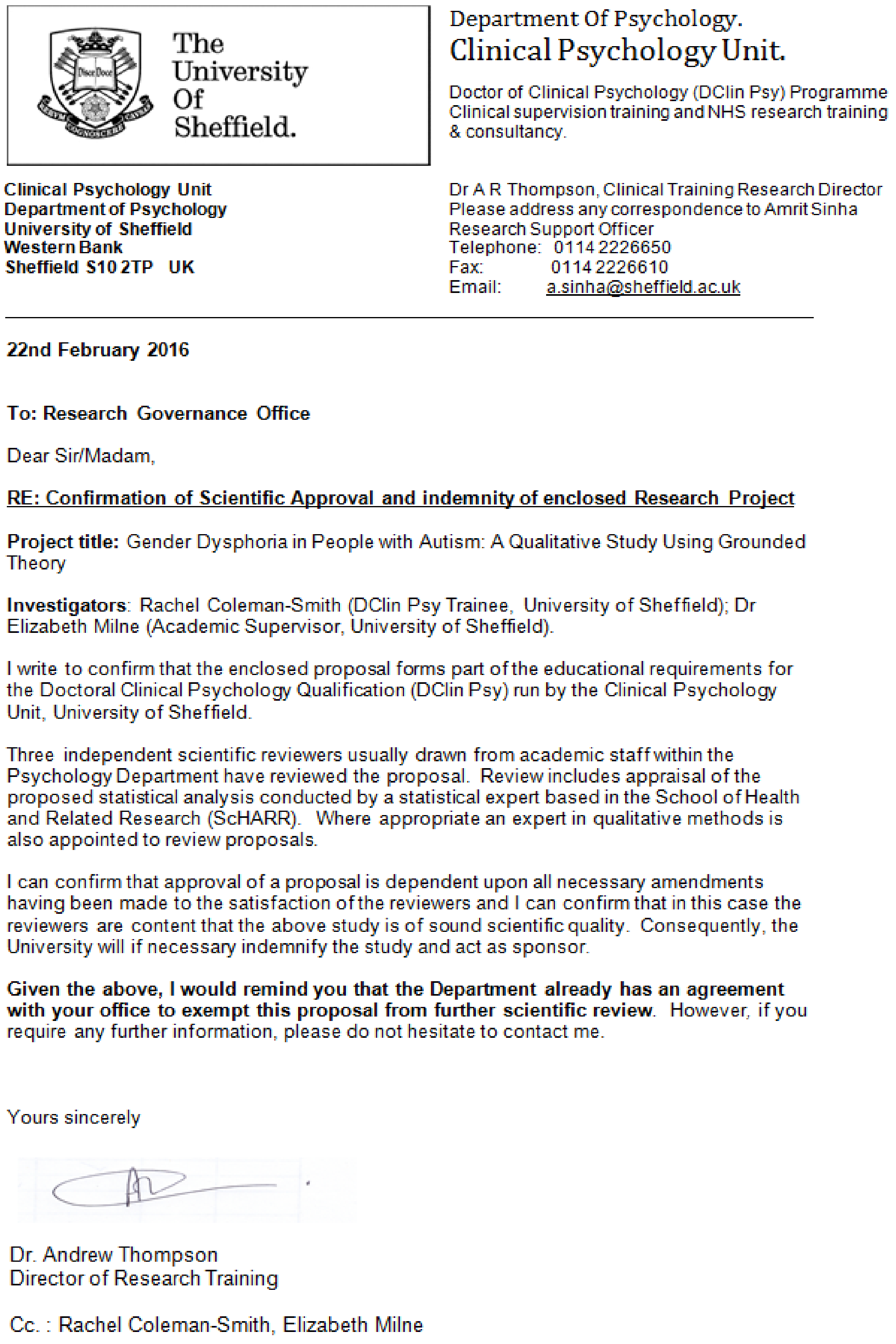
Critical mass: creeping change but more measured and about building the necessary resources for change: confidence, health, knowledge and a supportive network.

Building understanding and language: through supportive networks/ individuals, research and experimentation


Conflict: "something feeling not right"; knowing they are trans but others not validating their experience "not fitting" socially including family, experiences not witnessed and invalidated (i.e. physical, social/interpersonal, emotional, identity conflict)
Conflict
Hide, conceal, ignore, can't express gender concerns
Isolation
poor physical and mental health
"The boiling frog": a time of percolation of gender concerns. A metaphor for understanding their experience(s) and effecting change being gradual, "creeping". For some, it's a time of "tolerating" the feelings, leading to the experience of a "precipice". For others it is a measured change process involving building resources: confidence, health, knowledge, a supportive network to make changes and transition if desired - a sense of reaching critical mass.
Building understanding and language: through supportive networks/ individuals, research and experimentation
Autism as a barrier or "shield"
Social environment (facilitative or restrictive, discriminatory, stigmatising)
Social role transition: gender social role transition and wider new social groups/ affiliations e.g. friendships, political groups, advocacy for other LGBT people, careers
If surgery is wanted and granted
Surgery: 'completion' or comfort aim to align gender and physicality or personal comfort e.g. get rid of problematic body features e.g. breasts. Involves balancing: risks, costs (including moral principles)
Engagement
Witnessing and validation
Wellbeing
Congruence

Appendix I

University Ethical and Scientific Approval



The
University
Of
Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Dr A R Thompson, Clinical Training Research Director
Please address any correspondence to Amrit Sinha
Research Support Officer
Telephone: 0114 2226650
Fax: 0114 2226610
Email: a.sinha@sheffield.ac.uk

22nd February 2016

To: Research Governance Office

Dear Sir/Madam,

RE: Confirmation of Scientific Approval and indemnity of enclosed Research Project

Project title: Gender Dysphoria in People with Autism: A Qualitative Study Using Grounded Theory

Investigators: Rachel Coleman-Smith (DClin Psy Trainee, University of Sheffield); Dr Elizabeth Milne (Academic Supervisor, University of Sheffield).

I write to confirm that the enclosed proposal forms part of the educational requirements for the Doctoral Clinical Psychology Qualification (DClin Psy) run by the Clinical Psychology Unit, University of Sheffield.

Three independent scientific reviewers usually drawn from academic staff within the Psychology Department have reviewed the proposal. Review includes appraisal of the proposed statistical analysis conducted by a statistical expert based in the School of Health and Related Research (ScHARR). Where appropriate an expert in qualitative methods is also appointed to review proposals.

I can confirm that approval of a proposal is dependent upon all necessary amendments having been made to the satisfaction of the reviewers and I can confirm that in this case the reviewers are content that the above study is of sound scientific quality. Consequently, the University will if necessary indemnify the study and act as sponsor.

Given the above, I would remind you that the Department already has an agreement with your office to exempt this proposal from further scientific review. However, if you require any further information, please do not hesitate to contact me.

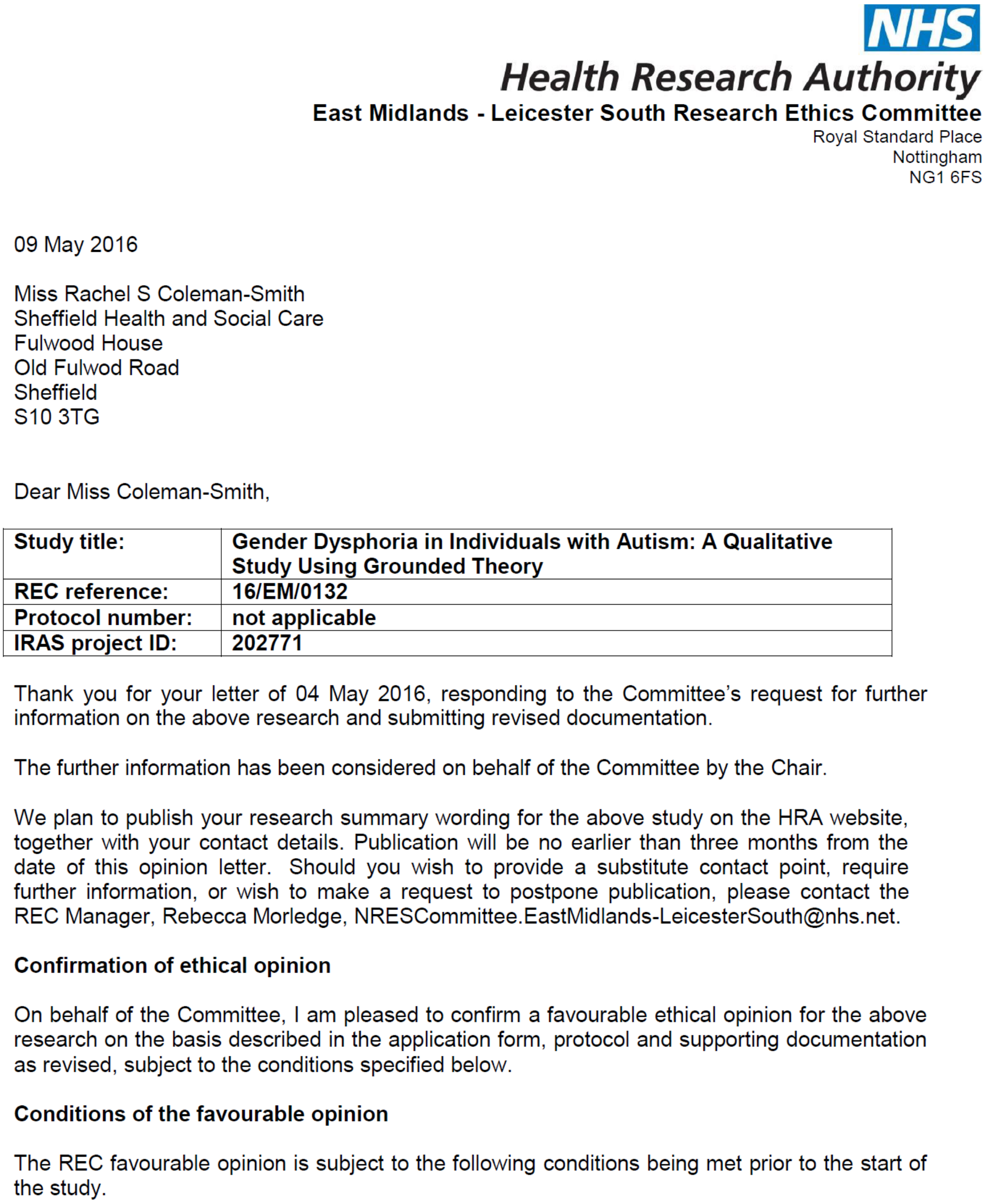
Yours sincerely

Dr. Andrew Thompson
Director of Research Training

Cc. : Rachel Coleman-Smith, Elizabeth Milne

Appendix J

IRAS Approval Letter



NHS
Health Research Authority
East Midlands - Leicester South Research Ethics Committee
Royal Standard Place
Nottingham
NG1 6FS

09 May 2016

Miss Rachel S Coleman-Smith
Sheffield Health and Social Care
Fulwood House
Old Fulwod Road
Sheffield
S10 3TG

Dear Miss Coleman-Smith,

Study title:	**Gender Dysphoria in Individuals with Autism: A Qualitative Study Using Grounded Theory**
REC reference:	**16/EM/0132**
Protocol number:	**not applicable**
IRAS project ID:	**202771**

Thank you for your letter of 04 May 2016, 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 Chair.

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 the REC Manager, Rebecca Morledge, NRESCommittee.EastMidlands-LeicesterSouth@nhs.net.

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 of the study.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Headed cover letter]	1	27 February 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Document]	1	03 May 2016
Interview schedules or topic guides for participants [Research interview schedule/outline]	1	27 February 2016
IRAS Checklist XML [Checklist_07032016]		07 March 2016
IRAS Checklist XML [Checklist_04052016]		04 May 2016
Letters of invitation to participant [Study invitation letter]	1	27 February 2016
Letters of invitation to participant [Second interview invitation letter]	1	27 February 2016
Other [A13 of IRAS form Answered]		
Other [Response to IRAS committee]	1	04 May 2016
Participant consent form [Consent form]	2	03 May 2016
Participant information sheet (PIS) [Participant Information Sheet]	2	03 May 2016
REC Application Form [REC_Form_07032016]		07 March 2016
Referee's report or other scientific critique report [Letter of scientific approval]	1	22 February 2016
Research protocol or project proposal [Protocol ethics submission]	1	27 February 2016
Summary CV for Chief Investigator (CI) [CV to support ethics application]	1	27 February 2016
Summary CV for student [CV Chief Investigator]	1	27 February 2016
Summary CV for supervisor (student research) [Research supervisor]	1	01 March 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research Synopsis]	1	27 February 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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 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 R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

16/EM/0132 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,

pp

Mr John Aldridge
Chair

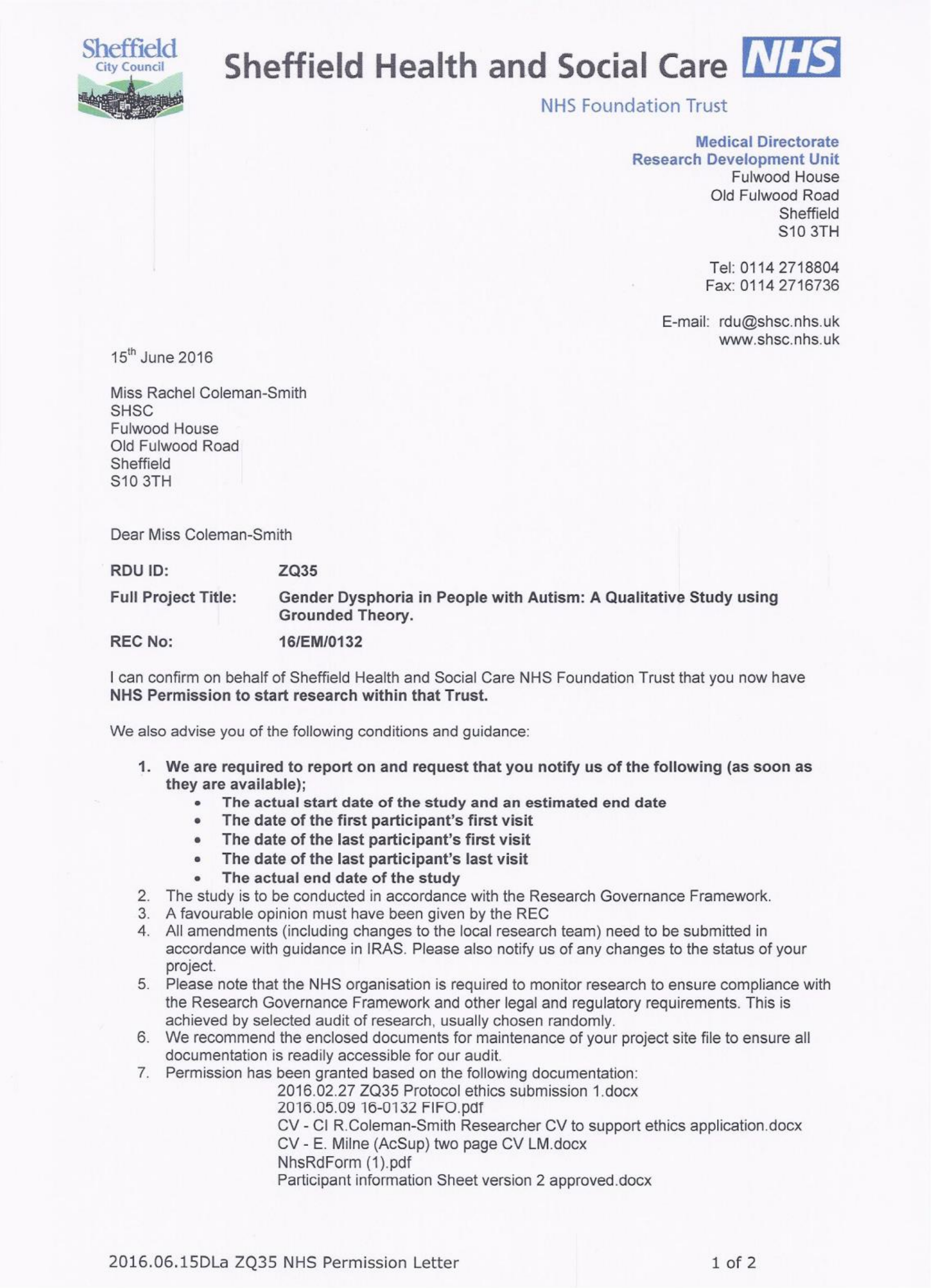
Email:NRESCommittee.EastMidlands-LeicesterSouth@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Doctor Andrew Thompson*
Mr Daniel Last, Sheffield Health and Social Care

Appendix K

Governance Approval



Sheffield
City Council

Sheffield Health and Social Care NHS
NHS Foundation Trust

Medical Directorate
Research Development Unit
Fulwood House
Old Fulwood Road
Sheffield
S10 3TH

Tel: 0114 2718804
Fax: 0114 2716736

E-mail: rdu@shsc.nhs.uk
www.shsc.nhs.uk

15th June 2016

Miss Rachel Coleman-Smith
SHSC
Fulwood House
Old Fulwood Road
Sheffield
S10 3TH

Dear Miss Coleman-Smith

RDU ID: **ZQ35**

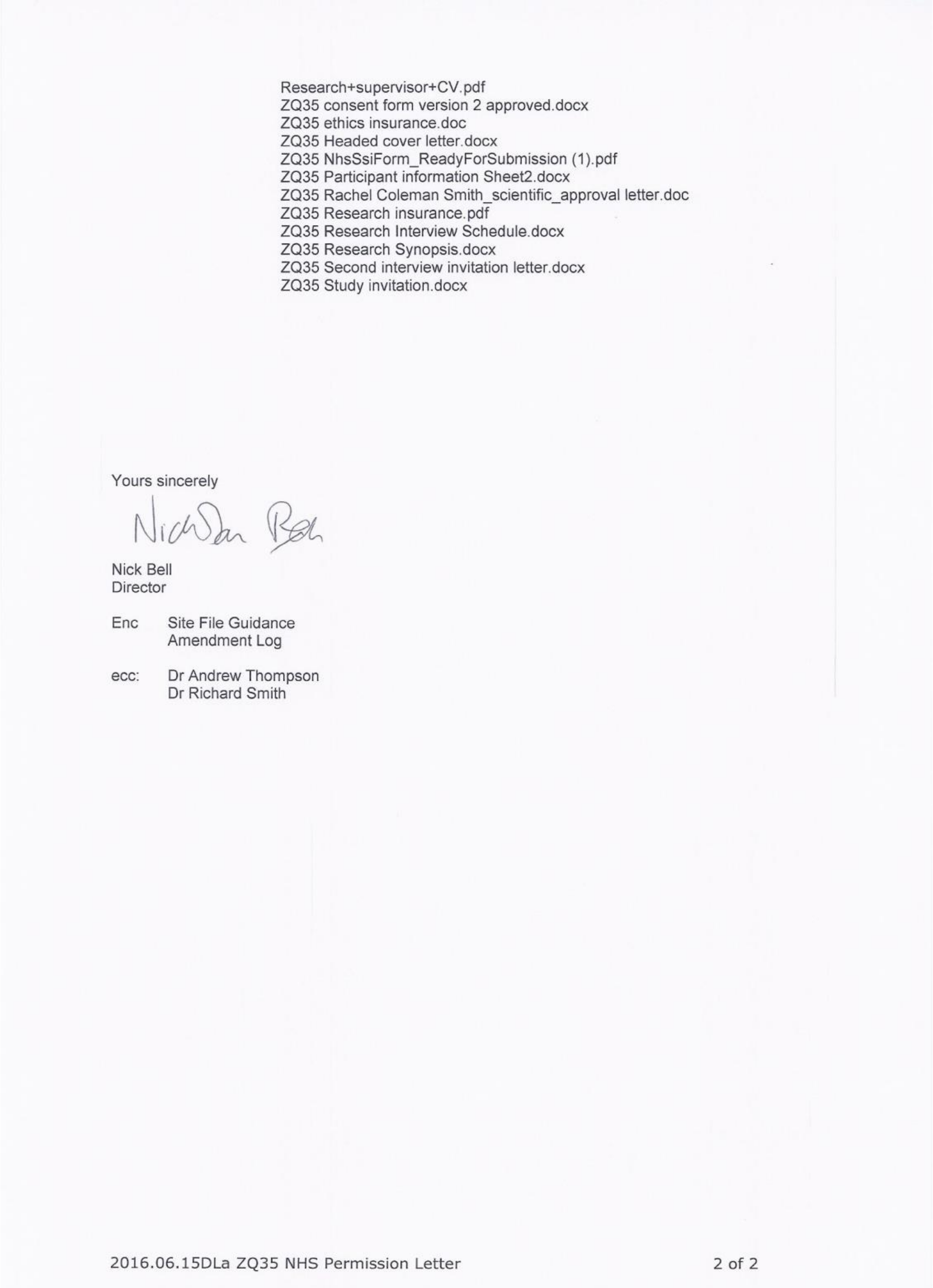
Full Project Title: **Gender Dysphoria in People with Autism: A Qualitative Study using Grounded Theory.**

REC No: **16/EM/0132**

I can confirm on behalf of Sheffield Health and Social Care NHS Foundation Trust that you now have **NHS Permission to start research within that Trust.**

We also advise you of the following conditions and guidance:

1. **We are required to report on and request that you notify us of the following (as soon as they are available);**
   - **The actual start date of the study and an estimated end date**
   - **The date of the first participant's first visit**
   - **The date of the last participant's first visit**
   - **The date of the last participant's last visit**
   - **The actual end date of the study**
2. The study is to be conducted in accordance with the Research Governance Framework.
3. A favourable opinion must have been given by the REC
4. All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS. Please also notify us of any changes to the status of your project.
5. Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by selected audit of research, usually chosen randomly.
6. We recommend the enclosed documents for maintenance of your project site file to ensure all documentation is readily accessible for our audit.
7. Permission has been granted based on the following documentation:
   2016.02.27 ZQ35 Protocol ethics submission 1.docx
   2016.05.09 16-0132 FIFO.pdf
   CV - CI R.Coleman-Smith Researcher CV to support ethics application.docx
   CV - E. Milne (AcSup) two page CV LM.docx
   NhsRdForm (1).pdf
   Participant information Sheet version 2 approved.docx



Research+supervisor+CV.pdf
ZQ35 consent form version 2 approved.docx
ZQ35 ethics insurance.doc
ZQ35 Headed cover letter.docx
ZQ35 NhsSsiForm_ReadyForSubmission (1).pdf
ZQ35 Participant information Sheet2.docx
ZQ35 Rachel Coleman Smith_scientific_approval letter.doc
ZQ35 Research insurance.pdf
ZQ35 Research Interview Schedule.docx
ZQ35 Research Synopsis.docx
ZQ35 Second interview invitation letter.docx
ZQ35 Study invitation.docx

Yours sincerely

Nick Bell
Director

Enc Site File Guidance
Amendment Log

ecc: Dr Andrew Thompson
Dr Richard Smith

Appendix L

Participant Consent Form

*As stated above this term is used as the preferred term of the population

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Title of Research Project: **Gender Dysphoria in Autistic* Individuals: A Qualitative Study**

Name of Researcher: Rachel Coleman-Smith

Participant identification number for this project:

1. I confirm that I have read and understand the information sheet/letter (delete as applicable) dated *[…………..]* explaining the above research project and I have had the opportunity to ask questions about the project. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. I may contact the lead researcher Rachel Coleman-Smith on 0114 222 2000 or rcolemansmith1@sheffield.ac.uk if I wish to withdraw. ☐

3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐

☐

4. I agree for the data collected from me to be used in future research.

5. I agree to take part in the above research project. ☐

____________________	________________	______________
Name of Participant	Date	Signature
__________________________	________________	______________
Name of person taking consent	Date	Signature
____________________________	__________________	______________
Lead Researcher	Date	Signature

Appendix M

Additional Risk Considerations

The researcher acknowledged the interviews may illicit strong and/or distressing emotions for participants. The researcher used their core clinical skills to communicate warmth, empathy and respect for the interviewee to minimise distress (Rogers, 1957). The interviews being for research and not therapeutic purposes, meant it was not appropriate to undertake a risk assessment with participants as part of the interview (Thompson & Russo, 2012). However, if during the interview significant risk to the interviewee or others had been disclosed, this would have been shared with the clinical research supervisor, other relevant health professionals, the Autism or Gender service or Crisis Team. This was outlined on the participant information sheet.

References

Rogers, C.R. (1957). The necessary and sufficient conditions for therapeutic personality change. *Journal of Consulting Psychology, 21,* 95-103. doi: 10.1037/0033-3204.44.3.240

Thompson, A., & Russo, K. (2012). Ethical dilemmas for clinical psychologists in conducting qualitative research. *Qualitative Research in Psychology, 9,* 32-46. doi: 10.1080/14780887.2012.630636

Appendix N

Full Quality Control Considerations

Elliott, Fischer and Rennie (1999) outline quality guidelines for qualitative research. These are detailed below along with the ways in which the researcher implemented them in the study:

1) ‘Owning one’s perspective’ involved the researcher acknowledging their theoretical orientations and personal anticipations before and during the research process, and the impact they may have on the data collection and interpretation. This required a reflexive approach which was facilitated through the use of a research diary, and supervision with the research supervisor and other qualitative researchers (see Appendix Q for the reflexivity protocol).

2) ‘Situating the sample’ was achieved by obtaining demographic and other relevant contextual information (e.g. timing of autism and GD diagnosis) from the participants. This information was provided in the results section to aid the readers’ judgment of the persons/situations the findings may extend to.

3) ‘Grounding in examples’ was implemented through the researcher providing illustrative quotes within the narrative for each category.

4) ‘Providing credibility checks’ involved asking interviewees whether the developing conceptual model represents their experiences. The data analysis process was also audited by a fellow qualitative researcher to verify the developing categories were grounded in the data and to interrogate category properties (see Appendix Q for the audit protocol).

5) ‘Coherence’ was achieved by presenting a narrative overview of the theoretical framework along with an illustrative diagram of the links between categories before describing the categories in more detail.

6) ‘Resonating with the reader’ was aimed for by using participants’ language to bring the categories to life. The researcher’s interpretation of the common experiences was hoped to provide language and understanding for difficult-to-express experiences.

7) ‘Accomplishing general versus specific research tasks’ involved the researcher making clear the limitations of extending the findings to other contexts and informants.

Appendix O

Reflexive diary excerpt

First trans man. This felt a relief as it was the first time I didn't struggle with mis-gendering which makes me feel awful. This was a sharp contrast to the interviews with trans women so far. To a casual observer this participant would have no issues being read as a man. It really brought into focus how we are culturally programmed to make assumptions about who people are and based on binary stereotypes. If people don't match that we get stuck. I wonder how that must change the experience of the person in the community at large compared to transfemales?

I recognised I was more intrigued by whether they had the lower surgery than the transfemales. I realised I had a preference for them to have lower surgery as the gender clinic seemingly had. Is this again cis-normativity? Their identifying as male but not having male genitals didn't fit with my world view.

This person seemed very calm and together. Again, a shock? Is this because I expected them to be more un-composed as someone with autism and transgender? Is this the influence of clinical practice and the population I encounter? From the details of the interview I realised they had had a 'good enough' family background. Again a contrast to the awful experiences I've heard so far. This person was able to plan their transition in cautious, measured way. This was different from the other interviews and the idea of individuals reaching a precipice. Does this suggest another option than the boiling frog to precipice? Is this measured approach to do with the coping style in autism, routine and planning? Influenced by the family background? 'A' also had a good enough family experience yet still experienced a precipice. I need to compare between participants and explore this more.

Reflecting I notice my embarrassment attached to a judgement which is hard to explain. I think I have an idea about transgender people being transmale kind of 'social oddities' and 'obviously transgender'. I'm almost caught off-guard by the person infront of me talking about being part of the trangender network- this isn't for you; you're a straight-forward guy from an ok family- Transphobia? Layered stigma? I have an idea of who transgender people and people with autism are? I need to be mindful of this in future interviews. This is painful but important to acknowledge as likely represents a common perception which is stigmatising of these individuals.

S talking about the [redacted] group- it dawned on me that this is an autism-friendly activity- they unlike some others, have been able to access the trans community. I need to think about this in implications.

Appendix P

Peer Audit and Reflexivity Protocol

The aim of this peer supervision is to audit data analysis processes in order to verify the themes are grounded in the raw data. In addition, supervision aims to consider reflexivity, i.e. the influence of the researcher on the analysis process.

Before the peer supervision afternoon, each researcher should provide each peer auditor with the following:

- Aims of the research
- An annotated and non-annotated version of a transcript
- Summary of over-arching and sub-themes
- The reflexivity journal entry for the same participant

The first hour of the session will be for finishing reading the data provided, which should be started beforehand. The following steps should be followed:

1. Read the non-annotated transcript and note initial thoughts and emergent themes.

2. Read the annotated transcript and summary of overall findings. Look for discrepancies with the raw data and particularly note any sections of the transcript that have not been coded.

3. Re-read any 10% of the transcript:
    - Is the noted emergent theme grounded in the data?
    - Is there any suggestion that outside influences (e.g. pre-existing theory) has influenced the coding?
    - Is the summary of themes a good fit with the data?

4. Feedback reflections and queries with the researcher, who should make a note of any concerns and discuss how anything could be changed.

5. Discuss the reflexivity journal entry with the group. Consider the emotional impact of the interview, previous theoretical understandings, and personal characteristics of the researcher which may have impacted on the analysis process.

References

Harper, D., & Thompson, A. (2012), *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. UK: Wiley-Blackwell.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory Method and Research*. London: Sage.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15,* 215-228. doi: 10.1080/08870440008400302

Appendix Q

Position of researcher declaration

I am a 34 year old white, heterosexual, neurotypical, cisgender female. These factors may have influenced participants' view of me, and were acknowledged to shape my conducting of the research and interpretation of data (see Appendix P).

I obtained my first degree in sociology and undertook a dissertation on sexuality and disability from a social constructionist standpoint. I continue to be orientated towards a social constructionist stance. I also hold an essentialist view of gender identity i.e. gender identity is innate, but its expression and the meaning one attributes to gender identity is shaped in interaction with the social environment.

I have studied some of the various theories of autism such as the Extreme Male Brain/Hyper-Systemising Theory (Baron-Cohen, 2002), the Weak Central Coherence theory (Happé & Frith,) and the ethological theory of autism (Richer, 2001).

I previously worked as a support worker for young adults with learning disabilities and autism. A key part of that role was supporting young people in socialising, including dating. I am also a member of the local council LGBT hub, seeing this as a valuable platform to share my passion, and work for change regarding the rights of people with disabilities to have their sexuality and gender identity acknowledged and supported.

References

Frith, U. (1989). Autism: Explaining the enigma. *The British Journal of Developmental Psychology, 21,* 465-468. doi:10.1348/026151003322277801

Richer, J. (2001). An ethological approach to Autism. In J. Richer & S. Coates (Eds.), *Autism: The search for coherence* (pp. 22-34).London, England: Jessica Kingsley

Appendix R

Additional Quotes

Category	**Illustrative quote**
Feeling different from an early age	Rihanna: "*I'd...put on my little sister's dresses and get laughed at by my parents and not be sure what I'm supposed to be doing.*" Autism compounds difference: Alex: "*Autism added to the sense of alienation…I didn't think or feel the same because of my autism. Then I also wasn't like everyone…because of [being transgender]…*"
Concealing and suppressing gender feelings	Conflict with the body entering puberty: Rihanna: "*Someone else is in my place…it's not my voice, it's not, that isn't my face*". Autism-related difficulties enacting assigned gender role due to impairments: Felix: "*I think it took me a bit longer than people who don't have autism, but I learned how to do a convincing version of the feminine role…but that always took effort*".
Isolation and poor mental health	Kate: *I don't have a very high opinion of myself, [and]... assume that people don't have a high opinion of me.*
Reaching a precipice	Alana: *…how many options have I got? This is one [transition], the other one is to deal with it and suffer…bombard myself with anti-depressants, try and push it out my head; [suicide] I don't consider an option because of my family... it's that*

	fundamental choice'
Achieving critical mass	Zain: *"I've done a lot of work with therapies, trying to get on top of my health so by the time [addressing gender dysphoria] came round I was really strong …within myself.* People with autism need to prepare for change but that's frustrating as leads to further delays: Sam: *"the years of waiting …trying to find the confidence to [transition], and the nagging voice inside your head... 'you need to do something about it…now'...and being like 'I know, but I need to feel comfortable, I don't feel ready'… that's difficult".*
Social transition	The importance of gender-affirming relationships: Felix: **"***I got in touch with a support group for trans masculine people and made friends …the support I've had from them has been massively helpful during a really stressful time…having friends that were outside that group that I knew were open enough to discuss gender with helps…I had some people to l bounce my ideas…off".* Increased congruence and wellbeing: Alana: *"I feel there's a point to it. It's not, oh, what's the point?"* Conflict between desire for authentic gender presentation and managing risk: Kate: *"there's always that…conflict between gender expressions, gender expectations and the risk …because there are intolerant people".* Autism as a shield:

	Felix: *"I was just like 'well what the hell, I'll just be weird', I'm gonna get told I'm weird anyway!"*
Wellbeing, witnessing and engagement	Feeling confident to access services as a man and having his identity validated by others increases wellbeing and confidence: *Sam: "…going to a male barber shop.. as opposed to going to like a unisex hair salon …they sort of know to give you a male haircut…I think the first time or two they charged me female rates and then after that I've always been charged male rates…all those little things just make you feel more confident that you're passing as a man...I'm happy about that"*
Physical Transition	Increased body-gender congruence and wellbeing: Sam: *"…it's just good to… relax and…enjoy being free of having [breasts] and…just to be able to move on with my life, for it to feel natural and to be able to be happy when I look down at my chest".* The importance of supportive environments post-surgery. Providing a "confidence bridge" to entering the wider social world: Sam: *"…bringing trans people together and helping them to get confidence to participate in sport or go back to sport and giving them a safe environment…I think that's quite important…I don't know whether I would have gone to these having [had] my chest surgery, if there hadn't been a safe place for me to go out and do that."* Fear of hostility shaping the embodied self: Felix: *"I think in a better society I might not have had all of the changes that I had but I still would have had some… the main driver of needing to have*

	my chest altered was to be able to fit in with the society that wouldn't have been able to accept me otherwise". Ongoing conflict: Wez: *"there's still this niggling feeling…others realising[I'm transgender], questioning my masculinity…I'd get beaten up"*