'Lost in the literature'. People with intellectual disabilities who identify as trans: A Narrative Review

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Abstract

Purpose

This narrative review examines how trans people with intellectual disabilities are perceived and discussed in the academic literature.

Methods

A narrative review was carried out in order to better understand the positioning of people with intellectual disabilities who identify as trans.

Findings

There was a lack of clear terminology, an over medicalization of both people with intellectual disabilities and trans people, and evidence that identifying with a non-conforming gender identity was seen as a problem by services. Services need to better informed about issues around gender identity so that they are able to better support trans people with intellectual disabilities.

Originality

To our knowledge, no previous literature review has focused only on trans people with intellectual disabilities.

Introduction

Despite advances in the rights of people in the Gender and Sexual Diversity (GSD) community in recent years, questions of rights and access for transgender people have been raised (henceforth transgender and trans will be used interchangeably). With national media questioning rights to access facilities (Petter, 2018) and legislation defining gender by primary sexual characteristics (Walker, 2020) being a trans person is becoming increasingly politicized and policed. For those living in a marginalized group, being transgender becomes exponentially harder (Ballan, Romanelli and Harper IV, 2011).

A narrative review was carried out to explore the positioning of people with intellectual disabilities who identify as trans. The review included publications which made reference to people with intellectual disabilities who identified as transgender, were non-binary or who were experiencing gender dysphoria.

[Insert table 1]

Lack of clear identity

The majority of research has focused on trans women (Alexander, 2006; McClelland *et al.*, 2012; Newman *et al.*, 2018; Parkes and Hall, 2006; Türkoğlu and Türkoğlu, 2016; Wilson, 2006; Wood and Halder, 2014) and non-binary people with intellectual disabilities (Alexander, 2006; Duke, 2011; Griffiths *et al.*, 2010; McClelland *et al.*, 2012; Newman *et al.*, 2018; Parkes and Hall, 2006; Ramasamy *et al.*, 2017; 2021; Smith et al., 2021; Tallentire *et al.*, 2020; Thompson,

2014; Türkoğlu and Türkoğlu, 2016; Wilson, 2006; Wood and Halder, 2014; Wylie *et al.*, 2014 and there is a marked lack of representation of trans men. In addition, there is often an amalgamation of trans and transvestite/cross-dressing (Alexander, 2006). Although cross-dressing can be an early transitioning stage for some people (Ramasamy et al., 2021), cross-dressing is not synonymous with being trans (Stavney, 1999; Ruby, 1993). Where an individual appears to be gender questioning, support to cross-dress is more likely to be provided rather than support to explore gender identity (Alexander, 2006; Parkes and Hall, 2006; Wilson, 2006; Wood and Halder, 2014). Behaviours that may be associated with gender questioning may result in support teams questioning whether people with intellectual disabilities understand the concepts of gender (Parkes and Hall, 2006; Griffiths *et al.*, 2012)). For example, when Mr. X (Parkes and Hall, 2006)expressed a desire to live as a woman, the staff questioned Mr. X's desires and his understanding of not only his own gender identity but the wider concepts of gender roles and positions

Furthermore, intersectional identities of trans people with intellectual disabilities can lead to multiple difficulties (King,1988). Each identity has its own challenges but at the point of intersection, they are further accentuated. Currently, authors have tended to explore intellectual disabilities and trans identifies separately. The impact of multiple intersectional identities which may be perceived as 'other' need to be considered.

Medicalization

The current research into trans people with intellectual disabilities seems to reflect a medicalized context, where people are patients and their assigned gender dysnormative behaviour must be managed. The medical model of disability focuses on the concept of the disability itself as the root cause of any issues faced by the disabled person. Six out of sixteen studies: Griffiths *et al.*, 2010; Moreno *et al.*, 2017; Newman *et al.*, 2018; Parkes and Hall, 2006;

Türkoğlu and Türkoğlu, 2016; Wood and Halder, 2014) seemed to be embedded in an approach

and/or use of language associated with the medical model of disability in relation to the trans

person's experience. For example, Griffiths *et al*. (2010) examined gender identity disorders in

relation to being trans. There is little writing that focuses solely on trans men and women with

intellectual disabilities from a purely social model of trans inclusion. More research that

privileges the subjective voices (e.g., lived experiences) of trans people with intellectual

disabilities is needed.

Behaviours seen as problematic

Trans people with intellectual disabilities may experience their behaviours being problematised

(Alexander, 2006; McClelland *et al*., 2012; Newman *et al*., 2018; Tallentire *et al*., 2020; Wood

and Halder, 2014; Wilson, 2006). For example, when a person with intellectual disabilities

chooses to identify with their preferred gender, they may be perceived as going through a phase

or lacking capacity to make such decisions. Alexander (2006) stated that staff may characterise

trans people with intellectual disabilities as being less educated, lower social skills, or having

behaviour that challenges. People with intellectual disabilities are routinely infantilised and seen

as immature and incapable of making affirmative decisions.

Discussion

 Trans people with intellectual disabilities are 'lost in the literature', often mixed in amongst wider

GSD samples with papers focused on sexuality and sexual behaviours rather than on gender

identity. Whilst there were examples where individuals accepted and advocated for people with intellectual disabilities who are trans (McClelland *et al*., 2012; Ramasamy et al., 2021), overall, perceptions of trans people with intellectual disabilities were negative. In particular, there is little research investigating the views and needs of trans people with intellectual disabilities. More research is needed to ensure the voices of trans people with intellectual disabilities are heard..

Wylie *et al*.'s (2014) 'Good practice guidelines for the assessment and treatment of adults with gender dysphoria' outlines good practice for trans people with intellectual disabilities, Those people who are supporting trans people with intellectual disabilities need a better understanding of trans issues. Supporters need to understand these issues so that they can reduce stigma and better explain trans issues to other people (Winter *et al.*, 2016).   Winter *et al*. (2016) identified a number of difficulties faced by the trans population in accessing medical care and support, highlighting in particular, issues around of primary health care staff's lack of knowledge and understanding of the needs of transgender people. Furthermore, Winter *et al*. (2016) and Safer *et al*. (2016) indicate staff prejudice is a potential issue. Staff bias can lead to a hostile and abusive environment (Newman *et al*., 2018).

Training could increase awareness and decrease bias and improve the experiences of trans people with intellectual disabilities. Staff, family carers and people with intellectual disabilities need access to information about gender identity. Organisational and intrapersonal biases need to be addressed. Training should be co-produced in conjunction with disability organizations, trans advocacy organizations and with trans people with intellectual disabilities. Trans people with intellectual disabilities should be supported to speak and share their experiences.

Conclusion

There is a dearth of empirical research on trans people with intellectual disabilities. The research that has taken place highlights a number of issues that arise: the lack of clear terminology and the medicalization of both intellectual disabilities and transgender people. Whilst more research is clearly needed, including research into the experiences of trans people with intellectual disabilities, organisations and supporters need better knowledge about trans people and intellectual disabilities in order to better understand and meet needs.

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Table I - Study Characteristics

Citation	Rationale for Inclusion (e.g., participant demographics)	Study design and methods used	Findings

| Alexander (2006) | Topic of commentary paper on gender identity (in relation to Wilson, 2006, see below) In the case example, the person was diagnosed with intellectual disabilities (n=1, male, age: 60s) | Commentary (using a case example) | ● Amalgamation of trans and transvestite/cross dressing Dilemma of how to support a GSD person with intellectual disabilities in practice, whilst being aware how this could be perceived by others, e.g., inappropriate or confusion with it being a sexual pleasure
● Provision of a safe space to talk for the GSD person with intellectual disabilities.
● Met with support to cross-dress as a way to manage behaviour
● People deviating from this norm may be perceived as presenting 'behaviour that challenges'
● Staff may characterise trans people as being less educated, or having lower social skills or challenging behaviour
● Lack of awareness, knowledge, experience, ignorance and naivety of staff
● Staff do not recall meeting GSD people with intellectual disabilities in their practice frequently
● Paucity of information available for staff to support trans people with intellectual disabilities
● People with intellectual disabilities are unable to access mainstream groups, or reluctant to attend such groups
● Lack of research on people with intellectual disabilities who are GSD. |

Duke (2011)	3 studies included people with Trans characteristics and intellectual disabilities 42 participants within samples were self-identified or diagnosed with (learning) disabilities, including 8 males and one female.	Review	● People deviated from this norm presenting 'aggressive behaviours' ● Prejudice and discrimination (in intellectual disability study) ● Inadequate sex education ● GSD friendly education and supported living can help the development of queer and non-normalising, disability friendly identities
Griffiths *et al.*, (2011)	The chapter discusses 'trans-sexualism' and 'gender idenity disorder' (GID) Case examples included people diagnosed with intellectual disability (including cerebral palsy), n=12, 7 males, 5 females Age: 28-45, 7 not reported	Book chapter using case examples	● Comparison of diagnostic manuals regarding the criteria of GID and GID in childhood ● Discusses the power dynamics surrounding people with intellectual disabilities may lead to confusion ● People with intellectual disabilities seen as asexual ● Need to use language people are accustomed to in education ● Recommendations are given to clinicians diagnosing GID

| McClelland *et al.*, (2012) | The study included participants with ID, 4 trans, 4 males, 2 females (n=10)

The inquiry included their experience of being trans

Age: 17-26 | Qualitative Methodology | ● From the perspective of GSD groups and mainly focuses on sexuality

● Barriers to HIV prevention and Sexually Transmitted Infections

● Common misconception that disabled people are not GSD

● GSD people with intellectual disablities an under researched group

● Group homes banning sex

● Participants report not having sex in places they feel safe in

● There is a need for safe spaces, e.g., a place to meet and socialise and place for consensual activity.

● GSD youth to be involved in policy

● Educational resources needed which are relevant to GSD people with intellectual disabilities

● Information needed for people who support/work with these youth |
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| Moreno *et al.*, (2017) | Gender and sexual diverse people including trans with neurodisability (e.g., ID) were in the samples within the review | Review | • Expressing sexuality lead to a decrease in aggression in one case

• There is a lack of support and education.

• There is a need for safe spaces, e.g., a place to meet and socialise and place for consensual activity.

• More evidence base needed regarding support groups.

• Lack of literature on trans people including intellectual disabilities |

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Newman *et al.*, (2018)	The study included a transgender woman with ID, fetal alcohol syndrome, borderline personality disorder Age: 23	Case study	- Dismissal of trans identity - The reporting of incorrect pronouns used - Barriers to facing health care - Lack of knowledge and lack of services - Healthcare system discrimination present - Little current support within the intellectual disability community - Dual marginalisation present as systems only set up to deal with one difference at a time - Paucity of information available for staff to support trans people with intellectual disabilities

| Parkes and Hall (2006) | The review included samples diagnosed with GID, who cross-dress and intellectual disability, Age (range): 3 - 42 | Review | GID does occur in the population of people with intellectual disabilities Met with support to cross-dress as a way to manage behaviour Queries whether people with intellectual disabilities understand the concepts of gender - traumatic sexual assault in their teens People deviated from this norm presenting aggressive behaviours People with intellectual disabilities 'see gender roles as very concrete' GID might be more common in people with intellectual disabilities but prevalence is unknown. Little is known regarding the outcomes for the population of people with intellectual disabilities There is a need for more information to clarify issues; Service staff need to be open to considering GID and how it may present differently |

Ramasamy *et al.*, (2017)	Protocol about the experiences of people with ID who are trans	Systematic review protocol	● No systematic review on the experiences of GSD adults with ID at time of publication. ● The systematic review will exclude cross-dressers. ● The systematic review will include trans people.

Ramasamy *et al.*, (2021)	The review included 15 qualitative studies of LGBT people with an ID Age (range): Only studies with people over the age of 18 were included.	Systematic review	- Intersecting issues and multilevel environmental challenges experienced - The review found a profound and adverse impact on the daily lives of participants and development of a positively evaluated sense of self in the reviewed papers - Cross-dressing precursors transition - A staff member helped with name change procedure - Gender-based discrimination due to non-normative gender identity

Smith *et al*., (2021)	The review included 2 trans people identified (three papers referred to trans people with ID) of the 99 participants within the total samples.	Review	• Previously, trans people with intellectual disabilities have been marginalised and relative invisibility at a societal level • Lack of support may lead to inability to explore or express gender identity • Power imbalance found between staff-service user • Intellectual disability identity overshadows sexuality and gender identity

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| Tallentire *et al.*, (2020) | Participants were trans within a secure ID service, diagnosed with intellectual disability, n= 18, 17 males, 1 female

Age: 24-57 | Qualitative Methodology | ● From the perspective of GSD groups and focuses on sexuality

● Group attendance was useful, but some found it hard at first as they had to 'come out'; this helped them feel better (attendance at the group)

● Mostly men in the support group

● Group helped them to show their true identity

● Name calling by others who didn't attend the group caused distress

● Talking to people with different sexualities was useful

● Group attendees wanted to help others with their sexuality and developed pride in their own sexuality

● Group seen as valuable by researchers |

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Thompson (2014)	The commentary paper discussed transgendered people with ID in relation to Woods and Halder (2014)	Commentary	- Limited research in this area - Limitation of this area is that those with severe/profound intellectual disabilities have little or no opportunity to 'perform gendered social roles' - A discussion on the 'conservative treatment of people with intellectual disabilities' - Low number of trans people with intellectual disabilities are reported
Türkoğlu and Türkoğlu (2016)	The letter to editor is about co-occurring gender dysphoria Case study participant diagnosed with fragile X syndrome (FXS) and intellectual disability and ADHD, n=1, Age: 11	Letter using a case study	- More research needed to know re FXS and GID - First case of FXS and GID together - Unclear how much info given to child or his family

Wilson (2006)	The report discusses men with ID that desire to crossdress or want gender reassignment Additionally, the paper defines gender identities including transgender	Practice feature	• Met with support to cross-dress as a way to manage behaviour • Paucity of information available for staff to support trans people with intellectual disabilities • Misunderstanding of GSD people with intellectual disabilities within intellectual disabilities services • Sexuality 'an area of denial' in learning disabilities • Rights recognition improving paucity of research in this area • Little understanding of the function of cross dressing for individuals with intellectual disabilities • Lack of understanding by staff in services of how someone with intellectual disabilities might present as trans

Wood and Halder (2014)	The review focused on gender identity disorder and included people with ID. The samples included 15 participants diagnosed with ID, Age: range 3-47	Review	• Dearth of guidance on appropriate treatment or management' • 'Little evidence' if counselling, education or psychotherapy had been offered to those with intellectual disabilities • Few alternatives provided
Wylie *et al*., (2014)	There is inclusion of some guidance for people with ID who have GID	Medical Guidance	• Details support for both social and medical practices: e.g., counselling/psychotherapy as necessary prior to any treatment, support groups as recommended good practice and counselling/psychotherapy also to be offered if not accepted for treatment