

# Autism and Learning Disabilities: A relational-intersectional perspective

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## Abstract

In this article, I develop a relational-intersectional perspective in my work with autistics with learning disabilities and their paid care staff in social care in England. I propose and illustrate a shift from normalisation to depathologisation in autism as it has already occurred with “homosexuality” classified as a mental disorder in the 70s. I also explore the performativity of “being LGBTQ+” and “being autistic” in a neurotypical-heteronormative-ableist-led society. I point out a possible confluence of intersectionality and the social graces model. I also dig into what research tells us about the lives of people with learning disabilities and autism and the lives of care workers in social care. Finally, I emphasise the benefits of working from a relational-intersectional perspective in a relational approach that has social justice at the heart of its values.

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## From normalisation to depathologisation

As a queer cisgender man who works with autistics who have learning disabilities and their care staff, I have always felt moved when thinking and connecting the similarities in how LGBT people and autistic people want to achieve our basic human rights, for example the right not to be treated in an inhuman or degrading way (British Institute of Human Rights, 2021). In this sense, it is shocking to see how psychology as a discipline has been and is still instrumental in trying to eliminate or erase homosexual traits as well as autistic traits in people.

Science has been trying to suppress homosexual and autistic traits for at least 50 years. Behaviourist psychologist Ivar Lovaas tried in 1974 to attempt a “reparative therapy” for homosexuality and gender nonconformity to a young child in what was called the Feminine Boy Project (Pountney, 2016). Lovaas is also the founder of Applied Behaviour Analysis, a behavioural approach to autism that aims to make autistics “indistinguishable” from the non-autistic population (Milton and Moon, 2012).

Citation Link

The labels of homosexuality, transsexualism, and autism have shared the same space in different Diagnostic and Statistical Manuals of Mental Disorders. Although homosexuality was removed from the DSM in 1973 (Drescher, 2015), it took about forty years to remove transsexualism (sic) in 2012 (Heffernan, 2012) and another seven years to remove it from the World Health Organisation’s mental health manual called ICD-10. The neurodiversity movement continues to ask the psychiatric and medical establishment to remove autism from the manual of psychiatric disorders by arguing that autism is not a mental health condition.

In thinking about a possible common pathway, I’ve designed the following graph (Figure 1) to visually compare the LGBT+ and Queer rights movement and its particular social and cultural battle for trans rights, and how the neurodiversity movement continues to fight for autistic rights.

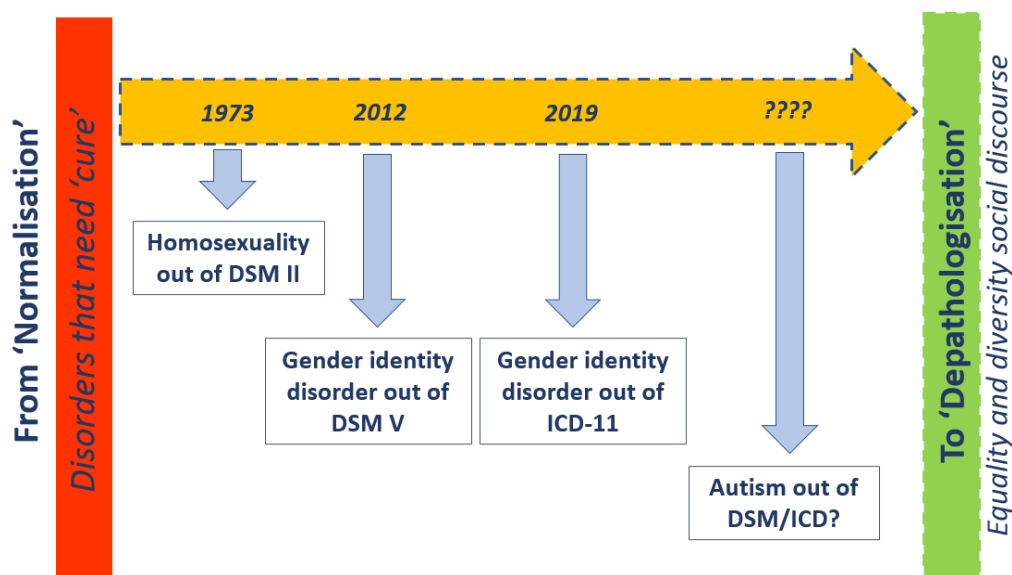


Figure 1: From considering disorders to understanding diversity.

The creation of the autistic pride movement takes some of its inspiration from the Queer liberation movement, as well as from the disability rights movement that started in the 1970s (Pountney, 2016). LGBT+ rights charity Stonewall continues to denounce that many lesbian, gay, bi and trans people are being poorly treated by health and social care services, including staff who believe that sexual orientation or gender dysphoria is something that can be “cured” (Stonewall, 2021). In this sense, a recent survey found that 5% of LGBT+ people have been pressured to access services to question or change their sexual orientation (Stonewall, 2021). LGBT+ people were more pressured if they were disabled (8%), young (9%), and of a Black, Asian and minority ethnic background (9%). Stonewall’s report found that 20% of trans people have been pressured to access services to suppress their gender identity when accessing healthcare services. In May 2021, the UK Government set out a plan to ban conversion therapy (UK Government, 2021a). Some trans individuals want to self-identify as transgender without the validation of the legal and health systems (Amnesty International UK, 2020a). Other UK human rights organisations also speak out for trans equality and emphasise how dehumanising discussions and “debates” lead to human rights abuses (Amnesty International UK,

2020b). At the same time, autistics denounce a “normalisation agenda” that embraces the idea that autistic people could and should be “normalised” (Labour Party, 2018).

O’Brien (2021) suggests that LGBT+ people and autistics shared at least some experiences: their identity was or still is considered an aberration, there seems to be a lack of elders in their communities - as many have been institutionalised, harassed, or murdered- and society seems to have stereotyped and narrow representations of these communities still. Autistics and LGBT+ people report trauma and talk about the processes of coming out, a metaphor to describe self-disclosure, and masking, which refers to hiding aspects of one’s personality to conform to social pressures.

### **The performativity of “passing” to reach the norm?**

From my lived experience, I understand that some people seem to have internalised the “normalisation agenda”, and their goal is to pass as “normal” as much as possible. Some autistics use the concept of “passing as non-autistic” or “masking” with a positive connotation in the sense of “camouflaging” and appearing normal to survive. (Autistic, 2015). Autistic and trans activist Felix Moore (2021) says that “autistic people spend their lives taught that the good autistic person is the autistic person who does not appear autistic”. Moore suggests that he has spent his life constructing a neurotypical mask to hide his autism because that is what he has been taught to do, but the same mask makes it difficult to have his autism recognised or to get the accommodations that he needs (Moore, 2021).

The statement, “Oh, but you don’t seem autistic” (Paradiz, 2018) could be understood in the same semantic level as “Oh, but you don’t seem gay” (*Things not to say to gay people*, 2021). Some gay men refer to themselves as being “straight acting” or “masc” (abbreviation of masculine) to emphasise positively that they behave as “straights” and perhaps implying they are not feminine-acting men (Arana, 2019). For some trans people, “passing as” cisgender also seems a positive personal characteristic (Jacques, 2010). Are these gender and neurodiverse performances a survival mechanism? Is it that in the end, all we want is to feel that we are part of this global cis/heteronormative, white-led and ableist society? I wonder.

Code-switching is a term created to refer to linguistics and how a speaker alternates between languages within a conversation (Ray, 2009). Since the 70s, some African American academics have referred to code-switching to describe relationships between people of colour—particularly Black people—and the colonial other (Harris, 2019). Ray (2009) describes African American code-switching as a performance expression that is integral to the survival of Black people because it is a tool that allows minorities to blend into different social and professional situations. Demby (2013) argues that some people of colour feel the need to code-switch in more situations than white people because the unwritten rules of many social situations are dictated by white experiences. Butler (1990) introduces the idea that gender proves to be always a doing, a performance. Gender is performed through our clothes, shoes, hairstyle, body language, socialised behaviours, etc. Pountney (2018) wonders if autistics perform autism through clothes, shoes, hairstyle, selective shaving/trimming of facial and body hair, body language, and socialised behaviours?

## Some personal characteristics are protected by law

Identity could be defined as “who a person is, or the qualities of a person or group that make them different from others” (Cambridge Dictionary, 2021). Although there seems to be a component of identity that refers to differences from others, the etymology of identity refers to “sameness, oneness, state of being the same,” (Etymonline, 2021). When discussing the identity of a person we might refer to different qualities or characteristics: their age, gender, sexuality, religion, culture and so forth. In the UK, the Equality Act 2010 (Equality and Diversity Forum, 2010) intends to offer protection against discrimination for certain groups of people based on 9 protected characteristics:

- Sex
- Age
- Ethnicity/Race
- Disability
- Religion or belief
- Sexual orientation
- Gender reassignment
- Marriage & Civil Partnership
- Pregnancy and Maternity

The Equality Act 2010 is the major equality law in Britain and brings together 9 big equality laws, about 100 smaller laws and over 2,500 pages of guidance and statutory codes of practice (Equality and Diversity Forum, 2010). The Equality Act 2010 sets out that when someone is disabled, they should be protected from discrimination. The definition of disability is quite wide (Citizens Advice, 2021):

- You are disabled if you have a physical or mental impairment.
- That impairment has a substantial and long-term adverse effect (at least a year) on your ability to carry out normal day-to-day activities.
- An impairment doesn't have to be a diagnosed medical condition. For example, suffering from stress and having difficulty concentrating - as well as physical impairments such as extreme tiredness and difficulty sleeping.

The Equality Act 2010 understands autism as a mental health condition and protects people with autism by proposing a legal obligation to make reasonable adjustments and not treat autistics less favourably.

## When personal characteristics intersect

Cole (2014) argues that psychologists are more interested in the effects of some of these characteristics on people's health and well-being, personal and social identities, and political views and participation. When these characteristics or categories of identity, difference, and disadvantage intersect, it is useful to turn to the term intersectionality (Crenshaw, 1991) that links identity with power. Intersectionality as a term was originally used to show how black women experience racial as well as gender oppression (Crenshaw, 1991). Mahalingam (2007) understands intersectionality in

terms of the interplay between person and social location, and its power relations. In this way, categories such as race, gender, social class, and sexuality do not simply describe groups but involve historical and continuing relations of political, material, and social inequality and stigma (Cole, 2014). As a result, categories are not primarily characteristics of individuals but structural categories and social processes. Intersectionality seems useful to frame a person's circumstances and amplify their visibility and inclusion. For example, Dale (2019) who is autistic, trans, and gay, writes in her memoirs about life at the intersection of transgender and autistic identities. She argues that this overlap was never explained to her by anyone in the medical field and this led to years of struggle because "there are guides out there for trans people, there are guides for coping with autism, but none for how to deal with living at that intersection".

Walker and Michaels-Dillon (2015) have developed the term neuroqueer, which refers to a label of social identity as queer, black, deaf, or autistic. Neuroqueer as a verb means being neurodivergent and approaching one's neurodivergence as a form of queerness (Walker and Michaels-Dillon, 2015). "Neuroqueerness" promotes the engagement in practices intended to "undo" one's cultural conditioning toward conformity and compliance with dominant norms, with the aim of reclaiming one's uniquely weird potentials and inclinations (Walker and Michaels-Dillon, 2015). However, being a minority within a minority can also intensify the potential mental health impact resulting from "minority stress", or the difficulties of being part of a marginalised group (George and Stokes, 2018). When transferring the term intersectionality to understanding the lives of people with autism and learning disabilities, intersectionality allows us to explore different collective circumstances of individuals who are:

- Black and brown
- Women
- LGBT+
- Older adults
- Muslim or belong to a religious or cultural minority
- Are described as having different level of cognitive abilities

### **The Social Graces Model**

Born in the field of systemic theory, the Social Graces model is another term that could be useful to think about our complexities as people and our characteristics linked to our social and cultural contexts. The term social GRRRAACCEESSS (Burnham, 2012) is an acronym that describes 15 aspects of personal and social identity which afford people different levels of power and privilege: gender, geography, race, religion, age, ability, appearance, class, culture, ethnicity, education, employment, sexuality, sexual orientation, and spirituality. From the field of social care, Pierre (2020) argues that Social Graces is a tool that can allow us to name power differentials and then identify our prejudice, privilege, and use it to redistribute power. Naming power differences can invite service users, support workers and professionals working with them to share reflections on the social graces which they feel can influence their judgement of others. The graces in the list can be adapted to place, time, and culture. Birdsey and Kustner (2020) point out the limitations of the social graces theory (Burnham, 2012):

- Its restrictive linear nature is in opposition to the complexity of people's lives.
- It should be considered more like a kaleidoscope (Burnham, 2012) with the capacity to focus on multiple aspects of social difference, bringing them into the foreground in different contexts and at different times (Totsuka, 2014).
- It should be considered in the context of power and privilege, diversity, and the commitment of therapists to social inclusion, with therapists enacting ethics rather than merely talking about them (Nolte, 2017).
- It should include disability/disablism and impairment (physical as well as linked to mental health) as this would facilitate curiosity about structural and psycho-emotional disablism and about the lived experience and the psycho-emotional impact of impairment (Jones & Reeve, 2014).
- It should also be extended to include anatomical differences, behavioural responses, and language, because communication differentiates and illuminates social group membership (Smith, 2016).

### The relevance of Intersectionality and Social Graces

I am using intersectionality and social graces together to foreground some aspects of the personal and social identities of people with autism and learning disabilities. I expand the list to 13 categories in a specific order according to their relevance (Figure 2). However, you could think of your own list with categories that are relevant to your context. For each category, I summarise an emerging amount of research available for some of the following areas:

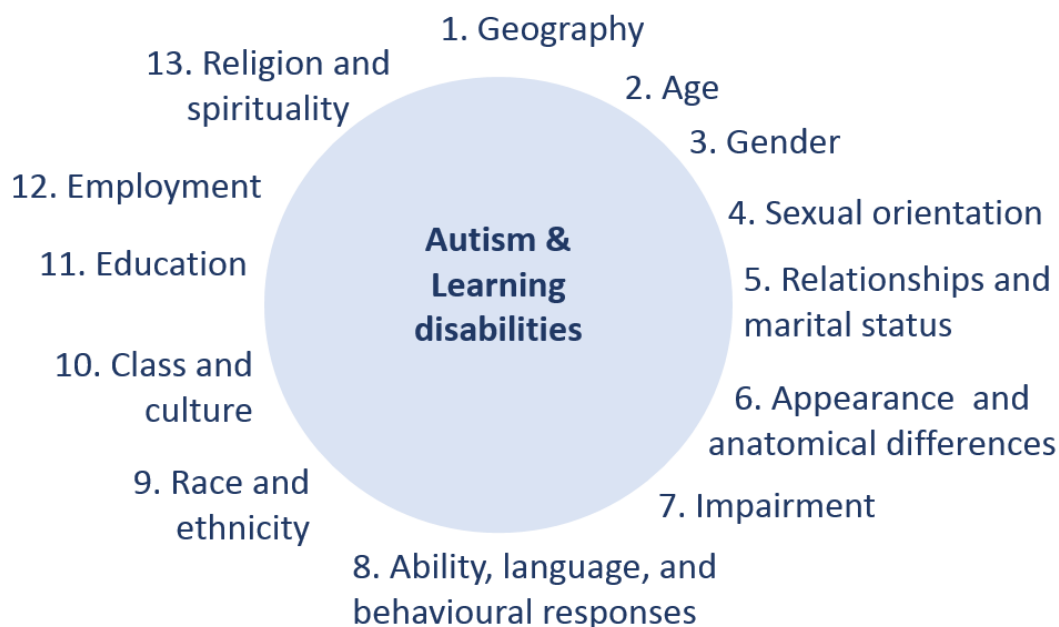


Figure 2: A possible map with aspects of personal and social identity.

## 1. Geography

### **It matters if people with learning disabilities and autism live in the south or the north of England.**

In terms of the general population, there is a North-South economic, cultural, and societal gap in which (Marmot et al., 2020):

- People in the north are less healthy and die from heart, respiratory disease, as well as lung cancer earlier than people living in the south (Marmot et. al, 2020; Bamba, 2021).

People living with areas of income deprivation are also more likely to present serious mental illness, obesity, diabetes, and learning disabilities (Baker, 2019).

## 2. Age

**People with learning disabilities live shorter lives.** In what are absolutely shocking numbers for the UK as the 6th richest country of the world, the University of Bristol and Norah Fry Centre for Disability Studies (2021) report that:

- Men with a learning disability die on average 23 years sooner than men in the general population, while women die 27 years sooner than the female population average.
- The average age at death of people with a learning disability in 2020 was 61 years.

People with a learning disability who are most likely to die at age 18-49 years are (University of Bristol and Norah Fry Centre for Disability Studies, 2021):

- People of Asian ethnicity.
- People from Black ethnic groups.
- People from mixed or more than two ethnicities.
- People with severe learning disabilities.
- People with profound and multiple learning disabilities.
- People who had had their freedom taken away by the Criminal Justice System or by being in secure mental health services.
- People who had not had an annual health check in the past year.

**Older adults with autism are a neglected group** (Boehm, 2013):

- Most autism research has been focused on children, so there is little information about autistic adults and older autistic adults (Stuart-Hamilton et al., 2009).
- Older adults report high levels of anxiety, depression, are socially isolated and have difficulties sustaining employment and relationships (Stuart-Hamilton and Morgan, 2011).
- For many people with disabilities in general, growing older means poor health, poverty and, in some cases, homelessness (Nuwer, 2020).

### 3. Gender

**Women struggle to receive a diagnosis due to a diagnosis gap.** The male-to-female ratio is closer to 3:1 (Loomes et al., 2017). However, females who meet the criteria for ASC are at risk of not receiving a clinical diagnosis (National Autistic Society, 2021a).

Women with learning disabilities are dying 29 years before women in the general population and for men, it is 23 years (University of Bristol and Norah Fry Centre for Disability Studies, 2021).

Women also tend to be less employed (5.2%) than men (6.6%) (National Health Service Digital, 2018; and tend to live in their own home or with family (77.8%) than males (76.9%) - (National Health Service Digital, 2018).

**Transgender and gender-diverse people are 3 to 6 times as likely to be autistic as cisgender people are** (Warrier et al., 2020). Research also suggests that:

- Gender-diverse people are also more likely to report autism traits and to suspect they have undiagnosed autism (Warrier et al., 2020).
- Clinicians treating transgender and nonbinary individuals should consider whether their clients, especially those assigned female at birth, have undiagnosed autism (Stagg & Vincent, 2019).
- Autistics are less susceptible to social pressure to conform so this resistance to social conditioning might play a role in the incidence of trans identity (Walsh et al., 2018).

### 4. Sexual orientation

**Autistic people are more likely to be sexually diverse (homosexuality, bisexuality, and asexuality) than the non-autistic population** (George & Stokes, 2018).

The sexuality of people with learning disabilities continues to be taboo in a context in which:

- People with LD often have incomplete or inaccurate knowledge of relationships (including LGBT+ relationships), sexual health and the legal and emotional aspects of sex (Jahoda & Pownall, 2014; Sinclair et al., 2015; Whittle & Butler, 2018).
- People with learning disabilities experience bullying and harassment. Some people need to hide their sexuality to avoid expected negativity. (Rushbrooke et al., 2014).
- Family members or service staff might not acknowledge the identities or relationships of people with LD (LGBT HIP and Lewis, 2015; Abbott et al., 2005; Harflett & Turner, 2016).
- Support workers see their role as limited and report a lack of guidance on what they can and cannot do or say in relation to supporting sexuality (Mencap, 2021).
- There seems to be a tension between trying to enable positive relationships and trying to protect the autistic person with a learning disability from abuse or exploitation (Harflett & Turner, 2016; Maguire et al., 2019).



O'Brien (2021) speaks from her lived experience as an autistic and bisexual woman. She reports that bisexuals are less valued as partners due to biphobia in the LGBT+ community. Bisexuals are told that they are confused, they are fake, they are not to be trusted. O'Brien (2021) reports that her queerness and her autistic experience have been described by professionals as "behavioural choices" that she could change, but this is based on stereotypes.

## 5. Relationships and marital status

### **People with LD report that they feel lonely and want to have friends and a relationship:**

- Almost 80% of disabled people in the general population aged 18-34 reported feeling lonely (Sense, 2017).
- 23% say they feel quiet or very lonely on a typical day (Sense, 2017).
- 6% of disabled people have no friends at all (Sense, 2017).
- 50% of people with a learning disability experience chronic loneliness (Gilmore & Cuskelly, 2014).
- Just 3% of adults with a disability live as part of a couple, compared with 70% of the rest of the population (Mencap, 2021).
- Loneliness is associated with physical and mental health problems and poorer quality of life (Gilmore & Cuskelly, 2014).

People with learning disabilities experience many barriers in developing and sustaining intimate relationships (National Development Team for Inclusion, 2019) such as:

- Limited opportunities to meet potential partners.
- Sometimes staff and family members prevent people from being in a relationship or make it very difficult to stay in a relationship.
- People with learning disabilities are sometimes not treated as adults who have the right to relationships by people around them.
- Some services do not give staff training on how to support people in intimate relationships.
- People with learning disabilities themselves have limited knowledge about sexuality and keeping safe.
- Intimate relationships are not seen as a priority when commissioning services unless there are concerns about risks and safeguarding.

## 6. Appearance and anatomical differences

There seems to be an opportunity for research in the following two questions:

- How are the experiences of people with a learning disability who are perceived by others as less able or more disabled?
- How are the experiences of people who are described as having different “levels of learning disability”, such as mild, moderate, or severe?

Kamstra et al. (2015) report that people with profound and multiple learning disabilities (PMLD) have smaller social networks, which consist mainly of family members. The friendship needs of people with profound and multiple learning disabilities (PMLD) are often ignored, perhaps due to their communication difficulties.

## 7. Impairment (Physical and psychological)

**50% of people with learning disabilities have a comorbid physical health condition:** this means it occurs at the same time due to a combination of factors (National Institute for Health and Care Excellence, 2020):

- Increased rates of obesity and of being underweight due to dietary factors, lack of physical exercise, and difficulties accessing healthy lifestyle advice and support.
- Increased risk of epilepsy compared to general population rates.
- Increased risk of dysphagia leading to eating and drinking problems and aspiration pneumonia.
- Increased rates of visual and hearing impairment.
- Increased rates of constipation, dyspepsia, thyroid disorders, eczema, and Parkinson disease or Parkinsonism compared to rates in the general population.
- Difficulties accessing healthcare and communicating needs.

**40% of people with learning disabilities experience mental health problems.** These can include anxiety, depression, phobias, psychosis, bipolar disorder, and schizophrenia. There is a higher rate of dementia (22%) in people with learning disabilities compared to 6% in the general population. Dementia is particularly prevalent in people with Down's syndrome with an earlier onset than in the general population.

The Office for National Statistics (2021) reports that:

- Disabled people (aged 16 to 64 years) average well-being ratings in the UK are poorer than those for non-disabled people for happiness, worthwhile and life satisfaction measures.
- Disabled people report higher anxiety levels than non-disabled people (4.47 out of 10, compared with 2.91 out of 10 for non-disabled people).

## 8. Ability, language, and behavioural responses

There seems to be an opportunity in research to explore the links between people's ability, language skills and their perceived behavioural responses. In this sense:

- People with mild/moderate learning disabilities are more likely to undertake education and training (Emerson & Hatton, 2008). Perhaps these skills are associated with having more opportunities in the job market.
- People with profound and multiple learning disabilities and people with severe learning disabilities tend to attend a day centre (Emerson & Hatton, 2008).
- Autism research focuses only on the more able end of the spectrum (Russell et al., 2019). However, around 50% of autistic people have a learning disability, compared with just 1% of people without autism.
- Autistics with a learning disability represent a "harder to reach population" and are massively under-represented in research (Russell et al., 2019).
- A severe learning disability increases the risk of a person presenting "behaviours that challenge", linked to difficulties with communication.
- 30% of autistics speak few or no words.

For people with learning disabilities who are described as being in contact with the forensic and criminal justice system due to their high-risk behaviours, the Foundation for People with Learning Disabilities (2012) indicates that:

- At least 7% of adult prisoners have an IQ under 70.
- 25% have an IQ under 80.
- 60% of prisoners have problems with communication.

Prisoners with learning disabilities are five times more likely than other prisoners to experience control and restraint, three times more likely to experience segregation and three times more likely to have depression or anxiety.

According to the Royal College of Psychiatrists (2014) there are almost 3.000 persons with learning disabilities in secure settings:

- 48 high, 604 medium and 1741 low secure beds.
- 345 forensic rehabilitation beds for people with learning disabilities in England.

## 9. Race and ethnicity

**Black autistic people with LD are stereotyped.** McEwen (2021) denounces how black autistic men with learning disabilities suffer from being stereotyped, as well as being perceived with bias and prejudice because their colour is more recognised than their diagnosis and needs:

- Black autistic men with LD are stereotyped as threatening, which can have grave consequences for interactions with police, with the prison, the court system and probation services, as well as mental health services.
- If they are tall, this might constitute a barrier and a negative physical attribute.
- Antipsychotic medication is used to “turn the black autistic man into a zombie” and shut down their physical attributes (McEwen, 2021).

Research also indicates that people from Black and minority ethnic groups in the general population tend to have poorer socioeconomic circumstances and the worst level of low satisfaction with life (Public Health England, 2017).

Black people in the general population are more than four times more likely to be detained under the Mental Health Act and more than 10 times likely to be subject to a community treatment order (Mohdin, 2021).

People with LD from black and ethnic minority communities are doubly disadvantaged and any strategy addressing their needs must include specific service objectives encompassing both race and disability (Baxter et al., 1990). Black and BAME communities report barriers in accessing services (National Autistic Society, 2014, 2021b):

- The process of getting a diagnosis is described as more challenging.
- Schools can fail to spot autism due to incorrect assumptions about a child’s behaviour or language abilities.
- Sometimes it is difficult accessing support services as information is often only available in English and professionals use jargon.

Some families feel that professionals could be patronising, lacking in cultural understanding, and as a result, families might not feel confident dealing with professionals.

## 10. Class and culture

**Disabled people in the general population are more likely to live with poorer living standards.** The National Institute for Health and Care Excellence (2020), a person with a disability is more likely than a person in the general population to:

- Live in housing that is rented and/or overcrowded and/or of a poor standard — around 60% of children and young people with learning disabilities live in poverty.

- Be exposed to tobacco smoke.
- Be bullied and/or physically, sexually, or emotionally abused — children with a learning disability are often socially excluded and 8 out of 10 are bullied.
- Have less social support.

According to the Office for National Statistics (2021):

- Almost 25% of disabled adults rented social housing compared with almost 8% of non-disabled people.

Disabled people were significantly less likely to own their own homes (40.9%) than non-disabled people (53.4%).

## 11. Education

**People with a learning disability are less likely to have access to education.** A survey (Emerson and Hatton, 2008) found that:

- Only 1 in 3 people (36%) were undertaking some form of education or training. It was higher among people with mild/moderate learning disabilities (36%) and people with severe learning disabilities (38%) than among people with profound and multiple learning disabilities (14%).
- 1 in 3 people (39%) attended a day centre. It was higher among people with profound and multiple learning disabilities (66%) and people with severe learning disabilities (49%) than among people with mild/moderate learning disabilities (24%).

According to the Office for National Statistics (2021):

- Disabled people in general are significantly less likely to obtain a degree and significantly more likely to have no qualifications than non-disabled people.
- 23% of disabled adults (not including people with a learning disability) have a degree, compared with almost 40% of non-disabled people.

15% of disabled adults (not including people with a learning disability) had no qualifications, which is almost three times the proportion of non-disabled people (5.4%).

## 12. Employment

**People with a learning disability are less likely to have a job:**

- Only 6% of adults with a learning disability known to their local authority in England are in paid work (National Health Service Digital, 2018).
- Only 17% of all adults with a learning disability in England are in paid work (Emerson and Hatton 2008).

- Only half of the disabled adults (52.1%) in the UK are employed, compared with around 8 in 10 (81.3%) for non-disabled people (National Health Service Digital, 2018).
- Only 21.7% of autistic people are in employment, this is the lowest employment rate.
- Adults with ASD who are employed need support in terms of greater awareness in the workforce, advocacy, and social skills training (Stuart-Hamilton et al., 2009).
- People who suffer long term unemployment have higher mortality rates than those in employment.

White people, married men, people with no disabilities and those with higher qualifications have higher employment rates than minority ethnic groups, women, lone parents, and people with disabilities.

### 13. Religion and spirituality

Some people report stigmatisation and lack of support from other members of their communities (National Autistic Society, 2014):

- Disability can be stigmatised and sometimes blamed on parents who might encounter hostile and judgemental attitudes. For instance, some parents feel that people assume that bad behaviour is due to their parenting.
- Some families report a lack of support from the faith groups they belong to and feel unwelcome in public places, including shops, libraries, and places of worship.

Some families find low awareness and intolerance towards autism and other disabilities at churches and mosques. Therefore, families are not able to turn to others for support. Feelings of blame and shame can lead to parents, carers and siblings missing support and becoming socially isolated.

## The new national strategy for autistics in England

In July 2021, the UK government (2021b) launched its new national strategy for autistic children, young people, and adults (2021 to 2026) for England. The strategy is the result of a public call for evidence that took a year to develop and received 2,700 responses. The strategy defines 6 priority areas to work on: a) improving understanding and acceptance of autism within society, b) improving autistic children and young people's access to education and supporting positive transitions into adulthood, c) Supporting more autistic people into employment, d) tackling health and care inequalities for autistic people, f) building the right support in the community and supporting people in inpatient care, and g) improving support within the criminal and youth justice systems. Although the strategy does not mention intersectionality, the priorities areas could be linked to some of the themes or categories from personal and social identities that I have previously highlighted: autism in women and girls, LGBT+ people, autistics from ethnic minority groups, education, employment, impairments (physical and psychological), and the category that includes ability, language, and behavioural responses.

## Intersectionality and care workers

Young people and adults with learning disabilities and autism are supported by paid care workers often called “support workers” or “staff” who are hired by companies called “care providers”. These are commissioned by local authorities to provide housing, care, and support to people with autism and LD, called “service users” in the ecology of social care (Urbistondo Cano, 2021).

In England, 10% of the population are employed in the NHS and social care. More than 1 and a half million people work in social care and 660,000 people are part of the learning disabilities and/or autism workforce in 2019/20 (Skills for Care, 2021). 59,000 were in the local authority sector and 600,000 were in the independent sector. It is largely a female workforce (Figure 3), almost half of them work part-time, and present the following characteristics:

### Support workers in Learning Disabilities and autism:

**82% female**

**47% employed part time**

**21% Black, Asian and Minority Ethnic (BAME)**

**84% British, 7% EU nationality, 9% non-EU**

**44 years old: average age**

**27% are 55+ years old**

**30.4% is the turnover rate of the sector**

Figure 3: Numbers reported by Skills for Care (2021)

Although the adult social care workforce is primarily female, only 33% had managerial roles (Skills for Care, 2021). From a gender and class perspective, law professor Lydia Hayes (2017) argues that the low pay, poor status, and lack of respect experienced by care staff account for the fact that this workforce is mostly female and working class. Hayes states that care staff are victims of what she terms “institutional humiliation”: a “process in which women who make their living by providing care in other people’s homes are widely judged to be inferior participants in the labour market” (Hayes, 2017, p. 196). These judgements are legal, managerial, political, and cultural, and find expression in poverty pay, disrespect and low social status. Hayes (2017) understands many of the failings of Britain’s care services for older and disabled people are “a result of a process of institutionalised humiliation in which age-old sexist ideas about the inferiority of women are reinforced and reaffirmed as sexist ideas and the inferiority of homecare workers” (p. 198)

Thirty years ago, Baxter et al. (1990) found that black and ethnic minority people tend to occupy lower positions where they are employed, being over-represented in low-status work and specialities, and under-represented in high status and managerial roles (Pearson, 1985). Black, Asian, and Minority Ethnic (BAME) workers made up 21% of the workforce in social care and this is more diverse than the overall population of England (14%). Workers from Black/African/Caribbean/Black British backgrounds (12%) accounted for over half of the BAME adult social care workforce, and this compares to 3% of the overall population of England. Black and ethnic minority staff working with people learning disabilities identified several issues of concern (Baxter et al., 1990):

- Challenging the racism of white clients and their parents.
- Poor promotion prospects for staff who challenge the system.
- Managers may not be supportive of antiracist training.
- Difficulties to establish their own cultural identity within a white institution.

The Equality and Human Rights Commission (2021) has started to develop an inquiry about racial inequality in health and social care workplaces. EHRC states that ethnic minority groups are over-represented in lower-paid roles and wants to understand the experiences of ethnic minority people during the COVID-19 pandemic. Particularly, how ethnic minority health and social care workers' treatment during the pandemic has been influenced by their race, employment status, immigration status, and working conditions. Skills for Care (2021) also found a lower prevalence of disability among workers, at only 2%. Sexual diversity did not seem to be included yet in the research that Skills for Care conducted.

### **A relational-intersectional-social graces perspective**

When working with support workers and people on the spectrum who have a learning disability, I find that it is important that care staff appreciate the interconnecting aspects of the person they are supporting that make up a whole self, not just a superficial cluster of diagnostic categories. It is important that staff understand how each of these identities or areas of life experiences are also a context for one another and are impacted on, separately and together, by external contexts. When working with another person, staff are part of the care relationship with their personal characteristics and aspects of their identities. Perhaps it could be useful to think about a relational-intersectional-social graces perspective (Figure 4) that includes social graces and that allows for reflection:

- 1) How can staff be responsive to understanding and reflecting on the intersectional aspects of their clients concerning their needs, wants and wishes?
- 2) How can staff be responsive to understanding their intersectional aspects interacting to their client's intersectional aspects?
- 3) How different contexts can foreground or background any of these personal characteristics and intersections in clients as well as in their staff?
- 4) How can we include references to the observer who is making a specific punctuation and who



might be producing a narrative in which some aspects of the person they work with are foregrounded over other aspects? This seems important in the context of social care in which often the life of people with LD and autism are narrated by professionals and paid care workers in psychology reports, support plans, needs assessments, training, and workshops about the person.

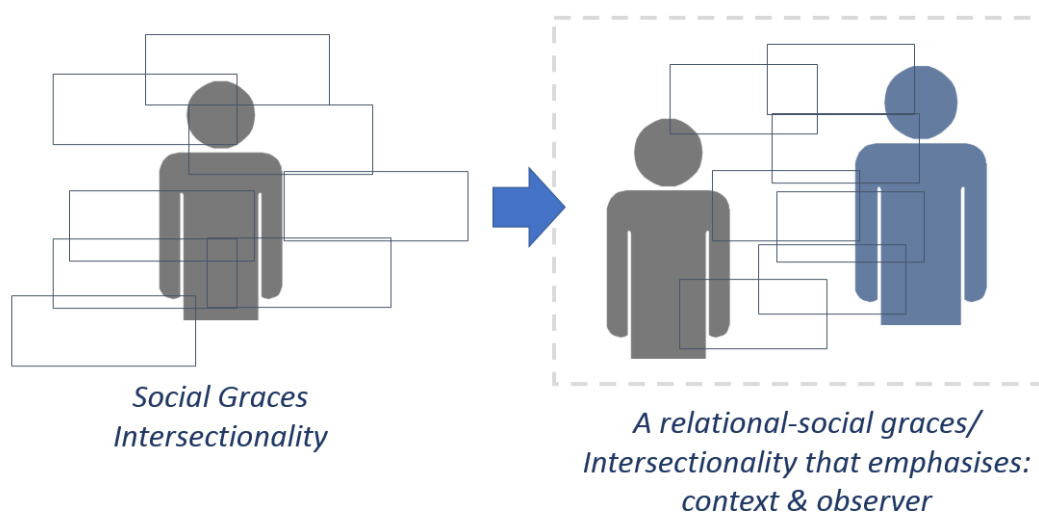


Figure 4: A possible map with aspects of personal and social identity

## Final thoughts

As I continue to work with people with autism and learning disabilities and their care staff in different contexts, I feel more and more that my work is somehow also about social justice for two disenfranchised groups of society. People labelled as “having learning disabilities”, called customers or service users, continue to claim more participation in society and in some cases basic human rights. People called support staff work in what could be described as a precarious and low budget model in the fragile ecosystem of social care (Urbistondo Cano, 2021). A relational and intersectional sensitivity is part of a relationship-centred approach in supporting people with autism and learning disabilities and their care staff (Urbistondo Cano, 2021). What I call RCA is an attitude and meta-position that integrates available training about autism and learning disabilities. The goal of RCA is to promote reflexivity, empathy, and a sense of equality in conversations with a team of support workers and their clients. Through this attitude and stance, we can contribute to generating relationship-led narratives in a context in which diagnosis and symptoms-deficit-led narratives seem to be dominant. When conversations between people focus less on individual deficits and more on relational difficulties, I find that we seem to find ways of moving on from what we call a problem, an issue, and be able to imagine a better future for service users and their support staff.

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