**Easy Read**

# Support and choices for LGBTQI+ disabled people in England

## Gender, Sexual Identity, and Social Care Support

This is an easy read version of '**Disabled people negotiate gender, sexual identity and self-directed social care support in England: how does choice and control operate?**'. Written by David Abbott, Edmund Coleman-Fountain, and Harvey Humphrey and published in the Journal of Critical and Radical Social Work (2024).

**February 2025**

# How to use this document

This is an easy read document. But you may need support to read it. Ask someone you know to help you. **This document has some upsetting stories.**

Words in **bold writing** may be hard to understand. We have explained these in the text.

Where the document says **we**, this means the researchers:

**David Abbott** - University of Bristol, UK

D.Abbott@bristol.ac.uk

**Edmund Coleman-Fountain** - University of York, UK

edmund.coleman-fountain@york.ac.uk

**Harvey Humphrey** - University of Glasgow, UK

harvey.humphrey@glasgow.ac.uk

Easy Read Wales made this document into Easy Read using **Photosymbols**. To tell us what you think about this easy read version, click here.

Photosymbols Licence number 403527247

# Contents

# Introduction

We wanted to find out what care and support is like for disabled people thinking about their:

- **sexual identity**

  and their

- **gender identity.**

We will explain some important words and terms that we will use. They help us understand some challenges people face.

For example, some people expect people's **gender** to match the **sex** they were when they were born. But for some people their **gender identity** is different.

This can be harder for disabled people who might need support to:

- live full lives,
- be independent.

Services are sometimes based on ideas of:

- what people are usually like
- what people usually need for a happy life

as if everybody is the same.

People **should** have services that:

- meet their wants and needs whatever their gender or **sexual identity**
- and help them to live full lives.

Not just services that meet their basic needs to survive.

There are lots of challenges to personalised care and support. This article looks at the challenges **LGBTQI+ disabled people** face.

## Important words and terms

### Sexual identity or sexuality

This means who you are attracted to. For example, you may want sexual or romantic relationships with men, women or both. Or not want them at all. We use words like lesbian, gay, bisexual and straight to describes people's **sexual identity**.

### Gender identity

This is how you feel inside about your own **gender**. **Gender** is about being female, male or **non-binary**. This does not always match the **sex** you were born with.

### Non-binary

This is a person whose **gender** does not match usual ideas of what is male and what is female. A **non-binary** person may feel or know that they are not a man or a woman.

### Sex

People are a particular sex because of physical things like sex organs and hormones.

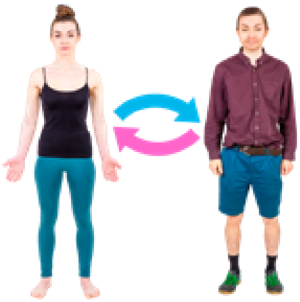
## LGBTQI+

**LGBTQI+** stands for:

- **Lesbian** - women who are attracted to other women.

- **Gay** - men are men attracted to other men.

- **Bisexual** - people who are attracted to both men and women.



- **Transgender** - someone whose gender is not the same as the sex they were thought to be when they were born.

- **Queer** - what people call themselves when they feel that words like straight, gay and lesbian do not fit them.

- **Intersex** –a person who has both male and female body parts, including hormones.

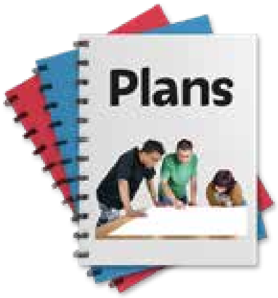
- The “**+**” symbol means all other **sexual** and **gender identities**.

We use **LGBTQI+** to talk about people who have similar experiences because of who they are and who they love.

# Self-directed support

**Self-directed** support means people have choice and control over:

- What support they get.
- When they get it.



- Who they get it from.
- How it is planned and given.

**Direct payments** are one way that people get self-directed support.

**Direct payments** are money from social services for you to use to organise your own support.
For example, you can find and pay for your own personal assistant (**PA**).

This is instead of getting care and support from social services that they organise for you.

Disabled people have fought for self-directed support, so they can:

- live how they choose
- and be who they are.

Like most non-disabled people can.

When social services organise your care, you often have no say over who comes into your home to give you support.

You cannot always choose a carer that can relate to you. This could be someone who:

- is a similar age
- thinks the same way as you
- is from the same background
- believes in the same things
- has the same **gender identity** and **sexuality**.

For **LGBTQI+** disabled people, this can make it harder to get support that empowers them.

People have different feelings and opinions about **sexuality** and **gender identity**. Some people treat others differently because of it.

Self-directed support is an important part of many laws and policies in the UK.

But this does not mean it is happening in real life.

There are many challenges:

- Government spending cuts.
- Not enough social care staff.

- Local authorities spending less on social care services.

- Less money for advocacy services and disabled people's organisations.
- Not enough help for people to manage Direct Payments.

- There are few services for people to choose from.

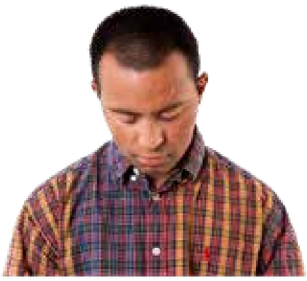
This has meant disabled people can only get care that meets their most basic needs. They do not get care than supports them to live full and meaningful lives.

People have strong opinions about how money from the government should be spent.

For example:

On the day we wrote this there was a news story. A disabled man saved his direct payments to go to Florida. He saved the money to take 2 personal assistants with him.

His council told him to give the money back. Lots of people were angry. They thought it was wrong for the government to pay towards him going to Florida.



This shows how people’s choice and control is limited. The council would not let this man spend his money on something that would make him happy.

# What we did

We looked at what 2 research studies found.

These studies looked at the experiences of:

- disabled **LGBTQI+** people,
- getting self-directed support.

**Study 1**

Study 1 took place from 2016 to 2018. The study did surveys and interviews with people who:

- identified as **LGBTQI+** and disabled
- and used Direct Payments or a personal budget to organise their care.

They also held a focus group with support workers who worked for **LGBTQI+** disabled people.

## Study 2

Study 2 took place from 2020 to 2023. This study looked at the experiences of young disabled adults.

It focussed on how they managed issues with their **sexual identity** or **gender identity** with personal assistants.

These 2 studies give disabled people a voice about:

- their experiences with personal assistants,
- and the challenges they face because of their **sexual identity** or **gender identity**.

As far as we know, these are the first studies to look at these things.

We looked at lots of other research to help us understand more.

# What people said

The voices of people are very important. We will share some of the things people said in the research studies.

## Relationships with PAs

People wanted to be able to choose their own PA. 1 person said:

"I wanted to be able to choose. It's **transformative [it changes everything]** if you get the right person."

Most people had experiences where their PA was chosen for them. This was difficult. Especially with issues around **sexual identity** or **gender identity**:

"How might **they [Personal Assistants]** react when out and about? Especially in gendered environments, like certain medical appointments. Will they feel confident in using my **pronouns [Like she/her]**, for example, in these settings?"

"I mean, **discrimination [being treated poorly because of who you are]** from carers and stuff and even abuse at the hands of carers is unfortunately quite a common thing. The kind of more subtle **bigotry [bad opinions about you]**, that's always a worry because you might not necessarily notice that until you're, like, months into having this carer or something."

People talked about having staff they did not know:

“She was coming in in the morning, telling me that I needed to strip naked and have a hot bath and pray to Jesus to take away my impairment. She was saying that I should put a boiling hot flannel against my genitals to shrink them back into a proper position so that they’d be more appealing to men. I’m **trans**. It felt abusive.”

People worried about telling PAs about their **sexual identity** or **gender identity**. PAs come into your home and become a big part of your life. This is a huge issue for people. They were not sure when or if to say something:

“I’ve had people turn out to be **homophobic [dislike of gay people]** after I’ve invested time and money in training them. It’s critical that they’re fine with this part of my life, so I prefer to find out earlier now. I use the same question every time. I look them in the eye and say, ‘I have romantic and sexual relationships with other women and am involved in political activities involving lesbian, gay, bisexual and transgender people. Do you perceive any problems as a result of this?’

Some people waited to see how things went with their PA before deciding what to do:

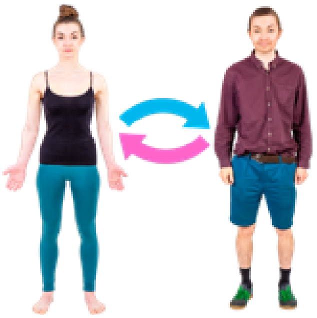
‘I tend to wait until I have developed a relationship with my carers and allow this kind of conversation to develop **organically [naturally and unforced]**.’

People did not tell their PA about their **sexual identity** or **gender identity** because they did not want to lose them.

“It’s really hard to find people who understand autism. I don’t want to risk losing someone who can help me well because they object to my sexuality. I honestly do not want to put them off from looking after me.”

Choosing what to do is hard for people. They think a lot about the decision. It can be easier to hide parts of themselves:

“I feel like gender is more important; **sexual identity** is generally quite easy to hide if you want to.”



A **trans** man said:

"I used to advertise [for PAs] just saying [that I was a] 'man' or 'male' and found that most of the applicants I got were men. I've now reached an uncomfortable **accommodation [agreement]** with myself where … I post the job saying 'female'…. In terms of care tasks, I remain biologically female … that's quite important information for someone to have. My personal care routine is incredibly intimate, so having people understand what my body set-up is crucial."

Lots of people had bad experiences with PAs. The PAs treated them poorly and abused them.

Some people hid things in their homes, to hide who they were:

'If I had a copy of Gay Times, I would probably make an effort to make sure it wasn't there … especially when you've got a new carer coming in … just in case they're **homophobic [dislike gay people]**.'

1 person said he had a secret cupboard, for all his gay things. He said he would love to have a rainbow flag on his wall, "but I can't; I just can't".

Someone told us about a distressing experience:

He told his PA that “you’ll have to be okay with gay people, okay?” He said, “Yeah, no problem.” The next day, he started helping me in the shower and he started to wank me off. I reported him to the police.”

It can be dangerous for people if their PA reacts badly to them. PAs know everything about you, including where you live and what you do most days.

Not being able to be yourself around your PA affects the relationship with them:

“Because I don’t feel able to come out to my PA (I still present male around her), I’m not able to go out as myself with her.... There is quite a lot I have to hide from her. Being able to explore my gender with the support of my PA is important both to my mental health and to my transition.”

People go through a lot to understand who they are and to feel good about themselves. **Sexual identity** and **gender identity** is an important part of who you are:

“I am a **queer** person. My **gender** and **sexuality**, along with general outlook on life, is inherently **queer**. My home, as the PAs’ place of work, reflects this to a degree. It gives me a sense of belonging to have that validation around me. [It’s] Important to feel safe in my home, without needing to hide or feel worried about any aspects of myself. Sometimes, they don’t think it is important to care about my **gender** or **sexuality**, but it matters to me that they do see me and my body as **non-binary**.”

Some people had good experiences with their PAs, they helped them take part in the **LGBTQI+** community. For example, going to events and dating. This shows important benefits to personalised care:

“My PA was delighted to come on Pride with me. My PAs, I’m very open with them about my **orientation [sexuality]** and about my **gender**. I need people to work with me that respect my independence and who are happy to see me participating in my community doing things that **enrich me [improves my quality of life]**.”

Many people talked about how good it would be to have more **LGBTQI+** PAs:

> "I'd love to have one actually. I'd feel more comfortable; I could say whatever I wanted. They might even suggest places to socialise and stuff. It'd be good. Because for any package to work, the person really needs something a bit more than people just understanding or accepting. It would be really nice to be with people that just know what living a gay life is like or just feeling totally comfortable with somebody else. So, that would be really brilliant."

# Help to organise your own support

Organising your own support can be hard.

Disabled people need to become an employer. They need to find, interview and hire people. And make sure they are paid.

They are their PAs manager. They need to build a relationship with them and let them into their homes and lives. Often this involves intimate personal care.

People want and need support with this:

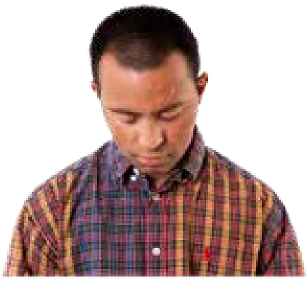
“Managing that fine line between employer and friend, because it’s miserable to spend time with someone that isn’t your friend to a certain extent, but, at the same time, it causes a lot of problems when they’re too much a friend. So, yeah, advice on how to manage that.”

“Like, the council have basically given me no support and particularly things like managing PAs.... I’m like, ‘I am a disabled 20-year-old. I don’t know how to write a contract.’ Some kind of support with the admin side of it is going to be quite helpful.”

“I find it very difficult to do management and stuff with somebody who’s also doing your intimate personal care.”

We think the problems people face are **bad bargains**. They cannot have full choice and control over their care because:

- There are few PAs to choose from
- There is little support for organising your own care
- They do not know PA’s attitudes towards their **sexual identity** or **gender identity**.



These bad bargains go against everything self-directed support is for:

"I feel a lot of shame, around my **gender** in particular. I often think about how much easier it would be as a disabled person hiring PAs if I didn't have this to contend with. This is a big reason I accept carers, etc, using he/him pronouns for me. I'm aware of how much easier it would be if I wasn't **trans** and **queer** when finding and training PAs.... When I am **misgendered [called by the wrong pronouns – he/him]**, I can struggle with correcting them because I don't want a debate or to have to give a lot of education in the moment, so let it slide."

"If I fire someone, I've got to have an alternative before I can do that. You can't just find people in two or three hours. It's meant I've had to put up with more bad behaviour if I hadn't had to think, 'Well what's the alternative?"

"I worry about losing otherwise good and valuable staff members if I am too open about my **sexuality** and **gender**."

# What we learnt

An important part of this article was hearing the stories and experiences of people.

Most people in the studies were white. We know this is a weakness in our research. We must do more to hear from people from different backgrounds.

People said things that show the importance of personalised care:

- ‘it felt abusive’
- ‘an uncomfortable accommodation’,
- ‘secret cupboard’
- ‘doing things that enrich me’
- ‘bad bargains’
- ‘let it slide’.

Personalised care should mean that people do not have to settle for:

- care from strangers,
- care where they have little say or control.

People should not have to:

- Hide who they are from their carers.
- Feel ashamed or bad about themselves.
- Worry about how someone might treat them because of their identity.

Especially when they have gone through a lot to understand their own **sexuality** or **gender identity**.

We have seen many examples of **self-directed** support that:

- Forces people to hide who they are because they are unsure how carers will react.

- Makes people put up with unfair treatment, because they have limited choices.

This means people do not get the freedom and choice they should have.

A lot of this is because local councils do not spend enough money on:

- Advocacy services.

- Services to help people to organise self-directed support.

- Organisations led by disabled people.

Other studies have shown that PAs want more support and training.

There are attitude problems:

- Disabled people are not trusted to spend money ‘properly’.

- Many people do not see disabled people as sexual beings. With their own **sexual identities** and **gender identities**.

The number of people using Direct Payments is getting lower.

Direct Payments only work well if there are enough PAs. But there are not. This is a difficult issue.

Most social care is provided by private companies that want to make money.

Private companies may care more about making money than about getting better outcomes for people.

The government has less control over private social care.

When choosing self-directed support, disabled people face issues like:

- poor quality of care,
- poor working conditions for staff,
- care providers going out of business.

Many people choose to get care and support from their local council, because:

- Managing their own PA is too difficult.
- There is not enough support with this.
- There are few PAs or services to choose from.

This means people do not get the choice and control they should have.

Some recent research shows that local councils are no longer providing services that promote:

- independent living
- and equal rights

This gives disabled people very little choice and control.

Care and support that can improve people's lives is not taken seriously enough.

Disabled people’s rights are being taken away. Rights around **sexual identity** and **gender identity** are being lost in the bigger fight for:

- equal access to jobs

- healthcare

- and physical access.

Our research shows that having good relationships with support workers can make a big difference.

# How things should change

We need to listen to people who have these issues.

Personal stories are powerful. We need the right people to hear them.

Personal stories can change ideas about people. They can show us what is possible and what should be happening.

We need more research and support.

We need the non-disabled **LGBTQI+** community to stand with disabled people.

The **National Institute for Health & Care Research (NIHR) School for Social Care Research** gave money to support this research.

This article shares the views of the writers. These views might be different from the views of the **NIHR** or the **Department of Health and Social Care**.

Thank you to all the people who took part in this research and everyone who helped with this work.