



LGBTQI+* Disabled People and self-directed social care support

LGBTQI+ Disabled People who use self-directed support reported many positives from having more choice, control and power

Concerns included: coming out to social care staff jeopardising support; difficulties in recruiting and retaining good PAs; difficulties in securing support for 'social hours' leading to social isolation; and reactions of other people

Assessments should emphasise the whole person, not ignore sexual orientation or gender identity. Staff should draw on their professional training, ethical practice and legal obligations to raise equalities issues confidently and sensitively

There is a need for more targeted support and information for LGBTQI+ Disabled People as well as more information for their PAs

* lesbian, gay, bisexual, trans, queer, questioning, intersex or who hold identities such as non-binary.

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Norah Fry Research Centre, University of Bristol
Regard
Stonewall
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BACKGROUND

Almost nothing is known about the use and experiences of using self-directed social care support by LGBTQI+ Disabled People.

We might assume the possibility of some tricky negotiations with the whole range of social care staff and providers when getting needs met that relate to sexual orientation or gender identity. Apart from initial decisions to 'come out', users may need: support to access LGBTQI+ venues, take part in social activities with other LGBTQI+ people, facilitate other 'ordinary' daily aspects of being LGBTQI+, physical support with sex (alone or with others). Those with learning disabilities may need particular support to assert and/or explain their needs.

Social care staff and social workers who assess, allocate and review support packages/budgets may or may not address questions of sexual orientation or gender identity. The underlying principles of personalisation and increased choice and control for Disabled People who organise their own social care is designed to maximise just that – choice and control – and to enable them to organise flexible and personalised support that meets their individual needs.

THE AIMS OF THE STUDY WERE TO:

- Understand more about the specific social care needs of LGBTQI+ Disabled People and how they are, or could be, supported by adult social care professionals through self-directed social care.
- Improve social care professionals' understanding of and approaches to the social care needs of LGBTQI+ Disabled People, thereby improving outcomes for service users.
- Gain insight from support workers and personal assistants (PAs) of potentially helpful and empowering ways of supporting and interacting with LGBTQI+ Disabled social care recipients and overcoming challenges or barriers.

Methods

The study involved qualitative interviews with 20 LGBTQI+ Disabled People, a focus group of PAs and a survey of 56 LGBTQI+ Disabled adults who use self-directed social care in England. Of the survey respondents:

- 53 described themselves as White, one as Indian, one as White & Asian and one didn't leave details. Most (60%) were aged 40 or younger, 36% aged 41–60 and 4% aged over 60.
- 53% identified as female, 30% as male, 15% as non-binary.
- 34% as lesbian/gay woman, 26% as a gay man, 32% as bisexual.
- 20% identified as trans.
- Respondents could multi-select from eight options to describe their disability/impairment: 'mobility impairment' was most commonly selected (33%), followed by 'long-term health impairment' (22%), 'cognitive impairment' (14%) and 'mental health difficulties' (13%).

FINDINGS

More than half of those surveyed said that they never or only sometimes disclosed their sexual orientation or gender identity to their PAs who they paid to support them. Less than one third said that they were 'very comfortable' talking about their support needs pertaining to being LGBTQI+ with their PAs.

There was a full range of being out to PAs: not out, out to some and out to all. Some that were out or out to all talked about how pleasurable and important it was to be open about their sexuality or being trans. Some interviewees said that they were not immediately out to PAs but adopted a 'wait and see' policy.

Several people said they were unhappily resolved to not being fully out because they were worried about the reaction of the PA and because they needed the support more than having a totally free reign on being out:

"I have the bloody right to be who I am in my own home. You know, if I can't be myself in my own house, I'm really screwed, you know. Because I need people working for me who can handle queers coming in and out of the house, who can handle maybe that one of my friends who used to be a girl is now a guy this week, who can handle going out to protests with me, who can handle turning up at LGBTQI+ events with me, you know."

"One of them's a very strict Christian. We don't really discuss my sexuality."

"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?'"

More than a third said that they had experienced discrimination or received poor treatment from their PAs because of their sexual orientation or gender identity.

Most interviewees recounted experiences with PAs and other social care staff associated with their

FINDINGS

package of support which were difficult and in some instances discriminatory and even abusive. The capacity or willingness of agencies to respond to issues of trans/homophobia was perceived to be inadequate by several interviewees.

One person said that a previous PA had become controlling and verbally abusive "...it was very, very difficult."

Another said that one of his PAs was 'lovely' but also 'blatantly homophobic'.

Two men said that some PAs refused to carry out some aspects of personal care. One of them said that his PA refused to shave his leg when he needed to wear a leg bag "...he wouldn't do it and I was snookered."

Some interviewees were quite careful to not have things or objects in their homes that would out them:

"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."

In the same vein one person (who lived alone in his own flat) referred to his "...secret cupboard where I put all my gay stuff in." He said that he would love to have a rainbow flag on his wall, "...but I can't, I just can't."

One of the interviewees told us about distressing experiences with two different support workers. Having arranged to go on a short break with some gay friends, he told his support worker about it:

"I said to him, '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."

In another instance, a man who was not out to his family with whom he lived at the time, said that he had built up enough rapport and confidence with one support worker to come out: "...so I thought I would tell him about my sexuality and he went straight downstairs and told my mum. She was crying. She said to me, 'Is this true?' So I had to lie to my mum and say, 'I'm not gay.'"

We also heard about instances of transphobic discrimination:

"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 don't need someone telling me there's something wrong with my genitals. I don't even use them most of the time; I'm trans. It felt abusive."

More than 90% said that their needs as a LGBTQI+ Disabled Person were either not considered at all or were only given some consideration when their needs were assessed or reviewed. Less than a third said that they were comfortable talking about these needs with staff in their local authority. About the same proportion said that they felt they had been discriminated against by their local authority on the grounds of the sexual orientation or gender identity.

There were very few instances of being LGBTQI+ being raised in assessments or reviews of support. In some instances when it was raised, it could feel like a 'tick-box' exercise. Several people commented on the emphasis being on physical care/support rather than the whole person.

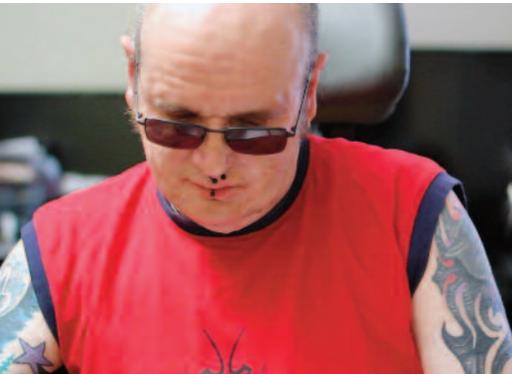
One person said that assessments had never touched on sexuality or gender identity even though on examining the assessment form, they had found a section entitled 'sexuality':

"I picked it up, signed it and wrote the date in the box, and I said to her, [social worker] 'Oh, what's this?' And there was a box about my sexuality, and she had not asked me. And I said, 'Oh, what's this bit? You haven't filled it.' She said, 'Oh, I never bother with that. I don't think it's really relevant.' But actually it's important that we are represented within these things, and that people know that trans

More often than not people in the study felt that their sexual orientation or gender identity was ignored



FINDINGS



people and queer people are being seen. I just said to her, 'Well I'm going to fill it in.' It felt a bit too much like sweeping it under the carpet. And I don't want to be swept under the carpet."

A commonly expressed preference was for reviewers and assessors to be proactive in raising support needs in relation to LGBTQI+ in the same way that they might raise needs in relation to age, culture, ethnicity, gender and so on. One interviewee said that he had never been asked about his sexuality and that there was, "...nothing on the forms, no, nothing."

He was asked how he would have felt about being asked:
"If they had little made-up stories about a person, you know, like, 'One of our clients, he's gay....', then I'd be okay, it'd make it safe to say something."

Some people voiced concerns about being too open in assessments in case it 'went against them':

"I do worry if a care manager was very religious or whatever that they may not give me a totally fair assessment if they're judging my life or lifestyle."

"I don't feel confident talking to her about my sexuality because I'm always worried that they might say something. I know they shouldn't but it's difficult."

When asked about getting support to do LGBTQI+ 'things' (e.g. go to an event/bar, have help to maintain friendships and relationships), 22% said that their PAs did not help them with any of these activities. When

asked why not: 40% said it was because they were not out to their PAs; 40% said they were not comfortable with their PAs helping with this; and 20% said that their PAs had refused to help with these type of activities.

There were examples of people being supported by their PAs to do things in LGBTQI+ spaces e.g. community events, activism, dating, pubs and clubs:

"My PA was delighted to come on Pride with me. My PAs, I'm very open with them about my work, my lifestyle, about my orientation 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. I need my PA to come to Pride and go with the flow and not care that some man may come and kiss him on the cheek. My PA enjoyed Pride, he was glad to go."

There was also some people who said they felt that their PA would not help with these activities and some who said they lacked the confidence to ask.

One of the interviewees who needed physical assistance with sexual activity spoke about how he managed getting support with cleaning up after masturbation. While he got support from some PAs with this, he only asked PAs he felt very comfortable with to the extent that had to plan ahead in a very unspontaneous way:

"...you can't meet your needs whenever you want. You have to schedule it."

Many interviewees talked about how good it would be if there 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's 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."

In the qualitative interviews and 'free-text' sections of the survey, people talked about the benefits and challenges of self-directed social care support.

Having control over support arrangements was the most commonly-cited reason for preferring self-directed support, and interviewees gave many positive examples of the benefits of self-directed support. Previous experiences with agency staff who changed frequently often led people to opt for self-directed support and have more choice and control over who came into their homes:

"You have different people all the time, you've got strangers coming into your house. I wanted to be able to choose. It's transformative if you get the right person."

"Because I hated the idea of not having control over who came in to see me. Not just because of my sexuality, but just because I liked the idea of being able to control who came into my life, who accessed, kind of, my environment."

Most of the interviewees said that they would like more support i.e. an increase in funded hours. This was often for so-called, 'social hours', to go out, be with people and/or do activities and for some, to combat isolation. There were also concerns about, and experiences of having support cut in the overall context of austerity and local government spending cuts.

"I would like more hours. I don't really get to go out to places, you know to enjoy myself, like cinema or bowling."

A recurring theme in the data was people saying that it was difficult to recruit and retain good quality PAs; that there was sometimes a lack of guidance and support with recruitment processes; and that overall, more support and information about managing disagreement or conflict within support relationships/arrangements would be helpful.

CONCLUSIONS & RECOMMENDATIONS

Self-directed social care support continues to provide opportunities for LGBTQI+ Disabled People to exercise choice and control over the support that they get. However, the reality of choice and control for LGBTQI+ Disabled People varies greatly.

In more instances than not, those in this study had: reservations about being open about their sexual orientation or gender identity; experienced direct and overt discrimination from some PAs or support workers; made 'bad-bargains' whereby they (out of necessity) carried on with PA relationships even when there was an element of self-censorship or less than positive attitudes. This was against a backdrop of austerity and threat of cuts to individuals' social care budgets so that some explicitly said that they would not 'rock the boat' about the support they were getting or their openness in assessment and reviews for fear of having hours cut or removed.

Social care staff involved in the assessment and review of social care should draw on their professional training, ethical practice and legal obligations to raise equalities issues confidently and sensitively. More often than not people felt that their sexual orientation or gender identity was ignored or treated as a 'tick-box' exercise. Several commented on the emphasis being on physical care/support rather than the whole person.

At the same time the study showed and reiterated important messages about the positives associated with self-directed support that was working well. When support from PAs really met their needs, people talked about the positive impact on identity, inclusion and belonging.

The importance of the working relationships between LGBTQI+ Disabled People and their PAs affords possibilities for both positive risk, creativity and choice (including in the domain of supporting sexual activity) as well as concern about relationships that go wrong. Recent work by Shakespeare et al. (2017) highlighted 'power, ethics and emotions' as determining features of the complex relationship between Disabled People and their PAs. Many interviewees were keen to know what other people were saying in their interviews – how were they overcoming problems, managing conflict, recruiting PAs, managing support with sex and intimate relationships etc. These themes suggest the need for targeted support and information for LGBTQI+ Disabled People who use self-directed support or those who are considering it.

Shakespeare T, Porter T, Stöckl S (2017) *Personal Assistance Relationships: Power, ethics and emotions*, University of East Anglia. Available at: www.careappointments.co.uk/reports/PersonalAssistanceRelationshipsReport.pdf

COMMENT



"This is the most significant piece of research about LGBTQI+ Disabled People's use of self-directed social care ever to be published. We finally have evidence about the barriers which LGBTQI+ Disabled People face in applying for and managing social care support, and

about the positive impact on their lives that good quality self-directed support can make. The research is particularly significant because the findings are being disseminated through the partners' networks, so these will reach researchers and policy makers and social care workers as well as the disabled and LGBTQI+ communities. There are also films and printed briefings for disabled people and the PAs who provide their support, aimed at increasing confidence and improving practice."

Dr Ju Gosling

Regard Co-Chair and user of self-directed support in the London Borough of Newham



"The work we're doing with the University of Bristol, Regard and the Social Care Institute for Excellence (SCIE) is vital. This ground-breaking piece of work will help us identify barriers faced by disabled lesbian, gay, bi and trans people when accessing social care. This is essential in helping us understand how we can create a world where all LGBTQI+ Disabled People are accepted without exception and can be free to be themselves."

Ruth Hunt,

Chief Executive of Stonewall

The full range of research findings and associated resources developed by the project are:

- **Short films:**
 - Understanding Self-Directed Support for LGBTQI+ Disabled People: a film for Personal Assistants and Support Workers
 - Understanding Self-Directed Support: a film for LGBTQI+ Disabled People
- **Written briefings for both films**
- **Summary of research findings**

View all resources at www.scie.org.uk/lgbtqi/disabled-people

School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

The School for Social Care Research
London School of Economics and Political Science
Houghton Street
WC2A 2AE

Tel: 020 7955 6238

sscr.nihr.ac.uk



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This was a highly collaborative project carried out by: Norah Fry Research Centre (University of Bristol), REGARD – a national Disabled People’s organisation of LGBTQI+ Disabled People, Stonewall – national campaigning organisation for LGBTQI+ equality, and Social Care Institute for Excellence (SCIE) – a national organisation with a remit to improve the lives of people who use care services by sharing knowledge about what works.

Principal Investigator

David Abbott
University of Bristol
8 Priory Rd,
Bristol BS8 1TZ

Tel: 0117 954 6755

Email: d.abbott@bristol.ac.uk

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