NIHR | School for Social Care Research

The supporting sexualities and genders study: : A Co-Production Project to improve sexuality-related support for Disabled Young Adults

OVERVIEW

- Personal assistance is support that provides disabled people with choice and control over their lives. This choice and control extends to all aspects of gender and sexuality.
- However, to date, sexuality has been a taboo topic in personal assistance research; research with young disabled adults has tended to focus on heterosexual men.
- There is a need for research on a broader diversity of gender and sexual identifications to inform the evidence base as well as social care practice.
- This includes reflecting the perspectives and opinions of disabled young people. in relation to the choices they wish to make over their gendered and sexual lives – which is understood as the basis of "intimate citizenship".

This research asked:

- How can personal assistants better support disabled young adults live out their gendered and sexual identities and lives?
- The research team used the theoretical construct of "intimate citizenship" to mean the choices that people make over how to live in the world as gendered and sexual beings.

The aims of this study were to:

- Explore the views and experiences of disabled young adults of all sexualities and genders – including lesbian gay, bisexual and trans (LGBT+) and heterosexual and cisgender disabled young adults – on how matters relating to sexual and gender identity affects their relationships with PAs;
- Explore ways to make PAs and social care services more aware of what disabled young adults want from their support in relation to gender and sexual identity;
- Create information and support resources with disabled young adults and PAs that can help PAs in their role, and disabled young adults to manage their care and support arrangements

METHODS

12 young disabled adults were interviewed aged between 21 and 32.

The research team used a wider age range to reflect (a) challenges in recruitment and (b) the fact that disabled young people can take longer to come to decisions around gender and sexuality, and feel comfortable sharing this information.

- 8 of these identified as LGBT+,
- 2 identified as British BME (Black and Minority Ethnic)
- 10 as White (British or Irish).

11 Personal Assistants (PAs) and 2 other interviews with social care professionals:

- 11 of these identified as White (British or Irish) and 2 as British BME
- 1 participant identified as trans male and 12 as cis female
- experience ranged from 6 months to 7 years in a PA role.

Data were analysed using an adapted grounded theory method – initial coding was done by two members of the research team who coded interview transcripts line-by-line. This was followed by focused coding.

Focused codes were developed inductively from the data and were extrapolated to themes using the comparative method. This enabled the research team to define and refine codes as they looked over transcripts and mapped connections across rich qualitative data, identifying 'the most theoretically significant and frequently occurring initial codes' in relation to working with personal assistants.

Finally, themes were shared with the project advisory group, the wider research team and Disability North to check their significance and discuss their meaning.

From this process the research team worked with the Project Advisory Group (PAG) and Disability North to develop stories for sharing through constructing vignettes. This involved the research team using key themes to construct vignettes and then exploring these with the PAG and Disability North to check their value in creating useful reflections.

Involvement and Co-Production/Co-Creation

We worked with a Project Advisory Group of LGBT+ disabled young people to:

- Design the core study of the project, including data collection materials.
- Make sense of the data including agreeing core themes.
- Select vignettes to take forward to the future output (the animation).
- Choose the format of the final output.

We worked with disability and user-led organisations throughout, including with Disability North to shape the direction of the study, including:

- Research questions and aims
- Developing project outputs.

The research team used a creative and flexible model of involvement and knowledge exchange to begin exploring methods of co-production by co-creating an output from the study, including thinking about the practicalities and ethics of this work.

FINDINGS

The following indicative themes have been

selected from the data:

1. Experiences of Young Disabled Adults of personal assistance

Disabled young adults described the labour they undertook to manage PAs; this included a lot of skilled labour doing the job of managing shift patterns, payments,and recruitment and training.

This was a complex and ongoing issue for the young people, particularly in a context in which finding good PAs was hard and there was sometimes reliance on agency staff and parents to relieve the workload. This work of being a manager also involved the emotional labour of judging the moods and perspectives of personal assistants and balancing them against their own needs.

Personal assistance was described as intimate and personal in ways that were important for how they expressed gender or sexuality. Participants tended to focus on the private spaces of the home and the body and what PAs might do and say in these situations. These intimate relationships also opened up participants to a sense of risk linked to being vulnerable, uncomfortable and a target of discrimination.

Gender was important in decisions about personal space and care, particularly for cis woman and AFAB (assigned female at birth) trans and non-binary people. These participants articulated concerns in relation to personal care and who they would feel comfortable employing to provide sensitive care. It was important that people felt that they were able to receive care from people who had a shared understanding of their body. This group would not recruit cis men for these tasks.

Trade-offs affected those who identified as lesbian, gay, bisexual or trans (LGBT+). E.g., participants might use pronouns that were not the same as they would usually use to ensure the applicants for roles would understand their physical care needs. Some participants felt they sometimes had to accept hiring someone who was less good in some areas (e.g., LGBT+ inclusive practice) in order to get support for other needs, especially as the rate of pay they could offer was not high.

"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 don't want to confuse them anymore, when basic tasks like how to make toast need to take up my energy in explaining to them. I feel ashamed that I need strangers with varying opinions in my home, to see me in the states of undress etc. I'm aware of how much easier it would be if I wasn't trans & queer, when finding and training PAs."

For many, particularly LGBT+ disabled young adults, having PAs come into their home, working on their body, and seeing private information raised questions about closeness, proximity and trust; the nature of the relationships that disabled young people and PAs had with each other; and the extent to which information might be shared.

For example, some described a close 'friend-like' relationship in which there was trust and sharing, while others felt that something more professional was required in order to establish rules, but with some degree of self-censoring.

2. Training needs to promote inclusive practice

The fears and risks described above meant that there were a number of strategies employed by young disabled people to mitigate risks of having to hide or conceal things from their PAs. This included

significant effort in vetting PAs prior to employing them, searching for the right attributes and qualities that meant they could locate that PA in their lives. There was a lot of discussion about the nature of adverts, how they should look and what they should include.

Young disabled adults and personal assistants were asked about how to promote more balanced and equitable relationships. There was a desire to see useful training and resources that would support and help improve practice in relation to offering respectful support. This was articulated by both young people and PAs as a way to ensure that there was a good level of comfort for both parties to the interaction.

PAs in particular expressed generally inclusive values, particularly in the context of understanding personal assistance as enabling someone to make choices about their lives. They felt that it was crucial that they do not act as a barrier to those choices, but also that they needed to do things to positively facilitate choices. For many this meant being simply respectful, however, they were aware there might be times when they got things wrong or made mistakes that could be hurtful.

For disabled young adults, there was a desire for tools and resources that could help inform PAs, particularly where they understood that conversations could be complex and take time (where they were already 'energy limited' and focused on other tasks and responsibilities). These could be examples of stories of people who use particular pronouns and what those mean to them, or a guide to terms and words and what they mean.

In some instances, more extensive and contextual narratives that allow personal assistants to explore the complex issues involved in supporting trans and non-binary people in advance of them working with such groups and communities might allow them to think through their own decisions.

Some were cautious, however, about the role and purpose of training resources. It was important that these were used as tools for critical reflection and meaning making as opposed to authoritative guides on what to do in every situation. This was because people recognised that what works for one person might not work for another. This was in keeping with a critical understanding of 'training' in the context of personal assistance generally.

The research team's work with personal assistants found that they often found instances of words which they were not familiar with – they would value a resource that would allow them to read up on these things beforehand.

The following ideas were suggested:

- Introduction to pronouns and spaces for discussion around proper usage. Navigation of mistakes and mis-steps and how to correct mistakes.
- Avoidance of overly formal training that suggests one approach to support trans and queer disabled people in particular
- An approach that foregrounds different stories and perspectives, so that people can hear the diversity that exists within the LGBTQ community
- A focus on rights and choice and control within the context of personal assistance – as well as tolerance, respect and dignity.

3. Developing training resources

The project was not fully able to respond to the question of how to develop the training resources. However, we started to explore some of the issues involved, including through developing an output

from the project as the basis of a larger set of resources to be developed under other auspices (e.g., follow-on impact funding from NIHR SSCR or another source).

Through developing vignettes and stories for sharing accounts from the data, the research team engaged in questions of the ethics of sharing stories from data from a small group of participants. The research team think there is more work to be done in this area in order to co-create usable narratives in public settings such as training resources in ways that are informed by a queer disability ethics.

The research team also, through their knowledge exchange activities, begun to develop networks and connections, and test working spaces and practices that could be used to build out for a more meaningful co-production project that brings together actors from across the sector to design training resources. 3.d.

The research team sees this as ethically slow work, particularly given the previous context of the pandemic and how this has shaped the work of academic research and social care.

CONCLUSIONS & IMPLICATIONS

This project has evidenced the approaches taken by disabled young people as users of adult social care, specifically personal assistance.

In relation to aim 1, the data provides insights into the challenges that young disabled adults face managing their care, including:

- The emotional labour involved in this work
- The anxieties and fears that young disabled people have about talking to support workers about their own private lives, particularly where they anticipate prejudice and discrimination in relation to those lives and identities, notably LGBTQ identities.
- The research team also evidenced young people's strategies, and the implications of those strategies, for ensuring their safety when facing possible prejudice.

In relation to aim 2, through work with PAs and young disabled adults, the research team provided insights into:

- The values and approaches of PAs in relation to working with a diverse client base, including in relation to gender and sexuality
- PAs' desires for greater knowledge and training around sexuality and gender in adult social care as a facet of providing good adult social care – these are currently lacking and affecting practice
- The need for critical and reflective spaces and resources that allow PAs to reflect on the support they give for people with different gender and sexual identities – these would improve the practice of personal assistance
- Support for young disabled adults in thinking through choices around hiring and recruiting PAs carefully and thoughtfully.

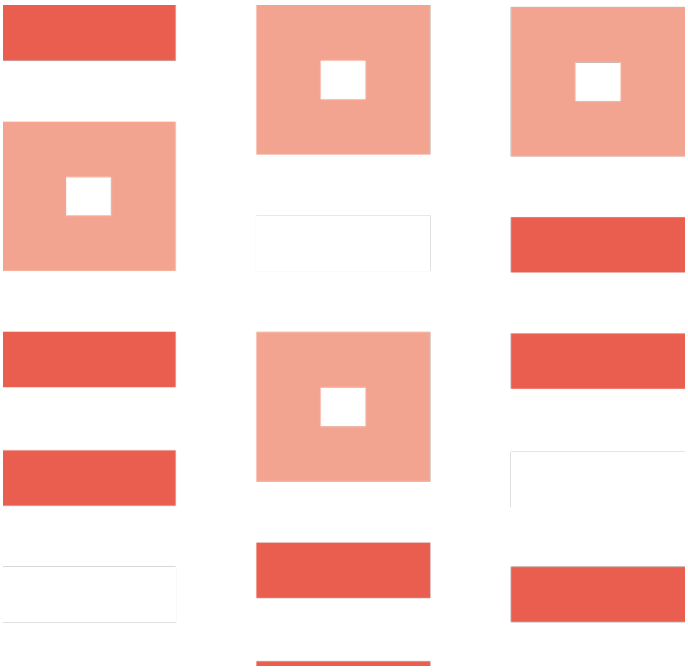
In relation to aim 3, to support workforce development, the project has begun the process of thinking through how to co-create with disability and service-user led organisations tools that:

- Can be used in training with personal assistants as well as with other adult social care professionals.
- Can be used more generally with a wider audience to educate on PA support which is informed by a queer disability ethics of co-production alongside recognition of the need for confidentiality (can be developed with additional financial support.)

The following limitations can be observed from this study:

- The sample did not include many (heterosexual) cis men and their perspectives are not strongly reported.
- The majority of the participants identified as cis women or trans and non-binary (including AFAB and AMAB – assigned male at birth – non-binary).
- The sample, for both PAs and young disabled people, was largely white and could offer more on the experiences of BME people.
- Learning disabled people were not interviewed for this study and therefore their experiences are not reported.
- The third part of the study is not addressed fully. The study identified ethical and methodological complexities in sharing stories from a small sample of largely LGBT+ disabled people – this work takes time to think through carefully and sensitively when developing training resources and would better suit a standalone study.

The videos produced during this study can be viewed on the SSCR website.



Research Team

Edmund Coleman-Fountain
David Abbott
Bryony Beresford
Victoria Armstrong
Angie Stewart
Vici Richardson
Alex Toft
Harvey Humphrey

Contact

University of York
Department of Sociology
Heslington
York
YO10 5DD

Email

Edmund.coleman-fountain@york.ac.uk

PARTNERS

University of Bristol
Disability North
Northumbria University
Nottingham Trent University

NIHR | School for Social Care Research

The NIHR School for Social Care Research (SSCR) is a research and capacity-building partnership between leading centres for social care research across England.

To find out more visit:

sscr.nihr.ac.uk