Article:

Humphrey, Harvey, Coleman-Fountain, Ned orcid.org/0000-0003-1622-7026, Abbott, David et al. (1 more author) (2024) Fitting comfortably together:doing and imagining gender and sexuality in personal assistance. Feminism and Psychology. ISSN 0959-3535

https://doi.org/10.1177/09593535241283729

Article

Feminism & Psychology

Feminism & Psychology
1–18

DOI: 10.1177/09593535241283729
journals.sagepub.com/home/fap
Sage

Fitting comfortably together: Doing and imagining gender and sexuality in personal assistance

Harvey Humphrey
University of Glasgow, UK

Edmund Coleman-Fountain
University of York, UK

David Abbott
Bristol University, UK

Alex Toft
No academic affiliation

Abstract
This article reports a UK study in which 12 young disabled adults took part in in-depth qualitative interviews that explored how gender and sexuality mattered for their personal assistance. We draw on queer, trans, and disabled feminist research and theory to discuss the ways that genders and sexualities are part of the decisions that young disabled adults make when arranging and managing their personal support, from drafting support plans and recruitment adverts to working out how to share personal space and display the body. We discuss how gender and sexuality are part of the interactions that young disabled adults imagine as necessary for them and their personal assistants (PAs) to be able to work together. The article also offers a creative approach to representing the data. Composed from young disabled adults' words following a grounded theory analysis of the data, vignettes were developed to respond to ethical challenges

---

Corresponding author:
Edmund Coleman-Fountain, Department of Sociology, Law and Sociology Building, University of York, York YO10 5GD, UK.
Email: edmund.coleman-fountain@york.ac.uk

of representing the stories of disabled queer, trans, and nonbinary young people. The article ends by discussing the ethical work of enabling gendered and sexual lives through personal assistance. The project was funded by the National Institute for Health and Care Research (NIHR) School for Social Care.

Keywords

disability, gender, personal assistance, sexuality, social care, United Kingdom, young adults

This article reports a study in which 12 young disabled adults with different gender and sexual identities discussed how they arranged their personal assistance. The qualitative study was funded by the National Institute for Health and Care Research (NIHR) School for Social Care, and provides evidence from England and Wales, UK. In addition to a focus on the practicalities of personal assistance, this article contributes an original perspective on the interpersonal dimensions of support by asking how gender and sexual identities influence and complicate the decisions young disabled adults make about their care and the relationships and power dynamics that emerge (Ahlström & Wadensten, 2010; Shakespeare et al., 2017). It also explores the less often reported accounts of queer, nonbinary, and trans disabled young adults alongside those of cis gender and heterosexual disabled young adults (Abbott, 2017). By drawing on queer, trans, and disabled feminist research and theory, we explore how diverse gender and sexual identities were made part of personal assistance, from the imaginative ways these were suggested in support plans or written into recruitment adverts, to the interactions that took place around the body and in the home in which genders and sexualities are enacted or displayed as valued identities, but which also occasion risks and vulnerabilities.

Personal assistance is a form of support that involves disabled people choosing what tasks they need help with, how and when, and who helps them (Morris, 1993). Support tasks vary from person to person and may include intimate personal care, support with everyday chores, and/or ways of moving through the home and world. Personal assistance is a tool for disabled people to use, but it is also a space of interaction and meaning-making (Shakespeare et al., 2018). We situate the *doing* and *imagining* of gender and sexuality within these support practices and relationships. Our data show how personal assistance can be how many disabled people live their embodied lives and enact genders and sexualities in embodied ways, from "girly days" for some women seeking an experience coded as feminine, such as accessing a spa or having their nails painted, to accessing transition related healthcare for trans and nonbinary people. For young disabled adults who employ personal assistants (PAs), there is a need to ground practices in shared understandings and values around genders and sexualities. This can involve negotiations and translational work of understandings between imagining and doing gender and sexuality through these support relationships.

We also offer an original creative approach to representing the data, acknowledging the need for care when sharing stories from minority communities who can become particularly visible when multiple aspects of identity, embodiment, and support are combined (McElhinney & Kennedy, 2022; Willis, 2019). Composed from, and grounded in (Charmaz, 2014), our participants' words, we developed composite vignettes to respond to ethical challenges of representing the stories of disabled queer, trans, and nonbinary young participants who access personal assistance. Our vignettes are narratives of three disabled young adult characters who map gender and sexuality differently: these characters are a trans masculine person (Vignette 1), a nonbinary person (Vignette 2), and a cisgender woman (Vignette 3). A final extract (Vignette 4) imagines these characters in interaction. Before we introduce our study and the composite stories, we explore the embodied and interactional work of disability, gender, and sexuality, and introduce discussions about the theory and practice of personal assistance.

Doing and imagining gender and sexuality in personal assistance

In keeping with our focus on genders and sexualities, our analysis applies feminist scholarship on gender and sexuality to understand the experience and practice of personal assistance and disability. We use a poststructural sociological approach to help us grasp how gender and sexuality are part of the decisions that disabled young people make about their support as they seek to feel comfortable in their own home and skin with PAs (Butler, 1990, 2004). Our approach also speaks to ideas within relational sociology which foregrounds mutually interacting bodily/embodied subjects (Burkitt, 1998; Crossley, 2010).

We see gender and sexuality as intimately bound up in the social world, and as mattering for the support practices that shape young disabled people's embodied presence in the world (Fritsch, 2010; Gibson, 2006). We contribute this understanding to the emerging policy literature on power and personal assistance relationships, which recognises that an individual's gender or sexual identity can play an important role in the choices they may make about their support (Jones, 2020; Shakespeare et al., 2017). Our analysis provides theoretical rigour by focusing on the ways that disabled young people who use personal assistance are engaged in different forms of imagining gender and sexuality through negotiation and understanding of support needs. We explore how the embodied interactions of disabled people and their support workers in personal assistance are sites of doing and imagining gender and sexuality.

We use Judith Butler (1990, 2004) to attend to the body as a site of doing and imagining gender in personal assistance. Following Butler, *doing gender* refers to the ways that people enact gender in everyday practices, and *imagining gender* means the ways that people come to their interactions with images and expectations about the genders they and others embody. As Butler (1990, p. 90) offers, "always already a cultural sign, the body sets limits to the imaginary meanings that it occasions, but is never free of an imaginary construction." The physical body is bound up with the cultural expectations of bodies in situational contexts and the respective imaginings of the self and others in those situations (Burkitt, 1998). These imaginings are important and powerful parts of the ways bodies are made sense of and interacted with by others. Images of gender shape how one is imagined as a man, a woman, a nonbinary person, or any other gendered way of being human, and these categories and their meanings are embedded throughout social life (Lennon & Alsop, 2020). They become part of the way people do gender. Sexuality is implicated in this doing and imagining, for instance, heteronormative gendered expectations frequently flow through images of "normal" life (Marchia & Sommer, 2019; Warner, 1993).

We explore how doing and imagining gender and sexuality shape support practices in several ways: how bodies and identities are represented in depictions of support needs and tasks; in the specific identities and knowledge sought from assistants; and in the ways young disabled people live and express themselves. How disabled young adults engage with their support workers is important for the possibilities that get crafted for imagining their own embodiments and lives, the possibilities of which may be foreclosed by the very people they bring into support them. As Butler (2004, p. 1) reminds us, "one does not 'do' one's gender alone. One is always 'doing' with or for another, even if the other is only imaginary." Yet, Butler also conceives of imagining as a space of possibility, and we maintain this in relation to young disabled people's capacities to imagine desired lives. For Butler (2004, p. 29), "Fantasy is what allows us to imagine ourselves and others otherwise; it establishes the possible in excess of the real; it points elsewhere, and when it is embodied, it brings the elsewhere home." In exploring personal assistance, we ask how disabled young adults' embodiment is imagined by them, their support workers, and those in their surrounding environments as they move through the world with support that works with their bodies.

A final concept we introduce is the *second skin* of identity. Prosser (1998) first coined this to name the doing and imagining of gender in social relations through a narrative of the self as a way to rectify the idea that trans people only perform their gender, and do not also embody that as a subjective identity and narrative of selfhood. For Prosser (1998, p. 101), stories of gender are "also a kind of second skin: the story the transsexual must weave around the body in order that this body may be 'read.'" By encoding meanings and values onto the body, the second skin acts as an interface between the body and the social world (Hennessy, 2012). It is, in short, a metaphor for identity that helps capture the relational sociological insight that identities become intensely embodied at the same time as they are transacted in social relationships (Crossley, 2010). We use this concept to understand the stories that disabled young people tell as they make decisions about and organise their support in ways that also suture their bodies into the support framework they must implement. The second skin makes gender or sexuality present to the support workers they introduce to their worlds, a practice that is fraught with tension. The second skin adds intentionality to the doing and imagining of gender.

Finally, we are influenced by the work of Slater et al. (2018) and their discussion of resistance to normative understandings and ways of doing gender and disability. Their approach to using Butler's work on "gendered intelligibility" (2004, p. 22) to understand experiences of un/intelligible gendered and disabled embodied experiences has influenced our approach to analysing our participant vignettes. This work of drawing insights from across gender, disability, and queer research and theory to understand the complexity of our diverse participant experiences is echoed in Humphrey et al.'s (2023, p. 22) "call to snails" to create time and space for these perspectives to inform each other. This work calls for a queer disability studies field that is collaborative and builds solidarities and coalitions across queer, trans, intersex, and disability perspectives and activisms. This recognises how, across these categories, exclusions and politics are interwoven, and also promotes shared learning across fields of study by resisting intellectual boundaries (Slater & Liddiard, 2018).

We therefore draw on feminist and disability research and theory that are explicitly trans inclusive, acknowledging the many ways trans inclusion may appear in feminist and transfeminist work (Stryker & Bettcher, 2016), in recognition of Slater and Liddiard's (2018) important work to challenge transphobia and transmisogyny in disability studies. We hope our approach follows their call for greater cooperation and allyship across trans studies and disability studies perspectives.

The relationship work of personal assistance

We locate this approach to understanding gender and sexuality within the theory and practice of personal assistance. Personal assistance originated within the independent living movement, which promoted disabled people's rights to have choice and control over the help they receive in everyday life. It was a riposte to models of support and care in which an ever-rotating number of relatively or entirely unknown staff would come into the lives and homes of disabled people and, by and large, "do" care "to" them (Morris, 1993). The shift in how support is organised in favour of choice and control reflected a desired transformation in social life. In contrast to representations of disabled people as "unequal, inadequate and in need of expert care" (Morris, 1993, p. 11), personal assistance became depicted as a "tool" for disabled people to use on their own terms in order to meet needs. Through this, disabled people sought agency in their everyday lives (Watson et al., 2004).

This formulation of personal assistance-as-tool is an important context for our analysis because it centres the practical work of support and its role in promoting agency and choice, which is crucial for people imagining and living gendered and sexual lives. But research shows that the positive outcomes of choice and control depend on the relationships and affinities that form between employer and support worker. Indeed, Kelly (2011, p. 566) argues that the formal relationships implied by the personal-assistance-as-tool image "do not always manifest in practice." Instead, this is one among a range of metaphors that disabled people and PAs use to imagine how they fit together in a practice with few conventions. As Shakespeare et al. (2018, p. 176) argue, "As there is no single, simple meaning to personal assistance, and no accessible definition, people have to find their own way of understanding and explaining the role, the tasks, and the relationship." Different metaphors—of employers and employees, colleagues, friends, or family—speak to different work undertaken in personal assistance, from practical support to the emotional labour that holds those relationships together (Liddiard, 2018; Scully, 2010).

Power imbalances can become part of this dynamic. Disabled people and their support workers tend to be relatively disempowered based on factors like disability, gender, race, and class, and, as these factors become part of the ways that both parties are sutured into the labour of receiving or giving support, they create a need to manage boundaries or protect oneself from exploitation. For example, Evans and Whitney-Mitchell (2023,

p. 1738) write about their experiences as two young disabled women who employ PAs and of the emotional labour involved in managing (in the broadest sense) this within a sociopolitical context in which keeping their PA "onside" may be essential given a lack of alternatives:

> The occurrence of emotional labour in caring relationships is widespread and [personal assistance] relationships are no different, perhaps even involving a heavier burden. Due to the increasing difficulty of employing PAs, we both live with the fear of our PAs leaving and are very aware of the amount of work we put into maintaining their happiness. This is with the hope that they will stay working with us.

Equally, PAs have found their own self and personhood diminished or overlooked as they have been treated as bodily extensions, another person's "arms and legs" (Shakespeare et al., 2018, p. 172). Ahlström and Wadensten (2010, p. 184) found this in their work with PAs who objected to being "used as 'tools." It is because of these dynamics that McLaughlin (2020, p. 400) imagines personal assistance as a "human intimate interaction." For Porter et al. (2021, p. 633), personal assistance is "socially embedded labour" that brings together people with different subjectivities and needs into a shared relational dynamic.

It is in this interactional space that doing and imagining gender and sexuality become important as these are folded into the work of fitting together of self and other. For example, gender often demarcates "caring" bodies, shaping the choices available to disabled people about who provides their support; gender can also matter in terms of the perceived ease of building a close relationship (Liddiard, 2018). Sex and sexuality are more often taboo subjects. Asked by Shakespeare et al. (2017, p. 9), PAs refused to discuss sexuality as a focus of support for reasons of comfort, privacy, and "personal sexual preference." This is in contrast to tasks like help to eat or bathe. Likewise, Bahner (2020) spoke to disabled people who refused to seek support in relation to sex to avoid these sorts of negative reactions. The prohibition that sex is subject to, can shape the way disabled people make their sexual identities visible to support workers who may react badly.

Personal assistance brings complex interactions that construct diverse possibilities for, or barriers to, moving through the world. Interactions between disabled people and non-disabled support workers, employers and employees, and normative and marginalised gender and sexual identities, shape the dynamics of personal assistance. Not a simple tool, personal assistance can entail silence and subjugation, such as when LGBTQ+ disabled people make *bad bargains* whereby they carry on "out of necessity with personal assistant relationships even when there was an element of self-censorship or less than positive attitudes" (Abbott, 2017). It can also create friendship and great closeness (Woodin, 2006). For this reason, feminist writers have sought a relational narrative that grasps the intersubjective "entanglements" of support and the importance of a harmonised ethical imagining. For example, Gibson (2006, p. 194) addresses sexual support as necessitating a greater dialogue around common attitudes and identity, as well as an openness to personal transformation for all those involved. For Fritsch (2010, p. 8), sexual support offers a “moment of affectual and relational embodiment and queered sexuality.” A PA is not a detached tool, but an agent in purposefully co-ordinated relational practices.

The study and our composite vignettes

Our data are from in-depth interviews with 12 young disabled adults. We interviewed five cis women, two cis men, two trans men, two nonbinary people, and one trans woman, who were aged between 20 and 32 years. Eight identified as gay, lesbian, bisexual, or queer; and four as heterosexual. All but two identified as White. To recruit this group, we shared materials highlighting the focus of the research on personal assistance, gender, and sexuality (and emphasising that young disabled people of any gender and sexuality could take part). This process was supported by disabled people’s organisations, independent living centres, LGBTQ disabled people’s groups, and disabled women’s groups. We also used social media to reach young disabled people directly. Participants were offered a voucher for their participation in the research. Interviews lasted between 1 and 1 and a half hours.

We sought feedback on interview questions from a project advisory group of seven LGBTQ+ young disabled people who also offered suggestions for ways to make the interview more inclusive (for more information on this group, including how it was formed at the outset of the project, see Humphrey & Coleman-Fountain, 2024). The interview schedule covered managing PAs, views on the significance of gender and sexuality in personal assistance, and recommendations on improving personal assistance training in relation to sexualities and genders. One innovation the project advisory group introduced was the option to respond to interview questions that might be perceived as more sensitive in a blank journal. To promote access, informed by their suggestions, we also offered interviews in a range of formats, including video call, telephone call, messenger interview, and the choice of receiving the journal and questions to complete in participants’ own time and way. Eight interviewees took part in a video call, two were interviewed using a messenger service, one was interviewed by telephone, and one participant opted to complete a journal only. Decisions around which method to use were sometimes based on personal comfort, including avoiding risks of outing oneself, especially for trans and nonbinary participants.

The interviews were carried out by two academic researchers, including a White cis male researcher and a trans researcher who identifies as a disabled person. Participants were given a choice over the gender of their interviewer, although in practice, most were happy to be interviewed by who was available; most interviews were carried out by the cis male researcher. Neither of these researchers use PAs, and this was made known in each interview. This might explain what was said versus what was not said in the interviews, which tended to focus on the practical work of personal assistance and how gender shaped specific decisions around whom to employ over matters of sex and sexuality. This also appeared to reflect the priorities and concerns of the individuals.

In this article, we add further originality and ethical rigour by adopting a creative approach with composite vignettes and scripts to present data as meaningful stories about personal assistance. Our decision to use vignettes responds to questions explored within the research team and with the project advisory group around how to share stories of people without identifying the participant. Echoing McElhinney and Kennedy (2022), we created composite vignettes that bring together multiple participants' accounts, emphasising shared gendered identities and experiences, to create the composite story as a way to avoid risks of identifying the real participant. Our vignettes reflect some aspects of the make-up of our interviewee group, particularly in relation to gender and sexuality. However, there are important silences in the stories where our group of interviewees were less diverse, for example, Whiteness as a dominant identity arguably shapes an absence of reflection on the importance of the intersection of race and ethnicity. Our use of vignettes also reflects our conceptual framework, which focuses on how genders and sexualities are encoded in the embodied interactions of personal assistance. Telling stories using data mirrors the way identities are sutured into social relations through a narrative second skin (Prosser, 1998).

Data analysis and vignette construction

To create the vignettes, we first coded the data taking an approach inspired by constructivist grounded theory (Charmaz, 2014). 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 us to define and refine codes as we 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 PAs (Porter et al., 2021, p. 637). We coded with gerunds throughout in order to capture processes described by participants and to "stick to the data" (Charmaz, 2014, p. 120).

The codes captured the active and interactional work of personal assistance, such as *defining* support needs, *organising* support, *managing* PAs, *setting* boundaries, and *feeling* comfortable, as well as the work of *navigating* these interactions in the context of gender and sexuality. Finally, themes were shared with the project advisory group, the wider research team, and a partner disabled people's organisation (who support the process of hiring and managing PAs) to check their significance and discuss their meaning. This practice of checking is consistent with principles of collaborative involvement in research design and can ensure the analysis has legitimacy in terms of the knowledge and experience of those to whom the research speaks (Birt et al., 2016).

From this analysis, we reconstructed stories through creating the composites. We first identified broad groupings of identity as the basis of our characters in order to connect transcripts, then constructed stories that incorporated significant themes, taking data within thematic categories from across grouped transcripts (Willis, 2019). The narratives focus on specific actions, including *recruiting* a PA, *disclosing* an identity, and *feeling* comfortable. Quotes were not changed except where a word was needed to link fragments (these edits are identified in square brackets in the vignettes). We created this process of composite writing as collaborative work, building in engagement with disabled young adults through our creative activities and discussion with our project advisory group, who read the stories for their meaning and to check they worked as stories. We also worked with a young disabled student intern on the project, who investigated the role and method of composites.

Our resultant composite stories tell of the importance of comfort and discomfort in different practices of support, including those that relate to home and body, the work of negotiating disclosures and access to personal information, and the importance of identity and recognition vis-à-vis the practical work of meeting needs. We also created a script to show these characters in conversation as a way to bring out themes in the data across the different participants. The final stage of analysis is the theoretical work of writing this article in which we interpret the stories through the conceptual lenses established earlier. We share extracts of these vignettes to illustrate the doing and imagining of gender and sexuality, and the ways in which participants shared experiences of feeling comfortable in these interactions and their associated imaginings. *Fitting comfortably together* was a central feature of the decisions the young disabled adults made, or anticipated making, about their support. These experiences were framed by their interactions and constrained support choices for bodies seeking a variety of personal care from PAs.

This work of vignettes therefore constituted part of our analysis. It was extended as part of later creative work carried out with community groups in order to find accessible and creative ways to make those stories available to a wider audience. Given our small group of interviewees, our continuing creative work, undertaken with the support, questions, and creativity of our participatory advisory group (Humphrey & Coleman-Fountain, 2024), allows us to share back these stories with disabled youth groups and communities without risks to anonymity. This decision to find ways to maintain anonymity is important when sharing the research with disabled people's organisations and community groups, especially those who helped us share the call for participants. This can also offer value as a technique for sharing data when participatory advisory group members may know participants. This work of creative vignettes and scripts also provides a further form of imagining gender and sexuality, and our ongoing work to share this research attempts to celebrate and extend the possibilities of such an approach.

Ethics approval for the study was received from the Health Research Authority's Social Care Research Ethics Committee (REC) in England, UK (21/IEC08/0007). All participants received an information sheet about the study that shared how their data would be used. Informed consent was recorded prior to the interview. We sought verbal consent where interviewers were being interviewed by video or telephone call, and then followed up after the interview to share the completed forms. Finally, in going back to disabled young adults, we checked with a group of participants whether they were okay with the way their data had been incorporated into the vignettes.

Fitting comfortably together

In this section, we introduce the vignettes and the imagined characters who narrate them to bring out stories in our participants' words. These composites are made of real words from multiple participants who shared a common gender identity. Around each, we engage in a discussion of the pertinent issues.

Identity in the recruitment stage

Vignette 1 draws together data from trans men/masculine participants. It focuses on how young disabled people recruit PAs, a core element of choice and control (Morris, 1993).

Recruitment brings together the identification and prioritisation of support needs, the "who" of the PA (their identity, personal attributes, and skills), and hoped-for interactions and relationships in personal assistance. This work has a narrative component, shown in the way people dwell over the language and words they would use to describe themselves. It was clear that this information told a story. In the vignette, a trans man assesses the words he felt comfortable using in a job advert to attract the right PA, as well as the drawbacks of those words in terms of how his gender is imagined.

> Vignette 1. I usually use the term transmasc or transmasculine. My first difficulty is recruitment. I think it's quite difficult because you can't put on an advert like, "Has to be ok with queer people," or something like that. I don't tend to hire cis men because it hasn't worked out for me in the past. I transitioned to male [several] years ago now. I used to advertise just saying "man" or "male," and found that most of the applicants I got were men. I've now reached an uncomfortable accommodation with myself. [In] terms of care tasks I remain biologically female. [H]aving people understand what my body set-up is and knowing that people are comfortable with female people, is crucial. I get a bit uncomfortable if it's just like male, because it just feels wrong, but I'm male aligned as such. I also just feel more comfortable around women more than men, or women, non-binary people more than men. I would still happily have an interview with a guy that was applying or something, but I just think that I'm biased more towards non-men.

Here, we see the differences in doing gender, imagining gender, and the elsewhere described by Butler (2004): the imagining work of others relating to the constrained choices this character has over whom to employ. This character, who used to advertise for PAs saying he was a man, found it led to employees imagining his body incorrectly. He had to find different words that do not necessarily correspond to his gendered experience to account for the imagined genders that a prospective PA might anticipate, in order to get the most appropriate care, concealing or delaying revealing aspects of his embodiment until a later encounter with his prospective PAs. He deploys a narrative that would allow his care needs to be understood and met by those he seeks to employ as PAs. His narrational labour is meant to allow prospective applicants to imagine and read his body temporarily and conditionally as "female."

For this participant, having PAs who understand his body set-up and accounting for anticipated genders of "female" bodies is more important for his intimate care needs than gendering himself the same way he would in a more public setting, or unrelated to his personal care needs. In so doing, he also anticipates the gendered work of potential PAs with a shared bodily and gender history, and therefore as someone who is, or has been, similarly embodied. This example shows us the imagined gender work that others are doing about him (and he is doing about others) and the ways in which he needs to anticipate and imagine those expectations of others to select appropriate language to describe himself in an advert for a PA that would not be appropriate language outside of that context. We also see the interactive work of doing gender (Butler, 1990); or more specifically, a desire not to have personal care tasks performed by cis men due to previous unsuccessful personal assistance relationships with cis men. We see the work of imagining gender being essential to the possibilities of this character feeling comfortable in personal care interactions. This includes the gender that he imagines others to enact when he seeks to employ them, as well as his own gendered narratives and performances.

We wanted to evidence the careful planning around language that our participants articulated, knowing that this would express the second skin of identity for the purpose of meeting needs (Hennessy, 2012; Prosser, 1998). For many, this was risky, involving disclosures, misreading, and potential misrecognition. This character could also articulate his frustration at how accommodating a representation of himself as female could lead to his enacted and embodied male identity becoming hidden and ignored. Our data also revealed frustration (being "bothered") at misgendering and incorrect pronoun usage that does not acknowledge the trans narrative second skin. There is a complexity of the stories our character has to tell about himself to both be gendered correctly and to receive appropriate care from PAs.

Navigating interpersonal relationships in daily life

Our next two vignettes explore the relationship between support, gender, and sexuality in the everyday work of personal assistance. We developed these to tell the stories of our nonbinary and cis women participants. As with Vignette 1, we dwell on themes of identity, how gender is seen as relevant to support, and the comforts and discomforts of support interactions. Here, we situate the work of personal assistance in the context of everyday interactions in order to show ways that gender and sexuality shape how disabled young people manage in contexts of vulnerability and potential power imbalances (Kelly, 2011).

Vignette 2 tells the story of a nonbinary character. In developing this, we wanted to reveal the pragmatic and routine work of personal assistance recounted by participants, acknowledging that personal assistance is not a one-time event but a day-to-day relationship (Woodin, 2006). One thing we coded during analysis was the work of *prioritising*, often related to tasks that a person could not do without, versus other support that was desirable but not essential. As we showed with Vignette 1, personal care could be prioritised in a way that compelled particular modes of bodily narration. Among nonbinary and trans participants, prioritising sometimes meant seeing correct gendering as secondary to "basic" support. In the following vignette, our nonbinary character articulates a set of anxieties around gender and recognition. They tolerate certain language use in order to prioritise giving instructions around having "basic tasks," such as having food prepared, performed correctly.

> Vignette 2. High staff turnover is a big issue to deal with when you have PAs. I've only just come out as non-binary and it's quite an emotive topic. It is a lot emotionally to think about coming out to everyone all the time, especially when I'm not sure about safety and how people might respond. Is that person going to misgender me? Is that person going to deadname me? Are they going to see my old name and just continue to use that because they've got their own prejudice? Is that person going to be homophobic? Support in the shower to wash my hair means that my trans body may well be visible. This puts me in a position of vulnerability. Is it a different body to what they were expecting? 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. When I am misgendered, I can struggle with correcting them. 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.

With this vignette, we demonstrate the bad bargains of support that LGBTQI+ disabled people accept (Abbott et al., 2024). We routinely came across bad bargains (framed in our Vignette 1 as an "uncomfortable accommodation"). Vignette 2 is intended to show how this works through the doing and imagining of gender within personal assistance. This character moves through the world as nonbinary: shown in their pronouns, the words they use to describe themselves, and in how they dress and decorate their home. We also show how this narrative work is situated in the practices of support, and the ways they encounter PAs as reading a different second skin of identity at odds with the one they desire.

Our participants usually hired PAs for their competencies at undertaking specific tasks. Where PAs lacked appropriate knowledge of gender identity (e.g., of nonbinary pronouns), this led to support needs being balanced, setting identity against "basic tasks" (mirroring a parallel sidelining of sexuality as shown by Bahner, 2020). Our nonbinary character prioritises instructing around food preparation, and repeatedly faces failure in their second skin with each PA, evidencing the practical and emotional labour undertaken in making personal assistance relationships work (Evans & Whitney-Mitchell, 2023). Making a bad bargain is arguably a way to avoid the kinds of "sticky" interactions that Scully (2010) describes, easing the flow of the interaction in order that some daily support may go ahead.

With this vignette, we also wanted to highlight the role of embodiment. We show how, as Prosser (1998) makes clear, skins are experienced at the level of the body, evidencing the emotion and anxiety provoked by something being out of joint between their self/ body image and the image they receive back. Such dynamics add to the work of making an imaginary skin matter, which is labour that takes energy, something this character has to ration. Accepting PAs using he/him pronouns demonstrates a prioritisation of being sustained with the right food, but with the simultaneous exhaustion of their gendered self. This is the hallmark of a bad bargain.

Vignette 2 shows how personal assistance work can revolve around the work of meeting needs through fulfilling tasks, and the ways this interacts with the second skin of gender. Vignette 3 builds on this theme of feeling comfortable doing gender in contexts of material support. This character is drawn from the data from cis women participants.

> Vignette 3. Someone easy going, that is my number one criteria, someone that walks through the door and seems relaxed. I can be quite an anxious person myself and I don't like it when someone else is too anxious around me. [PAs] are in a very personal space with you and there's a lot of personal care and they see everything that's going on in your home as well, so it's having that trust for them to not take what they see in your house outside of work and go and talk to somebody else about it. I like a female PA to support me with female personal care needs. [B]ecause of the nature of the care it's better to have somebody of the same gender. A girl will know what thrush feels like in a girl and they'll know what it looks like.

> [Or] if I'm tidying my bedroom and doing my laundry, I just prefer female PAs to help me sort and organise that sort of stuff. [But] it's really hard to say whether it's just for a female carer, or is it a female carer that I'm more comfortable with and have known for a long amount of time?

In this vignette, we see a clearly imagined PA who is the same gender as the character to ensure she feels comfortable receiving intimate personal care. She also wants to know this person will understand and recognise her embodied experiences. She seeks assurances that her narrative second skin will be correctly read and interpreted at a bodily level— that her PAs will "know what thrush *feels* [emphasis added] like in a girl." The narrative here reflects the narrative work in the previous vignettes, which involved working with or against the shorthand of routinely imagined genders, although with this vignette we indicate an easier fitting together with PAs. For this character, being a woman and describing themselves as female is a way to allow others to imagine her body, and for her to imagine theirs.

We also see how the second skin of gender translates into the encoding of identity into the physicality of the home. Allusions to the home often included descriptions of things on walls (posters and badges revealing tastes and identities), the organisation of personal possessions (such as home and kitchenware), and private things in drawers or cupboards (clothing, and sometimes toys). Sexuality is here too. Lingerie tucked away in a bedroom drawer extends the second skin of gender and sexuality across the home. Imagining who would be seeing and handling these objects, during routine tasks of cleaning and tidying, required a negotiation of gender and sexuality through imagining who they would feel most comfortable with being there (Liddiard, 2018).

However, this character also acknowledges that gender may not be the only factor in her experience of feeling comfortable, which is also shaped by knowing someone for a long time. She also focuses on the imagined PA and the ways in which she will "seem relaxed," which in turn creates an environment for them both to feel comfortable together in a personal space of the character's home. This reminds us that personal assistance is a deeply human intimate interaction (McLaughlin, 2020). It requires more than a fitting together of genders, but of persons (Fritsch, 2010; Gibson, 2006).

The relationships of gender and sexuality in the wider system

In this final section, we present an extract from a script (Vignette 4) that imagines a discussion on personal assistance support between our trans masculine character, nonbinary character, and cis woman character. With this extract, we wanted to explore how the young disabled people might interact around their shared experiences of arranging personal assistance support in an imagined informal meeting space such as the waiting room of a social care service. In this extract, we see their ambivalence about how the imaginative work of others relates to the second skin of identity, and how that is read, translated, and sometimes misinterpreted or resisted in personal assistance.

> Vignette 4. A: [L]ike the expectation that my partner will have a full-time job and do all of my night care every night for free, in a way that I don't think I would have expected if my

> partner had been a man rather than a woman. Like, it's made me quite uncomfortable in that way, that they're treating things differently with my partner's gender.
>
> B: [For me] I need to know that it would be okay for me to have my partner or friends over in the PA's presence, as many of them are non-binary, etc., too.
>
> C: My partner is a male and whenever I want to do anything girly like have my hair done or do my feet, or do my fingernails, like paint my fingernails, my PA can support me to do that. My male partner just hasn't got time. It allows me to have two like a girly life with my PA and then my life at home with my partner.

This script shows examples of how imaginings of gender, and more explicitly the weaving in of intimate partner relationships, factor into how disabled young people's support can get organised, extending through care packages to the interactions that take place within personal assistance. Here is an imagined discussion that considers the elsewhere imagined gender work done by those who make entitlement decisions over hours of paid support, assuming a partner who is a woman (to someone who moves through the world as male) will be providing care at night (Butler, 2004). We also see the importance for the nonbinary character to know that a PA feels comfortable with the character's own gender, and the genders of their partner and friends. The characters raise questions about the knowledge that PAs are able to access, for example, through training.

Here is the double work of feeling comfortable doing gender and feeling comfortable allowing for multiple people doing gender in that space. We also have the example of the possibilities of doing gender for the character seeking a "girly life," with hair and makeup experiences shared with a PA that they couldn't share with a partner. These shared "girly" experiences also highlight the importance of shared friendships with personal assistance relationships and the gendered experiences of "girlfriendship" (Winch, 2013) that this character can share with their PA, offering another experience of fitting into gendered social experiences. Although these examples all differ in their discussions of doing and imagining gender, it is only through the experiences of feeling comfortable together with PAs that life at home with their partners is possible.

With this script extract, we also wanted to provide a space for imagined comparisons between these characters. While personal assistance is intended to ensure that disabled people are able to move through the world in the way that they choose, in this article we have wanted to consider how the work of fitting together within this form of support shapes the possibilities for moving through the world for young disabled people with diverse gender and sexual identities. Our script draws into relief the complexities of this work as it involves bringing identity comfortably into the practices of support, in relation to being recognised and respected. We also use these narrative second skins brought into conversation with each other as a way to share these stories with disabled people's organisations and community groups. We have an imagined audience of young disabled adults seeking to negotiate sexual and gendered support in personal assistance, and imagined audiences of PAs themselves seeking to provide this support.

Conclusion

This article uses composite vignettes to share stories of disabled young adults who access personal assistance. These offer insight into the labour that takes place in interactions between disabled young people and their PAs, and in the exchange of identities between them. Our data show the significance of personal assistance as a tool for ensuring disabled young people can follow through on their choices, such as over the food they eat, who provides their personal care, and where they go and how they move through the world. We see this as simply the work of living "an ordinary dignified life" (McLaughlin, 2020, p. 398). We also show the interactional work within personal assistance as "socially embedded labour" (Porter et al., 2021, p. 633). Our original contribution is in the doing and imagining of gender and sexuality, looking at how the second skin of identity is represented, communicated, and potentially misrecognised in the interactions between disabled young people with diverse identities and their support workers. Linked to this is the interactional work of fitting comfortably together, and what this means for the identities, or second skins, that disabled young people carry with them through the world. In particular, we show the work disabled young people with diverse identities do to accommodate PAs in their lives so that the pragmatic, sustaining work of personal assistance may go ahead.

Finally, we want to offer a brief reflection on the interactions of gender and sexuality in personal assistance. Feminist research has highlighted the pragmatics and tensions of sexual support as an often-excluded dimension of social care (Bahner, 2020; Liddiard, 2018). What this article contributes is an attempt to theorise gender and sexuality as imbricated in the everyday work of personal assistance, through the relational work of "doing" and "imagining" gender and sexual identities (Butler, 1990, 2004). In the work of doing and imagining gender and sexuality, we learned about the work of fitting together through desired competencies, shared values and knowledge, and a complementarity of identities and bodily histories. Within this, gender was often prioritised as more important. This is not to say that sexuality was not important to this work, as evidenced in discussions of intimate partner relationships. What we would observe, however, is that the things that our participants were happy to tell us involved the everyday care and mundane tasks of fitting together with PAs through gender and support work, which are central to the embodied encounters that take place within personal assistance (Fritsch, 2010).

This work is no less significant to the kinds of ethical imagining that Butler (2024, p. 36) highlights when they discuss the importance of making liveable "the many relations to being socially embodied that exist." Personal assistance, we argue, has a role to play here in the way it brings about world-making bodily/embodied encounters. Here, we also see the struggles of intimate citizenship that Plummer (2003) has also described. We saw the work of making decisions about the self and ways of moving through the world that are at the heart of Plummer's analysis of choices about how to live with others and in our own skins. For the young disabled people that we spoke with, this was worked through gender, and we learned much about how support works (or not) as a consequence of this. Here, too, were decisions about sexuality, about partners and intimate identities. In our analysis, we would suggest there is a lot to learn about the potential for more harmonised and ethical relationships through looking at the work disabled young people do, and have to do, around identifying and recruiting PAs, as well as the structures that impinge and shape those decisions, and the potential good and bad bargains on offer (Abbott et al., 2024). We hope offering up these stories of fitting comfortably together can facilitate future conversations and imaginings of support for those audiences.

Acknowledgements

The authors would like to thank the participants, whose accounts informed the vignettes. We are grateful to Melissa Herron, who researched and trialled the process of vignette construction, and to the project advisory group, who offered their perspectives on the construction of vignettes from research data.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Disclaimer

This report is independent research by the National Institute for Health and Care Research School for Social Care Research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the NIHR School for Social Care Research (Grant No. REF# P147).

ORCID iDs

Harvey Humphrey https://orcid.org/0000-0001-5791-4522
Edmund Coleman-Fountain https://orcid.org/0000-0003-1622-7026

References

Abbott, D. (2017). *LGBTQI+* disabled people and self-directed social care support*. National Institute for Health Research School for Social Care Research. https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings_RF077.pdf

Abbott, D., Coleman-Fountain, E., & Humphrey, H. (2024). Disabled people negotiate gender, sexual identity & self-directed social care support in England: How does choice and control operate? *Critical and Radical Social Work*. https://doi.org/10.1332/20498608Y2024D000000043

Ahlström, G., & Wadensten, B. (2010). Encounters in close care relations from the perspective of personal assistants working with persons with severe disability. *Health & Social Care in the Community*, *18*(2), 180–188. https://doi.org/10.1111/j.1365-2524.2009.00887.x

Bahner, J. (2020). *Sexual citizenship and disability: Understanding sexual support in policy, practice and theory*. Routledge.

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, *26*(13), 1802–1811. https://doi.org/10.1177/1049732316654870

Burkitt, I. (1998). Sexuality and gender identity: From a discursive to a relational analysis. *The Sociological Review*, *46*(3), 483–504. https://doi.org/10.1111/1467-954X.00128

Butler, J. (1990). *Gender trouble*. Routledge.

Butler, J. (2004). *Undoing gender*. Routledge.

Butler, J. (2024). *Who's afraid of gender?* Allen Lane.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Sage.

Crossley, N. (2010). *Towards relational sociology*. Routledge.

Evans, K., & Whitney-Mitchell, S. (2023). The hidden work of self-directed support: A seldom heard reality from the perspective of two disabled women. *The British Journal of Social Work*, *53*(3), 1735–1741. https://doi.org/10.1093/bjsw/bcad038

Fritsch, K. (2010). Intimate assemblages: Disability, intercorporeality, and the labour of attendant care. *Critical Disability Discourses*, *2*. https://cdd.journals.yorku.ca/index.php/cdd/article/view/23854

Gibson, B. E. (2006). Disability, connectivity and transgressing the autonomous body. *Journal of Medical Humanities*, *27*(3), 187–196. https://doi.org/10.1007/s10912-006-9017-6

Hennessy, R. (2012). The value of a second skin. In D. Richardson, J. McLaughlin, & M. Casey (Eds.), *Intersections between feminist and queer theory* (pp. 116–135). Palgrave Macmillan.

Humphrey, H., & Coleman-Fountain, E. (2024). Creating time for LGBT+ disabled youth: Co-production outside chrononormativity. *Sociological Research Online*, *29*(1), 233–242. https://doi.org/10.1177/13607804231155001

Humphrey, H., Slater, J., Coleman-Fountain, E., & Jones, C. (2023). Building a community for queer disability studies: Lessons from the snail. *Canadian Journal of Disability Studies*, *12*(1), 1–28. https://cjds.uwaterloo.ca/index.php/cjds/article/view/969

Jones, N. (2020). *Personal assistance, disabled parents and their children: Roles and relationships* [Unpublished doctoral dissertation]. University of East Anglia.

Kelly, C. (2011). Making "care" accessible: Personal assistance for disabled people and the politics of language. *Critical Social Policy*, *31*(4), 562–582. https://doi.org/10.1177/0261018311410529

Lennon, K., & Alsop, R. (2020). *Gender theory in troubled times*. Polity Press.

Liddiard, K. (2018). *The intimate lives of disabled people*. Routledge.

Marchia, J., & Sommer, J. M. (2019). (Re)defining heteronormativity. *Sexualities*, *22*(3), 267–295. https://doi.org/10.1177/1363460717741801

McElhinney, Z., & Kennedy, C. (2022). Enhancing the collective, protecting the personal: The valuable role of composite narratives in medical education research. *Perspectives on Medical Education*, *11*(4), 220–227. https://doi.org/10.1007/s40037-022-00723-x

McLaughlin, J. (2020). Valuing care and support in an era of celebrating independence: Disabled young people's reflections on their meaning and role in their lives. *Sociology*, *54*(2), 397–413. https://doi.org/10.1177/0038038519868630

Morris, J. (1993). *Independent lives? Community care and disabled people*. Palgrave Macmillan.

Plummer, K. (2003). *Intimate citizenship: Private decisions and public dialogues*. University of Washington Press.

Porter, T., Shakespeare, T., & Stockl, A. (2021). Trouble in direct payment personal assistance relationships. *Work, Employment and Society*, *36*(4), 630–647. https://doi.org/10.1177/09500170211016972

Prosser, J. (1998). *Second skins: Body narratives of transsexuality*. Columbia University Press.

Scully, J. L. (2010). Hidden labor: Disabled/nondisabled encounters, agency, and autonomy. *International Journal of Feminist Approaches to Bioethics*, *3*(2), 25–42. https://doi.org/10.2979/fab.2010.3.2.25

Shakespeare, T., Porter, T., & Stöckl, A. (2017). *Personal assistance relationships: Power, ethics and emotions*. University of East Anglia.

Shakespeare, T., Stöckl, A., & Porter, T. (2018). Metaphors to work by: The meaning of personal assistance in England. *International Journal of Care and Caring*, *2*(2), 165–179. https://doi.org/10.1332/239788218x15187915600658

Slater, J., Ágústsdóttir, E., & Haraldsdóttir, F. (2018). Becoming intelligible woman: Gender, disability and resistance at the border zone of youth. *Feminism & Psychology*, *28*(3), 409–426. https://doi.org/10.1177/0959353518769947

Slater, J., & Liddiard, K. (2018). Why disability studies scholars must challenge transmisogyny and transphobia. *Canadian Journal of Disability Studies*, *7*(2), 83–93. https://doi.org/10.15353/cjds.v7i2.424

Stryker, S., & Bettcher, T. M. (2016). Introduction: Trans/feminisms. *Transgender Studies Quarterly*, *3*(1–2), 5–14. https://doi.org/10.1215/23289252-3334127

Warner, M. (1993). *Fear of a queer planet: Queer politics and social theory*. University of Minnesota Press.

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter)dependence, needs and care. *Sociology*, *38*(2), 331–350. https://doi.org/10.1177/0038038504040867

Willis, R. (2019). The use of composite narratives to present interview findings. *Qualitative Research*, *19*(4), 471–480. https://doi.org/10.1177/1468794118787711

Winch, A. (2013). *Girlfriends and postfeminist sisterhood*. Palgrave Macmillan.

Woodin, S. L. (2006). *Social relationships and disabled people: The impact of direct payments* [Unpublished doctoral dissertation]. University of Leeds.

Author Biographies

Harvey Humphrey (he/they) is a Lecturer in Social Research Methods at the University of Glasgow, UK, with an interest in queer, creative, and coproduced methodologies and theoretical work broadly relating to queer, trans, disabled, and LGBTI lives. They are a published poet and are interested in creative academic practice for research and teaching.

Edmund Coleman-Fountain (he/him) is a Lecturer in Sociology at the University of York, UK. His research focuses on social care contexts and identities, and involves working with young disabled people and LGBTQ+ groups through qualitative and creative methods.

David Abbott (he/him) is a Professor of Social Policy at the University of Bristol, UK. He researches alongside communities of people with learning disabilities and young disabled people on topics including social care, housing, inequalities, and relationships.

Alex Toft (he/him) was a Research Fellow, most recently working at Nottingham Trent University, UK, in the School of Social Sciences. His research focused on sexuality, gender, disability, spirituality, and identity. During his academic career, he published widely in academic journals. However, the world of academia with its obsession with making huge amounts of money became a stifling and unpleasant place to work. Nowadays, you will find him tending green spaces and caring for plants.