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# *Being just their hands?* Personal assistance for disabled people as bodywork

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**Abstract**

Drawing on the notion of bodywork, we analyse the bodily aspects of personal assistance to expand the dialogue between medical sociology and disability studies. We aim to, firstly, overcome the lack of attention to the bodywork of personal assistant (PAs) in disability studies; secondly, explore the micropolitics of personal assistance and the role of independent living mandates in configuring this bodywork of PAs; and, thirdly, propose a more relational and material approach to the impairment/disability debate. This exploration is based on qualitative semi-structured interviews with 23 PAs conducted in Spain between 2018 and 2020. Our research reveals that PAs' bodywork implies performing their body as body-absence, such as when they enact body-tool and body-prosthesis figurations, but also as body-presence, for instance, as acting bodies and affected/affecting bodies in specific situations. Through their analysis, we foreground how PAs' bodywork conveys normative ways of enacting the body and how these body figurations are not only challenged and negotiated but define the actual practice of personal assistance. To conclude, we stress on the theoretical

contributions of our study towards both disability studies and medical sociology.

# INTRODUCTION

The social model of disability represents a 'displacement of difference from the body, hitherto the defining characteristic, and an identification of social and cultural forces as key in the establishment of subordination' (Shakespeare & Watson, 1996, p.2), the latter being what constitutes disability. As a result, the body has become an 'absent presence' (Shakespeare & Watson, 2001) in disability studies. In the 1990s and 2000s, this led to criticism as it entailed removing important issues such as interpersonal relationships, affects and diversity in disability from the critical gaze (Crow, 1996; French, 1993; Shakespeare, 2000). As pointed out by Shakespeare and Watson (2001), ignoring the bodily aspects of disability (impairment) can lead disability studies to over-socialised and monolithic accounts of living with disability.

To overcome this problem, Thomas (2007) suggested that there is a need to connect disability studies and medical sociology, which, among other things, has led to interesting studies on the definition of the bodies of disabled children as 'leaking, lacking and excessive' (Goodley & Runswick-Cole, 2013). Along the same lines, Thomas (2021) connects both traditions in his study of the parents of children with intellectual disabilities. As his work shows, these parents engage with both medical and independent living repertoires to understand how 'impairment and disabling conditions intersect' and to develop 'an intimate knowledge of impairment effects privy to, and at the forefront of, navigating environments central to the social oppression of them and their children" (Thomas, 2021, p. 127). Thus, Thomas (2021) not only points out the need to reconnect disability studies with theories of the body developed in medical sociology but also, in line with Thomas (2007), the risk of naturalising disablism if these theories of the body do not engage seriously with the emancipatory concepts of disability studies.

Our contribution engages with these dialogs between medical sociology and disability studies through an analysis of the embodied experience of personal assistants (PAs). As we will show, the somatophobia of disability studies can become an obstacle in the comprehension of PAs' actual work, but so can the lack of attention of medical sociology to the role of independent living mandates and normative considerations in the definition of PAs' work. Similar to the perceived role of parents with intellectual disabilities (Mladenov & Dimitrova, 2022; Thomas, 2021), PAs define their job as a means not only to overcome and challenge the disabling social structures that oppress their employers but also to ease their daily life by accommodating their bodily impairment. For this reason, in practice, the distinction between providing personal assistance and care becomes blurred.

Drawing on the notion of bodywork (Twigg, 2002; Twigg et al., 2011; Wolkowitz, 2002), we analyse the bodily aspects of personal assistance to firstly, correct the lack of attention given to the bodywork of PAs in disability studies; secondly, explore the micropolitics of personal assistance and the role of independent living mandates in configuring PAs' bodywork, an under-explored issue in medical sociology; and, thirdly, propose a more relational and material approach to the

impairment/disability debate. In independent living arrangements such as personal assistance, the employer and the PA's bodies are mutually configured, which means that the PA's bodywork reconfigures what is considered disability and impairment. Thereby, what is considered impairment and disability are hard to understand without paying closer attention to the PA's work.

## Approaching personal assistance as bodywork

In one of the first studies in the field, Ungerson (1999) argued that personal assistance was marked by an 'inherent contradiction between command and obedience on the one hand and sensitivity to feeling on the other' (p. 586). In her opinion, the idea of personal assistance as 'command and obedience', as usually stressed by the Independent Living Movement (ILM), is based on 'the analogy of body parts controlled at will by a brain', the latter being the disabled person, and the PA being 'the arms, the legs, the eyes'. In contrast, the idea of 'sensitivity to feeling' places 'touch' at the centre of personal assistance and brings about a rather relational, affective and contextualised body figuration. This contradictory body figuration features in much of the debate about personal assistance among scholars and activists in the disability rights movement and the ethics of care (Hughes et al., 2005).

Yet, strikingly, the body in personal assistance has seldom been explored. Few studies take the perspective of PAs and most disregard the bodily aspects of important issues such as the relational-emotional work that both PAs and employers engage in (Ahlström & Wadensten, 2010; Glendinning et al., 2000; Guldvik et al., 2014), the multiple definitions of personal assistance that such relationships imply (Shakespeare et al., 2018; Yamaki & Yamazaki, 2010) and the role of independent living mandates or values in the conduct of personal assistance (Christensen, 2012; Guldvik, 2003; Kelly, 2010; Mladenov, 2020; Neumann & Gundersen, 2019; Shakespeare et al., 2018; Yamaki & Yamazaki, 2010). Yet how these mandates are embodied by PAs and employers is seldom explored, and how they are fleshed out in ways of 'using' and approaching the body, either by PAs or their employers, even less so.

In disability studies, the lack of attention to the bodily aspects of PA is due to the fact that disabled people are usually their main actors (the focus is rarely solely on their PA) and because, as stated above, the body is still an 'absent presence' (Shakespeare & Watson, 2001). This is also true in the medical sociology approach to care. As Twigg et al. (2011) have shown, this is largely because care work is performed by people who occupy lower and more precarious positions. In the social sector, for instance, although care is eminently corporal (such as in care homes), professional discourse is overwhelmingly dominated by managerialist and disembodied language (Twigg, 2006). As with most of the aforementioned studies, these considerations also apply to personal assistance.

Drawing on Twigg (2002), Wolkowitz (2002) and Twigg et al. (2011), we approach personal assistance as a form of bodywork to highlight the embodied experiences of PAs as configured by specific dynamics of power. This concept was put forward by Wolkowitz (2002) to pair the renewed interest in the body and subjectivity in the sociology of work with the critical analysis of structural forces. It is worth noting the similarity with the shift proposed by critical disability studies (Goodley, 2014) and more recently, the dialog between disability studies and medical sociology (Thomas, 2021), which also seek to reconnect the analysis and theorisation of the impaired body with social structures of oppression (such as ableism and disablism).

Up to now, bodywork studies have not paid enough attention to personal assistance, even though the concept throws light on some of its characteristics: it 'focuses directly on the bodies

of others, who thereby become the object of the worker's labour' (Twigg et al., 2011, p. 172). It is also paid work that involves practical and material (hands-on) activities, which necessarily imply co-presence, as well as emotional management and intimacy. Moreover, the concept of bodywork applied to the study of personal assistance foreshadows its emotional and relational aspects but without disentangling them from the bodily aspects of their work. This is important in order to 'highlight the corporeality of power relations between practitioners and patients or clients and the corporeal interdependence that characterises their interactions' (Twigg et al., 2011, p. 179).

In short, we take inspiration from the renewed relevance of the body in disability studies and its dialogue with medical sociology to explore the ways PAs in Spain enact the body in practice through the concept of bodywork (Twigg, 2002; Twigg et al., 2011; Wolkowitz, 2002).

## Personal assistance in Spain

Compared to other European countries, personal assistance is a relatively new service in Spain. There are currently 7971 people with PAs in the country, representing 0.56% of all long-term care services (IMSERSO, 2021). It was included in the Promotion of Personal Autonomy and Care for Dependent People Act (LAPAD) of 2006 thanks primarily to disability rights activism, mainly the Independent Living Forum (FVID, in its Spanish abbreviation), although only as an underfunded skeleton service. Since 2008, there have been two ways of accessing public funding for personal assistance (Báñez & Comas, 2021): through direct payment or through service providers.

The FVID, following the traditional ILM framework, defines personal assistance as given below:

> A person who helps another to develop their life; that is, a person who performs or helps to perform **tasks of daily living** for another person who, because of their situation, due to a disability or for other reasons, cannot perform such tasks on their own. The PA accompanies the person, traditionally discriminated against because of their functional diversity, to perform the tasks that they indicate when indicated, thus **becoming their arms, eyes, ears**, etc. [...] The existence of a PA is based on the desire and right of **people with disabilities to control their own lives** and live them with the dignity that comes with having equal opportunities to the rest of the citizenry. [...] An assistant and the person they assist are linked by an employment contract, regardless of their personal relationship. In this **employment relationship**, decisions are made by the person with functional diversity[1] receiving assistance or their legal representative. This person acts as **the "boss"** of their PA.
>
> (Arnau et al., 2007, p. 5, emphasis added)

In this definition, neither the body of the disabled person nor that of the PA seems to be relevant beyond the metaphor of the PA's body as an extension of the disabled body. The job description does not establish their bodily capacities, nor is there mention of abilities, skills or professional experience. PAs must be open to engage in the personalised and non-standardised training usually provided by the employer. The right of the disabled person to live independently is realised through a labour contract in which the disabled person acts as employer and boss, making the decisions, and the employee executes these decisions. This claim is based on the European Network on Independent Living (ENIL) definition of personal assistance, which aims

to invert the power that professionals and family members have traditionally exercised over the bodies of people with disabilities (Ungerson, 1999).

However, while traditional disability associations, such as PREDIF in Spain and ECOM in Catalonia, define personal assistance in a similar way ('support in carrying out all those activities that they would do in the absence of functional limitations, allowing them to enjoy the maximum level of autonomy in the development of their life project and facilitating the exercise of self-determination'),[2] major differences appear in practice. The main conflict lies in the area of training (Arroyo & Cruz, 2015; Moya, 2021; Suñe & Martínez, 2015): these organisations promote the professionalisation of PAs by demanding mandatory and standardised training. Private companies, on the other hand, are simply renaming traditional home care services as 'personal assistance' for marketing purposes.

The other major issue is who should be the beneficiary of personal assistance support. Currently, all Spanish offices of independent living (OVI, in the Spanish abbreviation) are exclusively for physically disabled people, even if the original definition of personal assistance already specifies 'it is a way of providing required support for a person with functional diversity, whatever that functional diversity' (Arnau et al., 2007, p. 5). In addition, large social organisations are segmented by type of disability, and most of them offer personal assistance for physically disabled people only.

## METHODOLOGY

This paper draws on a study conducted between 2018 and 2020 that aimed to explore the practice of personal assistance in Spain. The study was approved by the *Ethics Committee of the Universitat Oberta de Catalunya* in 2018.

We interviewed 23 PAs from three different hiring schemes (see Table 1 for a detailed description of the participants). In 2018, we interviewed five PAs from the OVI, an association led by disabled people in Madrid. These PAs were gender-balanced, mostly from Spain, had no previous experience or training in care work, and their personal interest in the work had a major political component. We obtained these contacts through our political commitment to independent living activism: we have personal and political relationships with some of the disabled activists and PAs who work in different Spanish OVIs.

In late 2019, we interviewed 14 PAs from ECOM, one of the largest personal assistance providers in Catalonia. They had a slightly different profile from the OVI: most had worked and trained as care workers (8), they were mostly women (8) and some were migrants (6) and had unstable and precarious working lives. Their motivation for the work had more to do with the working conditions and their experience as care workers. As we were aware of this, we offered them a small remuneration to encourage their participation. This was previously agreed on with the organisation manager.

In the last phase (2020), we contacted four PAs who were directly hired by their employers rather than through an organisation. They viewed their work as a temporary professional and political experience. Some of them worked for the Barcelona OVI. We contacted them through our personal and political networks, choosing specific politicised profiles. These PAs were three women and a trans man; they were highly educated and had a strong background in feminist or LGTIBQ activism.

The interviews were semi-structured, lasting an average of 2 h and conducted in Spanish or Catalan, depending on the interviewees' preferences. Initially, the script aimed to explore the

**TABLE 1**  Participants profile

| Interview code | Gender | Age | Country of origin | Municipality of residence | Hired through | Years of experience | Number of people served | Training |
|---|---|---|---|---|---|---|---|---|
| Ana (E.1.1) | F | 20–30 | Spanish | Madrid | Association led by disabled people | 1 | 1 | Social integration and sociocultural animation |
| Nuria (E.1.2) | F | 30–40 | Spanish | Madrid | Association led by disabled people | 10 | 4 | Sociocultural animation |
| Eduardo (E.1.3) | M | 30–40 | Paraguay | Madrid | Association led by disabled people | 12 | 6 | No training |
| Raul (E.1.4) | M | 40–50 | Spanish | Madrid | Association led by disabled people | 10 | 10 | Baccalaureate |
| Nico (E.1.5) | M | 30–40 | Spanish | Madrid | Association led by disabled people | 4 | 3 | No training |
| Yousef (E.2.1) | M | 20–30 | Morocco | Barcelona | Service provider of PAs | 2 | 4 | PA degree |
| Lola (E.2.2) | F | 30–40 | Spain | Barcelona | Service provider of PAs | 7 | 9 | Higher degree in health documentation; social health accreditation in home care |
| María (E.2.3) | F | 30–40 | Portugal | Barcelona | Service provider of PAs | 4 | 1 | Sociosanitary techniques |
| Igor (E.2.4) | M | 40–50 | Spain | Barcelona | Service provider of PAs | 4 | 6 | Sociosanitary technician |
| Lucas (E.2.5) | M | 30–40 | Benin | Barcelona | Service provider of PAs | 2 | 1 | No training |
| Dani (E.2.6) | M | 40–50 | Spain | Barcelona | Service provider of PAs | 3 | 2 | Psychology (unfinished); sociosanitary assistant |
| Sara (E.2.7) | F | 30–40 | Spain | Barcelona | Service provider of PAs | 4 | 1 | Graphic design; currently studying to become a sociosanitary technician |
| Carla (E.2.8) | F | 30–40 | Spain | Barcelona | Hired privately | 2 | 4 | Degree in social education; master's degree in sexology |

**TABLE 1** (Continued)

| Interview code | Gender | Age | Country of origin | Municipality of residence | Hired through | Years of experience | Number of people served | Training |
|---|---|---|---|---|---|---|---|---|
| Montse (E.2.9) | F | 50–60 | Spain | Mataró | Service provider of PAs | 1 | 1 | No training |
| Lucia (E.2.10) | F | 50–60 | Ukraine | Barcelona | Service provider of PAs | 6 | 4 | No training |
| Laia (E.2.11) | F | 50–60 | Spain | Ripollet | Service provider of PAs | 2 | 3 | Baccalaureate degree; naturopathy; currently attending home care for the elderly |
| Juan (E.2.12) | M | 40–50 | Honduras | Barcelona | Service provider of PAs | 5 | 3 | Law school (incomplete) in Honduras; training courses for PA, geriatrics, and food handling |
| Luis (E.2.13) | T | 30–40 | Spanish | Manresa | Service provider of PAs | 5 | 4 | Not recorded |
| Magali (E.2.14) | F | 30–40 | Honduras | Barcelona | Service provider of PAs | 2 | 10 | Geriatric health assistant |
| Laura (E.3.1) | F | 30–40 | Spanish | Barcelona | Hired privately | 4 months | 1 | Criminologist, psychologist, social integrator, dependency care technician |
| Sonia (E.3.2) | F | 50–60 | Colombia | Barcelona | Hired privately | 12 | 1 | Baccalaureate degree |
| Marga (E.3.3) | F | 30–40 | Uruguay | Barcelona | Hired privately | 3 months | 1 | Degree in psychomotricity |
| Tania (E.3.4) | F | 20–30 | Mexico | Barcelona | Hired privately | 1 | 2 | Master's degree student in anthropology |

practical and material specificities of PAs' work, common conflicts and tensions, the role of independent living mandates and commonalities and differences with other care-related occupations. As the first interviews revealed, bodywork turned out to be critical, and the script was adapted slightly to focus more closely on the bodily aspects of their work. However, it should be mentioned that bringing out narratives regarding the body was not an easy task. As Twigg et al. (2011) have noted, one of the main challenges to understanding how these types of work develop is that they are difficult to verbalise, partly due to their social devaluation, partly because they are conducted in an intimate setting and partly because the work is usually provided by people in precarious socioeconomic situations. When we tried to focus our interviews on the body, the participants used disembodied technical jargon, such as 'providing hygiene' and 'mobilising', to sidestep the material and affective aspects of their work. This stems from the discomfort generated by the body, its potential sexualisation (Bahner, 2013) and, more generally, its functions and excretions, but also because referring to bodily aspects seems to be considered somewhat unprofessional, as PAs must detach themselves and therefore think in terms of 'it's not important' and 'it's the most natural thing in the world'.

As researchers, we ourselves experienced this discomfort, especially with the interviewees from whom we felt more distant, due to gender, age and/or cultural background, because we were afraid of making them feel uncomfortable or professionally discrediting them. Consequently, it was the bodily identification between researcher and interviewer that helped drawing out a framework of common understanding that facilitated talking about the body. It was between the youngest female researcher and the youngest female PAs that topics such as tensions regarding the sexualisation of their function as a PA were discussed, revealing how researchers position our bodies in a particular way in our work too. This also matters, because it influences our access to information and the analysis we (can) carry out on the data.

All interviews were recorded, transcribed and subsequently analysed using qualitative data analysis software. Joint meetings were held among the researchers to determine the coding framework. First, we selected quotations describing or reflecting on the nature of personal assistance work containing bodily aspects. Some were coded as body-tool or body-prosthesis, based on the ILM description of personal assistance, but most failed to adequately fit this definition. Inspired by the notion of bodywork in Twigg et al. (2011) and the critical disability studies literature, we realised that these were bodily figurations, which while providing guidance to the practice of personal assistance, were challenged by frictions resulting from mutually affected bodies. In this second stage, we re-coded quotations describing their embodied experience of personal assistance to finally divide them into two large categories: body-absence and body-presence.

## RESULTS

Our research reveals that PAs' bodywork implies performing body-absence with their bodies, such as when they enact body-tool and body-prosthesis figurations, but also body-presence, for instance, as acting bodies and affected/affecting bodies in specific situations.

## Personal assistance bodywork as performing body-absence

In the following section, we will present two body figurations (body-prosthesis and body-tool) derived from the previously mentioned independent living mandates, which convey normative

ways of enacting the body of the PA. Performing the roles of body-tool and body-prosthesis requires a specific type of PA bodywork: performing body-absence. This means that the PAs must manage their bodies to be physically present but symbolically and emotionally absent.

## Body-tool

The first definition regarding PAs is that they are a 'tool'. Most of the PAs interviewed tend to reproduce this discourse of 'command and obey': they stick to the idea that the employer is the person who knows and commands—the boss—and the PA has to only obey and follow. This is the description provided by Nico (E1.5), a Spanish PA who has been working for a personal assistance service provider for 4 years:

> I always wait to be sent for, you know? I'm a person who doesn't do anything on my own account. I mean, I don't take the initiative to say I'm going to... It's true that there is already a routine with my boss. So, I don't do things that are outside that routine. They are either explained to me or otherwise I don't act on my own. I always wait for my boss to tell me to "do this or do that".
>
> (Nico (E1.5))

Thus, PAs' bodies are transformed into tools in their employers' hands. Their main assignment is to do as their employers ask. For this reason, PAs also describe their work using expressions such as: '[you have] to learn to have patience, [because] you have to do things at their pace and in their way'; 'they have the right to make mistakes'; and 'it is not your life, it is theirs'. Even when this can make the PAs' work more complicated or cause them mental or physical stress, they must follow the principle of non-interference: executing rather than evaluating or judging the employers' requests. Like Nico, Juan (E.2.12), a PA from Honduras with 5 years of experience working for the same personal assistance service provider, gives a very good illustration of this:

> For example, if the user buys a wheelchair, I know as an assistant that this chair is very large and heavy and that it will create more work for me. However, I cannot make the decision and say, "Buy yourself a smaller chair" or "I will have double the work if you buy the big one." I cannot make those decisions.
>
> (Juan (E.2.12))

Body-tool is a key body performance in enacting the employer as the agent in command: PAs withdraw from taking part in situations despite being physically present. This fact is stressed by Igor (E.1.4), a Spanish PA very actively involved in the ILM, with 10 years' experience working both for a service provider and privately, who shows that this is accomplished through body performance rather than talking:

> There is one thing that usually happens a lot in this work: when you go outside with a disabled person and another person asks a question, that other person turns to you. So, when someone speaks to me, I always look at my boss, and then automatically, that person ends up talking to my boss.
>
> (Igor (E.1.4))

In this quote, we see how the PA's work is bodywork, since it is not simply about being attentive and executing the user's orders, but about doing so by positioning the body in a certain way (looking away or remaining silent) in a material and symbolic background that allows the employer to take the commanding position. PAs must remain physically present, close to their employers in case they need them, but with no agency, personal interest or concern in the situation. On some occasions, employers explicitly ask the PA to perform in such a way; on others, the PA figures out when it is more convenient to perform as a body-absence. As explained by Lola (E.2.2), a Spanish PA with 7 years' experience working for a big personal assistance provider, this can be done in many ways (from leaving the room to 'acting' as a plant-pot) and in a wide range of situations, not only when meeting people:

> Knowing how to interact is part of the job: if it is appropriate to speak a little or if you really have to make yourself invisible. Or there are times when you are there and, for example, they are in a relationship, and they are arguing; well, you are not going to be there, joining in... You look directly at the floor [LAUGHTER]. Or you look at your mobile but you don't want to see anything ... You just meditate as the Samurai do: they looked inward like this [LAUGHING].
>
> (Lola (E.2.2))

Performing body-absence is also a very common strategy when PAs engage with their employers in more intimate and bodily interactions, for instance, when assisting with hygiene. By performing body-absence, PAs aim to ignore their own sensations and feelings, which cannot be verbalised, withdrawing themselves from a potentially unpleasant situation and avoiding looking unprofessional. Ultimately, performing body-absence is a way of safeguarding the employer's intimacy and comfort. For this purpose, Lola explicitly uses the body-tool figuration:

> *Lola (E.2.2):* There are people who do not want you to approach, who are ashamed, right? 'Oh, blood or poop, or...' The person feels comfortable...
> *Interviewer:* Sure.
> *Lola (E.2.2):* Do not look at me as a person at this time, look at me as... [LAUGHTER] as a tool.
> *I:* Sure.
> *Lola (E.2.2):* I am used to it; I have seen everything [LAUGHING]. It's not a problem...

PAs learn to develop strategies of physical and emotional distancing as well as to explain professional distance without direct confrontation, that is, taking care not to harm the relationship. This bodily performance goes alongside particular ways of talking about and making light of the situation, for instance, by repeating that these are 'normal' and 'natural' things. Sometimes, the limits are directly established through the inclusion of objects that create physical and symbolic distance by configuring interactions in terms of health and care. As Carla (E.2.8), a highly educated Spanish woman and queer activist who has been working for 2 years as a privately hired PA, explains:

Carrying a few things, like my backpack with these things. Well, we carry wipes, gloves, a bottle of alcohol. More things when it comes to people who need cleaning, right? Both when they pee or poop, yes, I like to wear gloves and carry my backpack, right? I'm prepared with these things. (...) the issue of gloves, I do like to use them.

(Carla (E.2.8))

## Body-prosthesis

Secondly, the best known definition of PA uses the metaphor of being the user's feet and hands. This is what we have termed 'body-prosthesis figuration'. In this regard, PAs are defined as prosthetic extensions allowing disabled individuals to perform activities they would not be able to do on their own. In the following example, Laura (E.3.1), a highly educated Spanish PA who has been working for 4 months with a personal assistance service provider, explains how her work, in relation to personal hygiene, consists of completing tasks that the disabled person can only partially perform:

I do not clean her. She's sitting in the bathroom; I put a piece of paper here, I spread her legs like this with my hands, and she with her hand, like this, she does it like this; she cleans herself when she urinates, when she defecates, or whatever... Well, when she defecates, yes, then I help her, then I lift her with the crane, and I clean her from behind. I put on a glove, and that is it.

(Laura (E.3.1))

Thus, this requires the PAs to bodily intervene not only when requested but also in situations that can be interpreted as enacting their employer's impairment. This usually happens when performing intimate tasks such as self-cleaning, urinating and defecating, but also in social interactions. In the following example, also from Laura, we can see how her body is turned into a social and cognitive enabling prosthesis:

We (PAs) carry their mobile phone. I mean, she keeps it, right? We do not take it with us at any time, it is her mobile phone and she always has it. But if it rings or if someone calls or if there is a message or whatever, we take it and look at it. The other day, for example, she made me call a friend of hers who she hadn't talked to in a long time. So, I put it on speaker phone, and she told me before making the call everything I should say to her, more or less, but I was the one who spoke with this girl. However, I put the speaker on, and she could hear everything that I was saying and how the girl responded. In addition, at some point, she said something to me, and I said to the girl, "wait a minute, Rosa is saying something to me," and then, I repeated what she said.

(Laura (E.3.1))

As Luis (E.2.12), a younger and highly educated Spanish trans man who has been working as a PA for 5 years, told us, 'You might think it is like: 'Luis, go, get me the lemon', but it is not.

In fact, it is 'let's look for the lemon', the two of us. I go and open your wallet, give the money for the lemon, and put the wallet back.' Their goal as PA is to preserve the employer's agency, which is neither sidestepped nor expanded. As Laura's example shows, performing as a prosthesis does not imply taking over and carrying out those activities the employer is unable to do by themselves but to compensate for the specific disabling elements that might be hampering their agency:

> To reach what the disabled person cannot reach. We all have limits, it is clear, I mean, and I am not going to climb Everest. But if a person, because of the disability they have, does not reach things... That any person could or should be able to do, things like eating or walking? The PA should cover that.
>
> (Laura (E.3.1))

This definition of personal assistance is based on the assumption of bodily 'normality', which defines and limits what the PA should do. Sara (E. 2.7), a highly educated Spanish woman who has been working for 4 years with a personal assistance service provider, explains that her work is to 'do what the person would do if they were not disabled'. In other words, the PA's bodywork complements the disabled body so that it can do what an abled body would do. This assessment of the situation is based on a projection of bodily normality that is also defined by gender, class and age constructs. The gender and class identities of the employer and PA are also involved and may have a significant influence on the PA's decision on whether and how to intervene. Sara, for instance, tells us that cleaning was not part of the job because her employer, a married man, told her:

> If you want, for example, to wash the dishes after eating, wash them, but you do not need to wash them because my wife usually does that; I do not do it
>
> (Sara (E.2.7))

Because the employer's agency is also gendered, Sara taking over was not seen as eroding his sense of agency. Thus, along with ideas of disability, gender, age and class constructs play an important role in the configuration of the prosthetic body of PAs.

## PA bodywork as performing body-presence

We will see below how, in daily practice, the PA not only has to do bodywork to perform the body-absence that, as seen previously, is required to become a body-tool and a body-prosthesis, but also has to make the body present in specific ways. This is sometimes demanded when they are expected to decide or empathise as an acting body, and at other times, it inevitably emerges when PA's affections and needs come into play.

### Acting body

The normative definition of the PA as a body-tool is adjusted in daily practice because the PA makes, and should make, decisions. PAs seem to acquire a bodily awareness of the situations that require their active intervention or passive non-intervention. For instance, Igor (E.1.4) stresses the importance of empathy and touch rather than command and obedience:

> In the end, there is empathy and gestures because you already know if you have to enter or not. I mean, I enter conversations very gradually, you know? If you include me in a conversation, I'll look out the corner of my eye to see how it's going and I'll enter; I'll answer you a bit like that, you know? And I'll enter little by little to see how it feels, especially if it's the first time I've met you.
>
> (Igor (E.1.4))

PAs explain that some employers are not comfortable if they just wait to be given orders. Maria (E.2.3), a highly educated Portuguese woman who has been working as a PA for 4 years, talked about her current employer as 'not liking having a person always being there, waiting for him/ her to tell her how to do things'. Thus, when a PA and employer are acquainted with each other and establish certain work routines, it is quite common for the PA to make decisions, usually when undertaking bodywork tasks. In addition, there are situations when the employer does not know or want to decide how the PA must perform and leaves the decision to the latter. Interestingly, this seems to happen more frequently in relation to bodily and intimate tasks perceived as tedious, repetitive or unpleasant, usually associated with care work.

In this sense, Luis (E.2.12) explains that he is not comfortable when performing 'evacuations' without his employer's guidance because he feels he is acting as a caregiver rather than a PA. Luis is a trans activist who is also actively involved in the ILM and perceives this delegation as a 'betrayal' of the definition of the PA's role, which, he believes, should be differentiated from that of the traditional caregiver, in that the PA should be directed at all times by the disabled person.

> It seems that I have to decide how, when and in what way, you know? Which means that I have to put my fingers in your bum, get the shit out of you and know when it is done. Who really knows about these things...? Obviously, a nurse, and what kind of worker is a nurse? A care worker.
>
> (Luis (E.2.12))

Finally, an acting body is made present when PAs conduct emotional work. While PAs must learn how to perform body-absence and withdraw from taking part in certain situations, there is also an implicit expectation of empathy and intimacy with the employer. Many of them think, as Lola (E.2.2) says, 'nobody wants to have a robot at home'. Thus, a bodily and emotional adjustment between the assistant and the assisted arises. We now see how such adjustment work is handled, paradoxically referred to as 'normalised' and 'natural', between being close ('you cannot be insensitive') and, at the same time, professional and distant ('you cannot be affectionate').

> *Lola (E.2.2):* How do you manage the intimacy of the naked body, of hygiene...?
> *PA:* It is so normalised that ... (...) you are simply with the person. You are talking; you try to think that the person is not... [LAUGHING] she is not naked. You cannot be cold, but you cannot be affectionate either. But, of course, you are touching. It is skin.

## Affecting and affected body

The prosthesis bodily figuration ('being their hands') is also challenged when the PAs' body emerges as differentiated from that of the disabled body, that is, as a body that requires and experiences its own sensations and needs. PAs sometimes feel pressure to perform diligently

and efficiently and meet all the demands of fulfiling employers' sometimes unrealistic expectations regarding their abled bodies. PAs then need to show they are not machines, that they are not invulnerable. Thus, María (E.2.3) describes the job as exhausting and physically eroding:

> Let's see, you are not moving weights; you are not moving things. You are moving people. They are people who move and even though you have learnt in your head how to move them, that you must bend at the knees, keep your back straight, they might tug on you… [LAUGHING] Yes, the person trembles, for example, and you're moving them, and they give you a tug [LAUGHING]. Your back is already loaded. That is another thing. I have been doing this for a very short time, and I already have tendinitis, I have a back…
>
> (María (E.2.3))

In addition, PAs are sometimes asked to be ready and available outside of their work hours, compromising their free time, which they also need to rest and recuperate. This most often happens when PAs are hired to travel with their employers. Carla (E.2.8) describes her discomfort during a trip with a user who assumed they would spend all their time together. She wanted to take 'breaks' and felt she needed to 'spend time on her own'. The tension increased when she realised that they had to sleep in the same bed due to a lack of rooms:

> When we got to the hotel, the room was a double, with a big, double bed. So, at that moment, it was all crazy … My face made the person at the front desk say: "What's going on here? Everything's fine, right?" The woman I was with was nodding, saying "Yes, yes, everything is fine". But, for me, everything was not fine because it was a shared bed.
>
> (Carla (E.2.8))

This situation reveals the expectation of the PA body as an extension of the disabled person, not requiring physical space (a bed) or symbolic space (privacy). Hence, Carla's discomfort on seeing this bodily figuration demanded emotional work of exposing her body and her privacy at a moment of vulnerability, such as resting, and in a space of intimacy, such as the bed. In this regard, PAs must deal with the paradox that their body is seen and must act as a disembodied prosthesis while, at the same time, its social marks, such as gender, race and social class, intersect with certain body regulations and social expectations. For example, several PAs have sensed their relationship was romanticised by the employer. Yousef (E.2.1), a Moroccan national and a PA with 2 years' experience working for a big personal assistance provider, explains his discomfort in this context:

> I had been working with this girl for a year. I treated her very well. And… she fell in love with me, and that is not possible. Do you know…? And when she told me, I started to … I started to feel bad because I did not want anything like that with this girl. I treated her well; I treated her like a friend. I was her assistant, but no more than that. Well, when she told me, I immediately had to leave her. (…) She went too far, so… We had to… It had to end.
>
> (Yousef (E.2.1))

These situations are more frequent when the PA is a woman and the employer is a man. Female PAs employ different strategies to counteract and disengage from it. The main approach is to naturalise the crossing of boundaries as a product of a 'natural' masculine impulse towards all women and not as a romantic attempt to establish a personalised interaction. In the case of Maria (E.2.3), she sets limits by repeatedly referring to her relationship, 'I talk a lot about my personal life, and my boyfriend, my boyfriend, my boyfriend [LAUGHTER]. Normally, I don't talk so much but in this case, I talked a lot'. She is referring a specific case where the frontier between eroticism and assistance was blurred.

> **Maria (E.2.3):** I have had some situations... There was a young boy that I had to wash or something, and to remain in doubt about... To what extent [LAUGHING] this really is necessary.
> **I:** Ah, why? Did he have an erection or such?
> **Maria (E.2.3):** Yes, for example, I attached the collector, and he said 'squeeze hard' because he was afraid that the bag of pee would fall, right? Then, he repeated 'squeeze hard' [LAUGH]. 'You need to squeeze hard'. And I was like... I do not understand [LAUGHING] (...) He was looking for something else, but it was not just me ... [LAUGHTER]. And in the end, you learn to turn away a little.

Continuing this story, in relation to the same employer, when the interviewer asks about her feelings and emotions, the risk of eroticising intimacy and body contact is avoided by the dislike of certain bodily fluids and practices. Positioning the disabled body as undesirable helps maintain professional distance:

> The hygiene was so eww (LAUGHTER AND DISGUST). It was nothing like a sexual moment. So it cut you off from anything, you know? (...) There are some parts of hygiene that may seem pleasant for a person, but there will be others for whom it is not at all. Then, it takes away your... any fear of being able to reach that point... poop, pee, no.
>
> (LAUGHTER) Maria (E.2.3)

This excerpt shows how the PA's body affects but is also (potentially) affected. María expresses it in the form of a fear ('any fear of being able to reach that point') that she does not manage to specify ('that point'), which remains in the field of the unspeakable.

## DISCUSSION

Our research shows normative ways of enacting the body in PAs' work: on one hand, they learn to perform body-absence with their bodies when they become tools in the hands of their employers or a prosthesis for the disabled bodies of their employers. This is crucial to preserving the employers' intimacy and sense of agency. Moreover, it also implies that PAs perform with their bodies as materialising normative, abled and healthy bodies. But on the other hand, even though these bodily figurations guide PAs' bodywork, they are also challenged and negotiated. Our narratives reveal that PAs' body work also implies performing body-presence with their bodies, as acting and affected/affecting bodies in specific situations.

We use the concept of bodywork to understand how these body figurations are embodied in the PAs' daily lives. According to Twigg et al. (2011), this type of work 'involves both a knowledge of the materiality of the body and an awareness of the personhood that is present in that body' (p. 172). This is highlighted in several studies on personal assistance (Christensen, 2012; Guldvik, 2003; Porter et al., 2020; Williams et al., 2009; Woodin, 2006). Most of the work performed by both the PA and employer is aimed at establishing a 'friendship collaboration' (Christensen, 2012) or a 'commodified support relationship' (Shakespeare et al., 2018), free of abusive or dominant relations on either side. The interesting aspect of the bodywork concept is that it helps to show the extent to which establishing a good relationship depends on 'good' body management.

The narratives gathered in our research show how PAs learn to enact their own bodies or touch their employer's body in very specific ways, to establish a friendly but professional relationship with the employer. To do this, the PA has to learn how their employer's body functions and identify how to become a tool and a prosthesis through bodywork, to be absent both corporeally and emotionally and to be present materially and symbolically. In short, the PA's body is the employer's executive tool to live in an ableist world, and this means learning both how to affect and be affected, and how not to. PAs develop different strategies to ensure the success of the figuration, such as establishing limits physically (using gloves and face-masks), procedurally (moving into the background, 'becoming a plant-pot', asking before acting) or symbolically (describing a committed relationship). But, above all, a good PA is one who is able to adopt body malleability: they must be available as well as capable of adapting to and anticipating the needs of their employer.

Studies of bodywork (Twigg et al., 2011) show that it mainly occurs in the intimacy of the domestic space and thus 'is also linked to pleasure and emotional rapport as well as to abuse and discipline' (p. 172). Unlike other care professions in which power resides in the professional and this produces 'an epistemic injustice' (Mladenov & Dimitrova, 2022), here both the carer and the cared for may be in a position of vulnerability: the exploitation of the former if the demands for availability and flexibility are too great or the agreed working conditions are not respected; the dependency of the latter on the PA to perform the basic activities of daily living. It is therefore essential to establish contractual and bodily limits. As Twigg et al. (2011) explain, bodywork is highly regulated work, where establishing norms takes up much of the time, while situations arise that constantly breach them.

As we have shown, in practice, body figurations perform this regulatory purpose. Firstly, the PA's body has to become a tool, thus limiting their work to executing the employer's orders. Furthermore, the prosthetic prescription of the PA's body also serves as a limit to their work, as they must restrict themselves to substituting the employer's functional limitation ('doing what the person would do in the absence of disability'). However, as we have also seen, these body figurations are always partial, their adequate regulatory function depends on each situation, which requires constant calibration and adjustment between assistant and assisted. As Igor (E.1.4) explains, 'it is important that you have that definition of reference for when you get involved very, very much... that you know how to come back. You have to know how to always come back.'

In addition, Twigg et al. (2011) explain that bodywork implies redefining the ontological status of the body that is the object of the worker's labour depending on 'how it is read or known, handled, transformed, and understood' (p. 173). As we have seen, not only body-tool and body-prosthesis figurations aim to change the manner in which care is performed and conceptualised, challenging the epistemic superiority of professionals over care recipients, but so does

the ontological status of the care recipient's body: from being considered as causing the disabling experience (the impairment as the subject of intervention and transformation according to the rehabilitative medical model) to being defined by disabling social orders (which produce disability and need to be transformed according to the social model). Thus, PAs' bodywork implies intervening in the employer's bodies but in order to transform the disabling social orders.

However, as we have seen, PAs also deal with their employer's body, both as impaired and embodying specific gender, class, ethnic and age constructs. Together with disability, gender is especially significant (Bahner, 2013). As García-Santesmases and Sanmiquel-Molinero (2022) have shown, disabled people are subject to an ambivalent process of gendering and degendering, especially when they are hospitalised. Our study shows a similar dynamic affecting the PA. Their bodies perform as degendered in body-tool and body-prosthesis figurations or as gendered when their bodies are enacted as affecting and affected. The most visible and striking example of the latter is when PAs are seen as potential romantic or sexual partners, usually in the case of female PAs who work for heterosexual disabled men (Browne & Russell, 2005; Liddiard, 2017). This is a topic PAs find difficult to discuss, even more so when these are feelings and emotions towards their employers, an issue which clearly deserves further exploration.

Finally, we wish to highlight that, as occurs in other care-related professions, adjustments and tensions usually go unseen if we do not pay attention to bodily aspects. This can reinforce the idea that working as a PA does not require a learning or training process and comes naturally to certain subjects (normally groups such as working-class women and migrants). Raising the visibility of bodywork in personal assistance also helps highlight the learning involved between worker and employer to connect their bodies. Thus, although activist definitions of personal assistance do not refer to professional skills, this study shows there is a disciplining/training of the body related to managing relational, social and bodily competences. Therefore, with regard to local debates on the relevance/obligation of demanding standard training for personal assistance work (Satorras et al., 2020), we do not consider flexibility and training to be incompatible, as PA's learn to be flexible and to set limits.

## CONCLUSIONS

To conclude, we briefly discuss the potential contribution to the dialogue between medical sociology and disability studies that our study of PAs' bodywork can provide.

Our study first sought to overcome the traditional somatophobia of disability studies. It is not enough to unpack the values or beliefs of PAs and employers, nor appraise how well these arrangements put abstractly defined independent living mandates into practice. In our exploration of the bodily aspects of PAs' work, we show that using concepts such as bodywork enables disability studies to critically highlight the embodied and localised micropolitics of independent living arrangements. In line with critical disability studies, we have seen that the body matters because impairment plays a role in the experience of disability but also because it enables critical scrutiny of issues often considered 'natural', such as preferences and bodily configurations.

Secondly, our study points out the need for both disability studies and medical sociology to develop a more relational and materialist conceptualisation of the disabled body. We show how the disabled body is also configured in the practice of personal assistance: depending on the PAs' bodywork and how and what PA bodily figurations are enacted, the boundaries between what is considered the bodily cause of disability (impairment) and the bodily effect of oppressing physical and social environments (disability) can shift. Moreover, our analysis also shows that

personal assistance is indeed a collective endeavour: body figurations are enacted in practice by both employers and workers by making their bodies absent or present to each other in particular ways. In this respect, the bodily work that employers perform in personal assistance emerged in our study as a seldom explored aspect that deserves to be considered in future investigations.

Lastly, our analysis shows that embodying independent living mandates is crucial to redefining the micropolitics of care and disabled people's bodies. But it also shows the importance of challenging over-normative approaches, which are common in disability studies and have already been challenged in medical sociology. In line with Twigg (2002), we have shown that direct contracts based on independent living principles do not remove interpersonal conflicts, power struggles or make PAs 'abandon ideas of responsibility' (p. 194). Nevertheless, independent living mandates, rather than abstract ideals disconnected from practise, are indeed contextualised and very practical bodily dispositions. In this respect, we believe that our analysis can contribute to making disability studies more relevant to medical sociology by highlighting the manner in which normative and political values and concepts configure the contextualised and embodied experience and treatment of chronic conditions. This is important because the scientific definitions of these conditions are highly controversial political matters (Akrich et al., 2013) and the manner in which patients, relatives and professionals experience and treat these conditions is increasingly defined by rights-based principles and ideas of patient choice (Mol, 2008).

## AUTHOR CONTRIBUTIONS

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## DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions.

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## ENDNOTES

[1] This term is used by Spanish Independent Living activism as a substitute for negative terms such as disability (Palacios & Romañach, 2008)

[2] ECOM definition of Personal Asistance https://www.ecom.cat/es/que-ofrecemos/atencion-a-las-personas/servicio-de-asistencia-personal

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