ABSTRACT
Personal assistance is the key to the realisation of the independent living principles, as set out by the worldwide Independent Living Movement. In Scotland, consideration is under way to bring personal assistance within the realm of mainstream social care. This paper discusses the current debate around such a move from the perspective of postcolonial theory. Although more commonly used in terms of the impact of Global North political philosophy and practices on the Global South, this paper uses the term to criticise the maintenance of professional and hegemonic power over disabled people within the process of managing personal assistance within Scotland’s ‘self-directed support’ programme. The potential development of training, registering, and regulating personal assistants within Scotland is discussed with reference to Altermark’s (2018) ‘post-institutional’ theory of community support and Ratzka’s personal observations of fake personal assistance programmes. Further, it is suggested that by incorporating Mladenov’s (2019) study methodology of ‘good’ personal assistance, international studies of personal assistance might highlight where and how postcolonising of personal assistance happens within different states.

KEYWORDS
postcolonial theory; personal assistance; social care

Introduction
Formulated by the Independent Living Movement (the Movement) personal assistance is the manifestation of independent living principles: choice and control, dignity and freedom of the individual disabled person. During the UN International Year of People with Disabilities in 1981, and within England, Project 81 was the first attempt
made by physically disabled people to move from residential care into community living. This was facilitated by a ‘direct payment’, i.e. state money given directly to the person to employ their own personal assistant (PA).*1 Subsequently, local authorities throughout England were given the power to provide direct payments with the introduction of the Community Care (Direct Payments) Act 1996 (in force since 1997). However, although passing similar legislation in 1997, in Scotland the development of direct payments moved at a much slower pace. Eventually, the Scottish Government passed the Social Care (Self-directed Support) (Scotland) Act 2013, which made ‘self-directed support’ the default position of social care provision. The person was to be given the choice of how to receive their support, along a spectrum from state provision of a direct service to a direct payment to employ their own PAs.

In 2021, the Scottish Government published an ‘Independent Review of Adult Social Care’.*2 The Review noted how the implementation of the 2013 legislation varied throughout the country. Amid its 53 recommendations was the establishment of a National Care Service to make the implementation of policies and procedures uniform throughout the nation. Another recommendation was to improve the conditions of the social care workforce within the public and independent sectors, of which PAs should be recognised as members.

The Scottish Government subsequently conducted a public online consultation on its proposals to implement the Review. There was an overwhelming public response advising that there should be the same training, registering, and regulation of PAs as that of mainstream care workers. At ongoing meetings, including members of the Movement, the Scottish Government stated that PAs would not be regulated, however, mainstream training and registration would be provided on a voluntary basis and with the agreement of PA employers. It should be emphasised that no actual decisions have been taken to date (as of October 2022). However, there are many powerful people who wish PAs to have the same training, registration, and regulation as mainstream care workers. Even if they do not get their way, to a sceptic, as with assisted death, there is always the consequential issue of ‘mission creep’, in which legislation moves from its limited governance to larger areas and greater powers.

**Postcolonial/Post-Institutional Theory**

Niklas Altermark (2018: 157) describes postcolonial theory as ‘seek(ing) to understand how power lives on, ... after we have left the oppression of the past behind us’. This has primarily been discussed in relation to the aftermath of the rule of the Global South by the Global North. However, Altermark (2018) argues that postcolonial theory can also be used to develop a new way of viewing the history of disability politics – a history which has led disabled people from the exclusion of institutional life to the inclusion of community living. He calls this new perspective ‘post-institutional’. It allows the identification of aspects of institutional living that have spread over to contemporary support mechanisms such as ‘group homes’. Altermark’s overarching argument is that the post-institutional era is characterised by a transformation of how disabled people are governed. Rather than abolishing
state power and paternalism, contemporary governance of disabled people in the community has not only retained elements of that governance, experienced during the era of institutional care, but such has been complemented by new Foucauldian technologies of power (Altermark, 2016). The post-institutional era has failed to acknowledge this continuation of power by professionals and their apparatus. Disability politics is clearly not a simple progression, a gradual shift of power from state control to disabled people’s own self-determination (Altermark, 2018).

In Sweden, as elsewhere, the empowering nature of personal assistance has been shown to provide people with a better, more fulfilling life, as compared to traditional service provision (Altermark, 2018). Yet, locally implemented personal assistance programmes have often differed from the independent living values and ambitions, even when such programmes have been incorporated into state legislation. Exaggerated allegations of benefit fraud in Sweden have also justified cutbacks, with severe consequences for PA employers.*3 Similarly, throughout Europe, neoliberal cuts in the form of austerity measures have undermined personal assistance, thereby diminishing the control and self-determination of PA employers. For example, the introduction, in Scotland, of ‘self-directed support’ in 2013 enabled local authorities to review everyone receiving a direct payment to rebalance resources between those in receipt of services and those considered to have a ‘Rolls-Royce’ support system by virtue of managing their own support (Elder-Woodward, 2014; Witcher, 2014).

**Street-Level Bureaucracy**
Since the Social Care (Self-directed Support) (Scotland) Act 2013 came into force in 2014, the Scottish Government has provided a total of £46.6m to promote and implement the legislation, but with little positive outcomes. This reluctance to implement self-directed support can be reviewed in the light of ‘street-level bureaucracy’, a concept introduced by the American political scientist Michael Lipsky (2010). Street-level bureaucracy means that the delivery of state policies is dependent upon the interaction between frontline workers and the people who receive the services. The frontline workers have the discretion to implement, or not, state legislation, policies, practices, etc. Despite the efforts of the Scottish Government and other stakeholders, assessments of individuals seeking social care support often show how colonial behaviour works at the street level. The activities of the frontline workers, alongside their lack of knowledge of or outright antipathy towards direct payments, often prevent people moving from state provision to this type of support. Little information is transferred to the individual, who is primarily seen by the assessor as being the ‘object’ of care, rather than the agent, or ‘subject’ in control of their lifestyle and support system.

**Citizen Participation**
The lack of involvement by disabled citizens within these street-level processes is testament to how disabled people are viewed by those with power over their lives. The Movement’s slogan, ‘Nothing about us without us’, has yet to be understood in town halls and county chambers throughout the land. At the national level, the
Scottish Government is currently involving ‘people with lived and living experience’*4 of services in the development of the National Care Service. As part of their co-design of this Service, the Scottish Government has set up a working group of PA Employers and PAs. This group is looking at the similarities and differences between PAs and mainstream social care workers and making recommendations about PA training needs and fair work practices. Although reassurances are given at every meeting that the status of PA employers will not be undermined, the actions often do not match the words. As an example, foundation courses for social care workers have already been opened to PAs. These modular courses adopt a medicalised understanding of disability, i.e. they are based on the individual model of disability, rather than the social model followed by the Movement (Oliver & Barnes, 2012). The philosophy and history of independent living are not mentioned, nor is there anything relating to diversity issues such as a critique of disablist language. Terms such as ‘lifting and handling’ are often used. This term was taken from the training of warehousemen and other industrial workers to lift and move heavy objects and machinery safely. Applying the term to human beings strips them of their dignity and humanity. No one wishes to be ‘handled’ by another person, or treated as an object. The preferred term is ‘moving and assisting’. Naming the person by their impairment or their mobility aids (i.e. ‘paraplegics’, or ‘wheelchairs’) is also not always challenged within such training. Such language reduces people to one aspect of their identity, so negates their dignity and full humanity. It also maintains the power of the speaker over the subject they are addressing.

Again, in the absence of anything else, various private-sector organisations (i.e. private companies and voluntary organisations for disabled people) have set up PA support programmes and websites where PAs support each other and mainstream training opportunities are offered. Such developments have been initiated without the involvement of the Movement. This may easily be presented as an attempt to guarantee the right of PAs to develop their skills, voice, and unionisation. The irony is that the Movement has been seeking resources for years and without success to deliver training of PAs and PA employers, within the ambit of Independent Living. The current developments are also worrying in that there is, currently, no concomitant programme to train PA employers, nor their peer support systems.

**Ratzka’s Features of Fake Personal Assistance Programmes**

In a personal communication with the author, Adolf Ratzka, Emeritus Founder and Director of the Independent Living Institute in Sweden, has spoken about his personal observations of what he calls *fake* personal assistance (Ratzka, 2018). By observing personal assistance from around the world, Ratzka has identified certain features as indicating *fake* programmes, including:

1. Restrictions are placed on the choice of PAs or service providers. For example, the PA employer is limited to employing only certain categories of
people, e.g. long-term unemployed people: or they can only engage a care agency from the authorities’ predetermined approved list.

2. Recipients have not been given any control over the funding.

3. Direct payments are determined, mostly on the basis of available income, but occasionally, on the degree of impairment. Therefore, in the former case, the provision of direct payments is limited to people with low incomes, or is means-tested so that it is free only to those with low incomes.

4. The access to direct payments depends upon geographical residency. Therefore, the direct payment cannot be retained when the individual moves their residence to another area.

5. There is an imposition of minimum or maximum number of assistance hours per week.

6. The assistance is limited to personal care, i.e. washing, eating, etc.

7. The funds are not sufficient to cover people’s needs, including those involved in taking on the role of an employer.

8. The imposition of a minimum and/or maximum age range for the PA employer. (Adapted from Ratzka, 2018)

Of course, a true personal assistance programme would be the antithesis of these features. Although Ratzka has not mentioned it, an additional feature, which would fit a fake programme, is whether the programme has an artificial ceiling placed upon the direct payment, beyond which the cheaper option of institutional care is considered. For example, Norberg (2021) argues such neoliberal actions, which she asserts are shaped by disablism, are the experience of austerity for disabled people in Sweden. From interviews with disabled people, she explores how neoliberal welfare bureaucracy isolates and dehumanises disabled people; as well as obscuring, to the general public, the impact of austerity on this population.

Another key feature that would help distinguish fake from true personal assistance is the issue that has been discussed in this paper – the control of training and monitoring of PAs, as well as the amount and degree of support given to PA employers and their collectives. When authorities acquire such control over the management of personal assistance, the reassertion of professional’s power adds to the fakery of the programme and its (re)colonisation.

Conclusion

Altermark (2016, 2018) has discussed community-based services for disabled people through a postcolonial lens. This paper has identified similar processes in the area of personal assistance programmes. It has explored PA programmes through the lens of postcolonial theory, where past oppressions of subjugated populations are found to be reproduced within the systems of their emancipation. The exercise of such powers results in a demarcation of who ‘should be’ resourced to realise their rights as citizens and how much that person should be charged for those resources. Once those resources have been transferred to the citizen, it is suggested that the systems of oppression continue through the management of the said resources. The
limitations placed upon how much, and in what manner, these resources are used has led Adolf Ratzka to identify such limited personal assistance programmes as being fake (i.e. an illusion or Orwellian ‘Doublespeak’ and thus not real).

Ratzka (2004) had already suggested a series of features of a true programme. However, as Ratzka’s features of a fake programme are based on his personal observations, it would be valuable to complement these insights with international studies of personal assistance, in a similar vein to Mladenov’s (2019) study of ‘good’ personal assistance. Here, PA employers and members of the Movement in Europe were asked to assess a series of characteristics of personal assistance in terms of their impact on choice and control. The characteristics were assessed according to which were considered to be enablers of choice and control, which were perceived to be barriers, and which elicited disagreement or lack of consensus.

By combining Mladenov’s and Ratzka’s features of personal assistance, and applying Mladenov’s methodology and statistical analysis, comparative research could discover where individual states lie along a continuum of fake and true programmes. This would help identify specific targets in need of policy interventions that would help decolonise personal assistance.

NOTES

*1. Within this paper the abbreviation ‘PA’ will relate to ‘Personal Assistant’. The term ‘Personal Assistance’ will be written in full.


*3. The term ‘employer’ defines more accurately the status of the person than the terms ‘user’.


*5. Taken from George Orwell’s novel, 1984. Doublespeak is language that deliberately obscures, disguises, distorts, or reverses the meaning of words. Doublespeak disguises the nature of the truth.

REFERENCES


