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# The interaction between social equality and personal assistance: A crosscountry analysis

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#### Abstract

Several countries have enacted personal assistance (PA) legislation over the past few decades. Although this policy has been associated with improvements in the quality of life, here we explore how it interacts with the social environment. We examine how the existence of PA legislation influences the effect of social equality on the health and well-being of disabled people. Multilevel analysis was performed using data from the European Social Survey (n = 18,924), including 31 countries and 7 waves of data (2002-2014). Results show that social equality has a positive effect on well-being, but only in countries with PA. The relationship between social equality and well-being, in countries with PA, is explained by increased public participation, satisfaction with the political and economic situation, and a more positive opinion about the health services. Our findings highlight the importance of PA in influencing disability equality and improving disabled people's well-being.

Keywords: social factors of health and well-being; inequality; personal assistance; disabled people; disability equality.

### Points of interest

- The ways in which social equality affects the health and well-being of disabled people is underexplored.
- We analyze how personal assistance shapes the link between social equality and wellbeing.
- The well-being of disabled people improves when there is more social equality, but this
  only observed in countries with legislation on personal assistance.
- Social equality is associated with public participation, satisfaction with the political and economic situation in one's country, and a more positive opinion about the health services, which in turn are all linked with greater well-being.
- This study offers additional information on how social aspects influence the well-being of disabled people, highlighting the importance of personal assistance for disability equality.

#### Introduction

The wealth and social equality of a country are critical factors of the health and wellbeing of the general population (Marmot 2005; Marmot et al. 2012). Despite disabled people being one of the largest social minorities (15% of the world's population) (World Health Organization [WHO] 2011), they have received much less academic attention than other disadvantaged groups (Olkin and Pledger 2003) and the impact of social factors, such as wealth and social equality, on this group is still under-researched. Disabled people face particular social disparities due to discrimination based on disability, defined as ableism. 'Ableism is stereotyping, prejudice, discrimination, and social oppression toward [disabled people]' (Bogart and Dunn 2019, p. 645). Due to ableism, disabled people tend to have poorer access to health services, and lower levels of education and employment (WHO 2011). Implicit prejudice towards disabled people has increased (Harder, Keller, and Chopik 2019), or maintained over time in contrast to prejudice against other disadvantaged groups that has decreased in the last decades (Charlesworth and Banaji 2019). Moreover, research has shown that ableism is more adverse for well-being compared to other types of group-based discrimination (Branco, Ramos, and Hewstone 2019).

However, due to the tendency to treat disability as an individual and medical factor, it is still unclear what are the implications of the social environment for the well-being of this group. In this paper, we analyse the association of country's wealth and social equality with the health and well-being of disabled people and the role of personal assistance in shaping this association. In addition, we identify specific socio-psychological mechanisms explaining the relationship between social equality and health.

## Disability and personal assistance

The Convention on the Rights of Persons with Disabilities (CRPD) define 'people with disabilities' as 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (United Nations [UN] 2006, 4). Although the CRPD has a human-rights based approach that could be considered a social approach, it still uses a personenvironment interaction to define disabled people and disability (i.e., Kazou 2017). We agree that the definition of disabled people should include all characteristics considered as impairments, whether attributed by the person or by others. However, considering the social model of disability, we argue that it is more adequate to define disabled people in terms of social oppression. The social model of disability (Oliver 1983; Oliver and Barnes 2010) emerged with the spread of the disability movement throughout Europe, during the 80s', arguing that disability derives directly from environmental, social and attitudinal barriers, rather than from individuals' bodies and minds, as argued by the prior individual and medical model of disability (Brisenden 1986). In social psychology there is a similar paradigm (although it had no impact for a long time, Olkin and Pledger 2003). The social constructivism approach defines disability as a social construction, implying that disability results from the meanings, attitudes and institutions of the non-disabled people, rather than by individual limitations (Fine and Asch 1988).

Therefore, considering a social/constructivist model, and the definition of ableism, we define disable people as those who are oppressed by social, attitudinal and environmental barriers on the basis of a physical, sensory, intellectual or developmental/learning disability, or mental illness (i.e., on the basis of ability). In addition, an identity-first language (i.e., the term disabled people) is more congruent with the social model, than person first language (i.e., persons with disabilities). Disabled people is used to emphasize the group identity marked by

common historical, social and political experiences (Linton 2006). It also means that 'people are disabled by environmental, systematic and attitudinal barriers in society, rather than by their impairment' (European Network on Independent Living [ENIL] 2020). On the other hand, 'persons with disabilities' seems more congruent with the medical and individual model of disabilities as it puts disability on the person (i.e., the person has the disability and not the environment). Therefore, throughout this work we use the term 'disabled people'.

Driven by the independent living movement that started in the USA in the '60s (DeJong 1979), personal assistance is based on the independent living philosophy. This philosophy claims that disabled people should have the same choice and control over their lives as non-disabled citizens, through the combination of a range of tools, such as personal assistance (Morris 2004; ENIL, n.d.).

Personal Assistance (PA) is a support service, enacted by the state, for daily living activities, in which disabled people must have full control over the service, recruiting, selecting, training, and managing their assistants and daily schedule. The disabled person is considered an active recipient of the service, contrasting with the traditional home care services that offer few or no choices over the selection of assistants, type of activities involved, and how these activities are scheduled and performed (Beatty et al. 1998). Ideally, in its full empowering form (based on the experiences and policy recommendation of disabled people's movements; Ratzka 2004), PA should be funded by the state and funds should be channelled through the recipient (i.e., direct payments or personal budgets), making the user the employer of the service. Shaped by a strong component of collective action, peer-support is a strong element of PA as service users need appropriate support with tasks management, such as advertising, recruitment and employment of

assistants, which should be provided through user-led organizations (Barnes 2007; Morris 2004; Ratzka 2004).

Currently, several countries in Europe have enacted legislation on PA, but the characteristics of PA schemes vary widely across and within countries. PA services are mostly funded by the state through municipalities or regional agencies (ENIL, 2013, 2015). However, these schemes can vary at the level of administration (national, municipal), funding arrangements (e.g., option for direct payments), amount of control that disabled people have over the service (e.g., choice of providers) or in the availability of services (e.g., restrictions in age and type of disability, hour limit).

The impact of PA (commonly termed consumer-directed PA in this literature), primarily studied in the USA context, has been associated with better outcomes, compared to home care services (commonly termed agency-based PA). These outcomes are related to greater empowerment, satisfaction with the service, better quality of life (Hagglund et al. 2004), higher levels of safety and fewer unmet needs (Clark, Hagglund, and Sherman 2008; Benjamin, Matthias, and Franke 2000), greater control over the services (Fleming-Castaldy 2011; Beatty et al. 1998), lower costs, and better health outcomes (i.e., fewer re-hospitalisations for preventable conditions; Mattson-Prince 1997). More recently, a literature review (Anand et al. 2012) based on studies from UK, Ireland, Netherlands, USA and Canada showed that service users of direct payments or personal budgets have more choice and control over how support is provided, improved personal dignity, better health, better economic well-being, greater quality of life, and support for having paid employment, vocational skills training, to take part in volunteer activities and enroll in postsecondary education.

However, to understand how PA interacts with wealth and social equality, research needs to adopt new models accounting for these services together with societal variables. As an essential tool for disabled people's inclusion and self-determination, PA should have an important role in disability equality.

## The social factors of health: Wealth and social equality

For a long period, the level of wealth of a country, commonly measured through the Gross Domestic Product (GDP), was considered the main factor of its population's health. However, this is no longer the best indicator of health in developed countries, given that, despite their economic growth, some countries still have a high level of public health issues (e.g., drug abuse, violence, teenage births). Given that differences in income within societies are more strongly associated with health than are differences in income between countries (Wilkinson and Pickett 2010), the level of social inequality within a country emerged as a key determinant of health. The common interpretation of this relation is that inequality leads to chronic stress and anxiety that affects health and social relationships, by decreasing social trust and increasing status competition (Kawachi and Kennedy 1999; Wilkinson and Pickett 2006; Wilkinson and Pickett 2010).

In a review of 155 papers and 168 analyses, published between 1975 and 2005, a large majority of these analyses (70 per cent) concluded that health is worse in societies with larger income inequalities (Wilkinson and Pickett 2006). Additionally, a meta-analysis of 54 articles, published between 1997-2008, revealed that income inequality was associated with both mortality and poor self-rated health (Kondo et al. 2009).

Research has focused on how these socio-economic factors influence the health of the general population, including the prevalence of conditions related with impairment (e.g., mental

illness, physical morbidity), but not on how these factors determine the health and well-being of disabled people. A national survey in the USA revealed that disabled adults receive significantly fewer preventive health services and have poorer health status on secondary conditions (e.g., cardiac disease, high blood pressure, high cholesterol, diabetes, stroke, asthma) than non-disabled adults (Reichard, Stolzle, and Fox 2011; Reichard, Nary, and Simpson 2014). Although these differences are attributed to social factors rather than impairment, there is a lack of research linking disabled people's health with social factors. Moreover, we argue that despite the existence of social policies - such as personal assistance – with a positive impact on well-being of disabled people, the impact of these policies along with social factors remains unknown.

In fact, there is an ongoing debate about the relationship between personal assistance and equality. On the one hand, PA is considered a way to achieve social justice through greater autonomy, choice, and inclusion. On the other hand, there is a concern that the introduction of PA without considering specific needs or characteristics of different groups could result in more inequalities (Mladenov, Owens, and Cribb 2015). The idea is that user-centred models can increase inequalities by being more accessible for those who have certain characteristics (e.g., more educated, have a larger social network, being middle class) over others in a more disadvantaged position and with fewer resources (e.g., racial or ethnic minorities; Anand et al. 2012; Clarke 2006; Gadsby 2013). In addition, the majority of PA schemes exclude disabled people based on their age and or type of disability (ENIL 2013, 2015; Supplemental Table S4b). Therefore, it seems that in contexts with more inequality, in which some groups are less educated and have less economic and social resources, PA could enhance the negative impact of such inequalities, in cases where the cause of those inequalities is not addressed in its implementation. This can be more serious when PA is decentralized, promoting inequalities between regions

(Brennan et al. 2017); administrations do not guarantee users' control over the service; cuts or inappropriate funding leads to low number of assistance hours and failure to cover all expenses associated with users' training and peer support, which harms the maintenance of user-led organizations (Barnes, 2007; Mladenov, 2020). PA itself should not, however, be a factor of inequality; on the contrary, PA should be an enabler of social justice by promoting autonomy, participation and equal access to social goods and services. PA has been defended by disability advocates and in international documents as a crucial condition for disability equality, such as in the CRPD (UN 2006). The CRPD (UN 2006, article 19) recognises the right of disabled people concerning to living independently and being included in the community, on an equal basis with others, through access to a range of community-based services, including personal assistance. Similarly to other social movements, the pursuit for disability justice is not only a matter of welfare rationality (i.e., economic distribution) but also a demand for cultural recognition (i.e., respecting and valuing difference) and political representation (for the application of Fraser's [1996] work to disability equality, see Mladenov 2017). In this study, we seek to contribute to the understanding of how PA interacts with social equality.

In our analytical approach, we examine how personal assistance may interfere with the relationship between country's indicators (i.e., wealth and social equality) and disabled people's health and well-being, with a focus on within-country effects.

### The socio-psychological mechanisms explaining equality effects

There is some evidence from parallel work focusing on the mechanisms between inequality and health, that might be generalized to the context of the present study to understand the moderating role of PA – how PA interact with social equality to produce positive outcomes

for disabled people. These mechanisms include public participation, the political and economic situation, and the state of the health services.

Public participation. One of the main mechanisms suggested by previous work is that income inequality leads to the loss of civic trust and participation. More specifically, income inequality is positively correlated with low levels of civic trust and associational membership (e.g., sports groups, fraternal organizations, labour unions; Kawachi et al. 1997). Besides, it has been shown that income inequality decreases political participation (Solt 2008) and voter turnout (Cancela and Geys 2016). In other words, income equality is associated with increased public participation. For disabled people, however, this could be still undermined if PA is not available. For instance, PA leads to fewer unmet needs regarding daily living activities (Clark, Hagglund, and Sherman 2008) and it includes activities related to social participation, such as assistance in transportation, communication, and use of public infrastructure, which all promote inclusion in a broad range of social activities (von Granitz et al. 2017). On the other hand, disabled people are often excluded from activities related to political participation due to social barriers (e.g., lack of accessibility to build environments, political information, and communication; Priestley et al. 2016), that could also be overcome by PA.

Political and economic situation. Previous work suggests that income inequality threatens democracy given that it decreases political trust (Zmerli and Castillo 2015), political participation (Solt 2008), and voter turn-out (Cancela and Geys 2016). On the other hand, income inequality is a threat to the economic system as it is likely to increase corruption in government and society (You and Khagram 2005), and leads to debt and financial crashes (Iacoviello 2008; Wisman and Baker 2011). In other words, equality has a positive association with democracy and economic development, both positively associated in previous studies

(Burkhart and Lewis-Beck 1994; De Haan and Siermann 1995). For disabled people, however, PA could be an essential feature to enable a higher satisfaction with the democratic and economic system in the country. PA allows disabled people to participate in a major range of activities, including political activities, which would favour the democratic process. In addition, since PA is based on democratic and social justice values, it could promote a more positive perception of the democratic system. On the other hand, the economic redistribution of funding for PA, in addition to improving democracy, can also be a contributing aspect to the economic system. Public investment in community services should be based on human rights and social justice despite its economic value. Although evidence shows that from a financial perspective this is also the right policy to adopt, as PA can be the most cost-effective way of supporting disabled people. PA appears to be less expensive than the agency and residential models, and it generates employment for personal assistants and promotes disabled people's active participation in society, as customers, workers, students, and taxpayers (Doty, Kasper, and Litvak 1996; Hurstfield, Parashar, and Schofield 2007). Furthermore, PA is related to lower costs at the individual level, compared to home care services (Mattson-Prince 1997).

Health services. Income inequality is associated with cuts on health insurance, social welfare, and expenditure on medical care, which are expected to lead to poor health (Lynch et al. 2000). Additionally, primary care is positively associated with health status and serves as a pathway through which inequality affects health (Shi et al. 1999). In other words, equality is associated with the improvement of healthcare services. However, its positive effects are not necessarily extended to disabled people, who on average experience more difficulty in accessing health care and receive less preventive care than the general population (Reichard, Nary, and Simpson 2014; WHO 2011). PA could be an important feature enabling better health services

and more positive perceptions of it, given that its presence makes services more accessible to disabled people. Furthermore, PA is related to better physical and mental health (Nosek 1993), fewer re-hospitalisations for preventable conditions (Mattson-Prince 1997), reduced nursing facility use and improved medication management (Anand et al. 2012). In contrast, inadequate PA led to extended hospital stays, threats to safety, poor nutrition, and poor personal hygiene (Nosek 1993).

### The present study

The aim of this study is to analyse the association of both country wealth and social equality with the health and well-being of disabled people, and how the existence of personal assistance could shape this relationship. We bring to bear one of the largest data sets related to disability by conducting a secondary analysis of 12 years of data across 31 European countries. Moreover, most comparative studies examining the association between social equality and health are based on between-country comparisons, but it is not clear whether these comparisons would translate into similar within-country effects (i.e., tracking this association within countries and over time). In our work, we used a novel methodological approach (Fairbrother 2014), allowing us to disentangle between- from within-country effects.

We first test the direct relationship of wealth and social equality with the health and well-being of disabled people, which is followed by testing the moderating effect of personal assistance on this relationship. We hypothesise that better country-level socioeconomic conditions (i.e., higher levels of wealth and higher social equality) should have a positive impact on the health and well-being of disabled people and that these effects, especially that of social equality, should be strengthened in countries with personal assistance. In a second step, we perform conditional process analysis (Hayes 2018) to examine the role of personal assistance on

the relationship between social equality and the health of disabled people through specific sociopsychological mechanisms. We hypothesise that the relationship between social equality and health is explained through increased public participation, satisfaction with the political and economic situation, and more positive opinions about the health services, only in countries with personal assistance.

#### Method

#### Respondents

We used secondary data from the European Social Survey (ESS), a repeated crossnational survey conducted across 36 European countries, including nationally representative samples. We analysed seven waves of cross-sectional data (from 2002 to 2014), containing a wide range of measures assessing attitudes, beliefs, and behaviour patterns, which have been used in multiple publications relevant for social policy and practice. Data was collected through face-to-face interviews, using show cards containing the answer options to facilitate responses. We selected for analysis all individuals who responded: 'Yes, a lot' to the question 'Are you 'hampered' in your daily activities in any way by any longstanding illness, or disability, 'infirmity' or 'mental health problem'?' resulting in a total sample of 18 924 respondents, from 31 countries. This type of question is based on a functional, individual and medical approach to disability, which may not be the best way to measure disability (e.g., we do not know if people are hampered due to barriers or lack of support; there are disabled people who are not hampered in daily activities). However, this was the question available that most resembled disability and of those who could benefit directly from personal assistance. Of these respondents, 59% were female, 46% were married, and 15% were in paid work and 50% were retired in the last 7 days.

Respondents were on average 61.75 years old (SD = 16.9; range from 15 to 102 years old) and had completed 10 years (SD = 4.17) of full-time education.

#### Measures

Country-level variables: GDP and Equality. Country wealth was measured with the Gross Domestic Product (GDP per capita in current US\$) using World Bank data. We used the dissimilarity index (Massey and Denton 1988) to compute a country-level measure of social inequality based on respondents' educational distributions. We followed the procedure used by Ramos, Bennett, Massey, and Hewstone (2019) and adjusted these distributions with the statistical weights provided by the ESS, to minimise sampling bias and guarantee that these data were nationally representative. Moreover, the dissimilarity index is highly correlated with other inequality measures, such as Gini and Atkinson indices, suggesting that they all measure similar properties (Massey and Denton 1988). Note that the dissimilarity index provides a number ranging between 0 and 1, where 1 indicates maximum inequality. However, for our analyses, we reverse-scored this measure and multiplied the scores by 100 to get a percentage index with one-unit changes. Both country-level variables were matched by country and year and a higher score on these variables indicates, respectively, more wealth and social equality.

Note that we could not use a measure based on respondents' income because these data were missing from several countries and waves. Other typical inequality measures, such as the Gini index, had similar issues given that there were missing data for some years of the ESS and that would have resulted in analysis with several omitted country-waves. Nonetheless, education levels are a reliable indicator of social status and, as such, served as an indicator of social equality in our study.

Personal assistance (PA). A PA measure was created using a dichotomous variable (1 = With PA or -1 = Without PA) covering the (non)existence of national legislation on PA in each country and year of the survey, based on the ENIL (2013, 2015) and Academic Network of European Disability Experts (ANED 2017) database. The data was collected between 2002-2014, every two years, and the countries considered having PA legislation at the national level were Sweden (2002-2014), Great Britain (2002-2014), Estonia (2001-2014), Denmark (2002-2014), Italy (data available only for the years of 2002 and 2012), Germany (2002-2014), Norway (2002-2014), France (2002-2014), Spain (2006-2014), Czech Republic (2008-2014), Finland (2010-2014), Slovakia (data available between 2004-2012), and Switzerland (2012-2014). Countries considered without PA legislation at the national level were Austria, Belgium, Hungary, Lithuania, Netherlands, Poland, Portugal, Slovenia, Bulgaria, Cyprus, Greece, Ireland, Turkey, Ukraine, Kosovo, and Croatia. PA was contrast coded as -1 or 1, a recommended procedure to avoid problems of multicollinearity while allowing a centred distribution in interactions (Aiken and West 1991).

As previously mentioned, there is some variability in PA schemes across Europe, for example on the amount of control disabled people have over the service (e.g., option for direct payments, choice of providers, limit of hours) or in the availability of services (e.g., restrictions in age and type of disability, limit of hours). Service characteristics could even differ between municipalities. Due to this variability and because we lack individual measures on PA schemes in this type of survey, we measured only the existence of national PA-related legislation in each country. In addition, we only included in the sample respondents who answered: 'Yes, a lot' to the question 'Are you hampered in your daily activities (…)?' as this sample is more likely to

need assistance in daily living activities and thus benefit from PA. Some individuals answered 'Yes, to some extent', but, for the reasons above, they were not included in our analyses.

Public participation. Public participation was measured by summing answers to three dichotomous (0-No, 1-Yes) questions relating to political and civic participation, which loaded on a single factor: 'During the last 12 months, have you done any of the following? Have you…' '…contacted a politician or government official?', '…worked in a political party or action group?', and '…worked in another organization or association?'; ranging from 0 to 3 behaviours of public participation in the last year and explaining 51% of the variance.

Satisfaction with the political and economic situation. We measured satisfaction with the political and economic situation by averaging responses to questions on satisfaction with the state of democracy and satisfaction with the state of the economy together on a single factor (Spearman-Brown coefficient = .724): 'And, on the whole, how satisfied are you with the way democracy works in [country]' and 'On the whole how satisfied are you with the present state of economy in [country]' (answers ranging from 0-extremely dissatisfied to 10-extremely satisfied). As democracy has been associated with economic development in previous studies (Burkhart and Lewis-Beck 1994; De Haan and Siermann 1995), we factored them together as a measure of socio-political context to simplify the analysis.

Opinion about the health services. Opinion about the health services was measured with a single question: 'Please say what you think overall about the state of health services in [country] nowadays' (answers ranging from 0-extremely bad to 10-extremely good).

Health and well-being (HWB). Health cannot be reduced to a single aspect. As such, we measured HWB by averaging answers to questions on self-rated happiness, satisfaction with life, and health: 'Taking all things together, how happy would you say you are?' (answers ranging

from 1, 'extremely unhappy' to 10, 'extremely happy'); 'All things considered, how satisfied are you with your life as a whole nowadays?' (answers ranging from 0, 'extremely dissatisfied' to 10, 'extremely satisfied'); and 'How is your health in general?' (answers ranging from 1, 'very good' to 5, 'very bad'). The last question was reverse-scored. Responses to the three questions were standardized and then averaged to provide a single measure of HWB ( $\alpha$  = 0.703), with only one factor emerging from an exploratory factor analysis explaining 65% of the variance. A higher score on this variable indicated better HWB. These three measures were highly correlated in previous research (Clark and Oswald 1994; Kahneman and Sugden 2005) and have been widely used to measure HWB.

Individual-level controls. We controlled for a wide range of relevant individual-level characteristics, associated with health and well-being (Wilkinson and Marmot 2003). We included the following variables and coding: sex (0 = Female; 1 = Male), born in the country (0= Yes; No = 1); belonging to a religion (0 = Yes; 1 = No); group discrimination on the grounds of disability (0 = Not marked; 1 = Marked); marital status coded with 4 dummies (Separated; Divorced; Widowed; Never married), using the reference group 'Married'; employment status, coded with 3 dummies (Doing activity in the last 7 days: Permanently sick or disabled; Paid work; Unemployed), with the reference group 'Retired'; ever unemployed and seeking work for a period more than three months (0 = No; 1 = Yes); and feeling about household's income, coded with 3 dummies (Living comfortably on present income; Difficult on present income; Very difficult on present income), using the reference group 'Coping on present income'. We also controlled for other continuous and ordinal variables on which we maintained the original coding. These included age; years of education completed; how often meet socially with friends, relatives or colleagues (from 1-Never to 7-Every Day); and, whether respondents take part in

social activities compared to others of the same age (from 1-Much less than most to 5-Much more than most).

## Data analysis

We performed a multilevel repeated cross-sectional analysis (Fairbrother 2014) within the structural equation modelling (SEM) framework, using Mplus 8.0. This procedure was based on a three-level model in which respondents were nested within country-waves and then in turn nested within countries. With this specification, we accounted for dependence due to the hierarchical structure of the data. Moreover, it was possible, at a higher level, to control for differences between countries by introducing a coefficient representing the mean of each country-level variable across all waves for each country. In addition, at an intermediate level, it allowed us to control for within-country changes by introducing a coefficient representing how much a country had changed in each wave relative to its mean value across waves. Therefore, we have two coefficients per country variable (i.e., GDP and social equality) by disaggregating each variable into a between-country coefficient (time-invariant, representing the mean of the 7 waves) and a within-country coefficient (time-variant, representing the change from the mean). We also included in our equation a linear effect of time (i.e., survey year), to account for time trends in our coefficients. Accounting for differences between countries and within-country changes, this method allows us to consider the evolving nature of the social context in which respondents were embedded. For these reasons, we were particularly interested in the withincountry change coefficient.

At the individual level, we coded all 'don't know', 'refuse to answer', and no responses as missing values. We used full information maximum-likelihood estimation with robust

standard errors (MLR), which allows estimation with missing data and produces less biased results than other methods (Little and Rubin 2019).

First, in three initial steps, we estimated: (1) a model without control variables, testing the association of both GDP and social equality with health and well-being (HWB); (2) a model introducing both individual and country-level controls; and (3) a model including personal assistance (PA) and the interaction between PA and, respectively, GDP and social equality variables.

Second, we used conditional process analysis (Hayes 2018) to understand the effect of PA on the relationship between social equality and HWB through specific socio-psychological mechanisms (indirect effect). We specified three separate models in which we introduced, respectively, public participation, satisfaction with the political and economic situation, and opinion about the health services as mediators. In all models, we considered equality as the independent variable, HWB as the outcome variable, and PA as a moderator. In these analyses, we expected equality to interact with PA to predict HWB indirectly through the respective mediators.

#### **Results**

For our initial analysis, the SEM multilevel model revealed a good fit as shown by the comparative fit index (CFI), root mean square error of approximation (RMSEA), and standardized root mean square residual (SRMR) indices (CFI = 0.99; RMSEA = 0.001; SRMR = 0.001). Comparisons between models revealed that the full model with interactions fitted the data better than the other models, since fit indicators (i.e., log-likelihood, Akaike information criterion, and Bayesian information criterion) and unexplained variance were lower in this case.

Results show that between-country Gross Domestic Product (GDP) was positively associated with health and well-Being (HWB) (b = 0.983; p < .001), but changes in within-country GDP were not associated with HWB (b = 0.071; p = 0.695). It seems that in countries with higher levels of GDP, disabled people have higher levels of HWB, but that a change in GDP does not have an impact on well-being. Conversely, between-country social equality was not associated with HWB (b = 0.003; p = 0.695), but changes in within-country social equality were positively associated with HWB (b = 0.021; p = .004), only when PA was included in the model.

The interaction effect between changes in social equality and PA was significant (b = 0.020; p = .002), indicating that the effect of social equality on HWB depends on the existence of PA in the country. In fact, changes in terms of increasing social equality had a positive effect on HWB only for countries with PA (b = 0.042; p = .001), whilst there was a null effect for countries without PA (b = 0.001; p = 0.897). This finding suggests that changes in terms of increasing social equality do not translate into better health for disabled people unless the country has national legislation on PA. However, the opposite is true, because decreases in social equality (or increased inequality) lead to poor health in countries with PA legislation. In the discussion we mentioned some possible causes and ways to overcome inequalities that may be directly related to PA.

As a robustness check, we replicated the same findings with an additional relevant country-level variable in the model: Social Protection Expenditure (% of GDP; Eurostat data), which includes social protection expenditure on disability and old age. In this additional analysis, both main and interaction effects remained statistically significant, while Social Protection Expenditure revealed no significant effects on our dependent variable

In a subsequent step of our analyses, we used conditional process analysis to test the effect of PA on the relationship between social equality and health via public participation, satisfaction with the political and economic situation and opinion about the health services. All three SEM multilevel models revealed a good fit to the data (CFI = 0.99; RMSEA = 0.001; SRMR = 0.001). Results showed significant positive interactions of social equality with PA on each of the mediators: public participation (b = 0.014; p = .012), satisfaction with the political and economic situation (b = 0.080; p = .027), and opinion about the health services (b = 0.066; p = .047). In turn, these mediators were positively associated with HWB (b = 0.787; p = .023; b = 0.122, p < .001; and b = 0.119, p < .001, respectively). Below, we tested the effect of social equality in HWB via the mediators (i.e., indirect effect) for each level of PA, the moderator (countries with versus countries without PA).

*Public participation*. Results revealed a marginally significant indirect effect of social equality on HWB via public participation for countries with PA (b = 0.016; p = .082), whilst countries without PA showed a null effect (b = -0.005; p = .364).

Satisfaction with the political and economic situation. There was a significant indirect effect of social equality on HWB via satisfaction with the political and economic situation for countries with PA (b = 0.014; p = .027). Conversely, the indirect effect was not significant for countries without PA (b = -0.006; p = .455).

Opinion about the health services. There was a marginal indirect effect of social equality on HWB via opinions about the health services for countries with PA (b = 0.012; p = .071). In contrast, for countries without PA, the indirect effect was not significant (b = -0.004; p = .538). The direct effect of social equality on HWB was significant only for countries with PA (b = 0.026; p = .025).

These findings indicate that an increase in social equality is associated with greater disabled people's public participation, satisfaction with the political and economic situation, and more positive impressions of the health services, only in countries with PA.

Significant total effects of social equality on HWB were found only for countries with PA. These include the direct and indirect effects via public participation (b = 0.039; p = .002), satisfaction with the political and economic situation (b = 0.039; p = .002), and opinion about the health services (b = 0.039; p = .003).

Other mediators considered in the literature on the socio-psychological mechanisms behind the link between equality and health were tested in this analysis: trust in others, trust in government, and collective action, for which we did not find any significant conditional effect. There were, however, some direct associations between PA and these variables. Results showed that PA has a positive association with disabled people's trust in others and collective action, which seems to indicate that in countries with PA legislation, disabled people trust more in others and get more involved in collective action activities.

#### **Discussion**

Past research has mainly treated disability as an individual and medical factor, disregarding the implications of the social environment for the well-being of this group.

Moreover, there is a lack of evidence to inform the ongoing debate about the association between personal assistance (PA) and equality. The aim of this study was to analyse the moderating role of PA in the association of country wealth and social equality with the health and well-being of disabled people. Results showed that an increase in Gross Domestic Product (GDP) was not associated with health and well-being in an analysis of 12 years of European data, controlling for relevant individual- and country-level variables. We found, however, that increasing social

equality was positively associated with health and well-being – an association that was only present in countries with PA. This association between equality and health is explained by increased public participation, higher satisfaction with the political and economic situation, and more positive impressions of health services. These findings are in accordance with previous research with the general population (Kawachi and Kennedy 1999; Wilkinson and Pickett 2006), but, in this study, we found that among disabled people this is only manifested in countries with PA legislation. Therefore, this finding confirms our hypothesis concerning the effect of social equality, but the same hypothesis was not confirmed for the effect of GDP.

Although within-country changes in GDP were not associated with well-being, we found that the average levels of GDP between countries, across the 12 years represented by the ESS data, were positively associated with the well-being of disabled people. As such, our findings may suggest that a short-term increase in GDP is not associated with an improvement in the well-being of disabled people, but sustained and higher levels of GDP may, in the long-term, translate into higher levels of well-being.

Moreover, we found an association between within-country changes in social equality and well-being, but a null association with between-country correlations. These findings may suggest that immediate changes in one's context, in terms of increasing social equality, may prove particularly effective for improving the quality of life of disabled people. These differences between within-country and between-country associations illustrate why it is critical to model this distinction in studies to better planning policy intervention.

Our results support the ideas formulated in the debate on the association between equality and PA (Anand et al. 2012; Clarke 2006; Gadsby 2013; Mladenov, Owens, and Cribb 2015). PA enables the positive outcomes of increasing social equality. It is, however, a linear relationship,

which means that an increase in inequality still has negative outcomes for disabled people in countries with PA. In contrast, social in/equality has no effects at all in countries without PA. This supports the hypothesis that PA is a crucial condition for disability equality but also underlines the concern that in contexts of increasing inequality, PA can promote social disparities. This is more evident when PA schemes have relevant constraints (e.g., lack of direct payments, decentralization of services, restrictions in the number of hours, restrictions based on age and type of impairment). Therefore, this study emphasises the importance of adopting a PA policy to promote disability equality, considering the relevance of overcoming the barriers in its implementation to prevent social disparities.

First, social disparities in access to PA services must be prevented. User-centred models can be less accessible for those in a more disadvantaged position and with fewer resources (e.g., racial and ethnic minorities) (Anand et al. 2012). Moreover, older people or people with mental or intellectual impairments may be excluded by frontline workers, based on bias and stereotypes about who is best suited to have more choice and control over their lives (Gadsby 2013).

Besides, these users experience more stress as a result of the administrative and bureaucratic requirements (Anand et al. 2012). Policy and services should guarantee that PA is equally available across age, gender, race and type of impairment, through proper legislation and funding at the national level that also safeguards equal access across the country (for more details about the centralisation of PA schemes, Barnes 2007; Brennan et al. 2017). PA funding by a state authority frees users from dependence on charities, reduces administrative work and vulnerability in case of disputes among funders, and increases users' control over their assistance and daily lives (Ratzka, 2004).

Second, policy and services should guarantee users' control and choice over the service. Research has shown that life satisfaction is positively associated with perceptions of greater choice and control over the service (Mattson-Prince 1997). On the contrary, obstacles to self-managed PA are associated with decreased life satisfaction and autonomy (Fleming-Castaldy 2011). More recently, a survey conducted among PA users in Europe showed that the opportunity to choose one's assistant and have control over the timing of the assistance are essential enablers of choice and control; and, conversely, restrictions over these aspects are among the greatest barriers to choice and control (Mladenov 2020). The best way to ensure users' control is through legislation that covers direct payments to disabled people (Glasby and Littlechild 2009; Stainton and Boyce 2004). The continuity of traditional and bureaucratic models of service delivery, based on paternalism, control and inflexibility, with a high-level management and lack of a restructuring of funding has been a central barrier to person-centered services (Dowling, Cowley, and Manthorpe 2006; Innes, Macpherson, and McCabe 2006; Prandini 2018).

Third, governments should guarantee an adequate amount of funding for PA. In fact, several problems related to PA funding have been reported – inadequate personal budgets, low number of assistance hours, failure to cover all expenses associated with PA, including user's training and peer support, and erosion of PA provision due to cuts (Mladenov 2020). An insufficient number of hours of PA results in unmet needs and adverse health consequences (LaPlante et al. 2004). On the other hand, 'independent living' and 'personal assistance' have often been appropriated and exploited by companies not controlled by disabled people, to serve the interests of capital through marketization and privatization of services (Clarke 2006; Mladenov, Owens, and Cribb 2015; Prandini 2018). Consequently, user-led organizations have

disappeared due to under-funding and limited resources, which places them in a seriously disadvantaged position in the competitive market (Barnes 2007). Therefore, among the costs that should be covered by the scheme are those related to peer-support, training and advocacy activities related to PA (Ratzka 2004).

Services, and social policies, should be designed, managed and delivered in coproduction with the users, for instance, through the inclusion of user-led non-governmental
organizations in that process (Howlett, Kekez, and Poocharoen 2017). Two principles should
shape people-centered legal processes, which are the participation in the decision process of all
parties that are affected by those decisions and the accountability of those who make and
implement the decisions (Grossman and Bradlow 1993).

Finally, governments should also facilitate the access to relevant data to improve research, and support advocacy and legislation. Governments should report on PA key indicators such as the number of users, hours provided, funds invested, number and wages of personal assistants, factors controlled by users (e.g., choice of PA, management of PA hours), type of administration (e.g., national vs. municipal), and type of payment (i.e. direct payments or indirect payments through public entity).

### Limitations and future directions

In this study, there isn't a detailed analysis at the individual level regarding the use of PA schemes and their characteristics, since this type of information is missing from these surveys and there is a lack of systematic information within and between countries. Therefore, despite finding an interaction between personal assistance and equality we can only rely on previous research to draw some conclusions on the characteristics of the PA schemes that can promote equality or inequality. Future research should test the effects of different PA schemes in a more

specialized longitudinal survey, which could help researchers make stronger comparisons between schemes. Moreover, no previous studies examined the relationship between PA and social inequalities, which limits the possibility of comparing our results with other studies. In addition, we used a question to select disabled people based on a functional approach, however, definitions of disability and disabled people may vary between studies, which can make comparisons difficult and complex. Nevertheless, this study contributes to the debate on the interaction between equality and personal assistance with evidence from representative samples in a Europe-wide context and hopes to motivate new studies in the future.

#### **Conclusion**

This study provides additional understanding of the influence of social factors on the well-being of disabled people, as well as on the importance of the adoption of personal assistance (PA) for the promotion of disability equality. Our findings indicate that social equality is associated with better health and well-being outcomes, but only in countries with PA legislation. Therefore, national governments need to enact PA legislation, following CRPD Article 9 and Independent Living Movement principles, to ensure that '[disabled people] have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community' (UN 2006, 14).

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## Notes

There are additional materials in the form of tables and figures that are available in the following

link: https://mfr.osf.io/render?url=https%3A%2F%2Fosf.io%2F56zy2%2Fdownload

## **Declaration of interest statement**

The authors report no conflicts of interest.

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