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DOI:

[10.1080/09687599.2020.1848802](https://doi.org/10.1080/09687599.2020.1848802)

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Document Version

Peer reviewed version

Citation for published version (Harvard):

Carmichael, F & Clarke, H 2020, 'Why work? Disability, family care and employment', *Disability & Society*.
<https://doi.org/10.1080/09687599.2020.1848802>

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Why work? Disability, family care and employment

Fiona Carmichael and Harriet Clarke

Abstract

This article seeks to examine the ways in which 'work' is a crucial domain within a holistic approach to understanding disability and family life. The research is based on the experiences of 49 people who either self-identified as disabled or were family members of a person with an impairment. The analysis focuses on the meaningfulness of work and argues that the meaning of work needs to be expanded in order to be more inclusive of disabled people. Issues of accessing and maintaining appropriate work and harmful work are also discussed. The research highlights the importance of work, both paid and unpaid, for disabled people and their families. However, the wrong kinds of work can have harmful consequences for disabled people and this needs to be acknowledged in policy focusing on access to work.

Key words: disability, caregiving, meaning of work, unpaid work

Points of interest:

- The study explores the experiences of paid work and non-involvement in paid work of disabled people and their families.
- The participants discussed the value of different kinds of work for disabled people
- The research highlights the importance of unpaid work for disabled people, including voluntary work and activism.
- Some participants faced constraints accessing and maintaining appropriate work and careers
- Some work and ways of working can be harmful to the health of disabled people

Disabled people and their families make significant contributions to society

Introduction

This article informs debates relating to the exclusion of disabled people from the labour market (Barnes and Mercer, 2005) in the context of work-centric policy and social

organisation. In these debates, the sociology and politics of diversity in work has the potential to provide a strong anchor in challenging disabling social policies by expanding the meaning of work and recognising and addressing the potential harms of work. There also needs to be greater recognition of the importance of work for disabled people (Saunders and Nedelec, 2013) and the disadvantages they face accessing and maintaining work (Berthoud, 2008; Fevre et al, 2013; Randle and Hardy, 2017).

This research contributes to this literature in four main ways. First, the focus is on the work and non-working experiences of disabled people and other family members with caring responsibilities. This addresses a 'problematic' dichotomy between work and non-work (Riach and Loretto, 2009) and enables a clearer understanding of relational interdependences in the lives of disabled people and their families (Watson et al. 2011).

Disabled people are also a doubly marginalised group, marginalised from the labour market (Bates et al., 2017:165) and in the diversity and work literature (Foster, 2018:187). Second the study contributes to a better understanding of the importance of work and its meaning for disabled people, how work can be core to their experience and the costs of giving up or being excluded from work (Borg and Kristiansen, 2008). Third, the findings suggest that the meaning of work needs to be expanded to include for example, voluntary work and activism which have particular salience for many disabled people who can face barriers accessing and maintaining traditional forms of work. Lastly, the research contributes by highlighting how some work can be harmful to the well-being of disabled people and may therefore be inappropriate. Our analysis concludes that access to work is important for disabled people and their families but, as highlighted by Shakespeare et. al (2016) not all kinds of work are appropriate or possible. The tension between valuing (an expanded definition of) work and

asserting that 'no/low work' lives can be meaningful and should be respected, remains a challenge.

Research and Policy Background

Jones and Wass (2013:983) calculate impairment and disability employment gaps by defining those who report a long-standing illness or impairment as impaired and those who report this as activity-limiting, at work and in day-to-day living, as disabled. With these definitions, 2019 (quarter 1) UK Labour Force Survey data indicate that 32.88% of the population aged 16-69 had a long term health condition and the impairment employment gap was 20.99 percentage points, 22.86 for men, 18.64 for women. The incidence of disability was 12.34% and the disability employment gap was 34.55 percentage points, 38.02 for men, 30.89 for women. This gap is higher, 39.37 percentage points, for the population aged 16-64. The Office of National Statistics (ONS) uses a broader definition of disability requiring that a long-standing illness or impairment only limits activities in day-to-day living. Using this definition the ONS (2019) estimates that the disability employment gap for 16-64 year olds fell from 32.3 to 28.6 percentage points between 2016 and 2019.

These figures suggest the downward trend in the disability employment gap reported in Jones and Wass (2013) has continued. The trend is consistent with a 2016 government commitment to halve the disability employment gap (Department for Work and Pensions, Department of Health, 2016) and policy initiatives in support of these aims (Hoque et al., 2014; Hoque, 2019). However, the current government has downgraded the 2016 commitment to a pledge simply to reduce the gap (Conservative and Unionist Party, 2019). While these figures provide us with a framework within which to make sense of the lived experience of work and non-work for disabled people, less attention has been given to the

possibility of inappropriate work and potential harms from work. Furthermore, these measures only capture participation in paid work, ignoring the potential of unpaid work to constitute meaningful productive activity. The socio/political or social model of disability (Oliver, 1990, 2013) places great emphasis on social, material and interpersonal barriers to participation (Roulstone & Prideaux, 2012) including discrimination, ignorance and employers' reluctance to accommodate workers' needs for appropriate adjustments (Berthoud, 2008, Barnes and Mercer, 2005; Scanlon et al., 2019; Shier et al., 2009). This is in contrast to some forms of the biopsychosocial approach to disability where the social element is weak and employment rates of disabled people may be attributed to biological and psychological factors. This resembles a medical approach (Berthoud, 2008) which can be critiqued as reductionist and overly responsabilising i.e. victim blaming (Shakespeare, Watson and Alghaib, 2017).

While the social model of disability is not without critics (Foster 2018:193) the move away from deficit theories of disability and work to the analysis of structural causes of disability employment gaps is constructive. As argued by Barnes (2012:472) the social model shifts attention to the "social organisation of mainstream employment and the meaning of work". However, Barnes (2012) and Barnes and Mercer (2005) point to lack of attention to the social forces that shape disabled people's lives. They lay some of the blame for this on absence of discussion of disability in classical sociological theories. Barnes and Mercer (2005:532) argued that this prominence is maintained in discourses that tie citizenship to economic agency, which still holds in contemporary social science.

Understanding and Expanding the Meaning of Work

Two linked themes in the literature on the meaning of work are drawn on in this article. One is the meaning of work in the sense of meaningful work that contributes to human flourishing (Veltman, 2015). The other relates to how the concept of work is defined in relation to the circumstances of disabled people (Barnes and Mercer, 2005).

Meaning and purpose attributed to work is linked to working identities and generative opportunity, the latter implying scope for pursuing a psychosocial task enabling growth and development (Hagler et al, 2016; McAdams and De St Aubin, 1992 building on Erikson, 1963). Although much of the discussion of the meaning of work for disabled people is centred in the health sciences and on mental health (Saunders and Nedele, 2014) "disability studies have always engaged with labour" (Bates et al. 2017:161). A recent study by Castañeda et al. (2019) finds evidence of how meaning is drawn from work by disabled people through positive effects in addition to income including increased self-efficacy and self-esteem, personal growth and a sense of community. Borg and Kristiansen (2008) have shown how work can be central in providing social status, self-confidence and a sense of belonging for people with long-term mental distress. The study by Bates et al. (2017:172) leads them to argue that work can be "a place where people with intellectual disabilities can craft identities". Borg and Kristiansen (2008:521) suggest that due to under investigation such findings appear to be "not so obvious, judging from many research and rehabilitation efforts"

However, restricting the meaning of the concept of work to waged labour is limiting for disabled people not only because of constraints to accessing appropriate work, particularly in the UK context of 'austerity' (Bates, et al. 2017) but also because not all people with "an

accredited impairment can or should be expected to enter the conventional labour market" (Barnes and Mercer, 2004: 535). Furthermore, disabled people who are not in paid employment are often involved in forms of unpaid work including volunteering, household work (including caring) and some take on the role of employers for paid personal carers (Barnes and Mercer, 2005; Borg and Kristiansen, 2008). Riach and Loretto (2009: 105) in their study of the older unemployed, of whom 41% were claiming disability benefits, theorise the construction of 'non-working working identities' arguing that traditional dichotomies of work and non-work "are problematic when it comes to conceptualizing activities as either paid work or non-paid activities". Riach and Loretto's evidence and the findings of this study support Barnes and Mercer's (2005) call for a reconfiguration of the concept of work that is inclusive towards disabled people. Such a reconfiguration needs to move beyond traditional definitions in parallel with feminist writings that delineate unpaid family care as work (Folbre, 2006). It can also build on Rembis's (2017) concern to build an analysis of domestic life and disability, in ways which recognise (disabled and non-disabled) people's productive contributions within their social networks. Yakas (2017:1) addresses these challenges in her work on clubhouses, defining work as "purposeful activity that builds community". She argues that both purpose (in part derived from work's structure) and a sense of community can be as much a feature of unpaid work as paid work.

Health and/or harm? Accessing the right kinds of work

Work is not unconditionally good for all people and some work or ways of working can be harmful to the health of disabled people. For example, Foster (2018: 193) notes that 'impairment effects', such as fatigue and pain are "everyday work experiences of many

disabled employees". Employees with impairments, particularly psychological disabilities are more likely to suffer ill-treatment at work which can impact negatively on well-being (Fevre et al., 2013). Work can therefore conflict with a disabled person's care of their own health and make it a sensible choice for disabled people not to work. This conflict is in addition to the time and effort needed by many disabled people in order to maintain their own health (Barnes and Mercer, 2005). In a more medicalising context, this type of self-care has been categorised as a type of 'patient' work (Corbin and Straus, 1988) which can involve family carers.

For some participants in Frayne's (2015) study these conflicts were stark and lead to 'resistance to work' as 'an act of self-preservation' since freedom from the demands and routines of paid work was perceived as essential to personal well-being. Frayne links this resistance to the requirement for self-care and a refusal to make 'the bodily sacrifices' for employment. Frayne (2015) argues that disabled people face these kinds of conflicts because they want to "feel proud and normal rather than ashamed, powerless and medically ill" and they may not be willing to tolerate pain in order to work (Frayne, 2015:46).

These arguments contrast with the prevailing consensus, critiqued in Riach and Loretto (2009:105) that not being in work has negative and unhealthy consequences and non-working identities are unfavourable and unfulfilling. This consensus is itself part of the explanation for policy focussed on getting people into paid work as the most effective way of addressing social exclusion. However, while exclusion from work may be linked to stagnation and loss of identity the potential harms from work bring this consensus into question.

These debates around the meaning of work and the potential harms of work for disabled people are brought together by Frayne (2019:6) when he argues that a focus on paid work leaves no room to ask "what happens to people who cannot work, how work should be defined, or whether there might be other competing ideas of health, virtue and the good life" and "how we should value people whose efforts and contributions take place outside the market economy". The research reported in this article represents an attempt to respond to these critical questions.

Methods

Participants were recruited from families where at least one member had recently been eligible for or had applied for Disability Living Allowance, Employment Support Allowance or Personal Independence Payment. Using the receipt of disability benefits and/or experiences applying for these benefits as criteria for participation in the research ensured that participants self-identified or identified another family member as having a disability. Up to two family members in a family unit were interviewed: the disabled family member who had made the claim and/or another family member who identified as their 'main' carer. Where only family carers were interviewed, the disabled person was their child and either under 18, unavailable or chose not to be interviewed.

The sample were recruited using different methods including a project website, contacts with disability and carer support groups, social media including Twitter, contacts with training programmes and snowballing. In total 49 individuals were recruited to the project. The sample size is in line with Saunders and Townsend (2016) who recommend a sample of

around 50 when participants are selected from different groups. Semi-structured interviews were conducted with 41 individuals and eight individuals participated in a focus group. Twelve sample members participated as paired family dyads, a disabled person and another family member identifying as caring. 25 other participants identified as a disabled person, nine of whom also identified as carers. Twelve participants identified as parent carers.

A wide range of physical and mental health impairments and neurodiversity are represented. Family caring roles included care for adult, adolescent and young children, grandchildren, spouses and parents. All participants are adults, the youngest is 18 and the oldest over 70. Thirty-five are female. 15 participants were in paid work although most was part-time and/or irregular. One participant ran her own business and employed a team of domestic and support workers. Nine participants undertook unpaid voluntary work including activism. (For further details on individual sample members see [REDACTED]).

The interviews were conducted either face-to-face at a location of the participant's choosing, by phone or videoconferencing (according to individual preference). The focus group was conducted with members of a swimming group at a location where they had met for lunch. A semi-structured approach was used to encourage participants to talk openly about how their lives and those of other family members were impacted by disability and caring responsibilities. The use of different methods of recruitment and data gathering methods enriched the data by enabling us to achieve diversity as well as representation from different locations in England, Wales and Scotland. People were particularly forthcoming in telephone interviews possibly because the physical separation of the interviewer and interviewee provided anonymity making it easier to discuss sensitive topics

(Vogl, 2013). Informed consent was given by participants. Transcriptions were verbatim. Pseudonyms are used and identifiable data anonymised. Ethical approval was granted by the [REDACTED] Ethical Review Committee (ERN_14-0978).

The analysis of the transcripts used a staged, inductive approach focussing on themes evidenced through a staged ordering of the data (Gioia *et al.*, 2012). In the first stage multiple open codes were allocated to individual-level concepts, then similar codes were grouped into conceptual, first-order categories. The third stage grouped the categories into descriptive, second order themes. In the final stage of the analysis, four overarching dimensions were identified. At each stage, the coding and constructs were cross-checked between the researchers. Different interpretations were reconciled through discussion and reconstruction of the data. QSR International's NVivo 11 software was used to support these processes.

Findings

The participants talked about different ways in which their disability and/or family caring interacted with work. The main themes identified were: the meaning of work; expanding the meaning of work; accessing and maintaining appropriate work; and harmful work. The first draws together ideas relating to how work can be core to people's experience and the implied costs of giving up or being excluded from work. The second broadens the concept of work to include voluntary work, activism and caring. The third theme emphasises constraints on working and type of work due to disability, health condition and caring. The last theme highlights harms to health linked to working or the wrong kind of work. These

themes suggest a deeper and broader perspective on disability and work by integrating individual, family and social contexts.

The meaning of work

The participants talked about the intrinsic value of work in term of enjoyment and satisfaction, how work could be a 'lifeline', an escape from isolation, a confidence booster and provide structure and social support. Work could also provide a social contribution and was a source of financial security and independence. Although low wages could counteract these benefits, the costs of giving up or being excluded from work could be high.

The intrinsic value of work

Work can be very satisfying and add meaning to lives and participants appreciated the opportunity to work, for Kattia, who works in performing arts, it was core to her life experience: *I love doing what I do so much. I'm so, so lucky.* Claire has been working for the last seven years on a part-time basis for a disability organisation and says: *I enjoy the work, I enjoy the people.* Simon who is in his 60s, derives 'self-respect' and a lot of satisfaction from his voluntary work. Some disabled people, like Lisa, who have successful careers feel fortunate: *I work in a very well paid job and I've been very fortunate in my professional career.*

Being at work can help people by giving them back their confidence as was the case for James. He works in student admissions for a social work programme and says: *It boosts your confidence, that I'm getting my confidence back up again.* Similarly, Zoe told us how after

being diagnosed with a degenerative condition working abroad had really given her confidence and represented a turning point in her life.

Work can give structure to people's lives, keep them busy and active and has an important social element, providing social support and addressing feelings of isolation. For Bill, work can act as a '*lifeline*', he works in an arts centre and says: *The structure's very important so... and, you know, I have good friends at work.. It's... you know, I'd be lost without... I don't think I'd get out of bed to be quite honest with you if I didn't do that.* As argued by Yakas (2017), work does not have to be paid to fulfil this role. Simon used to be an engineer but had been '*out of the system quite a lot*' and was '*quite isolated*' but his voluntary work has changed his situation.

Karen says she cannot work and says '*I miss it, I miss all the social contact*' adding: *it's very isolating.* Exclusion from work was also an issue for parent carers. Elsie gave up work to look after her son, Alfie, because she '*wasn't going to get childcare*'. She says this '*was difficult, yes, for a lot of years. Financially it was difficult and I was very, very lonely.*'

Work as a social contribution

Supporting disabled people into work and ensuring they are not excluded is a way of enabling them to contribute to society (Scanlon et al., 2019). This was important for Lisa: *to do my work, to be a productive member of society, to pay in to society through my taxes and all the rest of it.* Helping other people with disabilities in her work as a young ambassador is also important for Amita: *I love taking part in projects and just making things better for people with disabilities.* Kattia makes a related point: *if people are supported to have what*

they need, they can contribute more to the community that they live in, you know, they can go to work. Participation in this research was also mentioned as a type of work that was helping others and a reason for participating. Stuart said he would answer what might be difficult questions *'If it'll help somebody else.'*

Work, financial security and independence

Income from work can provide financial security and support independence in the face of the extra costs of disability, if it pays enough. Shabina's income from her work as a self-employed consultant helps to cover the everyday costs of living with a disability e.g. *'electricity and gas'* and she uses her state benefits for extras. Zoe sees herself as fortunate because she works full-time and is therefore less dependent on disability benefits: *I'm in a fortunate position, I work. If I did lose it, it would be a financial hit, but it wouldn't be a lifestyle deal breaker.*

Low pay and precarity can reduce the financial benefits from work, but for some the intrinsic, non-pecuniary benefits are more important. Kattia says: *My friends always say to me, "I don't know how you survive on that money"* but the financial rewards are of less importance than the satisfaction work gives her: *I survive because everything else isn't really important.* She says she *'can get by'* with less food or delay paying her rent *"for a bit longer until the next job comes"*.

Expanding the meaning of work

Participants were involved in different kinds of unpaid activities, including voluntary work and activism, which were perceived as work. Voluntary work was often linked to disability or

caring and carers talked about their caring responsibilities in terms of unpaid work; as Ivan says *'looking after somebody 24/7 is a difficult job'*.

Importance of voluntary work

Voluntary work can play a significant role in the lives of people with a health condition or disability who cannot find suitable paid work. Simon's voluntary work includes working with a Food Bank and is very important to him, it fills a *'vacuum'* in his life: *And that's been my salvation.....That's why I do it, that's the reason I do it. It's not altruism, it's for me as well.*

Mirroring the reporting of disabled employees in Castañeda et al. (2019) Simon says his work gives him *'self-esteem'*. Similarly, Joe talks about how he benefits from his work for a mental health trust *'helping other people with mental health, who were socially isolated'*. He says *'the great thing was that, although it wasn't about me, it was also good for me'* that it was good for his development and *'social inclusion'*, that he was *'doing something meaningful'* and *'just the loveliness of sharing someone else's hobby'*.

Participants who had caring responsibilities were also involved in voluntary work that was often an extension to their caring role. Hannah assists in a day centre and helps out for a carers' organisation although she is clear that her voluntary work needs to fit around Stuart's support needs: *When he's okay, I can do stuff; when he's not, I can't.* Hannah's voluntary work is very important to her: *I couldn't sit at home all day. You need to be around people, you know.*

Activism as a productive contribution

Some participants were or would like to be involved in activities that could be considered as activism on behalf of disabled people or other groups or campaigns. Alanna who has a degenerative condition, says she is a '*bedroom activist*' and thinks of her activism as a kind of work for example: *getting the death stats published on people that committed suicide not long after having their benefits stopped*. Sally is 22 and says she would like to work as an advocate for other people's rights in the future: *that's the plan. I want to become an advocate. I want to fight for people's right[s]*.

Being involved in this kind of activism can also become important for other family members. Elsa advises in medical research projects as a carer representative. Elsie is engaged in both paid and voluntary work as a parent carer representative and in education for social workers, teachers and speech and language therapists. She has chaired a local Parent Carer Forum and writes for their magazine. She expresses surprise that she has now become so actively involved in disability related issues: *I would never, in a trillion years, have expected for things to have panned out this way*. She explains that when Alfie was born '*it was the world's deepest learning curve from day one onwards. But through him, I have got a new career*'. For Elsie there are costs and benefits of working in a disability domain: '*it's difficult because if you're living with it, you're also working with itBut, you know, it's been interesting*'.

Accessing and maintaining appropriate work

For some disabled people, choices about whether or not to work or what type of work to do are constrained. The reach of these constraints can also spillover into the lives of other

family members.

Impossibility or difficulty of work

Participants talked a lot about the challenges of seeking and remaining in work for themselves or the person they cared for. Some found it impossible to work. Karen had to give up work she enjoyed because of her health condition: *I had to give up any form of work and I haven't been able to sustain any kind of voluntary work either, because my health is so unpredictable.* Wendy says about her son Michael who has a neurological condition that '*He can't do a job*' and she finds it laughable that Job Centre officials expect him to work: *what sort of job would somebody like {Michael} do? He'd have to have three care workers with him all day.* She adds: *so it would be a bit of a false economy, wouldn't it?*

Some conditions may make it very difficult for people to sustain employment. Laura had always worked prior to having mental health difficulties. She now finds going out and being on her own at home difficult and no longer works although she says she wants to. Sally worked for 2 years in a research company before having to stop work about a year ago because of her health: *I wasn't managing at all. It came to April and it was my birthday. I was 21 and I was like, "I can't do this. It's making me worse."* The medication that people need to take may make it difficult for people to sustain employment as noted by Joe who says the '*downside*' of his medication is '*the side effects*' that make him feel '*emotionally blunt*'. Simon feels that he would not be able to take on paid work and worries about this: *I know I'm not ready for work, that's a fact. I know that in my own head. I'll either lose my temper or I'd walk out, you know I just can't.* Sally '*really want[s] to go back to work*' but says '*I need to wait for the flashbacks to give up a little bit and be able to get out by myself*'.

As highlighted by Shier et al. (2009) employers could do more to support disabled people into and in work. Sally is concerned that employers would not accommodate her needs and thinks that few employers *'are going to let me have someone sitting by me 24/7'*, perhaps worrying that this kind of support could stigmatize her (Mik-Mayer, 2016) by labelling her as someone with a disability (Scanlon et al., 2019; Shier et al., 2009).

Some participants really wanted to work and managed to do so but it had been difficult. Kattia's struggle to find work in mainstream performing arts is consistent with Randle and Hardy's (2017) finding that disabled people are 'doubly disabled' in the creative industries. As Kattia explains: *I tried working in normal arts but they don't understand that you work differently*. Some participants had tried working but given it up because the experience had been negative, in Pat's son John's case because: *people grow upset with him*. Over time, people's struggles to maintain employment can lead to chequered and precarious work histories as explained by Elsa talking about her son Daniel and his mental health difficulties: *his life was becoming disarrayed, he became a motorbike courier and all sorts of odd things and, again, got treated for depression*.

The onset of disability can disrupt career trajectories (Scanlon, et al., 2019:9) as was the case for Zoe: *I took that as a sign not to do medical reping anymore*. In her new career her condition has not been an issue: *at my interview it was just... it was a non... it was, "Okay, you've got it, thanks for letting us know. We know all about it, we're medics anyway"*. Zoe feels that informing her employer is the key to managing her condition at work, for the moment she says *'It's all manageable'*. Alanna was less fortunate, her debilitating condition ended her career as a self-employed veterinary nurse, in part due to the unpredictability of

her condition. She tried to keep going in a volunteer role but it was became too challenging, she *'kept having to phone up and cancel on them and that really puts them in the mire when that happens, so I had to stop doing that'*.

Educational hurdles

Disability in childhood can affect educational attainment and type of education (Scanlon et al., 2019) which can constrain opportunities for work. Joe said his mental health condition challenged him while at school: *I sort of messed up in the sixth form, because of the illness.* Asif was diagnosed with Schizophrenia while at university and did not finish his course and has not worked since. Kattia was studying for a BTEC and applying for drama school when she suffered an aneurysm and was not able to continue her chosen course. Amita left college two years ago and explains that it was not possible for her to complete her studies, she has a physical impairment and says she was not given enough time in exams: *I failed my exams because obviously, my hand coordination isn't that good.*

The challenges of education in childhood were also highlighted by participants with disabled children. Jenni says that her son is *'really, really bright'* but he *'struggles with like holding a pencil and stuff like that. So his writing looks like a spider has run across the page'* and she says teachers give him poor marks because they have difficulty reading his work. Lesley talks about *'continually having to fight'* for her son to receive the support he needs in school. Sarah worried about her son's future, she says he, Michael: *can't make eye contact or smile or answer questions under pressure, so how's he going to get a job?* However, Michael wants to go to University and tells Sarah: *"To get the best job I've got to have a degree, mum"* but Sarah thinks this will be difficult as she believe there is *'no way he can live away*

from home'. For some parent carers like Penny and Emma their child's opportunities for employment were of less concern than their ability to live independently and securely in adulthood, to have *'a life of their own'*. As Emma says: *I have to try and help him to be independent because one day I won't be around.*

Disincentive effects of the benefit system

Rules around accessing disability benefits can have perverse 'iatrogenic' effects (Clarke et al., 2019) that discourage disabled people from both paid work and voluntary work, particularly when work is inherently irregular. For Kattia claiming benefits was a *'nightmare'* because she works freelance sometimes going *'months and months and months without any work'*. If she earns enough to stop claiming benefits when her contract ends she has to re-register for benefits and this means another assessment. Sometimes the complexity of benefit rules can make it difficult to manage work and benefits. Amita was unclear about her eligibility for benefits. She thinks the company who manage her work *'make sure they only give you one or two things a month, so then it doesn't affect, because obviously I can't get paid too much'*. Daniel, who has worked intermittently in the past, says he cannot consider working at the moment because he is too worried about losing his entitlement to benefits if he gives up a job because it impacts on his health. Kattia said about some changes to 'Motability' rules that these could *'take your car away but that would be stupid'* as this kind of change could deter her from working.

If work is low paid it can create financial risks that people are protected from when they are on state benefits. Jane has some help paying her mortgage because she is eligible for benefits but worries that if she worked she would lose her home. At the same time she says

she really needs to work as: *I'm also responsible for any repairs, any issues with the house, I've got to try and find that money.*

Constraints on other family members

There is considerable evidence that caring for another family member can constrain employment (Van Houtven et al., 2019). This was an issue for the nine disabled participants who were also providing family care, carers interviewed in dyads and parent carers and.

Time constraints, impracticalities of combining paid work and care, benefit rules and lack of (affordable) support can constrain the type of paid work that can be accessed and some felt they had little choice but to give up work. Elena says her opportunities for work are limited because someone usually needs to be with her daughter, Jessica, if left on her own '*she gets depressed*'. Jenni says that her caring role for her son is essential to his well-being making it difficult for her to consider working: *there's nothing that we could buy that could make up for me picking him up from school because that's what he needs.* Lesley gave up her career to care for her son Kyle who is autistic because of the costs of childcare: *It would just have cost so much than anything I could've earned.*

Finding a job that fits in with family responsibilities can be difficult. Jenni says: *Everything is like full time. You can't, you have to be flexible with your hours.* While Penny managed to work while her son, Jon, was in school she gave up teaching when he reached adulthood because she could not '*take care of Jon and get his future sorted at the same time, it wasn't possible*'. However, some parent carers like Sarah found work that fitted in with their family caring responsibilities: *I work at a breakfast club in the junior school just opposite.*

Conflicts between work and care needs

When one family member gives up work because of an impairment or to care for another this can create financial insecurity impacting on the well-being of all family members.

Family carers in particular have to make decisions weighing up income from work against the care needs of others. Hannah, Ivan and Jim all gave up work to care for their partners and this meant there was no one in their households in paid work. For Ivan this meant he and Pauline *'just had to struggle from that moment onwards'*. Jim is feeling financial pressures from not working and is: *just hoping as she [Laura] gets a bit more better and that, that I'll be able to go out to work*. Emma talks about the longer term effects of not working and says *'it effects the whole future life chances and my quality of life when I'm retired, everything'*.

However, financial considerations can appear secondary when weighed against the needs of another family member and sometimes the well-being of the family carer. Ellie is a single parent feeling pressure to go back to work as her son, Alfie, is *'wanting new things and posher things'*, but if she went back to work this would mean Alfie would have to go to *'after school clubs or holiday clubs and things. And I don't think he could handle it'*. Mrs Crawford, who has multiple health impairments, stopped nursing to care for her husband when he developed a slowly progressing condition, her double day combining paid work and unpaid care simply became unsustainable: *the only time it seemed as though I had a bit of peace was coming home on the bus*.

Harmful work

Welfare policy focuses on moving people into work in order to address poverty. However, work is not always good for disabled people; work or the wrong kind of work can impact negatively on their health and that of other family members.

Difficulties managing work and health

Work health balance can require a strong focus on health care for people who already have a disability or health condition. As Joe explains, looking after his own health while working requires self-management: *mental health conditions, chronic ones, can be quite fatiguing physically, as well as mentally and a lot of it is time management, of looking after yourself, of not doing too little and not doing too much.*

Health conditions can change and may conflict with people's wishes to stay in work. This was true for Jane when her health deteriorated, *'to a stage where I actually had to leave'* but she wanted to *'get back to work'*. When Alanna first became ill she had managed to complete the work she needed to do to maintain her professional qualifications; *I did that and was really proud of myself that I'd got through that.* However, this work had been intensive and conflicted with her own self-care: *immediately afterwards, got hit by shingles. And again, it was just because I'd allowed myself... I'd overdone it, I'd weakened my immune system too far and left myself susceptible.* She describes pushing herself beyond her body's capabilities and when she stopped it was as if she had *'hit the floor'*. She ended up in *'in excruciating amounts of pain'* and says she was *'a complete wreck'*. She had stopped work six years ago.

Types of work and work pressures

Some types of work and ways of working may conflict with a disabled persons self-care.

Kattia has *'to think very carefully'* about what she can do so she does not *'mess my body up even further'*. She says *'I can't really work on a cash point because this is my only hand'* and she could not take a typing job because *'I've already got carpal tunnel'*. She says that Job Centre officials have no understanding of these longer term conflicts with the work of self-maintaining her own health and try to pressure her into taking on unsuitable work: *you want me to go home and continue my life, it's just not possible.*

Stuart thinks the flexibility of his work in insurance sales may have been a reason why his mental health condition remained undiagnosed for so long, that his condition might have *'been picked up earlier'* in a different job: *I went missing for a couple of days, they didn't mind as long as I hit my target.* His condition *'suited the life'*: *When I was on a high, I was doing incredibly well. In one of those high episodes, I was always very productive for what I was doing.* However, in line with the evidence of Pagán (2009) which shows higher rates of self-employment among disabled people, Shabina says that being self-employed is helpful because she *'can pick and choose'* the hours she works and this means she can take better care of her health: *it makes me spread it out to take care of my health properly as well. I'm not sort of cramming everything in.*

Pauline draws a link between her son's mental ill-health and his work: *[Ian] has been diagnosed with manic depression these past three years and he was in a very good job but the pressure of it was too much.* Karen alerted us to the possibility that participation in research related work can be detrimental to people's health; while she was participating in another study she had to tell a researcher that the interviewing was just too tiring for her.

Caring and ill-health

There was discussion of the well-evidenced health and well-being impacts of family caring (Vlachantoni et al, 2016). Jane seems to attribute some of the blame for her own health condition on the pressures of caring for two children with disabilities, she thinks that carers put their own health '*on the backburner*' prioritising the needs of those they are helping: *your trial is looking after your loved ones, trying to go to work, trying to do everything else you have to do and then you end up ill*. Jane's own health problems also make it harder for her to help her daughter: *when I was feeling better, I was able to take more care of my daughter as well, and that's not always possible now*. Elsa explains how the mental pressure her husband put her under when he suffered from a mental health condition left her unable to talk to men and meant she gave up her voluntary work: *All this underneath, you know, used to follow me, I had to stop*.

Discussion

The findings of this research have brought to the fore the importance of expanding the meaning of work in ways which encourage and aid understanding of the experience of disabled people in paid and unpaid work. By referencing meanings other than economic value the research has enabled us to consider how people experience low value work, including precarious, low paid, voluntary and unpaid work. This intention recognises that the social organisation of under-valued work (paid and unpaid, and including caring) is closely intertwined with the marginalisation of many disabled people. As such, these kinds of work raise an imperative to consider justice based arguments for supporting and valuing interdependent lives both in the public and domestic domains (Kittay, 2011).

The participants also talked about the harms associated with some kinds of work and the difficulties they faced accessing work. That some of these difficulties also impacted other family members and that some disabled participants were also family carers, underlines the importance of recognising relational interdependences in the lives of disabled people. A similar point is made by Rembis (2017:3) in highlighting the significant contribution made by disabled people and their families to social and communal networks.

The non-financial benefits of work that give work meaning derive from the potential to contribute to 'self-worth and self-development' through for example, a sense of fulfilment, self-respect and pride (Veltman, 2015:4) as well providing structure and social support. Such benefits accrue to unpaid voluntary work, activism and caring, including self-care (Borg and Kristiansen, 2008) as well as to paid work (Yakas, 2017). Ignoring the non-pecuniary private and external benefits from these different kinds of work can skew policy towards encouraging disabled people and carers into full-time, permanent paid work at the expense of their participation in irregular, low paid and voluntary work. This is problematic as opportunities for work for disabled people are often constrained (Shier et al., 2009) and some kinds of work and ways of working are harmful to their health and conflict with their own self-care. However, there is tension here in that by increasing recognition of the narrative value of work in people's lives we may unintentionally appear to excuse exploitative practices. Challengingly, and as highlighted in the US context by Yakas (2017) these may be more likely in areas where disabled people access work for example, in designated disability areas, as employers of lowly paid carers and in unpaid work. As argued

by Bates et al. (2017:173) work can exploit as well as be debilitating and we should "treat work with caution."

In the UK, the focus on paid work in disability policy is transparent in the government's pledge to reduce the disability employment gap. However, some of the policy initiatives introduced in support of these aims have had perverse effects. For example, Beatty and Fothergill (2015) argue that the introduction of the Work Capability Assessment has diverted "substantial numbers" of people with ill health or disability into "unemployment, onto other benefits, or out of the benefits system altogether" predicting that: "'Hidden sickness' will increase; 'recorded sickness' on disability benefits will decline." (Beatty and Fothergill, 2015:175). This is arguably one way of closing disability employment gaps but the approach is not one that looks to be in the best interests of disabled people.

This research has highlighted the intrinsic value of different kinds of work for disabled people as well as the potential harms, however the findings represent the views of the sample and are not generalisable. In addition, the recruitment purposefully targeted people who had made a claim for disability benefits in order to sample people who identified as disabled. However, disability social security rules cannot be assumed to provide an inclusive boundary for a construct of 'disabled people' (Roulstone, 2015). Beatty and Fothergill (2015) highlight that many people who might previously have self-identified as disabled through the receipt of disability benefit may no longer do so and as such would have been excluded from this research. Disabled people may also be deterred from applying benefits for other reasons including fear of stigmatisation, the sheer complexity of the processes involved and lack of information about entitlement (Clarke et al. 2019, Hui et al., 2018; Garthwaite, 2011,

2014). The research will therefore have excluded people for a range of reasons including those in employment who are getting by without financial support. Future research would therefore benefit from targeting disabled people in work including those in vulnerable social and economic situations (Hui et al., 2018).

However disability is constructed, for example through social policy and the application of that policy by employers, there needs to be clearer understanding of how the organisation of paid and unpaid labour intersects to produce different experiences of disability marginalisation. The 'problematic' dichotomy between paid and unpaid work (Riach and Lorreto, 2009) masks another artificial divide between work as economic production or social reproduction. In this divide, unpaid family and self-care, household work, creative and knowledge sharing based activities (including activism) and voluntary work are traditionally designated to the latter and accorded lower value. In a world in which the valorisation of paid work is mirrored in welfare policy, future research in employment studies needs to build on work that has engaged with the value, meaning and identity of unpaid, often caring work (Braunstein et al., 2011; Folbre, 2006) and not-working or resisting work (e.g. Frayne, 2015; Riach and Loretto, 2009).

Conclusion

Access to work is important for disabled people but as highlighted by Shakespeare et. al (2016:36) "Society must accept that work is not always appropriate or possible, and that for many disabled people humane and supportive alternatives to work are needed."

Furthermore, generative opportunity (McAdams and De St Aubin, 1992; Hagler et al, 2016).) needs to be held at least as (if not more) central than economic productivity for human

well-being. These arguments suggest a need for significant socio-economic and cultural change supported by policy that prioritises an alternative approach to work and disability. Stronger integration of disability analysis in work and employment focused studies could also help to foment a commitment in work politics to countering the harms of disability marginalisation.

Emphasising relational interdependencies draws attention to how disabled people and those in their networks may not be *uniquely* socially located as either disabled people or carers, but can (at the same or different points in their lives) experience both. It is therefore vital to focus on what is shared, the 'common agenda' (Parker and Clarke, 2002), rather than risk contributing to what Chang (2017) posits as 'divide and conquer'. This requires research to challenge divides between paid and unpaid work, disabled people and non-disabled people, paid carers and non-paid carers. As such, this research aims to support policy research and practice that bridges divides rather than enabling them.

References

- Bates, K., Goodley, D. & Runswick-Cole, K. (2017) Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity, *Disability & Society*, 32(2):160-175
- Barnes, C. (2012) Re-thinking Disability, Work and Welfare, *Compas* 6(6):472-484.
- Barnes, C., & Mercer, G. (2005) Disability, Work and Welfare: Challenging the Social Exclusion of Disabled People. *Work, Employment & Society* 19(3):527–45.

- Beatty, C. & Fothergill, S. (2015) Disability Benefits in an Age of Austerity. *Social Policy & Administration*, 49:161-181.
- Berthoud, R. (2008) Disability Employment Penalties in Britain. *Work, Employment & Society*, 22(1):129–48
- Borg, M. & Kristiansen, K (2008) Working on the edge: the meaning of work for people recovering from severe mental distress in Norway, *Disability & Society*, 23(5):511-523.
- Braunstein, E., Van Staveren, I. & Tavani D. (2011) Embedding Care and Unpaid Work in Macroeconomic Modeling: A Structuralist Approach, *Feminist Economics*, 17(4):5-31
- Castañeda, E., Chiappetta, C., Guerrero L. & Hernandez, A. (2019) Empowerment through work: the cases of disabled individuals Laura and low-skilled women workers on the US–Mexican border, *Disability & Society*, 34(3):384-406
- Chang, G. (2017) Inevitable Intersections: Care, Work, and Citizenship, chapter 7 (pp 163-194) in Michael Rembis (ed) (2017) *Disabling Domesticity* New York: Palgrave Macmillan.
- Clarke, H., Carmichael, F. & Al-Janabi, H. (2019). Adverse Effects of Social Security on Disabled People and Their Families in the UK: Iatrogenic Outcomes of Quasi-Clinical Administration. *Scandinavian Journal of Disability Research*, 21(1), pp. 218–227.
- Conservative and Unionist Party (2019) The Conservative and Unionist Party Manifesto 2019 https://assets-global.website-files.com/5da42e2cae7ebd3f8bde353c/5dda924905da587992a064ba_Conservative%202019%20Manifesto.pdf
- Corbin, J. And Strauss, A.L. (1988) *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco, CA: Jossey-Bass Publishers

- Department For Work & Pensions & Department Of Health (2016) Improving lives, The work, health and disability Green Paper, Cm 9342
- https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/564038/work-and-health-green-paper-improving-lives.pdf
- Erikson, E. (1963) *Childhood and Society* (2nd Ed) New York: Norton.
- Fevre, R., Robinson, A., Lewis, D. & Jones, D. (2013) The ill-treatment of employees with disabilities in British workplaces, *Work, Employment & Society*, 27(2):288-307
- Folbre, N. (2006) Measuring Care: Gender, Empowerment, and the Care Economy. *Journal of Human Development*, 7(2):183–99.
- Foster, D. (2018) The Health and Well-Being at Work Agenda: Good News for (Disabled) Workers or Just a Capital Idea? *Work, Employment & Society*, 32(1):186-97
- Frayne, D. (2015) *The refusal of work: the theory and practice of resistance to work*. London: Zed Books.
- Frayne, D. (2019) Introduction - Putting Therapy To Work, in Frayne, D. (Ed.) *The Work Cure: Critical Essays on Work and Wellness*, Monmouth: PCCS Books
- Garthwaite, Kayleigh. 2011. The Language of Shirkers and Scroungers? Talking About Illness, Disability and Coalition Welfare Reform. *Disability & Society*, 26:369–372.
- Garthwaite, Kayleigh. 2014. Fear of the Brown Envelope: Exploring Welfare Reform with Long-term Sickness Benefits Recipients. *Social Policy and Administration*, 48(7):782–798.
- Gioia, D. A., Corley, K. G. And Hamilton, A. L. (2012) Seeking qualitative rigor in inductive research: Notes on the Gioia methodology, *Organizational Research Methods*, 16(1):15-31

- Hagler, M., Hamby, S., Grych, J. & Banyard, V. (2016) Working for Well-Being: Uncovering the Protective Benefits of Work Through Mixed Methods Analysis, *Journal of Happiness Studies*, 17:1493-1510.
- Hoque, K., Bacon, K. And D. Parr. (2014). Employer Disability Practice in Britain: Assessing the Impact of the Positive about Disabled People 'Two Ticks' Symbol." *Work, Employment & Society* 28 (3):430–51.
- Hoque, K. (2019) How can we close the disability employment gap? CORE Magazine, Warwick Business School, University of Warwick, <https://www.wbs.ac.uk/news/how-can-we-close-the-disability-employment-gap/>
- Hui, F., Cortese, C., Nikidehaghani, M., Chapple, S. & McCombie, K. (2018). Hard to Reach: Examining the National Disability Insurance Scheme Experience - A Case Study in Wollongong. Australia, Faculty of Business Papers, 1523 University of Wollongong, <https://ro.uow.edu.au/buspapers/1523/>
- Jones, M. & Wass, V. (2013) Understanding changing disability-related employment gaps in Britain 1998–2011. *Work, Employment & Society*, 27(6):982-1003
- Kittay, E. (2011) The ethics of care, dependence and disability, *Ratio Juris* 24 (1), 49-58.
- McAdams, D.P. & De St Aubin, E. 1992. A theory of generativity and its assessment through self-report, behavioral acts and narrative themes in autobiography, *Journal of Personality and Social Psychology*, 62(6):1003.
- Mik-Meyer, N. (2016) Disability and 'care': Managers, employees and colleagues with impairments negotiating the social order of disability, *Work Employment Society*, 30(6):984-999
- Oliver, M. (1990) *The Politics of Disablement*. Basingstoke: Macmillan.

- Oliver, M. (2013) The Social Model of Disability: Thirty Years on. *Disability & Society* 28 (7): 1024–1026.
- Office Of National Statistics (2019) Disability and employment, UK: 2019, Statistical Bulletin, <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilityandemploymentuk/2019#disability-and-employment-data>
- Parker, G. & Clarke, H. (2002) Making the ends meet: do carers and disabled people have a common agenda? *Policy & Politics*, 30: 3, 347-359
- Rembis, M. (2017) Introduction Chapter 1 (pp 1- 23) in Michael Rembis (ed) (2017) *Disabling Domesticity* New York: Palgrave Macmillan.
- Ricardo Pagán (2009) Self-employment among people with disabilities: evidence for Europe, *Disability & Society*, 24:2, 217-229
- Randle, K. & Hardy, K. (2017) Macho, mobile and resilient? How workers with impairments are doubly disabled in project-based film and television work, *Work Employment and Society*, 31(3):447-464
- Riach, K. & Loretto, W. (2009) Identify work and the ‘unemployed’ worker: age, disability and the lived experience of the older unemployed, *Work, Employment & Society*, 23(1):102-19
- Roulstone, A. & Prideaux, S. (2012). *Understanding Disability Policy*. Bristol: The Policy Press.
- Roulstone, A. (2015) Personal Independence Payments, welfare reform, and the shrinking disability category, *Disability & Society* 30(5): 673-688.
- Saunders, S.L. & Nedelec, B. (2014) What Work Means to People with Work Disability: A Scoping Review, *Journal of Occupational Rehabilitation*, 24(1):100-110.

- Saunders, M. N.K. & Townsend, K. (2016) Reporting and Justifying the Number of Interview Participants in Organization and Workplace Research, *British Journal of Management*, 27(4):836-852.
- Shakespeare, T., Watson, N. & Alghaib, O.A. (2016) Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability. *Critical Social Policy*, 36(4):1-20.
- Shier, M. , Graham, J.R. & Jones, M. E. (2009) Barriers to employment as experienced by disabled people: a qualitative analysis in Calgary and Regina, Canada, *Disability & Society*, 24(1): 63-75.
- Van Houtven, C., Carmichael, F., Jacobs, J., & Coyte, P. (2019). The economics of informal care. In Oxford Research Encyclopedia of Economics and Finance. Oxford University Press. doi:<http://dx.doi.org/10.1093/atcrefore/9780190625979.013.265>
- Veltman, A. (2015) Is Meaningful Work Available to All People? *Philosophy & Social Criticism* 41(7):725–47.
- Vlachantoni A, Robards J, Falkingham J & Evandrou M (2016) Trajectories of informal care and health. *SSM-Population Health*, 2:295-501
- Vogl, S. (2013). Telephone Versus Face-to-Face Interviews: Mode Effect on Semistructured Interviews with Children. *Sociological Methodology*, 43(1):133–177.
- Watson, P. M., Dugdill, L., Pickering K., Bostock, S., Hepples, J., Staniford, L. & Cable, N. T. (2011) A whole family approach to childhood obesity management (GOALS): relationship between adult and child BMI change, *Annals of Human Biology*, Special Issue: 38(4):445-452
- Yakas, L. (2017) “Work is love made visible”: Purpose and Community in Clubhouses. *Disability Studies Quarterly* 37(4) <http://dx.doi.org/10.18061/dsq.v37i4>

