

Precarious Work, Rest, and Disability

Research Project

Research participants needed

Face-to-face interviews and/or diary entries

DO YOU WORK ON EITHER:

- * SHORT-TERM,
- * ZERO-HOURS,
- * OUTSOURCED,
- * PART-TIME CONTRACTS/
WORK ARRANGEMENTS,
- * THROUGH AN AGENCY,
- * OR AS SELF-EMPLOYED?

DO YOU IDENTIFY

AS DISABLED,
NEURODIVERGENT
AND/OR
EXPERIENCE
CHRONIC
ILLNESS?

For further information or to register your interest, please contact me:

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**FOR MORE INFORMATION ABOUT THE PROJECT, VISIT THE
WEBSITE MATERIALBODIES.WORK**



**UNIVERSITY OF
BIRMINGHAM**

What I aim to achieve with this study and why I find it important

This project is allowing me to create a space and time for conversations with disabled, neurodivergent, and chronically ill workers around the UK, with varying perspectives on and lived experiences of work, rest, and disablement. Your viewpoints and experiences will be placed at the core of the thesis of this doctoral study. I wish to find out about your experiences of daily life as a disabled gig economy worker, in relation to how you manage your job(s)/work, wellbeing, financial security, and sense of autonomy. I also want to know what you think needs to change so that work (as an 'institution' more generally, but also particular jobs) stops being used as a tool for disablement.



Through this project, I seek to do more than simply formulate a policy recommendation or reform for the state institutions to adopt. Instead, the conversations, diary entries, news stories, pamphlets, reports, and academic literatures will help me articulate a set of principles and a way of thinking, acting and relating to one another differently. This, I hope, will help us imagine, campaign, and reshape societal understandings of work and the body, and the way they permeate state policies. In other words, the implications of this project go beyond short-term solutions, for I wish to explore the multitude of ways in which we could understand and relate to work and the body, so we can critically re-evaluate the role of work within society. This includes interrogating the meaning of who a 'productive member of society is' and what productivity means. The overall story that will emerge through this project will hopefully have implications not only for disabled people, but also for other (non-disabled) groups who are facing social and political marginalisation. The knowledge, insights, and reflections on your own experiences (and of those around you) are the most important part of this project. I appreciate your input!

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Participant information sheet

Study title

Material Bodies, Precarious Work, and Rest: Reflections on 'gig economy' work and rest from the point of view of disabled, neurodivergent people and people with chronic illness

Researcher: Ioana Cerasella Chis, icc108@student.bham.ac.uk

Who am I and what do I hope to learn?

I am a PhD student at the University of Birmingham, based in the Political Science and International Studies Department. I'm interested in learning about experiences of insecure work among disabled, neurodivergent people and people with chronic illness. The formal research questions for my project are the following:

- How have conceptions of productive work been shaped by the widespread insecure work of the 'gig economy'?
- How do the insecure working lives of disabled people and/or people with chronic illness influence their experience of the body?
- What change is necessary for reshaping the conditions of work and living for disabled people in the UK?

Context and purpose of the study:

This project seeks to gather and disseminate accounts of what it means to be living while working on insecure contracts as a disabled, neurodivergent person, and/or as someone with chronic illness in the UK. By 'insecure work' I mean the following: zero-hours contracts, short-term contracts, agency work, casual work, self-employment, part-time, and payment-by-results.

This doctoral research project started in October 2019 and will take place over 3 years. In the second year of the programme, I will be undertaking one-hour interviews with approximately 30 participants, individually. At the end of each interview I will be asking participants whether they would be able and willing to keep a diary (paper-based or on a smartphone) over 8 weeks, documenting daily activities (especially in relation to work, rest, and living conditions). You can choose to be part of either both or one of the two activities.

What difference will this project make?

I cannot promise that my project will make an immediate, tangible difference. I wish to contribute and bring further evidence in the public domain with regards to the impact of work-related government policies, and the views and experiences that disabled workers hold in relation to work and the body. I will seek to act as a sounding board for the accounts given by the participants in the study, as examples of how precarious work is experienced by disabled workers. I want to do everything that my position allows me to bring participants' accounts to a wide variety of spaces, such as work and disability-related community groups, academic settings, trade unions, and

government-related institutions. By learning about your experiences, I can teach students and others about the politics of disability and work, join researchers and activists in talking about work in a way that is informed by the vantage point of disabled people, and put pressure (individually and with others) on decision-makers, to make the UK a better place for disabled people and for all other workers. My doctoral programme will last for 3 years, during which I will do extensive reading of: reports, pamphlets and other publications by disabled activist groups, artists, trade unions, and work-related campaigning groups and think-tanks; government documents and policies; academic literature on work and disablement, news stories and other platforms.

Who can participate:

As this study is about the experiences of disabled, neurodivergent and chronically ill workers in the gig economy, two criteria need to be met in order to be part of this study:

1. If you are currently working (or have recently worked) on either of the following types of contracts: zero-hours contracts, as self-employed, on short-term contracts, as an agency worker, part-time, as a casual worker, on commission (with payment-by-results).
2. If you self-identify as disabled, neurodivergent, and/or if you experience a chronic illness (including, for instance, experiences of physical, sensory, or learning impairments and mental illness or distress). I will aim to interview a diversity of people across the gender, ethnicity, nationality and migration status, and class spectra.

If, after reading the above, you think you are eligible to participate but aren't entirely sure, please do feel free to email me. I will try to engage with participants who have differing experiences of work and the body, to the extent that I can (due to time constraints, I estimate that I would be able to interview 30 participants).

What your participation would entail (if you agree to take part):

You can participate in two ways (either both or one of them):

Interviews:

If you agree to be interviewed, with your permission after signing the consent form (or being audio recorded consenting), the conversation will be audio recorded. This is so that I can later transcribe the discussion, reflect on what is said, analyse the interview, and link it to others' experiences. You can seek further clarification from myself if there is anything which you do not understand, prior to, or during participation. The interviews can take place either indoors, or outdoors – either while sitting or walking, depending on your preference. You are free to skip any questions that you do not want to answer. During the interview, I would like us to have an informal discussion about your everyday life in relation to how you manage your work, what your views on resting are, what benefits and struggles 'flexible' work poses, and how you envisage a society in which work and disability are valued and experienced differently. The interview itself will take approximately one hour. Before the interview, we will spend 10 or more minutes to go through any questions you may have about the study, and to make sure that you understand the implications of taking part. Half-way through the interview, I will offer to have short break. After the interview we will spend 10 minutes (or more) to talk about how you feel the discussion went, and whether you would be happy to keep a diary.

Diary entries:

If you agree to keep a diary to record your experiences of everyday life (while holding short-term/precarious jobs), you can record them either on paper (a diary will be provided to you by myself), or on your smartphone (through audio recordings, text, photos, or videos), for approximately 8 weeks. During this period, you will be encouraged to take note of your (if possible, daily) experiences of working, resting, and other aspects of living.

Do I have to take part? What happens if I change my mind after signing the consent form (or being audio recorded consenting to taking part)?

If you decide to take part, you will be given this information sheet along with a consent form. Participation is voluntary and you are free to withdraw within three months after the interview, without giving any reason. In that case, your data will be omitted from the study. Withdrawal during or after the interview will not impact upon your entitlement to be compensated. However, if you do not submit diary entries over the duration of eight weeks, you will not be eligible for a voucher.

What are the benefits of taking part?

The results will be published and shared to improve current understandings of precarious work and experiences of it among disabled individuals and people with chronic illness. By taking part you can contribute to shaping current understandings of work, 'the gig economy', disablement, and the body. I will also plan to find ways to use some of the stories (or part of the stories) in a creative manner, by collaborating with an artist (time and resource-permitting). Any ideas for how else I could make this project useful would be very welcome! I am happy to discuss ideas regarding how I could support your own initiatives/campaigns related to work or disability. **Compensation** will be offered as follows:

- £15/interview if you live outside of London; £16 if you live in London
- Travelling costs: a flat fee of £5 if you live outside of London; £6 if you live in London
- Submission of diary entries/participant: vouchers worth £15 if you live outside of London; £20 if you live in London. You can choose between Sainsbury's, Tesco, ASDA, or Morrisons.

Will what I say in this study be kept confidential?

All information collected about yourself (your name and other identifiable characteristics) will be kept strictly confidential (subject to legal limitations). Confidentiality will be ensured in the collection, storage and publication of research material. The audio file of the interview will be transcribed by myself. During transcription, I will use a pseudonym to hide your identity. I will also replace other names of individuals and organisations that you may mention during the discussion. This is to avoid anyone being able to identify you. The transcripts will be held on a highly secure platform that the University of Birmingham provides to researchers. The files will be encrypted and password-protected. If you agree to keep a diary, the same principles of removing personal data will apply.

The interview will be held in a space where you feel your privacy can be maintained. Nobody else will know that you are a participant in this study. Other participants will not know who else has been interviewed. A consent form will be provided before the start of the interview, and we will have time to go through anything you would like to ask me about the project. Both yourself and I will keep a copy of the signed form (or of the audio file with the consent); the form complies with EU General Data Protection Regulation (GDPR) and has been approved by the University Ethics Committee.

Data generated by the study will be retained in accordance with the University's policy on Academic Integrity and will be kept securely in paper or electronic form for a period of ten years after the completion of a research project, in the UK Data Archive. Only myself, my supervisors, and (if requested, for audit purposes) the funding body (the Economic and Social Research Council) can access the transcripts (after I have anonymised them).

After the interview and/or diary entries:

I will transcribe the interview and diary entries and look for patterns, themes and connections between experiences. I may use direct quotes in my thesis or other research publications, but participants will only be identified with a pseudonym. I will offer to send the transcripts and the thesis to participants. Once the diary entries are completed, I will request a follow-up interview (if possible).

How to 'opt in':

Please either email me at icc108@student.bham.ac.uk or visit the website materialbodies.work/join; you can also call or text me on 0774 2658 739 or send me a letter with your contact details at Ioana Cerasella Chis, 2nd Floor, Muirhead Tower, University of Birmingham, Edgbaston B15 2TT.

What will happen to the results of the research study?

The results of the research study will be published in my doctoral thesis (as anonymised quotes and paraphrased accounts), in potential journal articles, conference presentations, reports, or arts projects. A copy of the findings of the study will be sent to each participant (as a short, accessible, 3-page report), and updates regarding the study will be posted on the website materialbodies.work.

Who is funding the research?

The scope, purpose, design, and approach to the study were set entirely by myself, when I wrote the research proposal. ESRC (the Economic and Social Research Council) are funding this project, as a result of an open research proposal competition which I successfully secured. I am registered as a full-time student at the University of Birmingham in the Political Science and International Studies Department. The quality of my work is reviewed by my supervisors (Dr Emma Foster and Dr Laura Jenkins) and by the University and ESRC through their standards and regular reviews.

Who has reviewed the study?

The research has been reviewed and approved by the University of Birmingham Research Ethics Committee.

Contact for Further Information

Supervisors: Dr Emma Foster e.a.foster@bham.ac.uk and Dr Laura Jenkins l.m.jenkins@bham.ac.uk +44 (0)121 414 4710. If you have any concerns about the way in which the study has been conducted, you should contact the University Research Ethics Committee at ethics-queries@contacts.bham.ac.uk.

Diary entries (written over approx. 8 weeks):

either via an app (timeframe TBA), in a hard-copy journal, or by uploading text/videos/audio/photo files in a secure folder that I would give you access to

To better understand the daily realities of what life is like while doing short-term jobs as a disabled person and/or as someone who experiences chronic illness, I am complementing interviews with diary entries. Although the title of this project refers specifically to work, rest, and disability, I am interested in finding out about the daily experiences of *living* (with all their complexities) with an impairment/illness, juggling paid and unpaid work, socialising, and making use of spare time. By having a clear sense of everyday life, I can more easily articulate the relationship work-rest-disability.

Why diaries?

Diaries are helpful for recording events, emotions, senses, and thoughts lived during everyday life. While interviews are also very important in exploring experiences and perspectives on various topics, they only take place once, and under specific time constraints. The diary allows for more creativity, and immediate (as well as later) recording of events that have taken place recently. The diary also gives you the time, space, and opportunity to reflect and contribute at ease, when you deem something to be of note. Even the most 'mundane' things (which are not necessarily explicitly about work, rest, and disability) are very meaningful for me to know about as they help me have a better glimpse into your experiences. Through the app, I would encourage you to use either video, audio, photo, or text – whichever option allows you to express your thoughts best!

The focus of the diary entries - anything related to (broadly speaking):

- how your day has been overall (with examples – positive, negative, regular, unique situations)
- paid and unpaid work: tasks, working environment, events, relationship with others, housework, care work, listening or giving advice, volunteering, etc.; are you able to completely switch off from work when you get home? How long has it taken you to prepare for/arrive to work today?
- disability: your feelings and experience of impairment/chronic illness throughout the day: on the way to work, in a meeting with your GP, while working, while at home; has a particular event eased or hindered your impairment/chronic illness and autonomy?
- the state: your encounters with state institutions – letters read, appointments attended
- rest and resistance - how you are spending your unpaid/spare time: how you are experiencing the time between job shifts, which activities are restful and which ones are related to paid or unpaid work, are there networks in place to support you? what strategies are you using to engage in meaningful activities and/or to make your work more meaningful?
- imagining alternative futures: what would make your life more fulfilling, if money weren't a problem? or if we lived in a society in which we didn't have to rely on wages to survive and in which disabled people would be fully accommodated; what do you think about the idea of 'productivity'?

If you have thoughts on the activity of keeping the journal (whether it's useful, stressful, enlightening), please record them.

Brief list of campaigning organisations

Disabled People Against Cuts

Campaigning group that lobbies state institutions for the improvement of disabled people's living conditions: <https://dpac.uk.net>

Recovery in the Bin

'We are a User Led group for MH Survivors and Supporters who are fed up with the way co-opted 'recovery' is being used to discipline and control those who are trying to find a place in the world, to live as they wish, trying to deal with the very real mental distress they encounter on a daily basis. We believe in human rights and social justice!' <https://recoveryinthebin.org/>

The Black Triangle campaign

'This group is established to galvanise opposition to the current vicious attack on the fundamental human rights of disabled people by the Government of the United Kingdom utilising "Work Capability Assessments" (as administered by 'AtoS Healthcare Ltd' on behalf of the Department of Work and Pensions 'DWP') to re-classify sick and disabled individuals as "fit for work" – in flagrant violation of all accepted medical, and human, ethical standards' <https://blacktrianglecampaign.org/>

Mental Health Under Capitalism

'Mental Health Under Capitalism (MHUC) is a solidarity and support group with a focus on capitalism, oppression and its effect on mental health' <https://www.facebook.com/MentalHealthUnderCapitalism/>

Social Work Action Network (SWAN)

'campaigning organisation of social work and social care practitioners, students, service users, carers and academics, united by our concern that social work practice is being undermined by managerialism and marketisation, by the stigmatisation of service users and by welfare cuts and restrictions.' <https://socialworkfuture.org/>

Mental Health Resistance Network

'The Mental Health Resistance Network was set up by people who live with mental distress in order to defend ourselves from the assault on us by a cruel government whose only constituents are the super rich and who value everyone else according to how much they serve the interests of this selfish minority.' <https://www.facebook.com/MHResist/>

Sisters of Frida

'Sisters of Frida CIC is an experimental collective of disabled women. We want a new way of sharing experiences, mutual support and relationships with different networks' <http://www.sisofrida.org/>

Greater Manchester Coalition of Disabled People

'GMCDP is [...] controlled and run by disabled people only. All Executive Council members and staff positions are only available to disabled people'. Aims: 'promote the independence and integration of disabled people in society; identify and challenge the discrimination faced by disabled people in society today; encourage and support the self-organisation of disabled people; ensure disabled people have equal rights in society and in access to opportunities' <http://www.gmcdp.com/>

ROFA (Reclaiming Our Futures)

'ROFA is an alliance of Disabled People and their organisations 's (DPOs) in England who have joined together to defend disabled people's rights and campaign for an inclusive society. ROFA fights for equality for disabled people in England and works with sister organisations across the UK in the tradition of the international disability movement. We base our work on the social model of disability, human and civil rights in line with the UN Convention on the Rights of Persons with Disabilities (CRPD)'. <https://www.rofa.org.uk>

ALLFIE (The Alliance for Inclusive Education)

'We campaign for the right of all Disabled pupils and students to be fully included in mainstream education, training and apprenticeships with all necessary supports' <https://www.allfie.org.uk/>

TUDA (Trade Union Disability Alliance)

'We are a campaigning group with individual members from over two dozen different Trade Unions. TUDA aims to: co-ordinate the perspective of Disabled people in the Trade Union movement; bridge the gap between the Trade Union and Disability movements; work within, and lobby, Trade Unions to ensure they make their own services accessible and relevant to Disabled Members; ensure that Trade Unions support our continuing campaign for full civil rights; promote understanding of disability as an equalities issues, giving talks and training to Trade Unions; work with Disabled people to persuade them of the benefits of TU membership and activity' <http://www.tuda-online.org/>

WinVisible

'An independent voice for women with disabilities, of all backgrounds, ages and situations since 1984. We are a multi-racial self-help group. We offer information, support, advocacy and campaigning' <https://winvisibleblog.wordpress.com/>

WoW Voices

Platform where people affected by austerity and the social system submit anonymous stories about their experiences. <https://wowvoices.uk/>

- Disability News Service: <https://www.disabilitynewsservice.com/>
- Rest for Resistance: <https://restforresistance.com/>
- Autonomy UK (thinktank) <https://autonomy.work/>
- 4Day week campaign: 4dayweek.co.uk
- FuturesOfWork: <https://futuresofwork.co.uk/>
- Centre for Labour and Social Studies: <http://classonline.org.uk/>

Brief list of charity organisations and unions for support and advice

Inclusion London

'Inclusion London supports over 70 Deaf and Disabled Organisations working across every London borough. Through these organisations, our reach extends to over 70,000 Disabled Londoners.'
www.inclusionlondon.org.uk

Trade Unions

Some unions in the UK organise in one sector only, whereas others have members across sectors and employers. Talk to your colleagues/family about which union is best for you to join. You can find a list of TUC-affiliated unions here: <https://www.tuc.org.uk/unions>. Unions that are known to focus on gig economy workers in particular/mostly are: IWGB, UVW, CAIWU, IWW (they are not affiliated to the TUC, thus they are not included in the link above). Unite and UNISON also have branches specifically for unemployed people – they are called Community branches (i.e. Unite Community).

Rape and Sexual Violence Project (RSVP) - Birmingham

If you have been affected by sexual abuse, you can access RSVP's free services. Get in touch with them to find out how they can support you on 0121 643 0301 <https://rsvporg.co.uk/>

Birmingham LGBT Centre

'We offer a range of services and activities for the LGBT Community in Birmingham and beyond. Including sexual health, events, domestic violence, counselling, support, fitness, arts and more'
<https://blgbt.org/about/>

Counselling for Social Change (Cornwall)

'Although we are focussed on working in a Person-Centred way, our Trustees and counsellors have expertise and interest in a range of therapeutic approaches including Mindfulness, CBT, existentialism and others' <https://www.counsellingforsocialchange.org.uk/>

Citizens Advice

'Our network of independent charities offers confidential advice online, over the phone, and in person, for free'. Areas: problems with benefits, welfare benefit check, debt and money problems, housing problems, employment problems, family and personal issues, consumer problems, immigration or asylum problems. <https://www.citizensadvice.org.uk/> Telephone Advice Line: 03444 77 1010. Lines are open Mon-Fri, 9.30am to 4.30pm. Calls to 034 numbers cost no more than calls to geographic (01 or 02) numbers. Textphone for deaf/hard of hearing people: 18001 03444 111445.

Advocacy Matters (Birmingham)

'Advocacy Matters aims to provide vulnerable people with an independent advocate to ensure individuals are heard and their rights, concerns and needs are acted upon. Address: 198 Boldmere Road Sutton Coldfield, Birmingham, B73 5UE. Email: info@advocacymatters.co.uk, 0121 321 2377'.

Support, advice and information in a crisis:

Samaritans - 08457 90 90 90 or email: jo@samaritans; NHS – call 111: they can help if you have an urgent medical problem and you're not sure what to do; [SANELINE](https://www.saneline.org.uk) on 0845 767 8000; Emergency Services 999: if you or someone else is in immediate risk of serious harm or injury.

If you are living in Birmingham without a GP:

If you, a friend or relative does not have a GP and lives in Birmingham, you can call the Birmingham and Solihull Mental Health Foundation Trust on: 0121 301 0000 (This service is for people aged 25 and over). For people aged 0-25 you can contact Forward Thinking Birmingham Single Point of Access – 0300 300 0099 or via <http://forwardthinkingbirmingham.org.uk/>

Tenants' Union (ACORN)

'We are rooted in communities, uniting neighbours in ACORN local groups and city branches. Our members lead this organisation, identifying issues that affect them and planning campaigns and activities to resolve them. Many of the problems our people face are not unique to a particular town or neighbourhood and our national organisation enables us to work both locally or in combination across the country as needed and so tackle issues that affect us all'. <https://acorntheunion.org.uk/>

The Free Psychotherapy Network

Free psychotherapy for people on low incomes and benefits <https://freepsychotherapynetwork.com/>

The Black, African, and Asian Therapy Network

'We are the UK's largest independent organisation to specialise in working psychologically, informed by an understanding of intersectionality, with people who identify as Black, African, South Asian and Caribbean' <https://www.baatn.org.uk/free-services/>

Homelessness - St Basils

'If you are aged 16-25 and at risk of homelessness or actually homeless text 'NEED ST BASILS' to 62277 for free from any mobile and they will call you back. If are concerned about someone else, please contact them on 0121 772 2483 or info@stbasils.org.uk. Open Monday - Friday: 9:00am - 5:00pm'.

Money, Benefits, and Debt Advice – The Project Birmingham

'[The Project](https://theprojectbirmingham.org) Birmingham offers a free and impartial money and debt advice service - if you are struggling with debt, homeless or at risk of becoming homeless, or just really confused by the benefits system and you live in Birmingham'. Address: The Depot, Belton Grove Longbridge Birmingham, West Midlands, B45 9PD, 0121 453 0606, info@theprojectbirmingham.org.

Turn2Us

'Turn2us helps people in financial need gain access to welfare benefits, charitable grants and other financial help – online, by phone and face to face through our partner organisations' turn2us.org.uk

Notable quotes:

No body stands outside the consequences of injustice and inequality...What our bodies require in order to thrive, is what the world requires. If there is a map to get there, it can be found in the atlas of our skin and bone and blood, in the tracks of neurotransmitters and antibodies.

Aurora Levins Morales

Nothing is absolute, everything changes, everything moves, everything revolves, everything flies and goes away.

Frida Kahlo

To be truly radical is to make hope possible, rather than despair convincing.

Raymond Williams

I want to affect the people like a clap of thunder... to inflame their minds with the breadth of my vision, the strength of my conviction and the power of my expression.

Rosa Luxemburg

If disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance. Such a view will be translated into social policies geared towards alleviating oppression rather than compensating individuals.

Mike Oliver and Colin Barnes

Thank you for taking the time to read this booklet!

Website: materialbodies.work