



Barriers and Enablers to Employment: Black Disabled Peoples Living with Sickle **Cell Disorder Project**

SUMMARY OF RESEARCH PROJECT FINDINGS

Introduction

In the United Kingdom (UK), over 15,000 people are living with sickle cell disorders and even more families are affected. Sickle cell disorders (SCD) are inherited blood disorders, which can have an impact on a person's quality of life (for more information see: <http://www.nhs.uk/conditions/sickle-cell-disease/>). SCD can present as acute condition, chronic illness and/or a disability. It is a complex and variable condition, both individually and across the life course, meaning that while one person can have a mild version for most of their life, another can have a life threatening and disabling condition. Many of the signs and symptoms of SCD are invisible, such as chronic pain, fatigue or long-term organ damage. Symptoms are also linked to extremes in temperature, dehydration and can be caused by stress and other illnesses. In the UK, people most affected by SCD are of African-Caribbean, African, Middle Eastern, Indian, Latin-American and Mediterranean origin.

SCD is recognised as one of the most common but also most serious genetic conditions in the UK. However, advances in medical treatment and healthcare provision for this population group, now means increased life expectancy. This entails that people with SCD are living longer and more people with SCD will be entering into employment in the future. Young people will be particularly affected, as they seek meaningful careers which encompass personal, professional, as well as social growth, while contributing to society.

The Research Project

The research project was funded by the Disability Rights for Independent Living (DRILL) programme and the Big Lottery Fund to understand the barriers and enablers to employment for people with SCD.

People with SCD have typically not viewed themselves as 'disabled' nor part of the disability movement. In England, the disability movement has strongly associated itself with the social model of disability. This makes a distinction between physical, sensory or mental impairment and the experience of societal oppression leading to disablement. The main feature of SCD, is pain, which the social model states is part of the experience of impairment but in SCD, pain is also linked to societal oppression, neglect, as well as racism.

The disability movement has struggled to accommodate the complexity of such experiences, advocate for rights of people with chronic long-term conditions and speak out strongly against all forms of racism affecting Black disabled people.

As a result, people with SCD have tended to view themselves as people with a chronic and life-limiting condition, advocating charitable, medical or human rights-based models instead of disability models. This is because those identities represented more hopeful discourses and were not in tension with their positions and issues facing the Black community.

Black people state that they value interdependence as part of the process of resisting societal racism. Thus, they may at first struggle to reconcile the importance of mutual aid and dependence on one another, with the high value placed on independence in

disability circles. This means Black disabled people may have missed out on some of the benefits of applying a social model, and other disability models to their experiences.

This project is thus important, as it means the disabled community have reached out to understand the real concerns of a population group that have been ignored and may not fit dominant models of disablement. It also presents an opportunity to understand how to work on issues that impact Black people and rethink the terminology and models around disability to be more inclusive and representative.

The project was a partnership between people with SCD, De Montfort University and two voluntary sector partners, the Sickle Cell Society and OSCAR Sandwell.

The research took place in London and several major cities in the Midlands and North of England. The study was democratically co-produced with people with SCD, which meant that people with lived experience took an active role in developing the research alongside academics. We used a method we called democratic co-production so that anybody with SCD could be involved, whenever they felt up to it. This allowed people with SCD to dip in and out of the project according to health, wellbeing, impairment and energy levels, and allowed anyone to take part if they wanted to. As everyone was involved, it meant nobody had to feel guilty or obligated if they were invited to do something but could not.

The process of democratic co-production began with two focus group discussions held in London and Birmingham which were led by people with SCD. These

discussions allowed people to share experiences of employment, as well as work and welfare, to illustrate the kinds of issues and questions academics needed to focus on. In total 47 adults were interviewed by academics to gain an in-depth understanding of employment and work histories. We interviewed 25 women and 22 men, with an age range of 18 to 66 years old. We were interviewing people with average age of 41, who were primarily employed or had been in paid employment.

We then presented and discussed the findings at two policy development workshops in London and Birmingham. People with SCD shared their critiques and solutions to the issues identified by the focus groups and individual interviews. These challenges and opportunities informed the writing up of a 'Sickle Cell, Work and Employment Guide' with people with SCD, which can be used by employers and employees.

Key Findings

In our study, the majority of people with SCD either were, or had recently been, in paid employment. This included a lawyer, teacher, nurse, entrepreneur, engineer, laboratory scientist, pharmacist, driving instructor, actor, sales manager, administrator, events manager, care home owner, bank clerk, factory worker, cleaner, transport worker, youth worker, community worker, fashion model and musician. At the same time, we found that people with SCD experienced various forms of discrimination in employment, work and welfare.

Additionally, SCD can be visible but is mostly an invisible chronic condition, fluctuating illness and/or disability about which some employers may have very little knowledge. Similarly, people with

SCD do not always view their condition as a disability and did not understand what services they had a right to access or legislation that would protect their rights. We also found people with SCD engaged in self-management of their condition, simply in order to be able to participate in employment and various forms of work.

There was also a significant proportion engaged in self-employment but some people with SCD who wanted to explore this option, lacked resources and knowledge about how to become self-employed or entrepreneur. When people with SCD were too ill for employment and work, they faced further difficulties when accessing welfare support or facilitating early retirement.

Multiple and Simultaneous Forms of Discrimination

As SCD affects mainly people from ethnic minorities in the UK, and predominantly people of African-Caribbean and African origin, we recorded both historical as well as present experiences of indirect and direct racism. This was often alongside experiences of bullying, harassment, marginalisation and micro-aggressions in employment.

“So, he said, “Oh do you think that was racist?” I said, “It’s up to you if you think it was racist.” And then the next thing he started saying now I own you! I own you.”

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MAN, 53, AFRICAN-CARIBBEAN

Older and younger women with SCD also explained how they had and continue to encounter everyday sexism in the workplace, with women also detailing cases of historic and present sexual harassment. Worryingly, women with SCD who were pregnant, in more precarious forms of employment or with no

permanent contracts, were encountering maternity discrimination with several recounting employers had laid them off after discovering they were pregnant.

People with SCD who had visible manifestations of the condition, serious illnesses or disabilities recounted experiences of disablism in employment, such as not being invited for interviews, not being accommodated at work, explicit hostility to their disability and loss of employment. Participants related being passed over for promotions and women being forced into part-time work which employers justified by reference to their condition.

“I did notice that there was a period of time where I wasn’t getting interviews and someone suggested that I just remove the sickle off the form and just, you know, don’t admit to having a disability at all.”

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WOMAN, 32, AFRICAN-CARIBBEAN

We also had people with SCD who had other life-threatening illnesses, such as cancer, requiring significant time off work. They experienced discriminations, for instance, being ostracised at work, being driven out of employment and difficulties re-entering the job market. Participants also related difficulties and fears about taking time off work to recover from illness or to go to medical appointments, such as for blood transfusions. Medical leave was often denied and people took annual leave instead.

“...if we needed to have time off for hospital appointments, it was just given, but now we have to take it as annual leave.”

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WOMAN, 29, AFRICAN-CARIBBEAN

While everyone will encounter periods of physical and mental illness across the life-course or require time off work to undertake caring duties, some employers seemingly only wanted to recruit fit and able employees. This is a form of discrimination termed 'ableism' and not in keeping with valuing diversity in the workplace.

Furthermore, it was noted that the unions were not always able to support people and even legal action was becoming increasingly difficult, both affecting employment rights and enabling discrimination to occur unchecked.

Employment, Reasonable Adjustments and Disability

There was a lot of confusion about whether people had to disclose their condition when applying for a job or at interview. Few participants realised that they should not be asked about their condition during an interview and should decline to answer. However, they could disclose their condition to get reasonable adjustments in a job application. This is to make sure they were not at a disadvantage during the interview, or after appointed.

When people did disclose, employers often did not understand their condition. Employers also struggled with how to implement reasonable adjustments in the workplace, which their employees had a right to under the Equality Act 2010.

"That's probably why I haven't mentioned it because I do feel telling an employer you do have sickle cell, it's kind of a thing where you are looked at a bit differently."
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MAN, 19, AFRICAN-CARRIBEAN

Despite this, many participants related good practices in the workplace, as well as what they felt could be done better to ensure inclusion. One area around which employers were successful, was at making simple and low cost reasonable adjustments to accommodate people with SCD, such as guaranteeing a working environment that was, for instance, adequately heated, where employees had access to water, could take medications, have regular toilet breaks; and where employers had made adjustments to the uniform required for work, so their employees could stay cool or warm.

Other successful adjustments included provision of specialist equipment (e.g. height adjusted chairs or screen readers), allocated parking spaces, flexible policies around starting and ending times of work to escape rush hour commutes, as well as working from home. We also found that a few people with SCD were accessing forms of government support like *Access to Work* schemes. They understood that their form of SCD was categorised as a disability and that they were entitled to support in the workplace.

"Access to Work is a government organisation. It's part of the DWP and they essentially help people with long term conditions and disabilities get into work. So, they can do this through things as simple as ergonomic equipment for your office or taxi rides into work if you are not feeling so well."
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FEMALE, 23, AFRICAN

Many people with SCD discussed self-employment as a way in which they could manage their own time and accommodate periods of ill-health. While several participants had done this successfully, it was not without challenges. It also meant having financial resources and business acumen. Most participants struggled with

accessing financial information, small loans, business mentorship and/or skills training.

“I did have a business plan but usually they are not catered for people with a condition or a disability, and that makes it very hard to show them what you really can do.”

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MALE, 25, AFRICAN

Self-Management as Work

People with SCD noted how in a difficult context of austerity, they were grateful for employment. They tried to do their jobs well and to work extra hard, in case of future absences. They also tried to manage workplace issues they knew would exacerbate their conditions, like stress. While not recognised as such, this precautionary and preventive physical and mental health work was self-management and/or impairment management. This behaviour was often misunderstood at work and become connected to racism.

“And I have found with this condition it’s the racial aspect as well, because they tend to think that black people are lazy.”

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WOMAN, FOCUS GROUP TWO

In our study, people with SCD managed their lives in terms of self-denial, restricting amount and range of leisure activities, including socialising with colleagues, in order both to remain healthy for work and stay out of hospital. This self-management improves their health status both directly (by reducing their use of health services) and indirectly (by enabling them to earn money and improve their standard of living and hence their capacity to remain well).

Even those living with SCD who were most ill contributed through activities such as

hospital visiting, community activities, fund-raising for support groups and social support for others with SCD. We noted that the only group of people who struggled with self-management were participants seeking asylum. Their physical and mental health was getting worse due to their lack of access to work, inability to stay well and in several cases extensive periods of homelessness.

Invisible Work and Welfare

While discussions around unemployment and disability emphasise economic costs and burden to the state, we found the opposite. Most participants and their families in our study had or were paying taxes and into national security contributions. Yet, it was the welfare system that was causing people more work to prove they were in fact seriously ill and had an entitlement to benefits. The system was also so punitive that it was preventing some people from re-entering employment, leaving them destitute or fearful of even trying self-employment.

“I have done a lot of voluntary work over the last 15 years (...) when people hear the word voluntary they are used to the person who goes out with the money shaker for a charity (...) All of the positions I have volunteered in have been anywhere between 32 to 42K a year - jobs but I am volunteering and I am sustaining myself on nominal amounts of benefits. Because of the problems I always go through when I do sign off. And what happens is I have been left in financial limbo on three different occasions where I have gone a whole year with no income, no benefit, no work, no anything.”

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MALE, FOCUS GROUP ONE

In several cases, participants with SCD had been stripped of their benefits after Work Capability Assessments and had to go to tribunals after life-altering periods of

illness, significant disabilities, and some acute life-limiting manifestations of the condition. We note that there will always be a proportion of people with SCD who cannot work and will need assistance. They often felt like they were punitively being singled out by the welfare system as second-class citizens.

Work is a much broader concept than just paid employment. Not all work is recognised as such, nor is it necessarily paid for. For example, many women with SCD undertake the care work in raising children (who are the next generation who can contribute to society through their work). In our study, some men with SCD who have not been able to stay in paid employment have taken on the role of main care provider in the home. Whoever does this role is working for the overall benefit of society, even if it is work that is not paid. Undertaking unpaid care work, whether of children, older relatives or disabled family members is not only undertaking socially useful work (unpaid) but may be enabling someone else in the household to take up paid employment. These are indirect contributions to the economy.

In our study, many people with SCD also carried out important voluntary and community work. This included: running youth clubs; taking Sunday school or other supplementary education classes; undertaking work for non-SCD charities; offering financial and social support to others living with SCD; raising funds for, preparing and distributing baby packs for mothers of newborn babies with SCD; running education sessions on SCD for NHS staff; and liaising with schools, employers or housing agencies in order to ensure best support for those living with SCD.

As well as being valuable activities in their own right, these activities contribute to the creation of good citizens (improving overall education levels in the community or reducing crime and anti-social behaviour, for example). In some instances, this work also helps reduce costs associated with treatment of SCD: giving doctors and nurses a better understanding of SCD for example, or ensuring that schools and employers do not damage the health of someone with SCD and cause them to require unnecessary treatment. We found that all the above was invisible work that people engaged in for their community and themselves but was not recognised as such.

Conclusion

People with SCD can be valuable employees if given the right kind of reasonable adjustments and support. They are used to managing their conditions to ensure they stay well. They often indicated that simple accommodations would allow them to do their jobs to the best of their abilities. The *Access to Work* and *Disability Confident Employer* schemes are available for employees and employers. However, few people in our study had heard about such initiatives or did not understand how it applied to people with SCD.

The study co-produced a guide for employers and employees on work, employment and sickle cell. We have tried to put together best practice guidelines for reasonable adjustments and recommend that all workers with SCD have a **Workers Individual Support Plan (WISP)**. This plan should be reviewed on a regular basis to make sure that it remains current. We hope that this is a useful tool for employees and employers to enable inclusion and wellbeing in the workplace.

We found that there were a number of structural issues in employment, work and welfare which are acting as barriers to inclusion, empowerment and citizenship. Participants noted experiences of multiple forms of discrimination, which can be experienced simultaneously, but for which employers have a duty to respond, under the Equality Act 2010. The role of the unions, bodies like Citizens Advice and legal representation to enforce rights, in or to employment, should also be safeguarded. Speaking out and taking action against discrimination is taxing to people's mental and physical health. Participants also related long-standing issues such as ability of parents in employment to pay for childcare or the impossibility to cope with caring for a sick child, as well as stay well and employed.

While participants have variable and sometimes serious conditions, many had spent long periods in employment and/or had contributed significantly to the economy through caring, volunteering and other forms of work. This should be celebrated, recognised and valued, in terms of contributions to community and good citizenship, but it was often ignored in favour of discourses around burden or cost. People who were seriously ill also had to fight to gain social security entitlements, with several resorting to going to tribunals. The welfare system itself and lack of welfare for people who were seeking asylum was acting as a burden by causing physical and mental health stresses, sometimes with ongoing periods of hospitalisation at great human, social and economic cost.

Meanwhile, the current social security system was also acting as a deterrent to work and self-employment because people were fearful of financial losses and penalties for themselves and their

families. Likewise, many participants expressed an interest in self-employment but lacked an understanding about business management, resources available and could not access small loans. Some participants also expressed a need to understand issues around entitlements to welfare, as well as plan for pensions and (early) retirement. As people with variable and/or chronic conditions, illnesses and disabilities are living longer, they need tailored social security advice across the life-course as well as financial and social care planning for the future.

Recommendations

Our recommendations are based on the findings from our participants and the barriers and enablers to employment that they are currently encountering.

Recommendations for Government

- Recommend policies for employees and employers like **Workers Individual Support Plans (WISP)** and embed this in employment law. This will enable health and wellbeing in the workplace, as well as cost-effective and simple reasonable adjustments which people have a right to. Link these to *Access to Work* schemes and reasonable adjustment financial support for employees and employers.
- As people with disabilities and chronic conditions live longer, they will be entering into employment. An issue will be unavoidable absenteeism but there are no government policies or incentives around this issue. The government should consider: 1) a financial reimbursement scheme for employers; 2) early retirement proportionate to life expectancy of employees with serious illnesses,

chronic conditions or disabilities; and 3) giving employment tribunal decisions the weight of case law, thereby establishing general principles employers must follow in law.

- We found multiple structural discriminations in the workplace. These require urgent action. It is important to enforce laws on protected characteristics, in keeping with the Equality Act 2010, to ensure people do not experience racism, disablism or gender discriminations in the workplace.
- Women in employment should not be experiencing any explicit nor implicit maternity discrimination or open sexism. Government backing should be given to employers to tackle this issue. More needs to be done to support women and parents in employment through specialised reasonable adjustments and flexible working schemes. Furthermore, there is a longstanding need for more affordable childcare and incentives for employers for keeping pregnant women, carers and parents with children in the workplace.
- Participants were encountering employers and a workplace that was geared towards an able-bodied employee. This is a form of discrimination called ableism, of which employers and employees knew little. People on temporary contracts or in precarious employment were at more risk of such discrimination but this was found in all areas of employment. More needs to be done to ensure diversity and equality in all workplaces regardless of contract. This needs more than a *Disability Confident* scheme.

Recommendations for Employers

- Ensure accessibility and transparency in recruitment. Ensure awareness of how *Access to Work* and *Disability Confident* and other schemes could support employees.
- Participants related that they were unsure about processes of disclosure for fluctuating physical and mental health conditions, chronic illnesses and/or invisible disabilities when applying for a job or un/paid internship, and legal frameworks around disclosure once in a job or clarifying why they needed designated parking spaces. Clarity and support around these issues is important.
- Ensure that travel to work is recognised as an issue where employers can make reasonable adjustments.

"It's not just the barrier to employment but for those of us who do gain employment and who have been fortunate to even sustain a career of some sort, it's the barrier to progressing into the kind of higher echelons of our jobs."

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WOMAN, FOCUS GROUP ONE

- We found that some managers, Human Resources (HR) and/or Occupational Health (OH) teams were making decisions about promotions, part-time employment or giving advice based on what they had erroneously read about SCD online. This is acting as a barrier to and in employment for people with SCD. One person related having been dismissed despite having a mild version of SCD. Do talk to your employees and let them be the

experts of their own condition by using a guide to reasonable adjustments and creating a **Workers Individual Support Plan (WISP)**.

- Dismissal based on any form of disability is illegal and there are duties on employers under the Employment Rights Act 1996 to provide a contract and not dismiss employees unfairly.
- There are also duties under the Equality Act 2010 to provide a workplace where reasonable adjustments are made so that no employees are at a disadvantage.

"I had HR engage with me right at the beginning, they called me they wanted to find out what I needed. And they said I can call them any time if there were any new adjustments that I wanted."

.....
WOMAN, 32, BRITISH-CARIBBEAN

- Employers should not discriminate against workers with SCD by writing into job descriptions requirements that exclude a worker with SCD. For example, physical capabilities could be enabled by technological adaptations; uniforms could be adapted, and lengths of shift could be varied: all reasonable adjustments that could enable a worker with SCD to do a job that the job description tries to disqualify them from.
- Women are experiencing multiple forms of discrimination linked to their gender alongside having SCD. These include a lack of promotion, unequal pay, disregard for their caring responsibilities and maternity discriminations. Employers should conform to the law with respect for

women's rights under the Equality Act 2010.

- Do ensure workplaces are enabling by educating employees about respect for diversity. This is inclusive of understanding that reasonable adjustments should also incorporate cultural and social reasonable adjustments. For example, some people with SCD may not join social activities, not because they do not want to, but because they have to focus all their energies on their job and need to rest after work to recuperate.
- Consider having policies in place so that employees can work flexibly and from home. Reflect on what equipment they would need to be able to do this.
- When setting deadlines and tasks, do ensure that periods of illness are taken into account to ensure flexibility.
- Try to mitigate and reduce stress in the workplace and create policies for good mental and physical health.
- If a person has a chronic condition, serious illness such as SCD or disability requiring periods of absence for medical treatments or hospitalisation, consider suspending the 'Return to Work' interview.
- Do ensure that people know that they can take time off for medical appointments such as for, antenatal care or for blood transfusions. They should not be required to use their annual leave for such absences. Do allow people time to rest and recover after a period in hospital or after a transfusion.

Recommendations for Employees

- According to the Equality Act 2010, SCD can be considered a disability if it causes a 'substantial and long-term adverse effect on a person's ability to carry out normal day to day activities.' If this is the case, consider what reasonable adjustments would prevent any disadvantage in the workplace.

"So, I have been in to see HR and their manager to discuss what actually works. And again, bringing in disability law so that they do review what they say."

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WOMAN, 53, BRITISH-CARRIBEAN

- When job seeking, look for employers who are positive about disability or *Disability Confident*.
- If you have a health and/or mental health condition or disability, one scheme that can help you and your employer with specific reasonable adjustments to or in the workplace is *Access to Work*.
- Consider using the 'Sickle Cell, Work and Employment Guide' to ensure reasonable adjustments in the workplace to identify and accommodate your needs. This may change over time, so don't be afraid to state this to employers.
- Adopt a **Workers Individual Support Plan (WISP)** with HR or OH and your sickle cell specialist nurse. Revisit it every 12 months or as needed. It was recommended to have reasonable adjustments agreed in writing and not just verbally, so even if your manager changes the reasonable adjustments continue to be respected.

"Never accept a reasonable adjustment that somebody's agreed to verbally. Have it done in the meeting, preferably take your union rep, and have it all written down."

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41, MAN, BRITISH ASIAN

- If you do encounter discrimination or an adverse work environment, do talk to your line manager or HR in a first instance. If they do not resolve the issue, talk to your union. We have also added some useful resources below where you can get free advice and support.
- Do think about your career and plan for the future in terms of savings, checking to see if your employer has pension schemes and/or policies in place to promote good work and life balance.
- Do find out about employers' policies with regards to flexible working hours or working from home, if you feel that will be important to you.
- Many employers will have an enabling environment. HR, OH or your manager should ask you about what you need to enable you do your job well.

Recommendations for Unions

- People with SCD related multiple forms of discrimination. Union reps. need to become aware of SCD and the multiple forms of discrimination that people with SCD may be subjected to, and why workers with SCD may be reluctant to disclose their condition in the workplace.
- Some participants did not understand the role that unions could play in

defending their rights and advocating on their behalf. SCD as a workplace issue cuts across issues of racism, disability and gender. Union reps. need training on SCD, its effects and how workers with SCD can be supported.

- Highlight in a simple way to workers with SCD, exactly what a union does. Unions are important resources to their members nationally as well as locally. In simple steps explain how a union has meetings, checks if a complaint is valid, gathers information and acts as support.
- When people want to take forward a complaint, ensure that they feel supported, understand the process and contact their voluntary sector organisations for advocate representation with proper expertise. Bearing in mind stress-induced illness episodes and chronic fatigue, consider any reasonable adjustments that would be needed in such a process or in tribunals.
- Unions will need to prepare to support a diversity of people with multiple forms of visible and/or invisible chronic conditions, illnesses and/or disabilities across the life-course as they enter employment but not enough resources existed for them nor was there enough understanding of intersectionality of their issues and realities of discrimination.

Recommendations for the Voluntary Sector

- Employment has been neglected compared to medical, welfare and educational issues but people have

expressed a need to gain advice across the life-course to social, cultural, political and economic issues that affect them. Consider adopting a life-course approach with information that includes SCD and employment, as well as other issues like living with disability, promoting savings and pensions.

- Gaining and staying in work or employment can have a beneficial impact on people with SCD but some work was making people physically or mentally ill because reasonable adjustments were being floated and then ignored, and thus discrimination was occurring. Ensure advocacy work that engages with policies that promotes health and wellbeing in employment through reasonable adjustment and tailored worker plans to promote equity. A first step in co-producing a guide has been made in this direction with further policy work required to promote this.
- One area where participants expressed an interest and a need for more guidance and support was around issues of self-employment and re-entering the job-market after a period of unemployment. They had fears of being unable to return to claiming benefits if they attempted self-employment and became ill. Voluntary groups should explore possibility of a holding company sheltering those engaged in self-employment.
- While people with SCD were employed and/or did a lot of caring and voluntary work in their communities, on top of trying to manage their conditions so they stayed well, not much was known

about this and it was not valued economically or socially. Consider countering discourses of burden by highlighting all the important roles and expertise that people with SCD have, for example, as expert patients, caring for families, improving NHS services or as volunteers for various charities.

- While participants related that they gained valuable welfare advice from the voluntary sector, there have been a lot of recent changes, with several recounting harrowing experiences of tribunals. Ensure that more advocacy is carried out with MPs and the Department of Work and Pensions (DWP) to understand the complexity of SCD and that there will likely always be individuals that will need social security support.
- Participants related anxieties and vulnerabilities around transitions to employment such as interview situations or when asking for reasonable adjustments. Mentoring was mentioned by people with SCD as proving successful in education. Likewise, mentors have a role to play in supporting those with SCD in employment. Mentoring should include addressing issues like pensions and support for people who are not in employment by building and sharing expertise about work.
- There were neglected issues linked to people with SCD who were refugees or asylum seekers. More outreach needs to be done to ensure that organisations understand the importance of adequate housing, good nutrition and medical and psycho-social care, as well as possibilities of exploitation in employment and work. We found that any periods of

homelessness only seriously exacerbated their conditions and led to intense periods of hospitalisation.

Useful Contacts:

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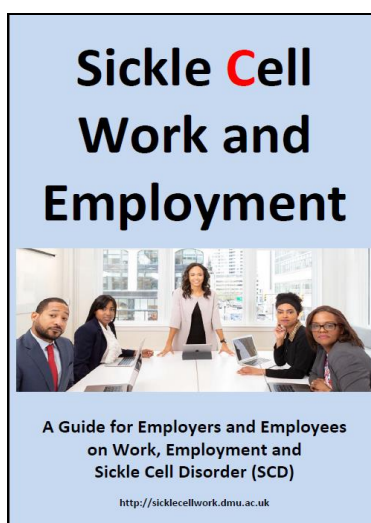
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Useful Resources:



This is available to download from the project web-site (<http://sicklecellwork.dmu.ac.uk>) which also contains useful resources. Hard copies and presentations on the research can be requested from the Sickle Cell Society and OSCAR Sandwell.

If you need more information and support for proving disability or gaining reasonable adjustments as employee:

Access to Work: <http://www.gov.uk/access-to-work>

UNISON: <http://www.unison.org.uk/>
<http://www.unison.org.uk/content/uploads/2019/02/25362.pdf>

If you need more information and support as an employer:

Disability Confident Scheme:

<http://www.gov.uk/government/collections/disability-confident-campaign>

Free services for employers and employees exist to get information and advice:

Advisory, Conciliation and Arbitration Service (ACAS): <http://www.acas.org.uk/>

If all mediation has failed an attempt at conciliation is necessary before bringing a case to an employment tribunal. If conciliation fails, ACAS will issue an Early Conciliation Notification Form.

Free employment advice for disability issues and in some cases support going to an employment tribunal:

Disability Law Service: <http://dls.org.uk/>

If you feel you have been discriminated against, it is important to know your rights and how to complain, for example, against racism:

Equality Act 2010:

<http://www.gov.uk/guidance/equality-act-2010-guidance>

If you encounter discrimination because of age, disability, gender, LGBTQ+, ethnicity or religion and need your trade union:

Trade Unions Congress (TUC):

<http://www.tuc.org.uk/>

Free advice if you feel you are being discriminated against because of pregnancy:

Maternity Action:

<http://maternityaction.org.uk>

