astriid

Employment And Long-Term Illness:
The Invisible Talent Pool

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Exploring Barriers In Recruitment, Job Roles, and Employer-Employee Relationships

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1. Introduction

1.1   Executive Summary

Many people with long-term illnesses wish to engage with meaningful work. However, there are many barriers which prevent these individuals from finding suitable opportunities and from pursuing a career in a way that's inclusive of their needs.

As a platform for matching talented chronically ill people with inclusive work opportunities, Astriid has seen first-hand that in the right environment, engaging with work can transform employees' quality of life for the better, as well as offer valuable benefits for employers and companies. However, the following research project has shown that talented chronically ill people are still being let down by challenges in employment and recruitment.

Despite being a motivated and highly-educated talent pool, we found that many individuals with long-term conditions find it difficult to find suitable opportunities to work – there is a lack of flexible, inclusive opportunities to apply for, and many chronically ill people face additional barriers during the recruitment process. For those who do manage to secure work, many experience issues securing reasonable adjustments, and the toll of working alongside managing their condition has a drastic effect on their mental health and work-life balance. The majority of our sample also strongly felt their employer or line manager could be better informed about their condition and how they can support chronically ill people in the workplace.

Experiences of work vary dramatically between individuals, but our sample overwhelmingly reported a need for more flexible opportunities, increased compassion and understanding, and improved education around long-term illness for employers.

Much of the previous research around accessible employment has focussed solely on the experiences of disabled people, with definitions of disability routinely excluding the unique and categorically different challenges that come with long-term illness. Therefore, we hope this research highlights the need for chronic, long-term conditions to become a more central part of this conversation, and that it facilitates discussions about how the experiences of chronically ill people in work can be improved.

1.2 About Astriid

Astriid's mission is to help people with long-term conditions find meaningful work. Founded by David Shutts OBE following his cancer diagnosis, we believe that the value of work is far more than the wages paid. In the right environment, employment provides routine, a sense of normality, challenges and rewards, and can also facilitate a greater sense of wellbeing in individuals with long-term illnesses.

As a charity, Astriid helps bridge the gap between the Invisible Talent Pool (people who have chronic health conditions who wish to use their skills and experience in work), and the UK skills crisis. Our talented candidates offer an ideal solution to many of the challenges businesses and organisations are facing: the need for bespoke skills, professionals who can work flexibly, and more diverse minds to influence decision-making. It's time the world stops seeing employing people with long-term illnesses as a good deed or an act of charity and recognises it as mutually beneficial for both parties.

As well as matching registered candidates with opportunities which meet their needs, Astriid plays an active role in consulting with employers and helping them to better support chronically ill people in their workplace. In this way, we hope to inform and educate the employment sector about the 'Invisible Talent

Pool' that various industries are yet to tap into.

We also recognise that chronically ill people may be at different stages of their journey, and not everybody will be 'work-ready' when they first approach us. Whilst some candidates may be esteemed and experienced, looking to return to work after a period of absence due to ill health, others may be at the beginning of their path to employment. Therefore, we also support candidates with securing suitable volunteering and work experience opportunities, offering skills and training workshops suitable for their unique requirements, and helping them to develop their CVs. As a charity, we also produce informational resources and advocate for more inclusivity in the workplace, benefitting both employers and prospective employees.

When the time is right, Astriid's online platform is there to match talented work-ready candidates with prospective employers, providing accessible employment opportunities for those who are seeking them. In this way, we hope to make the Invisible Talent Pool, Visible.

1.3 Prominent Long-Term Illnesses in Astriid Candidates

ME/CFS. Myalgic Encephalomyelitis (sometimes known as Chronic Fatigue Syndrome) is a long-term neurological condition, with characteristic symptoms including debilitating fatigue, chronic pain, extreme sensitivity to noise and light, post-exertional malaise, and cognitive impairment. Those with the more severe forms of the condition will be physically unable to work, but those with milder forms may, with suitable support and adjustments, be able to maintain a more typical occupation.

Not everybody with ME/CFS will be capable of or seeking work. However, those who do wish to work require opportunities with flexible, part-time hours so they can 'pace' themselves and manage their condition. Adjustments which may benefit people with ME/CFS include the ability to fit their working hours around their symptoms, working from home, adaptive equipment such as ergonomic chairs or noise-cancelling headphones, some lenience with deadlines, and ongoing communication with employers and peers. Diversity and inclusion training for all staff on chronic conditions may help reduce the potential for stigma and discrimination in the workplace.

Cancer. Cancer is when abnormal cells divide in an uncontrolled way, potentially spreading to other tissues and bodily systems. Different stages and grading of cancer affect individuals in different ways – not all types of cancer are treatable and can lead to mortality, whereas others respond to targeted treatment and lead to a full or partial recovery. Many people with cancer experience relapses and remission which fluctuate over time, depending on the progression of their disease and the treatment options available.

The symptoms of cancer, as well as the side effects of various treatments, can impact individuals' ability to work. Common symptoms which affect working life include widespread pain, severe changes to the digestive system, unpredictable fatigue and cognitive impairment. Additionally, routine appointments, tests and treatment often take place during the day, meaning reduced and flexible working hours to allow for time off work may be necessary. Lived experiences of cancer widely vary between individuals, meaning a more personalised approach to work and reasonable adjustments can be beneficial.

MS. Multiple Sclerosis is a neurological disorder where a person's immune system attacks their nerves by mistake. This can cause widespread symptoms and debilitation, including muscle spasms and tremors, cognitive and speech issues, loss of bladder and bowel control, and more. MS may be relapsing remitting (attacks of new and old symptoms followed by periods of remission), secondary progressive (where symptoms of relapsing remitting MS steadily get worse over time), or primary progressive (where a person's symptoms and overall health continue to decline).

People with MS who want to work may require workplace adaptations, open conversations about reasonable adjustments, and flexibility with working hours in order to manage their condition. Inadequate working policies and a lack of support from employers mean those with more severe health issues are often left with no choice but to leave their job, despite the fact they still wish to work and have valuable skills to offer.

1.4 Illness Variability Between Individuals

It is of utmost important we recognise that long-term illnesses can vary dramatically between individuals. No two people with the same condition and social demographics will experience their illness identically to each other. As such, we must recognise that each individual has unique lived experiences that will translate into meaningful work in varying ways.

2. Key Issues In Employment – Previous Research

Previous research into accessible employment has primarily been conducted with people who identify as disabled, as opposed to having a long-term illness. Although some disabled people will identify as having a long-term illness, and some people with long-term illnesses will identify as disabled, it's important to recognise that these two terms are not synonymous. In fact, many people with energy-limiting chronic illnesses are uncertain of whether or not they should identify as disabled, even if this is essential for accessing support and adjustments in the workplace[1] (Chronic Illness Inclusion Project, 2020).

At present, there is a lack of research focussing on the experiences of people who specifically identify as having a chronic or long-term illness. However, existing research points towards three central issues: a lack of inclusive and flexible opportunities, accessibility issues within job roles, and a lack of support and understanding from employers.

2.1 Finding inclusive, flexible opportunities

Charity reports suggest that traditional 35+ hour a week, full-time jobs are likely to be unsuitable for the majority of jobseekers with long-term illnesses. The primary limitation for people with energy-limiting chronic illnesses may not be the type of work but the amount, with reduced and flexible hours seen as the main reasonable adjustments required[1].

Despite this, it has been concluded in the past that only 6.2% of vacancies in the UK that offered a salary deemed high enough to live on mentioned flexible working options[2]. Since then, no significant policy changes have taken place.
Disabled people also face social barriers when applying for jobs because of ableist recruitment processes[3]

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[1] Chronic Illness Inclusion Project (2020) Submission to the Work and Pensions Committee's enquiry into the disability employment gap. Available at: https://www.centreforwelfarereform.org/uploads/attachment/757/disability-employment-gap-inquiry-submission.pdf (Accessed: 23 February 2021).

[2] All-Party Parliamentary Group for MS (2016) Employment that works: Supporting people with MS in the workplace. Available at: https://www.mssociety.org.uk/sites/default/files/2020-08/Employment-that-works--resource.pdf (Accessed: 23 February 2021).

[3] Scholz, F. (2017) Disability inequality and the recruitment process: responding to legal and technological developments. Doctor of Philosophy. University of Leeds. Available at: http://etheses.whiterose.ac.uk/21449/1/Scholz_F_LUBS_PhD_2017.pdf (Accessed: 23 February 2021).

– ableism referring to discrimination in favour of non-disabled people. Although job applications and interviews are designed to evaluate a candidate's abilities, these processes are designed with the assumption that the applicant will be non-disabled. Employers still do not routinely consider how to make the application process more accessible for people - even among their former employees returning to work after a period of sick leave.

Consequently, many chronically ill people face barriers in finding safe and accessible opportunities to secure work. There is a severe lack of opportunities for flexible and inclusive working, and ableist job application processes make it significantly more difficult for long-term ill people to secure these roles.

2.2 Accessibility issues within the job role

Under the 2010 Equality Act, employers are obligated to make reasonable adjustments, defined by The Advisory, Conciliation and Arbitration Service (ACAS) as 'changes to remove or reduce the effect of an employee's disability so they can do their job'[4].

However, the Business Disability Forum found that 34% of disabled workers did not request reasonable adjustments because they were worried their employer might treat them differently to how they did before. 43% did not make requests simply because they didn't want to approach their employer[5].

Even when reasonable adjustments have been implemented, issues can prevail. Workers with MS have reported stigma and resentment from their colleagues about their reasonable adjustments, 'accompanied by offensive and degrading treatment'. There have also been reports of reasonable adjustments being 'overlooked, ignored, and undermined', which have led to many long-term ill workers feeling forced out of work[6].

It could also be argued that reasonable adjustments have not yet evolved enough to accommodate the unique challenges of long-term illness, such as the need for pacing or to account for fluctuating nature of the symptoms people experience[7].

2.3 Experiences with employers and line managers

Research by the MS Society found that 74% of respondents looking for work feel that employers' attitudes make it hard for them to find a job. This stigma can lead to disability discrimination, and this in turn can lead to individuals being denied training or career progression. Some workers have even reported being the subject of gossip and the butt of offensive jokes due to their condition[8]. Similarly, 18% of managers reported being not very or not at all confident in managing the wider team's attitudes about colleagues working with an adjustment[9].
Some managers hold the view that that staff should only be at work when fully fit[10]. This immediately rules

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[4] ACAS (no date) *Reasonable adjustments.* Available at: https://www.acas.org.uk/reasonable-adjustments#:~:text=A%20'reason-able%20adjustment'%20is%20a,they%20can%20do%20their%20job (Accessed: 23 February 2021).

[5] Business Disability Forum (2020) *The Great Big Workplace Adjustments Survey*. Available at: https://dh1b0dk701o2c.cloudfront.net/prod/uploads/2020/06/The-Great-Big-Workplace-Adjustments-Survey-main-report.pdf (Accessed: 23 February 2021).

[6] All-Party Parliamentary Group for MS (2016)

[7] Booth, S., Price, E. and Walker, E. (2018) 'Fluctuation, invisibility, fatigue – the barriers to maintaining employment with systemic lupus erythematosus: results of an online survey', *Lupus* 27, pp 2284-2291. Available at: https://journals.sagepub.com/doi/pdf/10.1177/0961203318808593 (Accessed: 23 February 2021).

[8] All-Party Parliamentary Group for MS (2016)

[9] Business Disability Forum (2020)

[10] All-Party Parliamentary Group for MS (2016)

out the significant proportion of chronically ill workers who arguably do not feel fully fit at any time, but who still wish to work and are capable of performing their role.

Despite these issues, there are still no accredited training programmes that inform managers of best practice for employees with long-term illnesses. Small and Medium Enterprises (SMEs) in particular have been reported to be more problematic for people with cancer returning to employment, with smaller companies having reduced possibilities for cancer survivors to return to work[11]. This may be due to a lack of resources like occupational health services, and a lack of experience with managing people with long-term conditions. It could also be argued that existing disability inclusion training doesn't necessarily include chronic illness as a separate and meaningful distinction to disability as a whole.

As highlighted previously, much of the existing research in this area focusses on disabled people, or the select experiences of those living with a specific chronic condition. Not all disabled people identify as having a chronic or long-term illness, and not all chronically ill people identify as disabled, and the lived experiences of these two subgroups can differ dramatically in the workplace. Therefore, we hope to examine some of the issues faced in recruitment and employment specifically in relation to long-term illnesses, in order to inform possible steps and interventions to tackle these issues in the future.

3. **Our Findings**

We used an online survey to collect data from participants all over the UK. Some participants were already registered Astriid candidates, others were recruited from wider social media. In total we received 371 responses, and the 136 fully completed surveys were used for data analysis.

100% of respondents identified as having a disability or long-term illness. A wide range of medical conditions were self-reported from our sample, however a significant proportion (60%) of respondents reported a diagnosis of ME/CFS. Throughout the open-ended responses in the survey, participants used variable terms such as 'long-term illness', 'long-term health condition' and 'chronic illness' interchangeably to self-identify – for the purposes of this report, 'long-term illness' will be used as an umbrella phrase to express these variations.

All of our sample had attained a minimum of GCSE qualifications. 46% of our respondents had an undergraduate degree, 22% had a postgraduate degree, and 2% even had a PhD or Doctorate – reflecting a highly educated talent pool. When asked what sector the respondents were currently working in or seeking work in, a diverse range were reported.

3.1   Recruitment

3.1.1 Finding Inclusive, Flexible Roles

52% of our respondents reported that it was difficult, and 28% reported it was very difficult, to find job roles suitable for their health needs. When asked the open-ended question "What do you look for in a job specification when thinking about your health needs? What would encourage you to apply?", three aspects were reported remarkably frequently: **flexible hours** (67%), **home working** (42%), **part-time or reduced**

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[11] European Agency for Safety and Health at Work (2018) *Rehabilitation and return to work after cancer – instruments and practices.* Luxembourg: Publications Office of the European Union. Available at: https://osha.europa.eu/fr/publications/rehabilitation-and-return-work-after-cancer-instruments-and-practices (Accessed: 23 February 2021).

hours (34%), and **less physical labour** (13%). As this was an open-ended question, it seems likely that these percentages may have been even higher if people were asked about each of these aspects directly. Aspects which actively discouraged people from applying predictably were the opposite – strict hours and a lack of flexibility, as well as necessary physical tasks such as manual handling.

Interestingly, many factors that encouraged people to apply for roles fell outside of only the description of the job role and work involved. Open-ended responses also commonly reported that **compassion** (9%) and a **commitment to disability awareness** from employers (22%), **an established sickness policy and support system** (7%), and **the presence of other disabled employees** (2%) also made them more likely to apply.

Table 1: Most common factors that encouraged respondents to apply for job roles

Factors that encourage respondents to apply for job roles	Number of times factor suggested by respondents	Percentage of respondents who suggested factor (%)
Flexible hours	91	66.9
Work from home	64	41.7
Part time/reduced hours	46	33.8
Commitment to disability from employer	18	13.2
Less physical labour	18	13.2
Compassion	12	8.8
Sickness policy and support	9	6.6
Short commutes	8	5.9
Discussion of adjustments	8	5.9
Set rota	6	4.4

3.1.2 Disclosing Health Conditions

Participants had mixed experiences of disclosing their health condition during job applications and interviews. Most reported that they sometimes disclose during applications (35%) and interviews (34%), indicating that their decision is made depending on the specific context. When asked about any positive or negative experiences people of disclosing their condition at this stage, it was clear to see from open-ended responses that **many respondents were concerned about disclosing their long-term illness due to fear of discrimination**, or that it would affect their chances of securing the role. This led to some respondents categorically choosing not to disclose - as one respondent reports, "choosing to do this has prevented me from getting jobs I was more than qualified for" in the past.

Others felt they had no choice but to disclose due to the nature or severity of their long-term condition. One responded reported that "it's a difficult balance as many people feel they have been discriminated against when they disclose [but] I think I'm so ill now that I would need to disclose in order to get the help I need". Others agreed, feeling that "the level of adjustments I need mean that it's worth disclosing ASAP because if it's not going to be accessible for me, I think I'd rather know as soon as poss[ible]."

Other interesting responses from open-ended questions about disclosing conditions revealed strategies and preferred timings during the recruitment process. **Many participants preferred to disclose during interviews rather than on paper**. Some "find it's easier to explain my disability in person, as on paper it could be misinterpreted. In person [recruiters] can see what I can actually do/struggle with" and that face-to-face they can better "gauge the employer's attitude to chronic health conditions".

Others took a more strategic approach, choosing to "leave it to near the end when negotiating working

conditions" as they've "found in the past stating this upfront […] will mean I'm likely to be biased against". Others report they "decide based on the atmosphere at the interview", exhibiting control over how much they choose to share and the likely impact of this on their job prospects.

Another interesting point raised was issues with disclosing conditions on the application forms themselves, as "many online forms only give yes or no as the options for disability - there is no 'prefer not to say' as there is for other protected characteristics". Others reported that **belonging to another minority group made them feel less inclined to share their health status.** As one participant reported, "I'm already disclosing that I'm transgender, which I suspect has prevented the hire in the past. I think disclosing bipolar and transgender would probably cost me most jobs!".

3.1.3 Discussions During Applications and Interviews

Government policy states that employers can only ask about health or disability during recruitment 'if there are necessary requirements of the job that cannot be met with reasonable adjustments'[12]. However, 37% of our sample report they have been questioned about their health during the recruitment stage. In some cases, open-ended responses showed this led to a positive encounter where the interviewee could help the recruiter better understand their situation – in these cases, participants were asked variations of "what [their diagnosis] means and how it affects me and my work life", presumably for employers to better understand what support would be required if they were to land the role.

However, others report painful experiences of disclosing their condition. These ranged from the professional ("Initially it seems they see me as intelligent, competent and professional, but once my disability is disclosed, they often begin talking to me as if I'm stupid or incapable") to the personal ("I believe an employer told me to try weight watchers as she had previously had chronic fatigue syndrome"). One interviewee, after enquiring about how flexible the hours were, was "told by a recruiter to be careful not to come across like I only care about the time off and benefits".

Fortunately, more positive experiences were reported in these open-ended questions too. One respondent had a positive experience with requesting reasonable adjustments during the recruitment process ("the HR lady leading this part of the process made me feel completely normal"), and another felt "able to discuss my illness and working requirements completely openly without any judgement.".

Crucially, **a significant number of our respondents had learned how to use their condition to demonstrate their employability** during the recruitment stage. shared how their health challenges demonstrate transferrable skills ("I see my disability as being a strength and demonstrates resilience") and their personal assets ("I sometimes use details of my illness as a situation I've had to grow from […]. I had an HR rep say to me that that section of my application was really good"). Others show how their unique circumstances make them better equipped to work in the job role or sector they're interested in ("I wrote in my application how I felt my health issues helped me understand and appreciate equality and diversity").

Although some people would welcome the opportunity to talk about their condition during recruitment, so as to dismantle any stigma or assumptions, others felt there were better ways of facilitating this than during this stage. One, for example, were surprised to see that interviewers "had the information that I had submitted to HR in front of them" rather than having the same anonymity and impartiality at this stage of the process that non-disabled applicants would have.

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[12] UK government (no date) *Employers: preventing discrimination.* Available at: https://www.gov.uk/employer-preventing-discrimination/recruitment (Accessed: 23 February 2021).

For those who did choose to engage in discussions at this stage, **many (38%) felt their health needs were not taken seriously** and others (30%) had mixed thoughts on this topic. Disappointingly, participants reported being "made to feel like a waste of time and energy", being "told a lot of times 'we've taken a chance on you' which I don't feel would have been said to someone who wasn't ill", and feeling like they are "just there as a tick box exercise".

As one respondent aptly puts it: "I strongly feel that [asking about health conditions] should NOT be part of the interview process - a discuss[ion] around conditions and disability should be separate to the interview and should be done in a way that is neutral and done in a way that is sensitive to the personal details shared. It should be an arranged meeting specifically to talk about the adjustments needed - what you are able to do, what you need support to do and what these adjustments might look like."

3.1.4 Reasonable Adjustments During Recruitment

When asked open-ended questions about what would make the recruitment process feel more accessible, the preference of the majority would be **for application processes to be more simple and flexible**. Having access to **interview questions in advance** (5%) and **more time to answer questions** (2%) would reportedly enable people to pace themselves in a way that suits their condition management, as would **the option to save and return to online application questions** (2%). Some also felt that **more understanding** (13%) and **training for employers on flexible working and long-term illness** (4%) would be beneficial.

The most common adjustment that respondents wished for was for interviews to be conducted remotely (18%). Many preferred to take part in video calls rather than physically attend interviews, especially for initial interviews. A remarkable number of respondents cited how this adjustment, which became a necessity during the pandemic to reduce travel and maintain social distancing, has hugely improved their experiences of seeking work and how they hope it will remain even after it is no longer a necessity. Online interviews of this kind were found to be helpful for individuals' condition management ("being able to have a Skype kind of interview would be helpful subject to distance to interview and or how I feel on any given day which is hard to predict") as well as interview performance ("my body and mind aren't tired from making my way to a specific venue" and "I'm less anxious so […] I can be my best self for the interview").

Generally speaking, however, responses to this question were mixed. Some respondents would prefer more anonymity, others wanted a less formal and more personal approach. Some would prefer all interviews and assessment tasks to take place over a single day so they can better manage nerves and adrenaline, others would prefer more time between them so they can pace themselves. Some preferred more person-facing conversations where they can explain their skills, others felt that task-based assessments were more accessible and reduced discrimination. The bottom line, therefore, seems to be that a **more individualised application and interview process could ensure talented workers with long-term illnesses do not slip through the net when employers are recruiting for a role.**

3.2 Accessibility Issues Within Job Roles

3.2.1 Reasonable Adjustments In Work

Our respondents cited various reasonable adjustments that they believed would help them accommodate their condition in work. They can widely be grouped as the following:

- Flexibility with hours and working times (58%), including the ability to take breaks (21%)
- Working from home and remote working (46%) - all of the time or some of the time e.g. a few days per week

- Practical support in the workplace, such as quiet spaces to rest in (20%) and ergonomic equipment to help manage symptoms e.g. specialist chairs for desk-based roles (26%)

Despite reasonable adjustments being a legal requirement, **almost half of our sample (48%) reported it was difficult to secure necessary adjustments in their workplace.** Qualitative responses to this question implied that experiences vary depending on the process an individual must go through to secure their adjustments ("It depends on the person - I used to have a fantastic line manager and facilities team who were understanding, but my HR dept. wasn't so much. I had trouble finding the energy to fight for myself and my needs with them"), including the person they report to ("It has depended on the manager. Each interprets the policies differently").

3.2.2 Work-life balance

A fact that often goes unrecognised by those unaffected by long-term illness is that **those who are able to work in some capacity often have to make huge sacrifices to do so** – when asked to discuss their work-life balance in an open-ended question, 66% of respondents who are currently in work reported that their work-life balance is poor.

The 24% who reported their work-life balance was good tended to have reasonable adjustments ("now I work from home thanks to Covid [...] my balance is much better and I have energy to do other things") and/or more flexible jobs ("Working a small number of hours a week allows me to rest and still have a life outside of work") in place. Once again, this highlights the crucial need for more inclusive roles with fewer hours and increased flexibility that many people with long-term illnesses reqire. However, **an issue commonly cited by those who have more flexible jobs was the negative financial impact of this**. Working fewer hours was of course reported to require "a financial sacrifice", making it necessary to depend on others for support ("I have to rely on my boyfriend financially which I hate").

Among those who reported a poor work-life balance, **fatigue and exhaustion-related symptoms seemed to be a central issue**. Many people have to give all their useable-energy to their work ("There is no balance. I have to work and it uses all my energy"), and the 'payback' (post-exertional malaise) from this seeps into their lives outside of work hours too ("I crash every evening and weekend"). The decision to work therefore requires compromises in other areas of life, including personal hobbies ("I no longer horse ride, I don't walk like I used to") and social life ("I have sacrificed my social life to be able to continue working. Working 2 days a week means I'm unable to do anything else.").

Given these findings, there were unsurprisingly mixed reports on the impact of being in work on respondents' self-esteem mental health. However, it was clear to see from the qualitative data that experiences were more positive when participants felt supported in their role ("when in a positive working environment with understanding and supportive manager and team then there is a positive impact on your mental health"), and negative when they reported ongoing issues in their job role or working environment ("work related stress/disability discrimination has had a detrimental effect on my wellbeing").

These issues are also reflected in the experiences of people with long-term conditions who are currently seeking work, as opposed to in currently in work. Not one respondent currently seeking work felt this had had a solely positive impact on their mental health or self-esteem, with 76% reporting a negative impact and the remaining participants citing mixed responses. The simple act of searching for jobs can feel demoralising ("it's discouraging to have to automatically rule out so many jobs immediately. I sometimes feel depressed by the lack of options"), as can the process of applying ("Every ableist job advert is so upsetting. There are so many barriers for a disabled person and applications are so tiring").

In other cases, the experience of constantly being rejected or deterred from recruitment processes was

reported to feel similarly difficult. As one participant relates, "I have found myself feeling quite down when searching for jobs, often finding fault with myself […]. I work hard to keep myself motivated, but some weeks the thought of applying for jobs, or searching for jobs and not finding any is too great." Another feels they are "treated like I'm stupid or to be pitied. I feel like no one sees my worth as an individual or an employee. I feel like I'm treated as a liability, and like the effort they would need to put in to support me isn't worth it to them. Despite my experience, and my skills, I'm no one's ideal candidate."

3.2.3 Impact Of Work On Quality Of Life

Despite these countless barriers, however, it was clear from the data just how impactful suitable work can be on a person's quality of life. When asked open-ended questions about their reasons for seeking work, participants' responses stretched far beyond only the financial impact of earning an income – they also include a desire to make a difference ("I want to contribute to society and feel I have a purpose and can use the skills and knowledge I have to help others"), rediscovering their identity in the face of disability ("I have lost my identity and work was such a huge part of that. I don't even know who I am anymore"), and achieving personal goals ("don't want my disabilities to mean that I can't complete what I've been aiming for, for the last five or six years prior to becoming disabled").

Those who are currently struggling in work reported feeling discontented ("resentful I have to use what little energy I have to work, I want to use it for my daughter and to enjoy life") and categorically different from those around them ("It makes me sad that I can't be like other people who live normal lives without being Inhibited by a health condition").

However, those in better suited and more inclusive roles report notably different thoughts, including "[feeling] valued and useful" and that work is "allow[ing] me to feel productive, like I have a reason to exist". Many in this position also report "a sense of purpose, belonging and achievement" which in turn has positive effects on their self-esteem and mental health. As one candidate aptly puts it, "although it took years to realise it I have become very proud of what I do because despite my health I am delivering to the same level and in some cases better than my colleagues who aren't chronically ill.". These findings reflect Astriid's belief that **in the right environment, meaningful work can transform a person's life for the better.**

3.3 Experiences With Employers And Line Managers

3.3.1 Meeting Needs and Adjustments

Our findings confirmed that professional relationships with employers and line managers can play a pivotal role in a person's experience of work. **26% of our sample currently in work felt their health needs and adjustments were not taken seriously by their manager**, and a further 32% felt their experiences were only taken seriously sometimes. When asked open-ended questions about experiences of communicating with managers about health needs, reasons included perceiving managers to feel awkward about discussing health needs ("Often they seem a bit embarrassed / confused / scared – […] they seem unsure how to handle me - which just increases my fear of becoming too much of a problem"), stigma and unhelpful assumptions about long-term illness ("One manager said she didn't think I was 'that sort of person' when I received my diagnosis") and hostility around reasonable adjustments and absences ("I was made to feel guilty about the number of sick days I had taken in a year").

3.3.2 Information and Communication

However, 37% of respondents felt their needs were taken seriously. Examples of positive experiences included **regular and open communication with superiors** ("My manager makes a regular point of asking

at my annual review about how my health is and allows a good amount of time for us to talk about it. I could approach him in between too if it was necessary"), managers **trusting and respecting individuals' self-imposed capabilities** ("she trusted my judgement on when I needed to rest/delegate work"), and proactively **making contingency plans in case of ill health** ("We have a 1-10 scale, with pre-decided action points of what to do when I'm not functioning as well, when I need to take a sick day to rest, etc. I also wrote her a glossary of how I describe my symptoms and she's researched each and every one so she understands what I mean, which is above and beyond what I'd expect").

Although these responses reflected a wide range of experiences, **89% of individuals agreed that line managers or senior staff members could be better informed about managing people with long-term health conditions**.

When asked how this could be facilitated, increased training was recommended by over half of the sample in qualitative responses, with an emphasis on empathy and active listening. Areas of training candidates would like to see offered to senior and line managers could be grouped into the following areas:

- Awareness training specifically related to fluctuating and invisible illnesses, and the common symptoms of these
- Practical support with how health conditions can best be managed in the workplace, reiterating the individuality of these conditions and how they affect everybody differently
- Tackling unconscious bias about disabled workers and promoting equality, reinforcing the benefits of employing disabled talent
- Active listening, group empathy, and treating people with respect

Many felt managers would also benefit from health-related resources from charities, increased awareness of Access To Work and Disability Confident schemes, and more established guidelines and equality regulations to adhere to.

Respondents also highlighted interesting measures that could be implemented on a smaller scale. These included **disabled consultants in the workplace, clarity on internal processes** such as HR and Occupational Therapy**, availability of one-to-one coaching or therapy,** and **standards and performance measures tied to inclusion**. The feasibility of implementing such suggestions will obviously vary depending on the size and nature of organisations, and indicates there is a need for further conversations about how bespoke support of this kind could be distributed.

4.Conclusions

4.1 Directions for the Future

89% of our participants feel their health condition has had an impact on their career prospects – an unacceptable finding. People currently feel limited by the lack of suitable jobs they can apply for ("many jobs are ruled out straight away because of being too physical or too long hours etc. I wish there were more jobs available for me to choose from"), being prevented from promotions due to conflict between reasonable adjustments and the expectations of more senior workers ("I am part time and this is not expected at a more senior level"), and feeling obliged to stay within the same company due to worrying their needs will not be met elsewhere ("I'm scared of the thought of being rejected or not being able to step into the unknown").

In the future, participants would like to see **more flexibility, increased compassion and understanding, and**

improved education around long-term illness. They also reported **a desire for mentors, advocates, and more advice on their career and their rights**. Each of these responses warrants further research to explore how they could best be implemented.

The common theme among these qualitative responses was the need to tackle perceptions of long-term health conditions in the workplace and address the current lack of support in this area. Respondents feel "there is a lack of education in employers about the impact of living with a long-term chronic condition", leading to reports of unhelpful assumptions such as "either you're not well enough to work or you're well enough to work. There seems to be no consideration about people who fall between the two".

Participants want "dedicated agencies, who focus on everything you can do (and the fact that you really do want to work), instead of focusing negatively on your limitations" and "specific websites and services to support those with long term health conditions", as well as for "'inclusive employers […] to be somehow pointed out on normal jobs websites too". In short, respondents want more hands-on support and practical resources for chronically ill workers, and for these things to become more mainstream… and this is why Astriid's work is so vital.

Though not prompted to speak about Astriid specifically, many respondents highlighted how Astriid is "the first charity [they've] heard of who do help properly", and how "Astriid have been incredible so far. Not many other organisations that I've seen that help a great deal."

This project has highlighted the categorical difference between the experiences of disabled people seeking work as highlighted in previous research, and the unique and widely unacknowledged experiences of those with long-term illnesses. Our findings confirm that the UK's current working climate is letting down people with long-term conditions - skilled individuals are being excluded from employment simply due to having a health condition, which in turn means UK businesses are missing out on a huge talent pool which could enhance their performance.

Though the global pandemic was not a central part of our research, findings indicated that lockdown has in some ways made engaging with work more accessible for people with long-term illnesses. Despite this, Astriid has seen a decrease in the number of companies registering as employers and listing inclusive roles since the pandemic began. Recent research by Leonard Cheshire found that 42% of UK employers indicated that coronavirus had made them more hesitant to employ disabled workers, reportedly due to concerns around supporting them properly during the pandemic[13] – indicating what seems to be a missed opportunity to harness lessons learned from lockdown and encourage the sector to evolve. We must challenge this trend ensure commitments to diversity and inclusion are not compromised as a result of external circumstances – now, or in the future.

The lack of flexible, part-time roles excludes many people from entering or returning to the world of work. Accessibility issues within the job or working environment can lead to people feeling forced out. Managers need to be better informed about long-term illnesses.
However, when people have access to more flexible and accommodating work, have career prospects, and openly communicate about their needs with those around them, the transformative effect this can have on mental health, self-esteem and overall quality of life is undeniable.

4.2 Recommendations For Future Research
This is the first research project that Astriid has conducted, and our findings have highlighted multiple areas

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[13] Leonard Cheshire (2020) *Locked out of the labour market.* Available at: https://www.leonardcheshire.org/sites/default/files/2020-10/Locked-out-of-labour-market.pdf (Accessed: 23 February 2021).

where further investigation is warranted.

The primary limitation of this particular piece of work was the lack of demographic data collected for our participants, such as age and gender – a decision that was made to reduce the length of the survey and make it more accessible for those with limited energy, as well as ensure anonymity. However, the high number of partially completed responses indicates that this survey still felt too long for many respondents, and that having a greater proportion of quantitative rather than qualitative questions may have been beneficial. In future research, even more care will be taken to make data collection methods as succinct and energy-efficient as possible, whilst still collecting vital demographic data, exploring people's lived experiences, and ensuring anonymity for those who require it.

In conclusion, this report has uncovered the need for further research in the following areas:

- Similar data collection conducted with employers, investigating attitudes towards employing chronically ill people, the perceived benefits and costs of this, and how more inclusive roles can be created and fulfilled.

- Further investigation into reasonable adjustments specifically related to long-term illness, and how these can be more readily implemented for those who request them.

- A closer examination of the experiences and perceptions of employers towards chronically ill employees, investigating how perceived barriers can be addressed and how the working relationship between employer and employee can be improved.

These findings highlight the need for continued support and advocacy for people with long-term illnesses who are seeking meaningful work. Astriid is committed to this cause and ideally placed to tackle the issues raised by our findings.

However, meaningful change cannot be guaranteed without the backing of businesses, professionals, and the wider employment sector. As such, we ask for your support in spreading the word about the **#InvisibleTalentPool** and the challenges of working with a long-term illness faced in this current climate. To find out more about Astriid and to get in touch, visit our website at Astriid.org.uk.

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