

Disabled People's Experiences of Work-Related Systems

Early Insights Report

Produced by Difference North East as part of
the Economic Inactivity Trailblazer Making Every
Contact Count for Work (Disabled People)

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About This Report

Approach and Perspective

This report looks at disabled people's experiences of work over time, including periods when they are not actively looking for jobs or available for work, often described as economic inactivity.

Participants described their relationship with work as something that changed across their lives, influenced by health, caring responsibilities, financial security, and previous experiences of employment and work-related systems. Many did not use the language of "economic inactivity" themselves, instead talking about what felt possible or manageable at different points in time.

The report reflects this wider picture, bringing together experiences of looking for work, being in work, staying in work, and stepping back when work was not possible or sustainable. Economic inactivity is therefore not treated as a standalone issue, but as part of disabled people's working lives as a whole.

We use a social model approach, focusing on how systems, processes, and attitudes create barriers, rather than locating the problem within individuals.

The report explores where current systems support disabled people well, where they fall short, and what disabled people say would make work feel safer and more sustainable.

Purpose and Scope

In this work, we share disabled people's experiences of work-related systems.

All quotes in this report are verbatim and come from disabled people who contributed to this research. Quotes are anonymised to protect people's privacy.

Our aims are to:

- Share the main themes so far.
- Share people's experiences of how work systems respond, including where things work well and where gaps remain.
- Highlight how risk, trust, and sustainability shape disabled people's decisions about work, including whether and how they engage with job-seeking and work-related systems.
- Help inform the next stage of evidence gathering and planning.

Method

The research for this report was led by disabled people, informed and analysed by disabled people, and the recommendations are produced by disabled people; it is entirely user-led. The research methodology incorporates qualitative participatory research approaches which ensures that the findings that we have produced are based on the collective experiences of disabled people.

The research was informed and steered by an advisory group made up of disabled people from the North East Combined Authority's geographical footprint. Eight people with a range of impairments met each month and examined in detail the issues surrounding employment and disabled people. These critical reflective workshops were complemented by other detailed interviews with disabled people and employers.

The data produced were recorded and thematically analysed using Glaser and Strauss' grounded theory and constant comparative analysis (Glaser & Strauss, 1967). The report is constructed and presented in line with that thematic analysis.

Assumptions

Disabled people live with and often struggle against the language that is used by non-disabled people to describe and categorise them. These words often produce an unwelcome framing of what it is like to be a disabled person living in the North East. In the original outline and conception of this project, the term economically inactive was used to describe a type of person that the research was interested in finding out more about.

The term economically inactive implies a number of meanings, many of which are underpinned by the concept of worth and value: economically active equals good; economically inactive means not good. As you can imagine, immediately associating these terms with disabled people, responds to an ableist agenda, and create barriers to their involvement in any such research.

However, after building trust with our advisory group, we did examine this term with disabled people, and this is what we found:

1. Economic inactivity only really happened when somebody was ill or too sick to work. Because many disabled people live with ill health and chronic conditions,

some people became economically inactive for a period but then became economically active again when they were well enough to work.

2. Disabled people often occupy a multitude of positions throughout their life which vary as their life career changes, for example, one person will be employed, unemployed, looking for work, too sick to work, or involved in caring roles themselves for family members or children. There are only a very small proportion of people who remain too sick to work for much of their lives and in many cases the experiences of barriers to employment can exacerbate this position.

3. Disabled people define their involvement in employment/economic activity through their experience of barriers which make it impossible or very difficult to find or maintain employment.

4. Decisions which are taken by disabled people are mitigated by a number of different factors including their own health [will working make me more ill?], maintaining a minimum household income [is coming off benefits worth it and the risk of having to reapply if work does not work out] their own caring responsibilities [will somebody else suffer if I have to go to work?] and other varied risk management approaches.

5. Disabled people think it is better to frame this exercise as one which seeks to remove the barriers to employment which make decisions about entering the jobs market much more straightforward.

These findings suggest that economic inactivity is not a fixed identity, but a fluctuating position shaped by health, systems, and risk. Future phases of research could explore in greater depth how policy and employment systems might reduce risk and remove barriers, thereby enabling more stable and voluntary participation in work.

Where These Insights Come From

This report draws on:

- Written contributions from disabled people.
- Advisory group discussions held from December 2025 to February 2026.
- One-to-one conversations with disabled people about their experiences.

Section 1: What We Are Hearing So Far

The experiences described in this section reflect disabled people's interactions with work at different points in their lives, including times when work was neither sustainable nor safe to pursue.

Across the themes below, people described weighing risk and trust when making decisions about work, rather than a lack of aspiration or willingness to try work.

Wanting to Work

Many participants described wanting to work or to return to work, but feeling unable to try because of the risks involved if it was not sustainable. This came through most strongly among people who had been out of work for a long time, were managing fluctuating health, or had already been told they were not fit for work at this time.

People described wanting to approach work cautiously, to understand what they could manage in practice. The concern was often not whether work might be possible on a good day, but what would happen if it could not be sustained. Several people felt blocked by benefits rules, assessments, and a lack of secure routes back if things changed.

"It's actually a system that prevents me from, like, dipping my toes into the water."

Trying work was described as a high-risk decision. People talked about the possibility of losing income, risking their housing, or struggling to get back onto the right benefits if the work did not last. For some, this meant that even when they wanted to work, the safest option felt to remain in their current situation.

"How long would I last consistently, and then would I be penalised for trying?"

For parents, these risks extended beyond themselves. People described having to weigh up the impact on their children and the security of their home, not just their own health.

"If I take a job and after three months I can't manage it, I've got a little boy that needs housing as well. It's not just me."

Several participants described holding back from work, not because of a lack of aspiration, but because they were trying to avoid instability and systems that felt difficult to navigate once they were in them.

"I'm just wary of being possibly penalised for trying."

For many, the solution was not more encouragement to work, but the ability to try work and to return to financial support at the point they had left, if it was not sustainable.

Making it Safer to Try Work

In response to the risks described above, people spoke about what would make trying work feel safer and more manageable, and what would need to change for them to feel confident enough to try.

Several people said they would want to approach work slowly and cautiously, to understand what they could manage in practice. The issue was not whether work might be possible on a good day, but whether it could be tested safely without long-term consequences if it did not last.

People suggested options such as short trial or shadowing periods where benefits continue, clearer routes back into financial support if a role is not sustainable, and mentoring to support routines, confidence, and transitions.

People said it would feel very different to try work if nothing changed financially at the start. As one person said:

“If you had that trial week where nothing changed financially, you’ve lost nothing, but you’ve taken that step.”

Other participants felt strongly that feeling safe to try work meant having enough time to understand, over a longer period, whether work would be sustainable for them. One participant explained that short trial periods do not work for people with fluctuating conditions, particularly where health and energy are affected by seasonal changes. What feels manageable for a few months does not necessarily reflect how someone will cope across a full year.

For these participants, safety was closely linked to knowing that they could step back if work was not sustainable, without facing unintended long-term consequences. Feeling safe to try work meant having a clear guarantee that they would be able to return to benefits at the same rate, and without further assessments, for a defined period. This was particularly important for people who had already been through appeals, mandatory reconsiderations, or tribunals related to their benefit entitlement, and who understood the time, stress, and uncertainty involved in re-entering those systems.

One participant described how previous experience of reassessment shaped their confidence about trying work:

"If you're removing your benefit... you know how bad the system is to then go back into the system and have to fight."

Participants were also clear about the risks if these approaches were not carefully designed. Without clear rules and protections, trial periods could slip into unpaid work or leave people exposed, with no clarity about pay, rights, or what happens next.

The risk of exploitation was highlighted starkly:

"Someone worked for a supermarket for years for nothing, and when his mum asked them to pay him, they sacked him."

Making it safer to try work means reducing risk without creating income insecurity and ensuring that work trials are designed to help individuals test whether a role is sustainable for them, rather than to assess their suitability for the employer.

Getting into Work and Staying in Work

Participants consistently described a clear difference between the challenges of getting into work and those of staying in work or returning to work.

Employment systems were often experienced as focused on recruitment and job entry. Far less attention was paid to what happens once a job starts, or when someone tries to remain in work or return after a period of ill health. Participants described limited support for managing change, responding to fluctuating conditions, or preventing pressure from building into crisis or burnout.

People told us that once they are in work, or attempting to return to work, they are often left to manage difficulties on their own. This was particularly challenging for people with fluctuating conditions, limited energy, or additional pressures outside work.

Several participants described being pushed out of work or written off, despite wanting to contribute.

"I still feel I've got a lot to give to the employment market, but get blocked at every single turn."

For some, being blocked did not stem from an inability to do the job, but from how employers assessed and managed risk. One participant described wanting to work and being able to see a route back into work, but being repeatedly stopped at the point where Occupational Health became involved.

Although he believed adjustments could make work possible, employers told him it was not safe for him to work. Decisions about risk were made for him rather than with him, closing down options instead of exploring how work could be made safe and sustainable.

“As soon as we get to the Occupational Health stage, that’s when everything falls apart.”

For some participants, these experiences were compounded by problems with formal work-related schemes such as Access to Work. Delays, reductions, or changes meant support did not arrive when it was needed, or was withdrawn in ways that made continuing in work impossible.

“I got it on the last day of finishing the job... I had it for one day.”

Independent Support

People described a gap in support that could be met with a service independent of the DWP. The importance of independence came through strongly in discussions. Even in this trailblazer work, which was led by a Disabled People’s Organisation, some participants spoke about approaching it with caution because of previous experiences with government systems or initiatives.

One participant described feeling “slightly sceptical” about whether proposals from this work would be taken forward:

“The question is, what weight is this going to actually be given in reality?”

Participants also reflected on the wider context in which many employment initiatives operate:

“And all of these projects are about getting inactive people, disabled people, back into employment... But what worries me is when they set a target out, it's it's almost like the disabled person loses who they are. They just become almost like a sheep or a number in the government strategy of getting people back to work.”

These reflections help explain why independence mattered so strongly in discussions about support.

People also described wanting to access to someone independent of the DWP who they could speak to openly about looking for work, help with job applications, preparing for interviews, and support and advice to stay in work when something changes, without fear of consequences. They were clear that they did not want a service like this to feel like monitoring on behalf of the DWP.

The call for independent person-centred support came about, in part, as jobcentre interactions were often described as brief and transactional, offering little beyond compliance:

“If I waited for the job centre to do it, I would never have worked.”

For many, benefit-linked work schemes felt evaluative rather than supportive. People worried that what they shared could be used to judge or reassess them, or to push them towards work before they felt ready:

"I'm not the biggest fan of government funded projects or DWP projects, because I'm always worried that it's kind of a test."

Where people had access to support outside the DWP, the experience felt fundamentally different. It moved at the person's pace, focused on confidence and practical steps, and did not centre on returning to work as the only goal:

"They don't talk about returning to work all the time. They go at what level I want."

Independent support was seen as essential in making work feel safer and more sustainable. Participants described the importance of having someone who was focused on their well-being rather than organisational or performance priorities. This kind of support created space to talk honestly, to notice early signs that adjustments might be needed, and to think through next steps without pressure. Independence mattered because it allowed people to seek help without worrying that doing so would have negative consequences at work.

"I need someone who's there for me... not on the best interests of the company."

This kind of support felt neutral and safe because it was clearly separate from benefit decisions and employment outcomes. People said this made it easier to be honest about what they could and could not manage, without worrying about repercussions:

"If an independent person or organisation holds that pot of money, you can be completely open, because there are no repercussions for your employment."

These experiences point to a missing layer of trusted, independent support, focused on helping people navigate work over time rather than assessing readiness or compliance.

Ongoing support was seen as particularly important:

"Their help doesn't just stop there, like tick, she's got the job. They support you throughout your journey, which is really important."

These gaps in support were closely linked to wider questions about energy, sustainability, and whether work could be balanced with the rest of people's lives.

Life Outside Work

A recurring theme was how work affects people's energy and their lives outside their jobs.

Some participants reported that they gave their maximum effort for 7 to 8 hours per day. They could do their job, but had little or no energy left for housework, caring for others, socialising, rest, or enjoyment. Over time, this led to exhaustion, burnout, or the need for time off work.

A “successful” job outcome on paper can have a high personal cost. Caring for children, family, or others adds further strain, yet employment systems often do not account for these roles, even though they have a significant impact on wellbeing and staying in work.

People questioned how success is measured and pointed to the invisible effort that sustains employment:

“So it isn't necessarily always really good employer practice. It's actually all the support network and sheer effort that's going on around that that is sustaining a lot of people to remain in work.”

Some described only being able to work by sacrificing parts of life that non-disabled colleagues are able to maintain alongside employment:

“You might be able to spend six or seven hours a day doing the job, but then when you have to return to your household... cooking and cleaning and washing and ironing and all the rest of it... Who's going to do that? Because I'm absolutely done in now.”

This challenges how employment success is often measured. People talked about whether work could be sustained alongside the rest of their lives, not just whether they could meet required hours. Energy levels and quality of life outside work mattered.

When this is ignored, short-term outcomes can be prioritised over people's wellbeing and their ability to stay in work over time.

Disclosure

In discussions, “disclosure” was not a simple decision. People described having to repeatedly decide whether, when, and how to share information about their impairment or health. This included during applications, interviews, starting a job, or later in their employment. Disclosure was almost always experienced as risky rather than reassuring.

Participants described the risks of disclosure at the application and interview stage:

“I have struggled with employment, especially at the point of, do you disclose at the application stage, do you disclose and or at the interview? And so, I feel for a lot of years, I've not admitted that I have a disability because I don't want to be tracked differently to anybody else in the application process.”

Disclosure was also described as an ongoing uncertainty, particularly after periods of absence or when circumstances changed:

“...knowing what to disclose and when it's a very fine line. And that doesn't just go for applications. I also feel like when you've taken a period of absence from work, knowing how much or how little to say to line managers and senior managers can be quite a difficult thing to navigate...”

For some, disclosure had direct and negative consequences at work:

“I was going to my employer and talking about my difficulties and everything, then... they used what I was telling them as a way to basically remove me.”

Negative experiences at work do not end when the job does. These experiences shape future decisions about disclosure and trust.

This shows that policies alone are not enough. How disclosure is experienced and what people have lived through before matter as much as how systems work in practice.

Trust in Work-Systems

Trust played a central role in how people experienced work-related systems. Where trust was low, these systems were more often described as another barrier rather than a source of support.

People talked about being monitored, checked, or questioned through benefit assessments, work capability checks, and DWP-linked programmes. This shaped whether they felt able to share information openly or felt the need to protect themselves from it being used against them.

These experiences did not sit separately from decisions about work. For many people, past interactions with assessment and benefits systems shaped how safe it felt to try.

Several participants described holding back from work because of what they believed would happen if it did not work out. This was not about a lack of motivation or desire to contribute. It was about protecting stability in income, housing, and support, and avoiding systems that felt difficult to navigate once you were in them.

For people who had already been through work capability assessments, particularly when the process felt inconsistent or difficult to challenge, trying to work could feel risky if there was no clear route back if circumstances changed.

“I'm just wary of being possibly penalised for trying.”

Participants also spoke about ongoing reviews and checks continuing even when medical evidence was already in place, and their situation had not changed.

Rather than feeling supported, this created a sense of being repeatedly examined or questioned. Over time, this made people more guarded about what they shared and more cautious about engaging at all, especially where pain, energy, or mental health fluctuated day to day.

“So everything does feel like a test, and you do feel as if you’ve been scrutinised, even when you’ve got all of your medical information in front of you.”

As a result, people often approached new jobs already cautious about disclosure or asking for help, particularly where systems focused more on compliance and checking than understanding. People described feeling treated with suspicion and having to repeatedly justify their circumstances.

When people felt trusted, they spoke up earlier, asked for help before problems escalated, and were more likely to stay in work rather than leave or burn out.

Participants were clear that trust should not depend on having the “right” manager or a particularly supportive relationship at work. Instead, people said that systems themselves needed to feel safe and consistent, so that asking for help did not depend on individual personalities or goodwill.

Even when help was available, asking for it could still feel risky:

“If I was going to my line manager saying, I'm struggling with this and I'm struggling with that, then that's all noted down, and often their motivation isn't to assist me as an employee.”

Building Trust in Work-Systems

Before entering work, trust would be stronger if:

- Processes assume people are honest, rather than requiring them to repeatedly prove their needs.
- There is a support system in place if things go wrong, instead of people feeling blamed for a lack of resilience.

Trust was stronger in employment when:

- Wellbeing conversations were clearly separate from performance management, so people could ask for help without fear.
- There are clear boundaries on how information is used, including what it will not be used for.
- Arrangements continued even when managers changed, teams restructured, or roles shifted.

Trust isn't built simply by having help available. It depends on whether people feel safe using what is in place.

Where arrangements placed the burden on individuals to ask for help, people described feeling blamed or judged:

"I see that as a failure in me, because I'm having to ask for help... whereas if they were coming to me... I'm probably more likely to be truthful."

These experiences affect whether people stay in work over time. When the support available at work feels safe to access, people are more likely to ask for help early, before problems escalate. This can prevent situations from reaching a crisis point and reduce the risk of sudden departures or burnout. Where trust is missing, people delay asking for help or avoid it altogether, even when arrangements exist on paper.

The Role of a Trusted Person

Disabled people identified the importance of trusted support in work that sits outside line management and performance processes. Having access to independent support was seen as reducing risk, increasing trust, and making work feel safer and more sustainable.

People described the value of having someone they could turn to both inside and outside the workplace:

"I don't think it should be one or the other... you do need that person outside of work... but you also need somebody as a support mechanism when you're in work."

People discussed the limits of what line managers can reasonably offer, particularly when support is needed over a long period rather than at a single point in time.

In contrast, trusted support outside line management was described as focused on well-being rather than performance. This included helping people notice early signs that changes or adjustments might be needed, creating space for honest conversations without fear of consequences, and supporting routines, confidence, and transitions into and within work.

People also described wanting different roles to be responsible for different aspects of support at work:

"I would be happy for day to day working to fall under a new line manager, but my kind of mental health and well being side is to fall under the same person still."

In some cases, advocacy from a health professional made a practical difference:

"...I had my nurse to advocate on my behalf, with my permission, and she spoke to my employer... I wanted some distance between my well capable self showing up

at work and getting on and this unwell person I'd been in a time of crisis and left them to kind of deal with that, and that worked for me."

There was strong agreement that this kind of support should not be tied to performance management, disciplinary processes, or monitoring.

Existing options such as helplines, short-term counselling, or occupational health assessments were often not enough. People described these as lacking continuity, independence, and trust.

Independence itself was seen as important:

"If you're anxious and overthink things, an independent person or organisation holding the money that supports us would definitely be helpful."

People also discussed whether wellbeing should be treated as a disability-specific issue or as part of a wider, inclusive workplace culture. Approaches that were open to everyone, while still flexible to individual circumstances, were seen as reducing stigma and avoiding singling out disabled people.

Flexibility

For people considering a move into work, flexibility was a key factor in whether a role felt possible to take on. Participants described weighing up not just the job itself, but whether there would be enough flexibility early on to manage health, energy, or caring responsibilities.

Flexibility was seen as central to the sustainability of work. Problems arose for people when flexibility was only available after probation, treated as an exception, or made dependent on disclosure.

People with fluctuating conditions described how a lack of flexibility during probation left them with no room to adjust:

"There's quite a lot of jobs that say they offer flexi time, but you have to have passed probation. If you have a fluctuating condition, you can't just not have that fluctuating condition for six months."

When flexibility was delayed or conditional, people faced difficult choices. Some felt pressured to disclose earlier than they wanted to. Others struggled in silence or had to leave work altogether.

These experiences shaped how people approached work in the first place. Roles that did not offer early flexibility were often ruled out as too risky, particularly by people who had previously been forced to leave work when adjustments were not in place.

Good practice was described as building flexibility into roles from the start. This included ongoing conversations about how arrangements were working in practice, rather than using reviews to test whether flexibility was still needed.

Good Practice

Disabled people often found it difficult to point to clear examples of good practice in their work experiences and in work-related systems. This, in itself, is significant, as people's expectations about work are shaped by their prior experiences.

Where positive experiences were described, they were not always recognised as formal good practice. In some cases, what appeared to be working well relied on disabled people adapting to fit existing systems, drawing on informal arrangements, or managing additional emotional or practical work outside their roles.

As a result, the boundary between employer good practice and disabled people compensating for gaps in the system was often unclear. Outcomes attributed to organisations sometimes depended on support taking place elsewhere or on individuals quietly holding things together.

Some participants described having few, if any, positive experiences to draw on. Over time, repeated negative experiences affected confidence, trust, and how safe work felt to approach in the future.

Section 2: Implications for the Trailblazer

Taken together, the themes in Section 1 point to clear implications for how economic inactivity is understood and addressed.

The research shows that disabled people who are able to work often decide whether to take a job based on risk and trust, not just motivation. Many want to work but are cautious because they worry that trying a job could lead to instability, loss of income, being reassessed, or trouble getting support back if the job does not last. For those who have been left out of work before or have had unstable support, being hesitant to return to work is a reasonable reaction to a system they see as unsafe.

The evidence points to reasons why work can feel unsafe for disabled people. It also shows that lowering risks could help make trying to work feel safer and more supportive.

For some disabled people, moving between working, looking for work, and stepping away from the workforce is part of their wider life experience. These times of not working are not fixed, and the reasons behind them are linked to the themes discussed. Things like the risk of sharing personal information, breaks in

support, and how people are assessed all shape decisions at work and whether someone will try working again. This means that to understand why people are not working, we need to look at their experiences over time, not just label them as 'active' or 'inactive.'

If employment support programmes focus only on getting people into jobs, they may miss what is needed for people to stay in work safely and avoid harm or crisis. They might also overlook what makes people feel safe enough to try working in the first place.

Emphasising the sustainability of employment for disabled people would redirect attention from individual responsibilities to necessary systemic changes. These changes include reducing barriers, fostering trust, increasing flexibility, ensuring stable support, and providing access to independent advice that can be utilised without fear of negative consequences.

Finding and removing barriers that make work risky, and improving conditions so jobs are safe and lasting, can help prevent crises and support long-term, secure work. These steps would help employment programmes for disabled people lead to real, lasting change.

Section 3: Early Signals of What Helps

A small number of participants described support that felt different from formal or benefit-linked work programmes. These examples were limited, but they help show what “safer” support can look like in practice.

Where this worked well, it moved at the person’s pace and focused on practical steps such as applications, CVs, and interview preparation. Participants described this support as safe and non-judgmental, which made it easier to be honest about risk, health, and what was manageable, without fear that information would be used against them.

This was most effective when clearly separate from Jobcentre and benefit processes, and when there was no pressure to move faster than the person could handle.

Participants described these experiences as rare and dependent on individual people or circumstances, rather than standard practice. Positive experiences were also rarely attributed solely to formal policies. They were more often linked to involvement in decisions and to arrangements that could change over time.

As one participant summarised:

“It's about that flexibility. It's about me being part of the conversation, and it's about kind of like being open to changing things.”

Section 4: Recommendations

These recommendations reflect what disabled people said they would need to try to work safely, and what would need to change in systems to make that possible.

They are not about increasing pressure to work. They are about removing the risks that currently stop people from trying or staying in work.

- People need clear, safe ways to try work without risking their income, housing, or access to support. This includes options to step into work gradually and clear routes back if a role turns out to be unsustainable. Trying to work should not put people in a worse position than not trying at all.
- Support to explore work needs to feel separate from assessment and enforcement. People need access to independent advice, where they can talk honestly about work, health, and risk without worrying that what they say will later be used against them.
- Decisions about whether work is “safe” should not be made without the person involved. Systems such as Occupational Health need to work with people to manage risk, rather than using risk as a reason to close options down entirely. This includes recognising people’s own judgement and agency as adults.
- In work, conversations about health, wellbeing, and support should be clearly separate from performance management and capability processes, so people can ask for help early without fear of consequences.
- Employment support should focus on staying in work over time, rather than just on job starts. Support needs to be ongoing and able to adjust as health, energy, or life circumstances change.
- Measures of success should reflect energy, sustainability, and life outside work, not just hours worked or whether someone is in a job at a single point in time.
- Flexibility should be built in from the start, including during probation. People with fluctuating conditions should not have to choose between disclosing early, struggling in silence, or leaving work.
- Support arrangements should not depend on having the “right” manager or team. They need to continue through changes in roles, managers, or organisational structures.
- Systems should recognise the role of informal, family, and external support, rather than assuming work is managed in isolation from the rest of someone’s life.

- Any routes designed to help people try work must include clear safeguards against exploitation, including unpaid labour, unclear expectations, or roles that rely on people's goodwill without proper protection.

These recommendations reflect what people told us would help them stay in work, not just get a job. The report ends with a participant's words that capture this clearly:

"It's not about what I can't do. It's about creating the conditions for me to show what I can do. The mindset of the employer is everything."

Acknowledgements

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