

Working for all?

Experiences of employment support amongst disabled people with high support needs

Andy McKeown and Anel Nzeba
March 2017

About Scope

Scope exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here. We provide support, information and advice to more than a quarter of a million disabled people and their families every year.

Health and Care Voluntary Sector Strategic Partner Programme

This publication is funded through the Health and Care Voluntary Sector Strategic Partner Programme — Working together for better health and care.

The voluntary sector is vital for creating an affordable health and care system which is fit for the future. The Health and Care Voluntary Sector Strategic Partner Programme brings the power of the voluntary sector together with the Department of Health, NHS England and Public Health England, to improve services and promote well-being for all. This research forms part of the work of a Disability Partnership within the Health and Care Voluntary Sector Strategic Partner Programme. Its members are Scope, the National Autistic Society, Mencap and Sense.

In this report

About Scope	2
1. Introduction	4
2. Support into work	5
2a. Introduction	5
2b. Employment and Support Allowance	6
2c. Support with moving into work	9
2d. Recruitment	11
3. Support while in work	13
3a. Introduction	13
3b. Types of support	15
3c. Access to work	17
3d. Attitudes to inclusive working	20
4. Support to progress in work	23
4a. Introduction	23
4b. Continuity of support	24
4c. Discrimination	25
4d. Culture in the workplace	26
Appendix 1: Defining people with high support needs	27
Appendix 2: Methodology	29
Quantitative analysis	29
Qualitative analysis	29

1. Introduction

Employment support can enable disabled people to overcome the barriers that restrict them in the workplace. In our research we look at support across all areas of the employment cycle in terms of:

- Securing work
- Staying in work
- Progressing in work

Our focus is on working age disabled people with high support needs (for a fuller description of how we have defined this group please refer to Appendix 1), although the experiences described by our findings are likely to apply to a wider cohort of disabled people.

This group typically consists of those who are furthest away from the workplace, but many of whom are keen to enter work. The group represents around 1.4 million people across Great Britain, of which 1.1 million are out of work. A significant subset of these people are not — and may never be — in a position to work. However we know that three in ten (over 300,000 people) would like to work, and that barriers and a lack of support are preventing many from doing so.

The basis for this research is that disabled people know best about the barriers that prevent them from securing, staying and progressing in work. This is reflected in the research methodology:

- 25 in-depth semi-structured interviews with disabled people with high support needs.
- Quantitative analysis of the Life Opportunities Survey.

This research is primarily aimed at policy-makers within the Department of Health and the Work and Health Joint Unit. It identifies what works well for disabled people with high support needs in employment support and areas that need more development. The findings may also be of use to employers, managers and colleagues, to assist them in better utilising the full potential of the workforce and their employees. We also highlight key areas for improvement in the delivery of employment services.

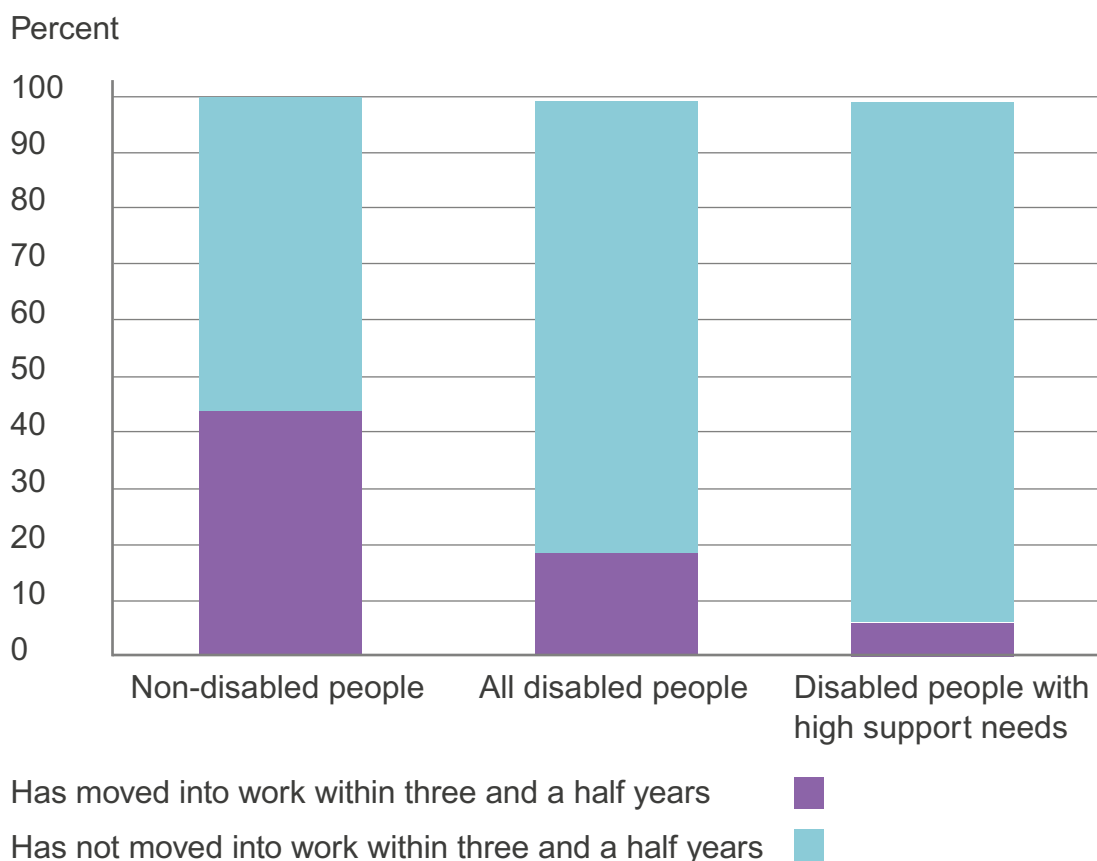
2. Support into work

2a. Introduction

Employment rates decrease with a disabled person's level of need for support, with only one in five working age disabled people with high support needs in work, compared to half of all disabled people and four in five non-disabled people.

While many disabled people with high support needs are not in a position to work, out of the 1.1 million out of work, three in 10 (28 percent) would like to work. However their current chances of entering work are slim. Between 2009/11 and 2012/14 only six percent of disabled people with high support needs who were out of work found work, compared to 18 percent of all disabled people and 44 percent of non-disabled people.

Figure 1: Proportion of people who have moved into work over time¹



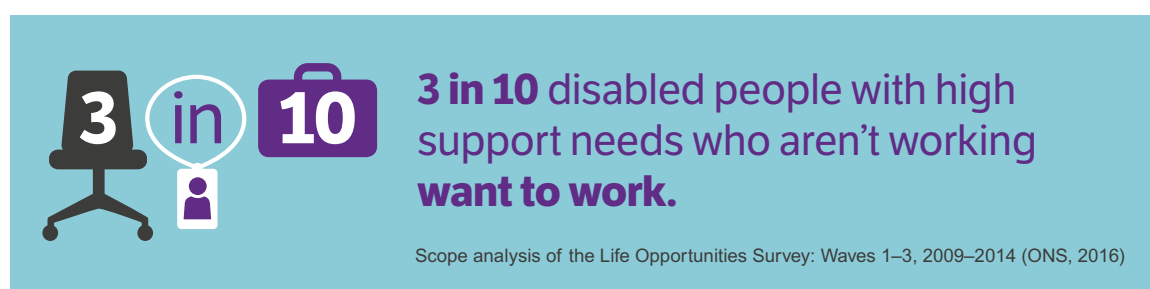
Source: Scope analysis of the Life Opportunities Survey: Wave 1 and Wave 3 (ONS, 2016)

1. This chart compares Life Opportunities Survey data collected in 2009–11 (wave 1) to data collected in 2012–14 (wave 3). The respondents in wave 3 were interviewed approximately three and a half years after their first interview.

The situation does not have to be this way. Our research showed that there are many disabled people with high support needs who want to work and are in a position to work, but the current barriers and inadequacy of support limiting their opportunities to find and secure work.

This section looks at the experiences of support to find work among disabled people with high support needs in three key areas:

- Employment and Support Allowance
- Support with moving into work
- Recruitment.



The infographic features a teal background. On the left, there is a black office chair with the number '3' on its backrest, a white circle containing the text 'in' with a person icon below it, and a purple briefcase with the number '10' on it. To the right of these icons, the text reads '3 in 10 disabled people with high support needs who aren't working want to work.' Below this text, in smaller font, is the source: 'Scope analysis of the Life Opportunities Survey: Waves 1–3, 2009–2014 (ONS, 2016)'.

2b. Employment and Support Allowance

Disabled people who are either out of work, work fewer than 16 hours per week or earn no more than £115.50 per week are entitled to Employment and Support Allowance (ESA). This income replacement support attempts to cover some of the loss to income incurred by being unable or restricted to work. ESA applicants must undertake a Work Capability Assessment (WCA) to determine the extent to which they are able to work. Based on this assessment, the applicant is placed in one of three groups:

- Fit for work: a person is eligible for Job Seekers' Allowance rather than ESA and must move towards work.
- ESA work-related activity group (WRAG): a person is required to meet regularly with employment advisors and may have to take steps to move towards work such as training.
- ESA Support Group: a person is not required to do any work related activity.

Work Capability Assessment

There is a clear perception that the Work Capability Assessment (WCA) does not fairly assess whether or not someone is in a position to work.

There were a variety of reasons for this:

- Some assessments were perceived to be cursory in the amount of time and attention given.
- Others felt the questions were not necessarily specific to their support needs for work and they were being assessed on what they cannot do rather than what support they needed to do tasks in the workplace.
- Some respondents reported feeling that assessors were trying to catch them out with their questioning or misrepresenting their answers to give the impression the person did not need a high degree of support.

This perceived suspicion from assessors and lack of clarity about the process creates a barrier to work for some respondents. The WCA is supposed to assess what support people need to work, but for some it leads to disengagement at the very start of the employment support process.

Employment and Support Allowance categorisation

Most respondents were categorised into the ESA Support Group. Our research shows that under this categorisation they are treated and perceived as a homogeneous group of people even though they have a diversity of experiences and expectations around finding employment. While many are not currently in a position to work, some have the ambition and the potential to find work, either now or in the future. However, the Support Group's current structure, and corresponding expectations and support available, do not support respondents to enter work. A more personalised approach to employment support that accounts for this diversity of experience, expectations and timescales is needed to ensure disabled people with high support needs can access the right level of support.

Lack of conditionality of support

For some respondents who want to work, the lack of conditionality within the Support Group was important, because it meant they concentrate on doing what they had identified as necessary for finding work. This freedom allows disabled people with high support needs to prioritise doing what was most effective for finding work without having to take steps towards moving into work which they considered irrelevant to their needs and priorities.

“I just need them [the DWP] to leave me alone for long enough... what I'm trying to do, is exactly what they want me to do but I need to do it my way. However, the way the system tries to do it is not just workable for me at all.” Sarah, North West

On the other side of the scale, some respondents want support with finding work and consider their allocation to the ESA Support Group to be a barrier to this. Being categorised into the Support Group made some respondents feel like society has told them not to look for work because this is something that they are not expected to do. Some respondents felt the problem originates from employment advisors not realising how best to support those people who want to work. This is resulting in disengagement and a decline in confidence for finding work in the future.

“I’m not going to be able to work because I’ve been told there’s no need for me to work.” Nikki, Wales

Working within the Support Group

Some respondents in the Support Group did manage to secure work. This was either:

- ‘permitted work’ under ESA or
- full time work and moving out of ESA altogether.

This tended to happen when respondents accessed person-centred employment support that focuses on what they want to do and what support they need to do it.

For some working within the ‘permitted work’, parameters can be an extremely positive arrangement. It is possible to work for a sustained period of time without experiencing an adverse impact on health while also having a secure income from ESA.

However, for others the restrictions on ‘permitted work’ can form a barrier to securing employment. If a new job position exceeds the time and pay thresholds of ‘permitted work’, but does not cover the loss of ESA income, respondents are disincentivised from applying because it would make them financially worse off.

“I was afraid of thinking, what if I came off benefits, and I try work and maybe for a couple of weeks or a month I’m fine. But then something happens with my condition, it was all or nothing.”
Nikki, Wales

This ‘financial cliff edge’ is creating a barrier to those who want to work more within the ESA Support Group. Without any kind of safety net in this

situation, respondents must risk taking on full time employment that they are not sure will be sustained, or else err on the side of caution and not fulfil their ambitions for work.

Opportunities are therefore limited to jobs that are close to full time hours, which offset the loss of income from ESA. Jobs greater than part time but shorter than full time may be an optimal arrangement for some disabled people with high support needs. However, respondents are being dis-incentivised from taking on these opportunities under the current Support Group structure.

2c. Support with moving into work

Like many people who are seeking employment, barriers exist that reduce job seekers' ability to find and secure work. These barriers are often more severe for disabled people with high support needs because they are furthest from the workplace, as evidenced by their lower chances of securing work, and that disabled people are out of work for longer periods of time².

Support with looking for jobs and preparing for interviews generally comes from Government bodies and third sector organisations. Job Centre Plus has specialist disability employment advisors (DEAs) who provide support with advice and information or refer people to Government funded employment support programmes such as Work Choice. These specialist employment programmes provide support with confidence building, training and interview skills.

Personalised support

Our research clearly shows that respondents want work-related information and advice that is personalised to their needs. This may involve an employment advisor asking a person what their skills and experience in work are and what kind of work they would like to do. Respondents who had an employment advisor who provided information and advice that was tailored to their specific needs, such as support with completing applications, were much more positive about the experience and more likely to engage with this employment service. While respondents who felt they were not gaining any additional knowledge reported a sense of frustration with the experience and a perception that it was a waste of time.

Employment advisors do not always consider what support requirements people with high support needs have. This lack of consideration is another source of frustration for respondents that can ultimately lead to disengagement from an employment service. Respondents were more positive of engagement with employment advisors who took their specific support needs into consideration.

2. Quarterly Labour Force Survey, October – December 2016 (ONS, 2017).

“...obviously having [an employment advisor] who can identify immediately the physical challenges that you’re going to have [is important].” Josh, London

Employment advisors who are disabled themselves are valued because they have lived experience of the barriers and support needs when looking for work.

Variability of service

The level and quality of support offered by government funded employment support programme providers was variable across respondents’ experiences. This is based partly based on issues mentioned above, such as a lack of understanding of support needs and a perception that respondents are not prioritised for employment support. These negative experiences of Government funded employment support programmes are creating a dis-engagement from future schemes. This is leading some to find alternative employment support from third sector organisations or complete disengagement from any employment support.

Lack of clarity

It is not always clear what support options are available and what will be learnt under some government funded employment support programmes. For some respondents, this fosters a perception that Government funded employment support programme providers cannot offer anything beyond what they are already doing. For those who do engage, they are not necessarily sure what they should be getting support with.

**“I don’t remember doing interview skills. I remember they looked at my CV, but they looked at it once and that was it really.”
Dora, North West**

Communication

Communication between employment advisors at Job Centre Plus, the government funded employment support programme provider, and the person being supported must be regular and coordinated. A lack of communication between employment advisors at Job Centre Plus and government funded employment support programme providers can result in the person being passed between the two agencies without being sure what kind of support they are supposed to be getting.

Respondents considered follow up contact with employment advisors at Job Centre Plus to be important. The opportunity for consistent contact means a person being supported can rely on an advisor who knows their skills, experience and ambitions, and support them through the process of finding work.

Long term disengagement

The long term impact of negative experiences of Government funded employment support programmes is a reluctance to engage with such schemes in the future. Faced with this situation, respondents may look for alternative employment support from third sector organisations or are disengaging with this support altogether. Consequently, it is essential that employment advisors ensure that they get this process right first time for disabled people with high support needs through a person centred approach.

2d. Recruitment

When applying to job vacancies and attending interviews and assessments, disabled people with high support needs can often face new barriers from employers. These are often due to a lack of understanding from recruiters that result in respondents not being given the opportunity to show their ability and talent on an even footing with other candidates. These negative experiences of recruitment can have an overall impact on disabled people with high support needs continuing to look for work. However, there are positive examples, which show how the effort to understand and make adjustments can lead candidates feeling fairly treated and engaged in the process.

Disclosure

Positive attitudes and inclusivity from recruiters at the interview stage are valued by disabled people with high support needs. This may be recruiters showing they are positive about recruiting disabled people as a Disability Confident or 'two tick' employer.

However, there is still a perception among respondents that they must show what they can offer in a role to employers first and then disclose their disability after being offered a job. This concern is often borne out of past experience where recruiters have questioned the extra costs of hiring a disabled person with high support needs and what specific tasks they cannot do.

“I would never take a guide dog to an interview unless I knew in mind that the company was predisposed [to hiring disabled people]. In the past, I would use a cane and put in my handbag.”

Madeline, South East England

Support requirements

Positive intent must be backed up by substantive action based on a clear understanding of an applicant's specific support requirements. Failure to do so can result in situations where a recruiter does not account for specific adjustments being made, such as not structuring an assessment exercise in such a way that ensures a person can use assistive technology to complete it. Without a clear understanding such situations can arise and ultimately present a barrier to securing a job for disabled people with high support needs, despite the employer's positive intent to inclusivity when shortlisting interview candidates.

Impact on respondents

Recruiters can remove barriers to finding work by ensuring the interview location and format is accessible and putting in place any adjustments necessary for the candidate to complete the interview. This means respondents do not need to worry about their support requirement being met and can focus on preparing for the interview and assessment itself. Recruiters who prioritise understanding a candidate's support needs and make adjustments will help ensure that candidate feels fairly treated and engaged in the recruitment process.

Negative experiences of interviews can result in respondents feeling like employers do not want to recruit them due to their impairment. This can lead to respondents feeling less inclined to apply for positions based on the belief they will not have the same opportunities as other candidates.

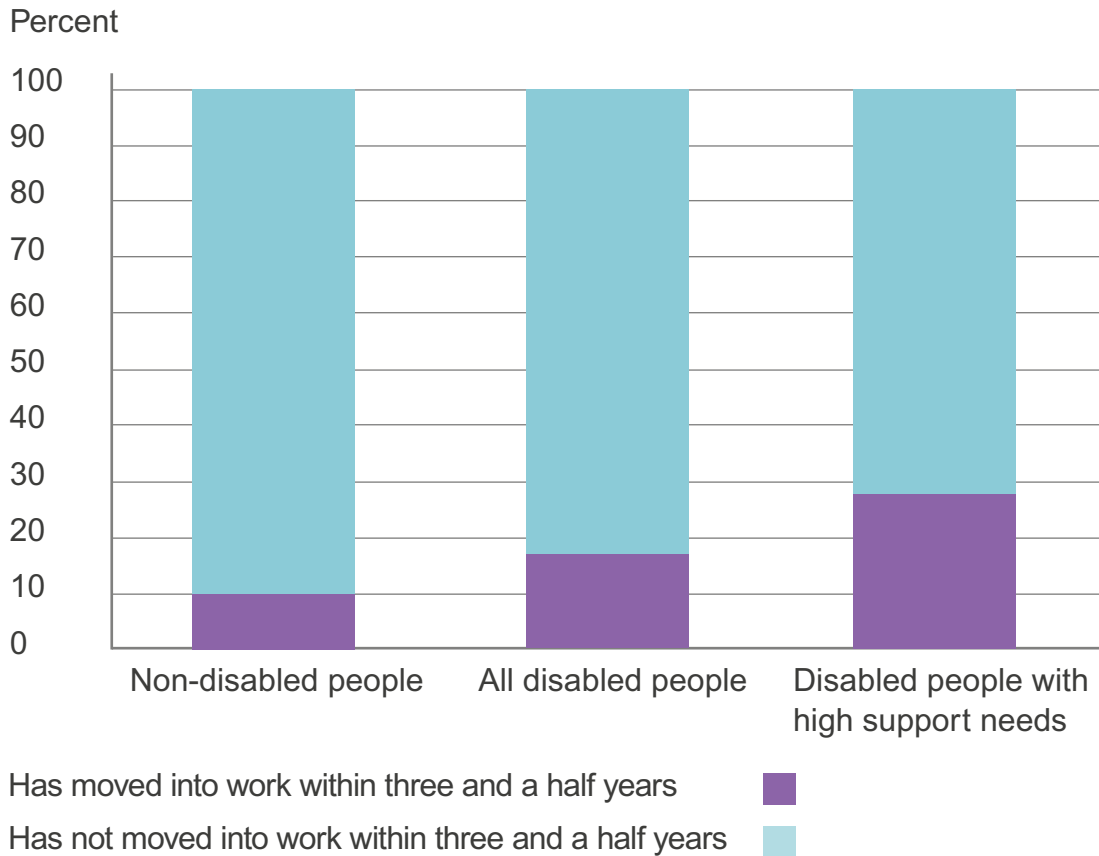
3. Support while in work

3a. Introduction

Retention is a key element to enable those who are able to work, to stay in work. The loss of employment to people who were previously getting on fine at work and who want to work has strong negative impacts on the person and is a waste of their potential.

Retention rates decrease with a disabled person's level of need for support, with three in ten (28 percent) of those who were in employment in 2009 / 11, out of work in 2012 / 14. This is three times the rate compared to non-disabled people.

Figure 2: Proportion of people who have moved into work over time³




Source: Scope analysis of the Life Opportunities Survey: Wave 1 and Wave 3 (ONS, 2016)

3. This chart compares Life Opportunities Survey data collected in 2009–11 (wave 1) to data collected in 2012–14 (wave 3). The respondents in wave 3 were interviewed approximately three and a half years after their first interview.

Under the Equality Act (2010) employers are legally required to provide support for their employees. However managers and colleagues' engagement, implementation and overall attitudes to adjustments play a key role in the experiences of disabled people with high support needs and usage of support in work.

This section looks at the experiences of support while in work among disabled people with high support needs in three key areas:

- Types of support
- Access to Work
- Attitudes to inclusive workplaces.



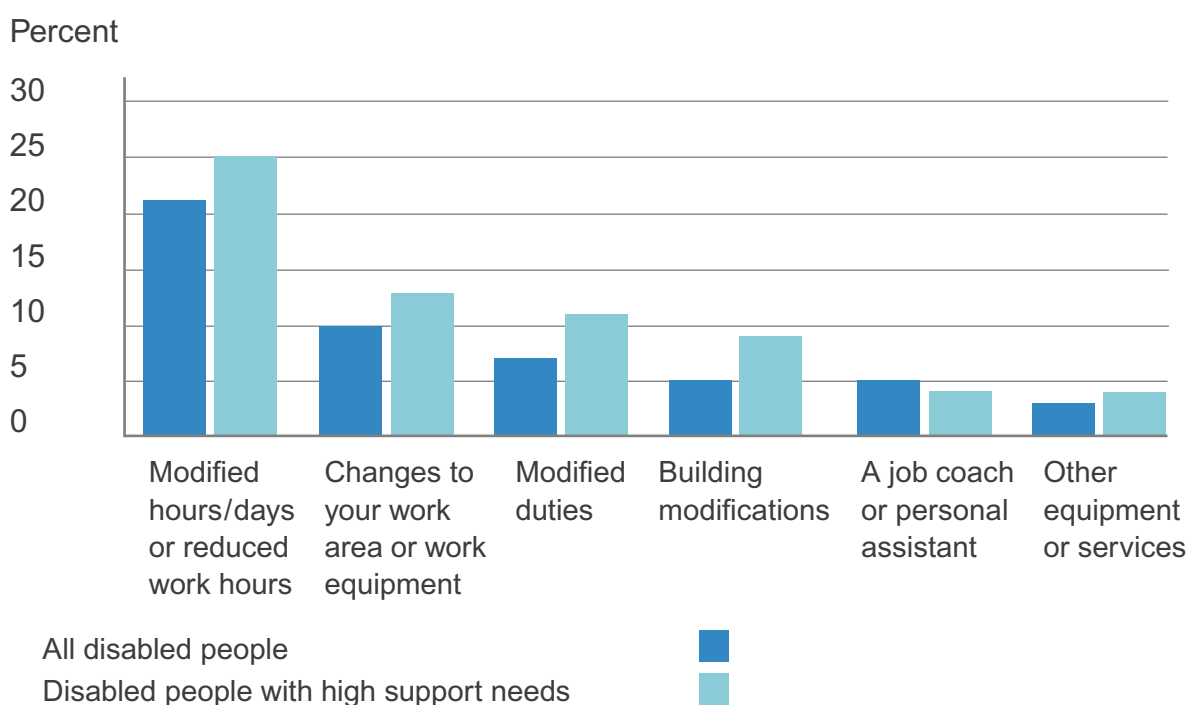
Exit → Employed disabled people with high support needs are **three times more likely to stop working** compared to non-disabled people.

Scope analysis of the Life Opportunities Survey: Waves 1–3, 2009–2014 (ONS, 2016)

3b. Types of support

Disabled people are in the best position to know their in-work support needs. It is essential that support is designed according to a person-centred approach and is based on what the employee has identified as being the best way to support them in work. The type of support used varies from person to person, but disabled people with high support needs typically access more support than other disabled people.

Figure 3: Types of support accessed in work by disabled people⁴



Source: Scope analysis of the Life Opportunities Survey: Wave 1, 2009 / 2011 (ONS, 2011)

Flexible working

Flexible working is the most common type of support, with one in four disabled people with high support needs accessing this in work. Among respondents, flexible working hours were particularly valued by freelance and self-employed workers because this provided the flexibility necessary to balance health appointments with work.

“... if I have a severe dislocation or my fatigue is too bad I can’t work on a certain day. So it’s impossible for me to work in a traditional way for an employer.” Natasha, London

4. This table is based on data from wave 1 of the Life Opportunities Survey (collected in 2009–11). This is the latest available data. A full explanation is in Appendix 2.

Working from home was also considered to be important for respondents for similar reasons to working flexible hours. This allows respondents to work at times that best suits managing health appointments as well as factoring in breaks to manage fatigue. It also provides a viable way of working for respondents who experience anxiety or distress working in an office environment. Some respondents reported a lack of access in their workplace, such as revolving doors at the entrance without accessible alternative doors. In situations such as this there was a clear need to work from home if no other offices were available.

Respondents also valued time off for health management and phased returns to work as measures of support. This supports respondents to ensure their working practices do not compromise their health that could result in no longer being in a position to work.

Change to work areas, equipment and building modifications

Changes to work areas, equipment and building modifications were accessed by more than one in five disabled people with high support needs (22 percent). Accessible workplaces and workstations ensure respondents can do specific tasks within their role. For example, assistive technology such as dictation software can support respondents to produce documents much more quickly than if they had to use a keyboard.

“...if I was using a [non-adapted] phone, normally, I wouldn't be able to write things down.” Dora, North West

Not having accessible workplaces and workstations means that specific tasks take longer to complete or cannot be completed at all. Furthermore, attempts to do tasks within a role without the right support can be at the expense of managing health conditions, ultimately leading to that person being forced to take time off work. With the right types of support these situations can be avoided.

Modified duties

Modified duties was sought by over one in ten disabled people with high support needs. Respondents reported on the benefits of having flexibility to complete office tasks, such as updating reports in a format that meets their support needs. Inflexible working practices mean respondents can take longer to complete tasks, if at all.

For some respondents, taking longer to complete specific tasks can have an impact on completing other tasks and even be framed as a performance issue by a line manager. As a result, flexible working based on the support needs of each employee is essential for ensuring they are adequately supported to do the tasks within their role.

3c. Access to Work

Under the Equality Act (2010) employers are legally required to provide support for their employees. This is known as arranging 'reasonable adjustments' and might involve modifying working hours, using different working practices or making adaptations to the workplace. The duty is to provide an adjustment that is reasonable for the employer to make, taking in to account impacts it may have on the organisation.

Support to overcome barriers at work is also available through the Government run Access to Work scheme. This can cover part or all of the cost of resources a disabled person needs to do their job such as assistive technology, training for colleagues, an interpreter or support worker or travel to and from work. It is available both to disabled people who are employees and who are self-employed. An Access to Work award can be used to pay for:

- Specialised equipment or adaptations to equipment
- Travel costs
- Support workers
- Support services
- Disability awareness training for colleagues
- Communicator at a job interview
- Cost of moving equipment for a new job⁵.

Once a person has made an application to Access to Work, an assessor determines what the applicant needs in their job. Depending on the size of the employer, Access to Work pays all or some of the cost necessary to implement the recommendations made after the assessment.

Access to Work is crucial to fund the necessary support for disabled people with high support needs to stay in work. The majority of interview respondents in this study who had experience of work were aware of Access to Work.

Application process and customer service

The application process for Access to Work is proving to be a barrier where respondents cannot access the support they need at the point they need it most. This is being exacerbated by a customer service contact system that is inflexible and unresponsive. As a consequence, where problems with applications arise, implementation can make an already lengthy process even longer. Unless support is available at the point respondents start a job, applicants are faced with a barrier to staying in their job from day one.

5. <https://www.gov.uk/access-to-work/what-youll-get>

Almost every respondent with experience of Access to Work said the application process was not straightforward. It was perceived to involve a lot of paperwork and be lengthy, leading to some respondents delaying their applications or not doing it altogether. Less experienced users of Access to Work said they had underestimated the length of the process, leading to a gap in support at the point they were scheduled to start a new job.

“...you’re trying to learn everything and maybe things are taking you a bit longer to do. I think that’s the time when you need the support the most, but that’s often the time when it’s not there.”

Sophie, South East England

The customer service contact system was noted as inflexible and unresponsive. Access to Work users can contact advisors via phone (office hours only), email or post. However users are required to submit supporting documents for applications by post only. If there is a mistake with the application the only way to correct it is to resubmit these documents. As a consequence Access to Work’s customer service contact system is failing to ensure users’ applications are processed in time to implement support measures before starting a new job.

In September 2016 Access to Work introduced an online platform for new applications. Interviews were conducted in November and December 2016 so respondents’ experiences of applying for Access to Work will not include using the online platform.

Self-employment and freelance work

Self-employed and freelance workers tended to find the application process even more complicated than employees for two reasons:

1. As with all applicants, self-employed and freelance disabled people are required to provide a business plan evidencing the need for the support they are applying for, but they do not necessarily know how to do this. Employees, on the other hand, tend to be supported with the application by their employer’s Human Resources (HR) department or line manager.
2. Self-employed and freelance respondents who work fluctuating hours have fluctuating support needs with doing a job. The amount of support needed may vary from week to week. Self-employed or freelance respondents can find themselves in a ‘catch-22’ situation where they are prevented from taking on new or additional work because they must show Access to Work they have the work before they can implement the support, but they cannot take on the work until they implement the support. These negative aspects of the

system are particularly pertinent to disabled people with high support needs, as the flexibility of self-employment can be an employment form that better enables them to manage their health.

Implementation

Even where respondents had secured recommendations for support from Access to Work, this was no guarantee they would be successfully implemented. If an organisation did not have a member of staff responsible for setting up specialist equipment and software to ensure it worked properly, respondents have to rely on a support worker or Personal Assistant (PA) to do it or try to do it themselves. Support measures were also poorly implemented when they were not considered a priority by management.

“A lot of their recommendations were never put into practice because they were just too expensive.” Sophie, South East England

Flexibility

In terms of flexibility, Access to Work is well set up to provide funding support for users who have a uniform working pattern where support can be planned in advance and easily accounted for. However, this model of support does not work for users who need support irregularly and at short notice, such as ad hoc and fluctuating taxi travel.

The method evidencing value for money is not suited for flexible working arrangements. For example, applications made for taxi travel requires applicants to provide quotes for the journeys from a number of different taxi companies, however this is not practical in situations such as taking a taxi from a train station or last minute travel arrangements.

Respondents also reported limitations when using Access to Work to fund support workers or PAs while in work. Access to Work is not flexible enough to support users in a way that accounts for personalised in-work support arrangements. Respondents who use Access to Work to fund support workers / PAs report that there is an assumption that they will work equivalent hours to the person they are supporting and does not account for providing support outside of the user's working hours. However, this does not account for situations such as working overtime or support with organising travel and accommodation relating to work.

The rigid categories of support available through Access to Work can frustrate users as it does not account for the different ways they need support to do their jobs. These types of support were perceived to be better served by a model of support similar to personal budgets in social care.

3d. Attitudes to inclusive working

As with Access to Work, the successful implementation of reasonable adjustments is dependent on employers considering them to be a priority. Managers as decision makers are 'gatekeepers' to enabling disabled people with high support needs can do their jobs by confirming reasonable adjustments should be made.

Implementation of reasonable adjustments

Failure to implement reasonable adjustments means that disabled people with high support needs must adhere to a work schedule or working environment that is not suited to their support needs, presenting an additional set of barriers to doing a job.

Some respondents had experience of managers who were reluctant to make exceptions in how they do their work.

“I was told that the rest of the team was not allowed to work from home, so I wasn't allowed to work from home.”
Paul, South East England

Some managers are creating barriers in not allowing adjustments in how respondents work in the office or the amount of time taken for specific tasks. This inflexibility towards working practices meant respondents took longer to complete specific tasks or were working in a way that was detrimental to their health. For some respondents this lack of support was framed by their managers as a performance issue, leading to these people leaving work through redundancy or resignation.

There is also evidence that managers do not always consider accessibility when planning meetings or the physical layout of an office. Where this happened, respondents had to take extra time for travel or relied on support worker / PAs to do specific tasks for them (rather than being supported by the support worker / PA to do a task themselves). Failure from managers to be flexible about how employees work means that respondents are facing pressure to work in a way that is unsustainable in the long term.

Discussing support needs

Managers who listen to what changes need to be made and understand why they have to be made are more receptive to making adjustments. They take the time to map out with respondents what adjustments should be made to specifically support that person to do their job and develop and agree a work plan.

This dialogue is important to respondents because as much as each person knows what support measures work and what does not, they do not necessarily know what options are available for reasonable adjustments. There is a responsibility from managers to proactively outline what adjustments can be made and to create a working relationship where disabled employees with high support needs feel they can request the adjustments they need to do their job, without being held back by a lack of support.

“I think at that time, I found it very difficult to articulate what my needs were. I think I’ve got better at doing that now that I’ve had more jobs... I just found it so awkward.”
Sophie, South East England

Some respondents did have confidence to ask their employer to implement the reasonable adjustments they needed. However, other respondents with experience of work still lacked the confidence to raise this issue with employers. There was a perception that reasonable adjustments would only be implemented if they had been working at an organisation for a long time or that asking for too many adjustments would affect their chances of employment. This indicates that even if disabled employees with high support needs are aware of their entitlement to reasonable adjustments, there is a pressure not to push too strongly that they be implemented.

Relationships with colleagues

Relationships with colleagues affect respondents’ ability to do tasks within a job role, given the interdependencies and social aspect of work. Respondents reported that negative attitudes and behaviours from colleagues tended to be:

- Lowered expectations for the amount of work that person can do
- Failure to work in an accessible way
- Not being included in social events, such as an office Christmas party.

These negative attitudes and behaviours can result in feeling isolated from the rest of their team. This is particularly evident for disabled employees with high support needs who work somewhere that is not accessible and prevents that person from attending meetings without support, or even working on the same floor as their colleagues.

Limited contact time with colleagues can lead to respondents feeling like they are not a full member of the team. It can also result in colleagues being less inclined to collaborate on work or even work inclusively.

This 'othering' of respondents in the workplace is creating barriers to staying in work, as they do not have the opportunity to foster social connections and networks with colleagues that are necessary to work as part of a team.

Colleagues with positive attitudes foster a sense of inclusion throughout an organisation that ensures respondents do not feel isolated within their teams and are comfortable asking for any additional support not already in place. Respondents in this situation did not feel they were a 'problem' to their colleagues because they focus on what a person can do with the right support. As with managers, colleagues who work inclusively show awareness of potential support requirements and proactively ensure respondents have the right support in place.

4. Support to progress in work

4a. Introduction

Progression in work is often an over-looked aspect of employment outcomes, yet plays an important part in facilitating disabled people's aspirations for employment and self-confidence.

Career progression is subjective and can mean different things for different people. For some, staying in work is closely related to progressing in work. Some respondents who are in work are satisfied with the progress they have made in their career. However, there are others who want to progress further and whose needs should be considered.

Disabled people with high support needs are under-represented in managerial or supervisory roles with only 25 percent in these roles, compared to 33 percent for disabled people in general and 35 percent for non-disabled people.

One fundamental barrier to progressing in a career is not being supported to retain a job. The outcome of this can be that disabled people make a decision to change sector to keep working or else leave the workforce altogether, creating a barrier to career progression.

This section looks at the experiences of support to progress in work among disabled people with high support needs in three key areas:

- Continuity of support
- Feelings of discrimination
- Culture in the workplace

4b. Continuity of support

Of those respondents with experience of career progression, there was a lack of consistency in the support available throughout their career. This was due to no longer having a direct line manager or else having a line manager who did not focus on providing the in-work support necessary for respondents to do their job. Being in this position means that respondents can reach a 'ceiling' of support available to them.

Continuity of support is important for respondents because it pre-empts additional barriers to progressing in a career such as setting up support arrangements for each new role. Where someone progresses within an organisation, continuity of support can mean easily transferring support arrangements such as working from home or using equipment paid for through Access to Work.

Respondents' support needs require a constant process of adaptations in the workplace and 'one fix' is not enough. The need to regularly revisit how disabled people with high support needs are supported in work means that the workplace environment has a significant bearing on career progression. Disabled people with high support needs who progress into senior or managerial positions benefit from the support of colleagues who are aware of their specific support needs in the workplace. Where this atmosphere does not exist, disabled people with high support needs are missing out on a resource for support to stay and progress in a specific organisation or employment sector.

Support in new jobs

The inaccessibility and lack of inclusiveness of new working environments limits the options for disabled people to move jobs. Access to Work support can help with this, and respondents reported that it is possible to transfer over support arrangements such as specialist equipment to their new job. However, respondents with support workers / PAs and awards for travel costs had to make a new application to Access to Work. As noted in the previous section, new applications can be complicated and take a long time to implement.

Lack of support

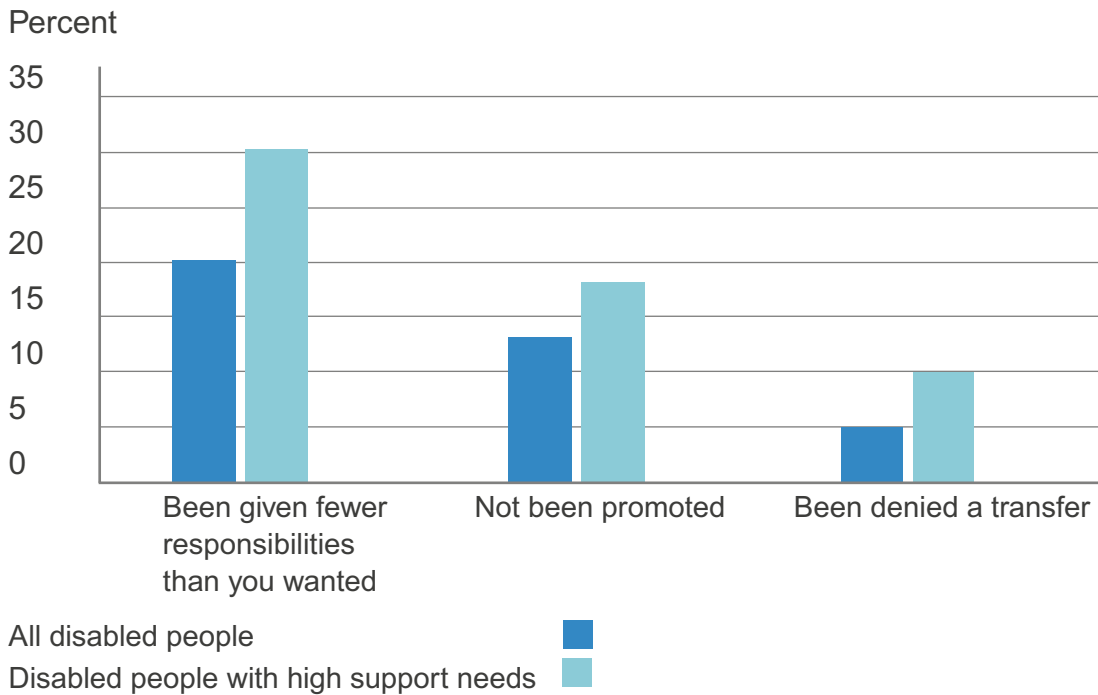
There was a perception among some respondents that they would not be supported with managing the adjustments necessary to work somewhere in the long term. Rather than thinking about a career, work is simply seen as a short term goal to make money.

“I’ve kind of given up the idea of having a career. I just do stuff [different freelance jobs from home] to make money. There’s no way that I can progress in a career because I’m unable to find a job that I’m well enough to do.” Natasha, London

4c. Discrimination

Disabled people with high support needs are more likely to experience discrimination in the workplace that is linked to career progression. This includes being given fewer responsibilities, not being promoted and being denied a transfer.

Figure 4: Experience of discrimination in employment due to a health condition or disability^{6,7}



Source: Scope analysis of the Life Opportunities Survey: Waves 1, 2009–2011 (ONS, 2011).

Respondents who have experience of applying for new roles have reported feeling like they have been passed over for these roles due to attitudes towards their impairment. This is a similar experience to those who reported they were being overlooked for positions while looking for work, particularly in respect to disclosing a disability on an application form.

6. This figure is based on data from wave 1 of the Life Opportunities Survey (2009-11). A full explanation is in Appendix 2.

7. Original survey question: 'In the past 12 months at work, have you experienced anything on this card because of a health condition or disability?'

“I was applying for jobs and even though I have a good CV, I wasn't really getting interviews and sometimes I felt like it was that little box that says, 'Do you consider yourself to have a disability?'”

Michelle, North West England

Respondents who reported feeling discriminated against in career progression due to their disability have generally sought a solution by moving into self-employment. This is either because they have ultimately lost their job through redundancy or feel that self-employment is the only way to progress if other routes are not available.

4d. Culture in the workplace

Respondents' experiences indicate that the way an organisation is structured and its workplace culture can impact on career progression. An organisation with an atmosphere of competition among staff can result in disabled employees with high support needs not being supported by colleagues.

“...I took a job as a senior analyst, and there were other analysts who had applied to that job. You could see them hoping for my downfall.” Michelle, North West

Disabled people with high support needs face a more significant barrier to progressing in a career than non-disabled people and disabled people in general when staff are not encouraged to work collaboratively and support each other.



One in five disabled people with high support needs feel they **have been denied a promotion** in work due to their impairment.

Scope analysis of the Life Opportunities Survey: Waves 1–3, 2009–2014 (ONS, 2016)

Appendices

Appendix 1: Defining people with high support needs

In this research we wanted to focus on disabled people with the highest support needs.

Our research is based on a mixed-method approach: qualitative interviews and a quantitative analyse of the Life Opportunities Survey. Using the same criteria for selecting disabled people with high support needs was not possible across both methodologies and our classification should not be treated as a 'hard definition'. However it allows us to analyse people across two sources, with each criteria roughly equating to just over one million people.

Qualitative interviews

Recruitment for the qualitative interviews was based on self-selection in the first instance. Respondents to our recruitment advertising were asked if they considered themselves to be a disabled person with high support needs. These people were then asked to provide more detail about benefits they were in receipt of, specifically Personal Independence Payment (PIP) or Disability Living Allowance (DLA). The rationale for doing this was that applications to PIP or DLA are assessed by support need and awards are graded across two components (support with mobility and care). On this basis, recruitment for the interviews focused on people who were in receipt of the higher rate payment for one or both of the two components. This creates a population for analysis of just over one million people in the Great Britain . However, it was also acknowledged that not all disabled people with high support needs have been awarded rates of PIP / DLA that reflect their support needs. There were some people who replied to the recruitment advertising who were on a low to moderate rate of PIP / DLA (or had no award at all). We asked these people to describe their support needs in more detail and then made a subjective judgement as to whether or not their involvement was appropriate.

Life Opportunities Survey

The Life Opportunities Survey was used for the quantitative research because it categorises disabled people according to a 'severity of impairment' index that is based on the level of difficulty and frequency experienced by a person to do specific tasks. These tasks relate to areas such as climbing stairs, reading a newspaper or remembering things and the frequency that people experience activity limitation.

These scores were ranked and used to develop a severity score. Category four was used to define disabled people with high support needs, which estimates the group as 1.4m people in Great Britain⁸.

Table 1: Life Opportunities Survey severity score ranking

Difficulty	Frequency			
	Rarely	Sometimes	Often	Always
Mild difficulty	Category 1	Category 1	Category 1	Category 2
Moderate difficulty	Category 1	Category 2	Category 2	Category 3
Severe difficulty	Category 2	Category 3	Category 3	Category 4
Cannot do	Category 3	Category 4	Category 4	Category 4

Source: Life Opportunities Survey user guide to defining and coding disability⁹.

This conceptualisation of disability has limitations from a social model of disability perspective. It focuses on what a person cannot do in a situation that is disabling rather than focusing on what level of support a person needs to do specific activities. However, the Life Opportunities Survey is the only national data set that considers people’s varying severity of impairment, which is often (but not always) linked to a person’s support need. The quantitative data presented in this report is framed on people’s support needs rather than what they cannot do.

9. <http://www.ons.gov.uk/ons/re/los/life-opportunities-survey/life-opportunities-survey/user-guide--defining-and-coding-disability.pdf?format=contrast>

Appendix 2: Methodology

Our research is based on a mixed-method approach that incorporates qualitative interviews and a quantitative survey. The quantitative analysis was used to understand the scale and need for employment support at a national level, while the qualitative analysis was designed to understand disabled people's experiences of employment.

Developing research questions

Findings from a literature review and previous Scope research were used to develop our research questions. The interview questions were developed in consultation with employment service professionals, Scope's policy advisors, members of the Disability Partnership, and government and non-government organisations who focus on employment.

Quantitative analysis

Our quantitative analysis was based on secondary analysis of the Life Opportunities Survey.¹⁰ The Life Opportunities Survey was used because it is the only survey that enables national cross-sectional and longitudinal analysis of disabled people with high support needs (see Appendix 1 for how we have defined this in the survey).

Cross-sectional analysis is only possible in the first wave of the survey, in 2009 / 11. Although the first wave of data was not collected recently, this was deemed acceptable given the benefits of using the Life Opportunities Survey and the relatively static nature of these observations.

The survey started with 36,000 adults in Great Britain in 2009–11, with the same respondents followed up in 2010–12 and then in 2012–14. Of the respondents surveyed in first wave, 5,000 people were recorded as category 4 in the Life Opportunities Survey's 'severity of impairment' index (14 percent of the total sample, unweighted). We have focused on this cohort of people for the quantitative analysis in this research.

Qualitative analysis

Our qualitative analysis was based on 25 semi-structured individual interviews of disabled people with high support needs in England and Wales (see Appendix 1 for how we have defined this in our recruitment). These interviews were conducted within a 4 week window (November to December 2016). Each participant was asked to confirm their preferred format for conducting the interview. The majority of participants preferred to conduct their interview in person. A small number of respondents stated their preference was to conduct the interview by telephone or instant messaging.

10. Life Opportunities Survey: Waves 1–3, 2009–2014 (ONS, 2016).

11. See About Scope section (page 2) for further details of the Disability Partnership

Recruitment

Our prime recruitment channel was to use partner social media and email networks to advertise participation in the project. Partner organisations included the Disability Partnership¹¹, as well as Disabled People's Organisations that support disabled people with employment (primarily Breakthrough UK and Evenbreak). We monitored recruitment to ensure the sample was heterogeneous across key demographic groups and impairment types and reflected a wide range of work experiences.

We used targeted social media advertising to recruit specific demographic characteristics that are typically under-represented using these channels. Being internet-based and self-selecting, there is likely to be some biases in the recruitment of participants, however the findings from our research are still likely to apply many disabled people with high support needs in general. We decided not to continue interviewing participants after the 25th interview as we felt we had achieved data saturation (further interviews would not have led to new data relating to the research questions). Each interview ranged in duration from approximately 50 minutes to 1 hour and 40 minutes.

Scope exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here.

We'll provide support, information and advice through our services when disabled people and their families need us. And we'll raise awareness of the issues that matter. We'll keep influencing change across society until this country is great for everyone.

For more information please contact:

The research team
research@scope.org.uk
020 7619 7245

 **@scope**
scope.org.uk

The Disability Partnership

