

Sharing Information on Disability

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Acknowledgements

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Most importantly, I want to acknowledge and thank all the Disabled people who participated in our survey. Your voices are at the heart of this report.

Rundip Thind
Advice Services Manager
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Foreword

This report casts light on a really important topic, what makes Disabled people share information on our impairments and health conditions with those providing us with education, training or employment.

As a Disabled woman with very little vision – only light perception, I've never had a choice. I've always had to share details of my disability on application forms and always asked for reasonable adjustments for interviews. It's impossible to hide information, when you need accessible recruitment documents, a guiding arm into interview rooms and support from Access to Work to do your job.

However, there are millions of Disabled people, for whom sharing information on disability is an active and real choice. They might decide not to share for a variety of reasons, such as feeling that information on disability is private, not being confident of the legal position, not requiring any reasonable adjustments or fearing prejudice, negativity or discrimination.

Whether we as Disabled people decide to share information on our impairments or health conditions or not, we should always be utterly confident that our disability won't be viewed as negative and more than that, will be viewed as positive and enriching, bringing diversity of thought and experience into the education or employment setting.

What needs to change to enable Disabled people to feel confident about sharing information on our impairments and health conditions? What do education and training providers and employers need to do differently to demonstrate that they will treat us with equality and value our contribution?

The following report helps us to answer these questions.

Fazilet Hadi
Head of Policy
Disability Rights UK

Introduction

This report presents findings from a survey conducted in March and April 2023, designed to better understand the experiences of Disabled students, trainees and employees in respect of sharing information on disabilities and exploring what could make sharing such information easier.

In this report, we refer to individuals with impairments or long-term health conditions as Disabled people, though we recognise that not everyone may identify with this term. This terminology highlights that disabilities stem from societal barriers, not individual impairments.

Research Sample

We used Survey Monkey to carry out the survey, which had 14 questions, to gather quantitative and qualitative data. The survey received 650 responses. We reached respondents via the Disabled Students Helpline, social media platforms such as Tik Tok, posts on our website and networks that we engage with.

Respondent profile

82% of respondents identified as having a disability as per the Equality Act 2010.

Disability is defined as *'a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities'*.

The survey was completed by respondents with a range of different disabilities.

Age

- 16-25 years: 14%
- 26-35 years: 43%
- 36-45 years: 28%
- 46-55 years: 9%
- Above 55 years: 6%

Employment and Education Status

- 22% of the respondents were studying
- 25% were considering or had applied for study or training
- 19% were trainees
- 29% were employed

Research Sample

1. Very few respondents felt completely confident on their rights regarding sharing information and Disabled people's rights in education and employment settings.

- **Only 3% said they had a complete grasp of the rules** around sharing information on their disability in education, training, and employment.
- **46% had a moderate understanding**, while **33% had limited to no understanding**.
- **18% felt they understood 'quite well'**.

This lack of understanding is very concerning as it is likely to lead to hesitancy in sharing information. This could negatively impact the support delivered and the individual's ability to fulfil the study, training or work requirements.

2. The most common reason for people sharing information about their disability was to access support or adjustments.

76% shared information about their disabilities and impairments with their education or training provider or employer.

The reasons for sharing were:

- **Need for individual support or adjustments (35%).**
- **The need for accessible accommodation (7%)**

- **Access to financial support** and grants such as Disabled Students Allowance and Access to Work to help pay for the changes or adjustments (22%)
- **Illustrating positive examples in applications or interviews** when tackling competency-based questions (11%).
- **To explain gaps** in an application form or CV (7%)
- **Protection from discrimination** under the Equality Act 2010 (6%)
- The **sense of comfort** from knowing that they have been open about their disability or impairment (5%)
- The employer being part of the **Disability Confident scheme** (4%).

These responses indicate that Disabled people largely share information on disabilities when it is vital to the securing and fulfilment of study or work.

3. Respondents most commonly notified Disability Advisers, above any other staff members.

- 26% shared with a Disability Adviser
- 21% with a Personal tutor or teacher
- 19% with their Line Manager
- 16% with Human Resources
- 9% directly informed their Examination Officer due to the need for access arrangements
- 4% shared with their placement coordinator.

Respondents were more comfortable sharing information with Disability Advisers or Personal tutors or Line Managers. This seems to be because of the perceived expertise and/or close personal relationships.

4. The majority of respondents who shared information did so before starting their course/training/employment.

- 17% of the respondents shared this information prior to attending an interview with their education provider or employer.
- 16% of the respondents used their Equal Opportunities monitoring form with 15% using UCAS or their application form.
- A further 9% used a cover letter or personal statement with their application form.
- 14% used their interview to first mention their disability with a further 14% only sharing this information after accepting their course or employment offer.
- 8% of respondents waited till they started their course or employment.
- 3% only shared information on their disability when they experienced difficulties.

Whilst the timing of when information about disabilities was shared varies widely, a significant number of Disabled people waited until accepting an offer or even starting their course or job. This suggests that people fear negativity towards their disability.

5. The majority of providers and employers took action once they became aware of the respondents disability or impairment.

- 24% were invited for a meeting with Disability Support Services or HR.
- 24% were offered reasonable adjustments and support.
- 21% were assisted with funding applications such as Disabled Students Allowance and Access to Work
- 7% were supported with applying for an Education, Health and Care assessment from the local authority.
- 4% reported no action taken despite sharing information on their needs.

It is positive that many providers and employers take proactive and supportive action, however, a minority fail to take action, therefore jeopardising the wellbeing, safety and performance of Disabled people.

6. The main reasons respondents chose not to share information was the feeling that their disability had no impact on their ability to study or work and their lack of confidence in how sharing the information would be treated.

- 20% felt their condition made no difference to their ability to carry out their role.
- 14% felt that sharing information on their disability would make no difference.
- 17% were concerned about being perceived only as Disabled.
- 14% didn't want to discuss their disability with a stranger.
- 12% were concerned about being treated differently, and 10% had confidentiality concerns.

Where disabilities don't require any barriers to be removed, it is perfectly understandable that they are not shared. What is of concern is where adjustments would facilitate the person's ability to study, train or do a job, yet fears of discrimination prevent people being open about their needs.

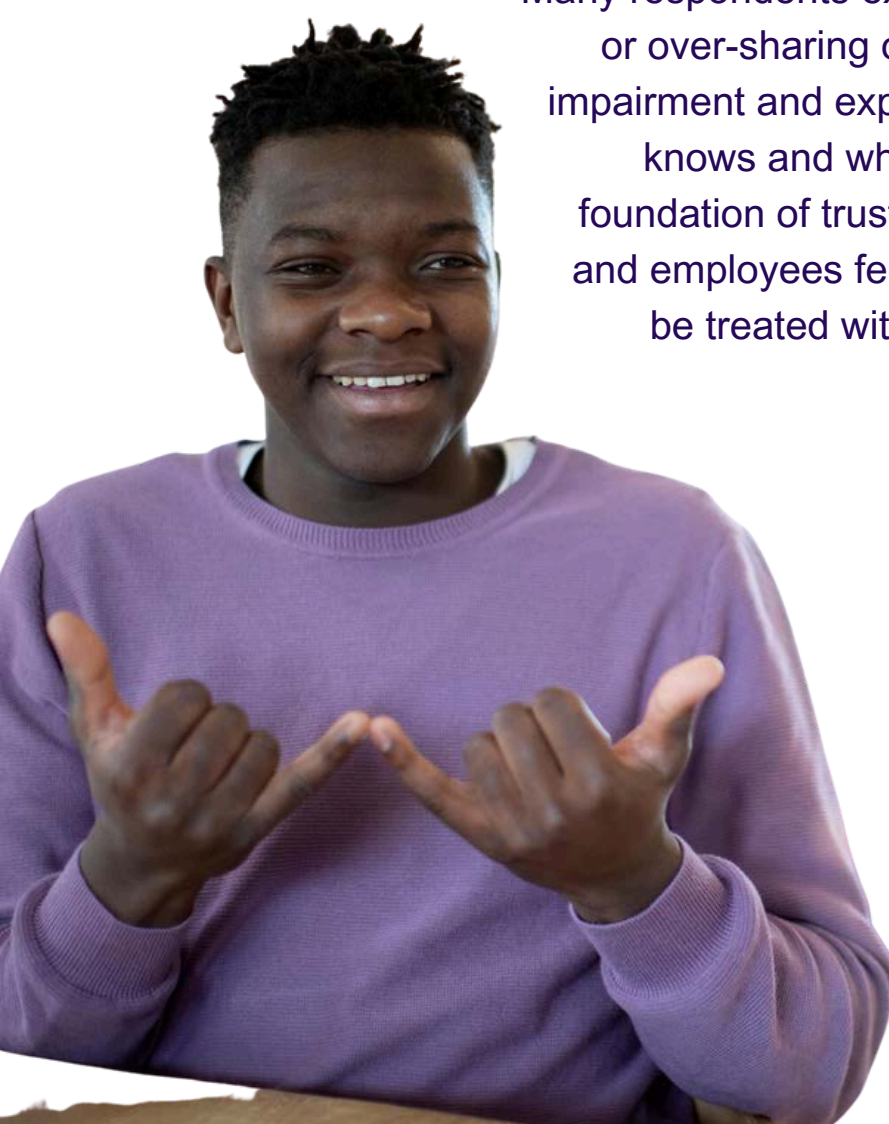
Ten Key Findings and Recommendations

Respondents provided various suggestions on how education providers, training providers, or employers could make it easier for them to share information on disabilities or impairments.

It is evident that respondents desired a supportive, understanding, and inclusive environment where they can freely discuss their conditions without fear of discrimination or prejudice. They also valued clear communication, proactive support, and a genuine commitment to inclusivity from their education providers, training providers, or employers.

Finding 1: Trust and confidentiality

Many respondents expressed concerns about the misuse or over-sharing of information about their disability or impairment and expressed a desire for control over who knows and when. Privacy is valued. Establishing a foundation of trust, where Disabled students, trainees and employees feel confident that their information will be treated with the utmost respect and discretion, is paramount.



“More confidentiality allows me to decide who knows and when - backs me when I do share.”

- Survey respondent

“An education provider, training provider, or employer should establish a stable relationship with you to build a foundation of trust and mutual understanding. This can be achieved through close and timely communication with you, understanding your needs and issues, and respecting your personal privacy.”

- Survey respondent

“The employer has a “disability passport”. However, this has been shared across multiple departments without my permission by email.”

- Survey respondent

“Providing a safe environment for me to speak out...I feel my ability to do the role will be questioned.”

- Survey respondent

Recommendation

Clear assurances about the confidentiality of information should be provided, allowing students, trainees and employees to control who is privy to it. A clear policy can alleviate concerns and encourage more Disabled people to share information about their disability.

Finding 2: Clear Policies and Procedures

The absence of a clear policy on disability left some respondents feeling uncertain and unsupported. Respondents indicated that clarity in policies, especially around reasonable adjustments, is crucial. A lack of clarity can deter students, trainees and employees from sharing their disability, fearing potential repercussions or misunderstandings. By having transparent policies that are easily accessible, education providers, training providers and employers can alleviate these concerns.

“Proactively share what support systems are in place for disabled colleagues (e.g. disability support leave, adjustment team, flexible working from day 1).”
- **Survey respondent**

“University could have provided more information about how to request reasonable adjustments in interviews/in the workplace and what to expect.”
- **Survey respondent**

“We didn’t have an official policy around disability at the time so I was worried about what would happen, so having a document that is clear would have been helpful.”
- **Survey respondent**

“A clearer reasonable adjustments policy, that has given forethought to how to accommodate mental disabilities.”
- **Survey respondent**

“Have a guide or information on the company policy and support offered for Disabled people.”
- **Survey respondent**



Recommendation

Easily accessible, clear and detailed policies and procedures regarding disability support should be established. Proactively communicating these policies will empower students, trainees and employees with knowledge about their rights and the support available to them

Finding 3: Training and Awareness

There is a clear indication of a lack of understanding and awareness about disabilities amongst staff which leads to misconceptions and inadequate support. A significant number of respondents felt that their education provider, training provider or employer lacked the necessary knowledge to understand their specific needs and would jump to conclusions about their abilities.

“More training and understanding on autism.”

- Survey respondent

“Maybe they need to actually pay attention to the response and equip themselves with knowledge and some awareness of how my hearing impacts my learning.”

- Survey respondent

“I was getting recommendations for an interpreter when my hearing loss was acquired and I didn't know BSL, there was an assumption that hearing loss and Deafness were the same thing.”

- Survey respondent

“That college needed some training around hidden disabilities, be flexible and open to hearing what my needs were and wiliness to help talk through what adjustments might be made.”

- Survey respondent

“Webinars (that I’ve found) have helped me to learn more about my disability so I can then better explain it to people. Perhaps if more sessions like this were directly available from a place of study or work via external partnerships e.g. charities.”

- Survey respondent

Recommendation

By investing in training by Disabled people and Disabled-led groups can ensure staff are equipped to deliver diverse adjustments. Training on the social model of disability is recommended to create a deeper understanding of the barriers and challenges faced by Disabled people.

The social model recognises our shared experiences as Disabled people and emphasises the broader societal barriers that exclude us from participating fully. It’s not necessary for employers to be medical experts, but it is essential that the student, trainee or employee’s unique needs are met and understood, and that assumptions aren’t made about a person or their disability. Disabilities can impact everyone differently, so you can’t assume you know the needs of one Disabled person because you’ve met someone else Disabled before. Always listen and be led by the individual you’re working with.

Finding 4: Open Communication

Respondents valued open communications and felt that education providers, training providers and employers should be proactive in initiating discussions about their adjustments.

They expressed a desire for more open channels of communication where they could discuss their needs without judgment and with the assurance that their concerns would be addressed. Respondents valued direct communication with those they work closely with, such as line managers, and expressed a need to be heard and understood.

“*Maybe more conversations with my line manager rather than someone else who isn't going to work with me day in day out.*”

- Survey respondent

“*They could have asked me for more information/details of how best to support me or what I might struggle with.*”

- Survey respondent

“*To not be judgemental in the first place. To ask questions about how health conditions affected me.*”

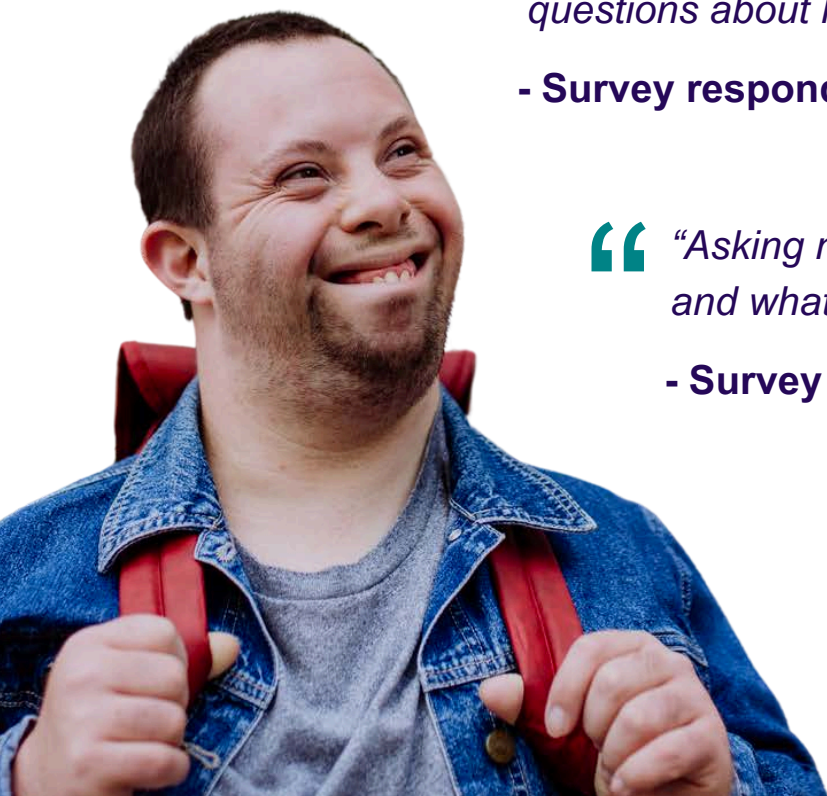
- Survey respondent

“*Asking me as an individual what works and what doesn't.*”

- Survey respondent

“*Sensitive and mindful conversations.*”

- Survey respondent



Recommendation

An environment where open communication is encouraged should be fostered. Regular check-ins with Disabled students, trainees and employees can help in understanding their evolving needs and ensures they receive the necessary support.

Finding 5: Proactive support and needs assessments

Respondents have highlighted the need for consistent, proactive, and tailored support, initiated from the outset and not just when issues arise. Support should not be a one-time offer.

They shared experiences indicating that an accessible and less intimidating process for needs assessment would be helpful. These assessments are important in identifying and understanding the unique adjustments of each Disabled student, trainee and employee, leading to personalised plan. The plan should detail the specific support or adjustments needed, ensuring that the Disabled person can fully participate in education and/or work.

Respondents emphasised that it's not enough to simply create a support plan, it must also be dynamic and adaptable, with regular reviews to ensure they remain relevant and effective. Moreover, these reviews ensure that the agreed adjustments are consistently implemented, and any potential issues are addressed promptly.

“Pragmatically implement plans rather than leaving them in abstract.”

- Survey respondent

“My employer was very supportive.”

- Survey respondent

“Your education provider, training provider or employer should develop a personalised plan to help you manage and treat long term health problems or injuries, with appropriate goals and strategies based on your needs and goals.”

- Survey respondent

“Proactively share what support systems are in place for disabled colleagues (e.g. disability support leave, adjustment team, flexible working from day 1).”

- Survey respondent

“They made it easy to disclose and said they would make reasonable adjustments and support me but that didn’t happen especially from line managers.”

- Survey respondent

“Make disability assessments accessible - reduce the amount of documentation and evidence that had to be acquired in such a short space of time.”

- Survey respondent

“Encourage disability assessments / make them accessible at a postgraduate level where there is less incentive to get assessed.”

- Survey respondent

“Be supportive and make disability assessments for support more accessible and unintimidating.”

- Survey respondent

“Join up all areas of a plan and communicate through departments.”

- Survey respondent

“I have had breast cancer and issues with lungs plus dyslexia. Just want to pick up a phone or send a simple email.”

- Survey respondent

“They made it easy to disclose and said they would make reasonable adjustments and support me but that didn't happen especially from line managers.”

- Survey respondent

Recommendation

To comply with the Equality Act 2010, initiating a proactive support system from the outset is essential, rather than reacting to issues as they occur. This includes carrying out an accessible needs assessment, which isn't intimidating, leading to a personalised support plan to be drafted. These plans should be flexible and regularly reviewed to ensure ongoing effectiveness. Clear communication about support and assistance with applications for grants such as Access to Work or Disabled Students Allowance should be provided as required.



Finding 6: Avoid Assumptions and Promote Inclusivity

Respondents felt that assumptions about their abilities or needs were detrimental and the responses highlighted a fear of discrimination. Education providers, training providers and employers' legal duties under the Equality Act 2010 are anticipatory – and they should proactively work to improve accessibility and inclusion.

Assumptions perpetuate stereotypes and can lead to misunderstandings. By seeking to understand each student, trainee or employee's unique experience and promoting a culture of inclusivity, education providers, training providers and employers can foster a safer and more accessible environment.

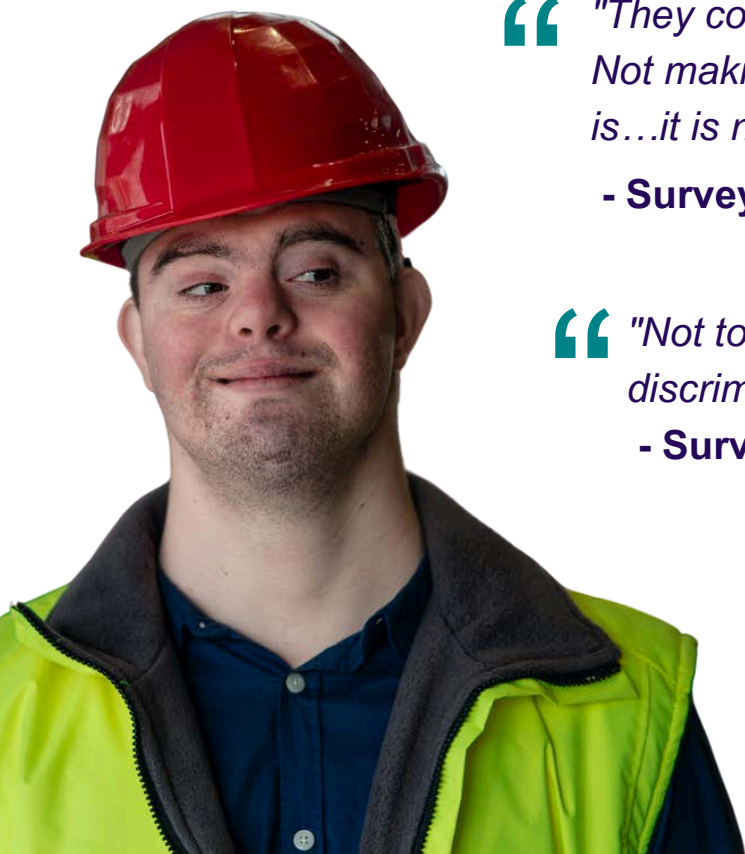
“*Private companies in the City of London in the realm of finance, will NEVER employ anyone like me if they knew I had ongoing chronic health problems.*” - Survey respondent

“*They could have led discussions on adjustments. Not making assumptions about what accessibility is...it is not simply disabled parking.*”
- Survey respondent

“*Not to assume & discriminate.*”
- Survey respondent

“*Reduce ableist discrimination.*”
- Survey respondent

“*Asking me as an individual what works and what doesn't.*”
- Survey respondent



“To not be in judgemental in the first place. Also ask questions about how health conditions affected me.”

- Survey respondent

“Committing to ending ableism and subscribing to the social model.”

- Survey respondent

“Challenge ableism from the top down and ensure management truly engages.”

- Survey respondent

“Be clear that being disabled is a positive and being a disability confident employer.”

- Survey respondent

“Writing in the job description that they welcome people with long term conditions to apply.”

- Survey respondent

“They would need to be non-discriminatory, pro-diversity and inclusive and train all staff to be so.”

- Survey respondent

“I feel able have this upcoming conversation with the college about my disabilities because they put information about how they support disabled students on their website and in their prospectus.”

- Survey respondent

“For an employer to state that it recognises that people with disabilities can experience additional challenges in the work place and it aims to actively support those with disabilities.”

- Survey respondent

Recommendation

A culture of inclusivity should be promoted, where students, trainees and employees are recognised and valued for their skills and abilities, challenging stereotypes and discriminatory practices. Regular awareness campaigns can help dispel myths and assumptions.

Finding 7: Feedback and Regular Check-Ins

There's a clear desire for regular feedback mechanisms and check-ins.

“Following up on the disclosure.”
- Survey respondent

“Create a disabled network to communicate issues.”
- Survey respondent

“The disclosure process is actually integrated pretty well into the student registration process, at least in the first instance.”
- Survey respondent

“Activities could be put on to help frame discussions amongst Disabled staff.”
- Survey respondent

Recommendation

A system for seeking collective and individual feedback from Disabled students, trainees and employees should be implemented. This will allow them to voice their concerns, experiences, and suggestions. The feedback should be acted upon, ensuring continuous improvement in support systems. There should be regular check-ins to ensure that support measures are effective and address the student, trainee or employee needs.

Respondents also expressed a desire for a Disabled Network to communicate issues, suggesting that creating such platforms can further enhance open communication and feedback. Organising open forums or discussion panels can provide a platform for broader discussions on disability and potential areas of improvement.



Finding 8: Transparency and Clarity

Respondents wanted to know what support systems were in place and how information about their disability would be used. They wanted assurances that being open about their needs wouldn't negatively impact their progression or acceptance into a course or job.

“Clarity on what help is available makes it easier to ask.”

- Survey respondent

“Assurance that being open about your needs won't impact progression or acceptance.”

- Survey respondent

“Making it clear what was available to me in terms of help and support.”

- Survey respondent

“Explicitly ask about reasonable adjustments, not just 'health and safety'.”

- Survey respondent

“I think all employers should make potential applicants, and new employees, aware of Access to Work.”

- Survey respondent

“By stating they are disability aware and a caring employer / college.”

- Survey respondent

“Stating the current percentages of employees or students/alumni who have identified as disabled and the aim from the provider to increase the percentage has always made me feel better about disclosing my disabilities.”

- Survey respondent

Recommendation

Policies and practices must be made transparent. Clear communication about available support systems, as well as how information about a person's disability will be used, can foster a sense of trust and encourage more open communication.

Finding 9: External Partnerships

Collaborating with external organisations, Disabled-led groups, and experts can enhance the support system available to Disabled students, trainees and employees. These partnerships provide a wealth of resources and expertise, ensuring education providers, training providers and employers are equipped to offer the best possible support. By tapping into external knowledge and resources, providers and employers can ensure that they are up to date with best practice and have access to a broader range of support mechanisms.

““If you need combination therapy, your education provider, training provider or employer should work with a medical team, including a doctor, physical therapist, dietitian, and social worker, to ensure that you receive comprehensive care and treatment.”

- Survey respondent

““I had a great support worker for a set amount of time, it would have been really helpful to have that person for longer.”

- Survey respondent

Recommendation

Forming partnerships with Disabled-led groups, external organisations, and experts can enhance the support system, providing additional resources, training, and expertise.

Finding 10: Promote Awareness and Confidence

A shared concern amongst respondents was the need for a more informed and empathetic environment that actively promotes awareness and instils confidence in Disabled people. Many respondents conveyed a hesitancy to share information about their disabilities, not necessarily due to the nature of their conditions, but instead due to concerns about potential discrimination, misunderstandings, or misuse of their information.

This hesitancy is emphasised by the significant number of respondents who only chose to share information after securing a position or starting a course, suggesting a deep-rooted apprehension about prejudice.

These findings stress the importance of creating an environment where students, trainees and employees feel empowered, informed, and confident in both understanding their rights and expressing their needs without fear of repercussions.

Recommendation

Proactive work towards building a more inclusive setting is crucial. This could include regular awareness building campaigns and training around what support is available, the steps a provider is taking to become more inclusive, the rights of a Disabled person and challenging stigma and assumptions.

Disabled people should feel informed and empowered about their rights and confident on what support is available, should they choose to share their information – including feeling reassured that they won't face discrimination.

By building awareness and confidence, and challenging bias, we can ensure that communication becomes easier - helping young Disabled people receive the necessary support and reach their full potential.





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